

HOW MODELS CAN TRANSLATE
THE LIVED EXPERIENCE OF RHEUMATOID ARTHRITIS
INTO MATERIAL AND FORM

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i. ABSTRACT

This research proposes that the conceptualization of embodied, abstract emotional experiences such as pain, which despite being multi-modal, non-visual and subjective, have the potential to be communicated visually using model making, as it is traditionally understood in the fields of Architecture and Design. To be able to do so, this research has prescribed a new methodological approach where a Gadamerian hermeneutic understanding of intersubjective interpretation has been married to theories drawn from embodied cognitive linguistics, sign language and translation studies.

This novel approach to design research was undertaken within the field of Health Sciences to produce metaphorically provocative, descriptive models of the lived experience of people with rheumatoid arthritis to help bridge the gap in understanding currently perceived in the public realm.

Rheumatoid arthritis (RA) a serious and growing public health problem, yet despite numerous campaigns by leading charities, misconstrued perceptions of what RA is and what it is like to live with, abound in the public imagination. The reason that this raises such concern is that preventive actions in the early stages of the disease make it easier and less expensive to treat; put more explicitly, knowing rheumatoid arthritis saves lives.

This necessity for understanding provided the motivation for this research and the conception that models, generated with the participation of people with RA, could lead to further insight into the lived experience of RA and provide an as yet uncharted means to communicate the human condition.

The thesis outlines contemporary visual approaches to describing RA in trying to educate the wider public and explains why they are limited in their current form to the very clichés and stereotypes that they wished to breakdown. In doing so, the research highlights the potential of models as an alternative in conveying the complexity of lived experience. The role and value of models is laid out in detail through a critique of historical and contemporary perceptions, whilst a definition of the model in research, placed within a theoretical context, provides the basis for its application in practice. The models made as the culmination of the analysis are discussed in detail in the light of this epistemological understanding.

The study involved three participants, all women above 40, working in the UK Higher education field, and all living with RA. The gender of the volunteers was coincidental, but the age, employment and condition were all requested in answering the open call. Their involvement came through in-depth conversations, where they traced their history with the disease, offering a portrayal of the day-to-day experience living with it. Although three maybe considered a small sample size, the engagement with these conversations was involved and layered with numerous stages of analysis, reflection, and practice; thematically analyzed in detail, coded by metaphoric association, abstracted through drawn analysis with drawing, which provided the platform for visualization into the models that represent the culmination of the analysis. This methodology and the approach to analysis is described in detail, outlining the different ways in which creative visual methods, such as sketching, were used to understand the text, and explaining the increasing abstraction in the analysis as part of the development of a visual language and as a visual reflection in the design of the models.

Due to the novelty of the approach, the evolution of the thesis design is discussed within a historical context from the pioneering work on visual perception by James Gibson, its relationship to art and language through the thoughts of Rudolf Arnheim through to the multi modal appreciations of communication in translation studies by Jeremy Munday and metaphor theory by Zoltán Kövecses.

In conclusion, the findings from this research raise awareness of how material culture as a tool of communication is undervalued in research practice, the consumer product market aside. It provides a means to navigate visual communication in design in a rigorous, applicable manner, and, whilst suggesting the potential benefits this could offer, and the drawbacks it imposes, in describing the complexity of human experience, the outcomes point to the value of the model as an aid to conversation and through that to understanding. Proposals are put forward for further study with the potential for further analysis of the models in the public realm.

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Finally, I would like to thank the three people who gave their time and their stories allowing me to discuss their experiences with them for this research. Without their input, offered with little concept of what the outcomes may be and with no thought as to what they would receive in turn, this research would have been a complete non-starter. I hope that whatever comes of this research and any research in this field justifies their generosity and enhances the happiness in their lives.

v. DECLARATION

I declare that the research contained in this thesis, unless otherwise formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree and does not incorporate any material already submitted for a degree.

Signed:

A handwritten signature in black ink, appearing to read "Peter Mel", written over a light blue horizontal line.

Date: 18/09/2021

vi. BIOGRAPHY

My initial training at undergraduate level was a BA (hons) in Silversmithing and allied crafts at the John Cass college, London Guildhall University where my interest in the relationship between materials, process, and the scope for interpretation these offered was sparked. This interest has continued throughout my career with explorations in stone, wood, ceramics, printing, restoration, casting amongst others.

I was self-employed for fifteen years as a professional model maker, where the focus of the practice lay in building historical, architectural models, specializing in recreating buildings or interiors that have been lost or destroyed, often working from photographs or paintings for information. The models were displayed in museums around the world, including the Victoria and Albert Museum, London, UK, the Catherine Palace, St. Petersburg, Russia, and the Ando Museum, Naoshima, Japan.

I have a Masters in Fine Arts, where my interest primarily lay with drawing. The work resulting from this led to my exhibiting individually and as part of collectives, enjoying success in competitions including the international Threadneedle prize on two occasions and at the Royal Academy. My personal artistic practice is currently exploring the surpluses and deficits of meaning produced in phenomenological approaches to quantitative methods; how we interpret our world through the prism of technology. The work shown in Figure 1 is a hand-drawing, a human representation of how machines show us the world via various stages of mechanical and chemical process of image capture, initially from photography through to digital printing. The drawing is made with charcoal, perhaps the most fundamental of representational tools.

I now work as the model-making technician for the School of Architecture and Design at the University of Brighton. Here the role varies from demonstrating building construction techniques through to guiding students through the creation of atmospheric, conceptual models and teaching the theoretical position of models in design practice. Despite the growing prevalence of digital technology in the architectural design process and education (Stavric et al. 2013) my pedagogical approach is underscored by the fact that we should not disregard physical models as anachronistic in our drive to explore the digital version of our world. I maintain that the infinite potential in the emotive, embodied understanding found in the perception of and haptic interaction with materials should not be ignored in education and practice. The aspiration is to teach a respect for materials and an understanding that their application can convey and question the ideas and intentions of design practice. This current undertaking started as an investigation of this potential.

I have no direct, personal experience and, until engaging with this study, was unaware of anyone I know of, having rheumatoid arthritis. In engaging with this project, I felt that the disease offered several key avenues for creative research. Although there are some discernible symptoms, such as joint distortion, widely recognised as the characteristic markers of the disease, it is the internally experienced, hidden symptoms that provide the challenge when a visual expression is sought. These are interesting precisely because they are subjective and easily misconstrued; rather than being able to point at the problem, they rely on language, description, and metaphors, for understanding. The symptoms and actions of the disease on the body immediately offer metaphoric and visual cues to explore through models and materials, such as the erosion of bone structure, the distortion of joints and the concept of eating oneself. Although it was initially an interest in visualising these, I grew, through this project to realise it is the expression of how life is lived in this circumstance that pushes materials and models beyond current prescribed or considered boundaries.



Figure 1: Pinhole-camera-print 1. (841x594mm hand drawn charcoal on Bristol board. Researcher's own, 2013).

vii. GLOSSARY OF TERMS

This thesis draws on varied strands of different fields of study. Throughout I have made every attempt to explain the meaning of terms or specialist words as they arise so that the reader is hopefully not too diverted from the intended path. For this reason, I have not included a glossary of terms in the traditional sense of a brief dictionary on this topic, but instead, I have provided a list of described keywords that help define what I believe holds significance as a cue to understanding and I have described them to help frame what I mean by using them.

EMBODIED	A way of describing the combination of things that make us who we are (mind, body, environment) not as a collective but as a singular indivisible unit.
LANGUAGE	The means of seeking and sharing knowledge between others.
TRANSLATE	The means of converting the different ways that others communicate so that we can understand or be understood.
VISUALIZE	To make something, whether it be an idea, a memory or a description, hold a form, nominally in the mind's eye, but primarily in this context to visualize something is to capture that imagined image so that it can be shared, as a drawing or an object for example.
MATERIAL	Materials are the physical <i>and</i> manipulable elements that make up our environment.
MODEL	An assembly of materials put together in such a way as to stir something in the memory, in this context an artifact (human-made)

viii. EPIGRAPH

As we have no immediate experience of what other men feel, we can form no idea of the manner in which they are affected, but by conceiving what we ourselves should feel in the like situation.

Though our brother is on the rack, as long as we ourselves are at ease, our senses will never inform us of what he suffers.

They never did, and never can, carry us beyond our own person, and it is by the imagination only that we can form any conception of what are his sensations. Neither can that faculty help us to this in any other way, than by representing to us what would be our own, if we were in his case.

It is the impressions of our own senses only, not those of his, which our imaginations copy.

By the imagination, we place ourselves in his situation.

Adam Smith, *Theory of Moral Sentiments* (2010)

1. INTRODUCTION

Language lies at the heart of this research and the ability to communicate and evoke feelings are the core principles behind its aims. This project is an exploration of how modelmaking, rather than offering a mimetic description, can instead be evocative, expressing a set of qualities that create an empathetic appreciation of a person’s experience in those who encounter it. In particular, the aim was to communicate the lived experience of rheumatoid arthritis (RA).

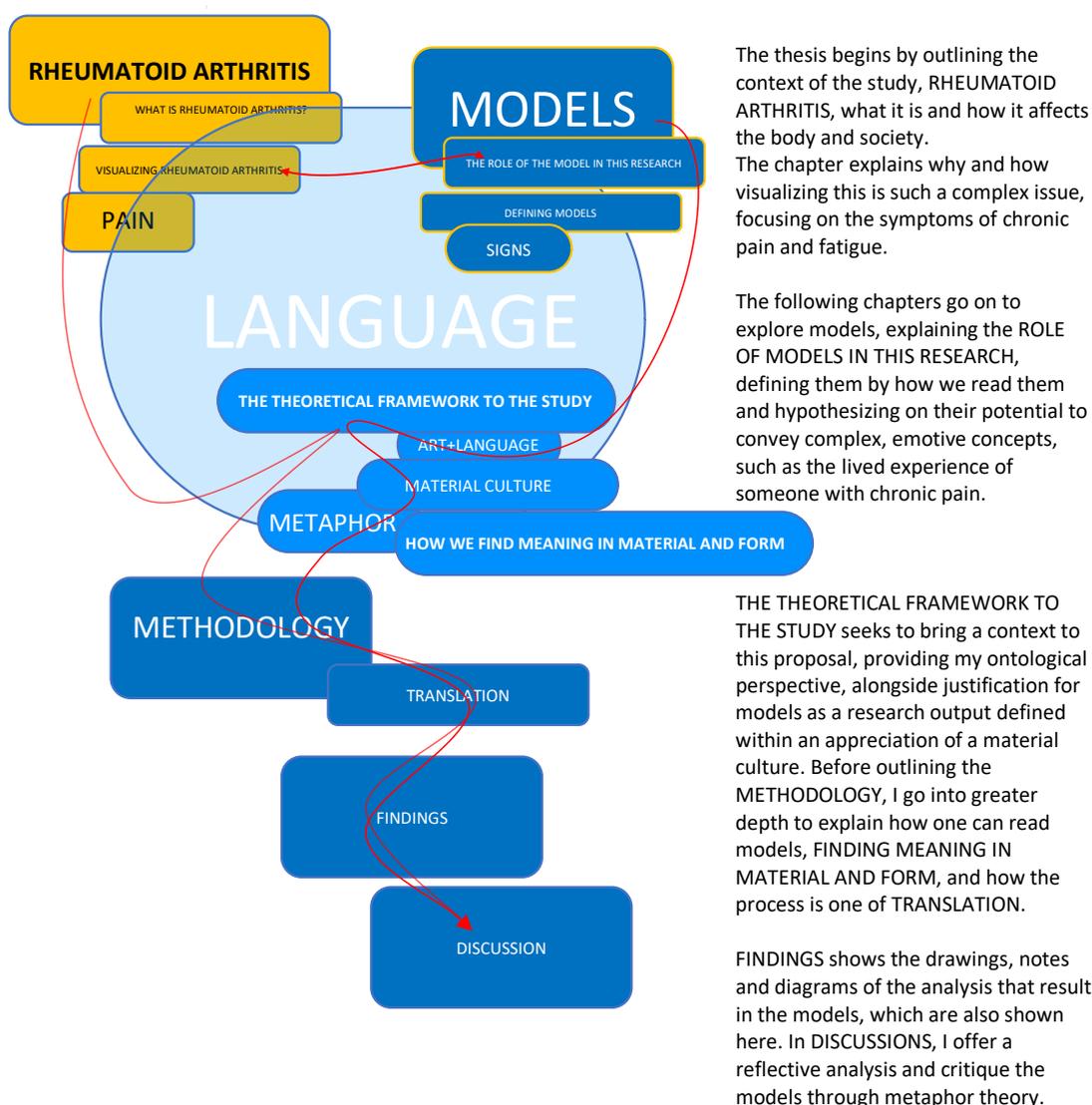


Figure 2: road map setting out the path and relationships of the following chapters.

The motivation for this project was to make a positive contribution towards the wellbeing of people who live with RA, providing new ways to open conversations about RA in the wider public realm, raising awareness in the process. RA is a chronic, idiosyncratic disease relying on medication to alleviate symptoms as there is currently no cure. The ability to treat RA is known to be more effective if it is discovered in the early stages yet the public understanding of what the disease is, and the effects it has, are sadly deficient. For those who live with RA, further complications arise from this backdrop of nescience as many of the symptoms they live with are hidden from the public gaze further scaffolding an environment of misunderstanding and increasing the hardship in coping. This study aims to extend the understanding of those without the disease through the perceptions and beliefs of those living with RA, focusing on expressing individual, expert perspectives.

Various visual approaches have been employed to communicate about RA to the public to counter this lack of understanding. This study discusses how these approaches draw heavily on metaphoric clichés and, although these may provide a quick fix to the initial awareness of the disease, they fail to flesh out the complexities or everyday realities that in many ways truly define the lived experience.

By highlighting the limitations in current approaches to improving public understanding of living with RA, this research explains how, in the worst cases, the public image of the disease can be misleading, questioning current visual approaches and how, when attempting to create a sense of empathy, defined in this study as a cognitive act of social embodiment, they instead generate sympathy, as in pity, or simple misinterpretation instead of understanding.

I will discuss how visualizing symptoms such as physical pain or fatigue are increasingly important in describing how we feel to others and the importance of this in appreciating a patient's condition as part of any medical diagnosis. I explore various routes taken, explaining how these increasingly rely on empathy and language drawing on a shared imagination and culture.

This thesis presents a qualitative approach to the communication of the lived experience of RA through a modelmaker's lens, drawing on perspectives to language that currently lay outside of practice led inquiry. This provides fresh scope to engaging in Arts and Health research practice. Rather than offering a protracted account of the disease and its symptoms, the study focuses specifically on how ways can be found to communicate the lived experience of RA. To appreciate

and attempt to understand this, one needs to empathize with the person with RA as a person in society and not as a case study of a disease. The project would have been impossible without the interest and support of three individuals who agreed to participate in this study, each bringing a unique appreciation of life with RA. All the information for this research has been taken from conversations with them.

Theoretically this study takes a hermeneutic path following the philosophy of H.G.Gadamer. His work on the role of art as both truth and method in approaching questions of the human condition provided the scaffolding for the whole study. Although Gadamer also wrote extensively on the concept of health and wellbeing throughout his lifetime (Gadamer 2018) this study will not draw on this work as it has not been my intention to draw out philosophical concepts of the nature of health and disease, or to offer a critique of a participant's perspective. Although connections could be drawn with comments made by the participants of their experiences, for example, Gadamer's ideas on health as freedom (Gadamer 1963) or the idea of health as a state of inner accord based on subjective evaluations of how one feels rather than a diagnosis (Gadamer 1987), my aim has not been to evaluate the participant's experience but to translate it.

My intention, in using Gadamer's philosophy, was to devise a process for dissecting verbal and visual languages as a means of communication and translating between these seemingly distinct orders. However, his was a purely philosophical undertaking and currently there are no research methodologies that frame his understanding through any practical engagement with the arts. This study therefore developed a new methodology, concentrated in visual practice but described so that others could benefit from the work if seeking approaches to analysis and investigation, communication and language, and the appreciation of models in research.

This thesis does not see the philosophical stance of Hermeneutics as a method of research but rather, a means to approach understanding. The attraction for this research in applying Gadamer's thoughts lays in the concept that truth is not reducible to a set of criteria but is an experience of change and reflection drawn from interaction and communication.

The structure of this thesis developed around this principle. Initially it provides the grounds and need for the study and then proceeds to lay out a path to understand material culture as a way to convey the lived experience of rheumatoid arthritis.

The hermeneutic methodology engages with design practice and cognitive linguistic theories as part of the process of analysis and translation, which is applicable but not specific to the analysis of the lived experience of people living with RA. The models, as outcomes of the research, demonstrate how the theory presented could be applied to future investigations involving phenomenological and arts/design-based research, but also offers approaches to how materials could aid understanding and communication in the Health profession.

This research has applied theoretical understanding from across numerous disciplines of philosophy, art, and science as I have sought to understand models as a communicative process. But this combination should not be seen as clashing. In her book, *'Echo Objects, the cognitive work of images'*, Professor Barbara Stafford of the University of Chicago, embarrassed by "the intense reluctance of art" to engage with the current cognitive revolution, discussed the need "to let art play a conceptual role in what neuroscience says about it" (2007, p.1-2).

In answer to this, as well as placing my understanding of the language of materials within a philosophical and practical framework, I also outline how theories in cognitive science engage with this concept, explaining how we find meaning in material and form through this perspective.

I will explain the foundational role that metaphor plays in understanding our world, both verbally and visually, through a discussion of Conceptual Metaphor theory (Lakoff and Johnson 1980, 1999). Gibson's theory of affordance (1954), explaining how we physically interact with our environment, will frame how I understand that an object's shape and material qualities can communicate expression, an approach that can be seen in sign language (Taub 2001) and the way that sign language finds meaning in cultural references to both visual and embodied multimodal experiences of the world. I will also discuss the role of memory, in particular exploring Barscalou's perceptual simulation theory (1999), explaining how our understanding of and engagement with the world around us, is framed by elements of experience contextualized through multi-modal, sensual awareness. These references provide the analytical structure to the research, a path to explore how models, as a combination of formed materials, draw on multimodal experience to evoke meaning.

The importance of appreciating the cultural, social, and historical context of empathy is discussed from the perspective of understanding another's situation but also as a route to communicating visually through models. The process will be explained as one of translation and I will be drawing on the principles devised by Seleskovitch and Lederer (1995) for the interpretation of the spoken word into sign language. This is a holistic act of comprehension and reformulation in context rather than a

purely analogistic approach to language that defines the meaning between words and ideas; the principle of understanding something as sense for sense rather than word for word.

The study extends our understanding of the complexities of describing the lived experience in research, proposing novel strategies for how this challenge may be overcome, and offers models as a mode of communication. Another ambition for this thesis has been to promote the value of model making's contribution to research practice. I therefore devote some time to provide a clear understanding of models and their role in framing our world view, offering a greater understanding of material culture as language and the role modelmaking can play in supporting these initiatives.

Throughout this research the term model is used in reference to 'material models', as opposed to digital or virtual 3-D models or theoretical models, these refer to purpose built, three-dimensional objects made from physical materials. To frame these models both conceptually and practically within research practice, I discuss the various perceptions and categories of the model as a vehicle in art and design. Drawing on how Gadamer sees understanding occurring through dialogue and how art brings knowledge through presentation (Gadamer 2004), I show that current definitions limit the model's potential to engage in research as a catalyst to understanding.

I avoid the use of the anonymous third person as narrator in this thesis, accepting that my voice is not neutral. The aim here was not casual but in the pursuit of reflexivity and to maintain the social, conversational appreciation throughout the research of what understanding is, in keeping with the epistemological understanding of Hermeneutic study (Webb 1992). The language I use, both material and linguistic, and the participant experiences discussed throughout this research project, take place in the United Kingdom, Northern Europe. I am aware of the importance of placing this study in its cultural context and, whilst this may offer what I see as definitive and rich parameters to work within, it may also potentially, however unwittingly, blinker my perspective. One of the wonders of human embodied experience is that it plays out differently in different situations, even iconic gesture, recognised as 'unmistakably similar around the world' is appreciated for its diversity (Cooperrider 2019). In the light of this, I am aware that what I may offer as an accepted norm as an example in the text may not translate verbatim if the reader has the good fortune to sit outside of my cultural context. If faced with this, I hope that the reader accepts the principle of translation applied in the methodology of this research and is able to appreciate the *sense* in what I am trying to say, the meaning beyond the words.

2. RHEUMATOID ARTHRITIS

2.1 WHAT IS RHEUMATOID ARTHRITIS?

Rheumatoid arthritis, as understood today, has been documented and described in medical literature for more than two hundred years¹. Rheumatoid arthritis (RA) is a chronic, inflammatory disease, principally attacking flexible joints though it also affects organs and other parts of the body. It is, potentially, extremely painful, induces extraordinary fatigue, and, if not adequately treated, it can lead to substantial loss of functioning, mobility, and increased mortality (National Rheumatoid Arthritis Society NRAS 2016).

Over time, all those affected by the disease suffer extreme pain and restricted movements in the joints. The progress of RA varies from mild, fluctuating periods of devolution with periods of good health to cases involving extreme joint damage, inflammation and damage to the vertebral column, vasculatures, and organs such as the eyes, skin, heart and lungs.

RA starts with inflammation, itchiness, soreness, and ache that builds to debilitating, gnawing, throbbing pain. This affects the soft tissue membrane (the synovial membrane) lining the two sides of the synovial joints, the most common type of joint in the body that facilitates movement. The inflammation tends to start in the smaller joints, those of the hands or feet (Robinson, 2008). As the inflammation increases it begins to destroy body tissue.

The synovial fluid that lubricates the joints and eases movement, accumulates in response, but now with greater viscosity causing the joints to swell and distort over time (a visible symptom known as deviation). The fluid forms into an abnormal tissue, a pannus, which, tumor-like, continues to grow. This stimulates aggressive enzymes and other inflammatory cells that attack and erode cartilage and

¹ The first recognized description of RA was in 1800 by Dr Augustin Jacob Landré-Beauvais at the Salpêtrière Hospital in Paris. Landré-Beauvais noted that the disease exhibited several distinctive attributes, including “predominance in women, a chronic course, involvement of many joints from the onset, and a decline in general health” (Landre-Beauvais, 2001, p.131). The name "rheumatoid arthritis" itself was coined later in 1859 by British rheumatologist Dr Alfred Baring Garrod.

bone. The body responds in defence causing more synovial fluid and building scar tissue over the eroded areas. This tissue ossifies over the joints leaving them immobilized and deformed. The surrounding structures of the inflammatory joints, including muscle tissue and tendon can then become affected increasing the deformation, putting pressure onto further joints, causing inflammation initiating the body's response with synovial fluid, described by Eileen Davidson as if 'someone has your extremities in a vice trying to turn and twist them into a new direction' (Creakyjoints.org 2020). These processes are generally irreversible (Marieb and Hoehn 2010). In conjunction with this, RA's relationship with the body's immune system invites the development of numerous comorbidities from cardiovascular disease, hemiplegia (a paralysis of half of the body), diabetes, liver disease, lung disease to stroke, asthma or obstructive sleep apnoea (Kronzer, et al. 2019), each or any of which greatly increase the possibility of premature death.

At the time of writing a true comprehension of this disease, its etiology (Stanich et al. 2009) or indeed, a cure has yet to be found (Versus Arthritis 2020). Although research is ongoing, current available treatments (such as disease-modifying anti-rheumatic or non-steroidal anti-inflammatory drugs) are intended to ease symptoms, such as pain, prevent joint damage and delay the progress of the disease working as part of a system of management of the disease organized around the understanding of the patient with support from professionals.

2.2 THE IMPORTANCE OF AWARENESS

This holistic approach to care needs funding if it is to be supported and directing Government funding towards this goal is a major concern for charities but this relies on generating and maintaining awareness in the public realm (NRAS 2018a), however, "across the board - RA patients, their families, healthcare professionals and patient organizations - all believe that greater public awareness is required" (NRAS 2013, p.11). In 2013, the NRAS undertook a major UK wide survey on the impacts on the family of living with rheumatoid arthritis, called 'Breaking Down Barriers: Rheumatoid Arthritis and Public Awareness'. In the survey, 93% approached said running public awareness campaigns would be "very helpful" (NRAS 2013, p.12), stating that a lack of awareness made it more difficult for them to cope and contributed to difficulties they experienced in talking about their partners' RA (Hewitt 2014). A further document by the Arthritis National Research Foundation (curearthritis.org 2021) described the 'myriad benefits' awareness brings, highlighting key points it felt most relevant including destigmatizing those with the disease, increase chances of

identifying the disease at an early stage, the ability to raise funding for research and care through charities but also government legislation, and helping to improve the quality of life of those with RA with accommodations in the workplace and fairer access to services, for example.

Awareness does not only bring benefits to those already suffering from RA; “given what we know about the striking impact that early diagnosis and appropriate treatment can have on disease progression, public awareness needs to be much higher” (NRAS 2013, p.3). Understanding symptoms and the importance of reacting to these within a set time frame of around 12 weeks (Simmons et al. 2016) greatly enhances the potential of successful drug treatment (Emery 2002; National Institute for Health and Clinical Excellence 2009). It has been estimated that with an increase in rapid diagnosis, and the improved responses to treatment that it brings, the health service would save around £2 million per year (Simmons et al. 2016).

Awareness brings other benefits, strong social networks and support has been shown to help deal with symptoms such as fatigue and pain in RA (Barlow 2001) and awareness reduces the potential for malinformed but well-meaning advice shown to worsen the experience of the disease increasing the sense of isolation for those with RA and those close to them (Morrison and Bennet 2009; Riemsma, et.al. 2000).

Campaigns set up to create awareness of RA are a significant focus for the leading charities in the field², and are constantly raised in proposals to Government as being of national importance (National Institute for Health and Clinical Excellence 2009; National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis 2016). However, despite regular action, public awareness about the

² National Rheumatoid Arthritis Society (‘Better be clear’ pre-emptive campaign 2015, RA awareness week 24th-30th June 2013, Responsibility Deal 2013), EULAR (European League against Arthritis (World Arthritis day Friday 12th October, since 1996, ‘Don’t Delay, Connect Today’ awareness campaign 2019, ‘Waving’ campaign 2012), The Rheumatoid Patient Foundation (RA awareness day Feb 2nd, Women’s Rheumatoid Arthritis Project 2013), The Arthritis Foundation (Arthritis month, May 2013, ‘I am the face of arthritis’ campaign), Versus Arthritis (merger of Arthritis Research UK and Arthritis Care) (Defy Arthritis campaign, 2018), the purple Rheumatoid Arthritis Awareness ribbon campaign sponsored by the American College of Rheumatology since 2016.

symptoms of RA has not improved over the last decade (National Clinical Audit for Rheumatoid and Early Inflammatory Arthritis 2016).

RA is alarmingly common, affecting 1 in 100 people of all ages in the UK (NRAS 2018) and more than 2.3 million individuals diagnosed in Europe (O'Hara, et al. 2017), Indeed the charity, NRAS, claims that the disease affects approximately 3.7 million people with the average onset between 30 and 60 years old, stating that "for every person [within the UK] with the disease, approximately 4 others will also be affected" (NRAS 2018, p.15). RA has also been found to be more prevalent in women at a rate of 3:1 (Wolf et al. 1968; Forslind et al. 2007). However, the argument that more elevated levels of activity has been noted in women needs to be appreciated in the light of other factors, not the least that measurements of disease are not sex neutral or that men and women are treated differently in health care (van Vollenhoven 2009).

Despite this, RA is a very misunderstood disease in the public realm (Westrich 2016; Hewitt 2014). The poll commissioned by the charity NRAS (2013) revealed that 62% of those polled mistakenly believed that RA was due to the wear and tear of joints over time (presumably drawn from the popular experience of the degenerative joint disease, osteoarthritis). This figure was worst among young people aged 18-24 (75%) exposing a worryingly common misconception about the disease. The King's Fund report (Steward and Land 2009) into the "Perceptions of patients and professionals on rheumatoid arthritis care" stated that "one major cause of delays for many patients is the low level of awareness of RA among the wider population, i.e.: patients may delay themselves seeking help" (p.11). One of the main challenges faced in combating RA is to get "members of the public to recognise the early symptoms of RA, understand the severity of the disease and to urgently seek out medical advice from their local General Practitioner". (NRAS 2013, p.2).

The understanding and awareness of the disease lurks "below the radar of public consciousness and - some would argue - below the radar of many in the health professional community" (NRAS 2013, p.4) highlighting the distinct need for contributions to enhance the understanding and awareness of RA "looking beyond the medical and physical elements of the disease" (Steward and Land 2009, P.14).

2.3 PUBLIC PERCEPTION OF RHEUMATOID ARTHRITIS

“Recognition of the impact it has on other activities of daily living...recognizing the social and psychological impact” (Steward and Land 2009, p. 12) could go a long way to tackling the “feelings of loneliness fear and despair” (ibid. p.22) that sufferers endure. However, in looking at the visual material relating to the experience of RA available to the public, the focus lies in readily understood metaphors to pain such as the ominous glowing red spot on a scientifically clinical, blue skeleton, which is used to convey the sensation of everything from lower back pain, migraines to toothache; so how a member of the public is supposed to judge the experience comes down to how many or how intense the red spots are.

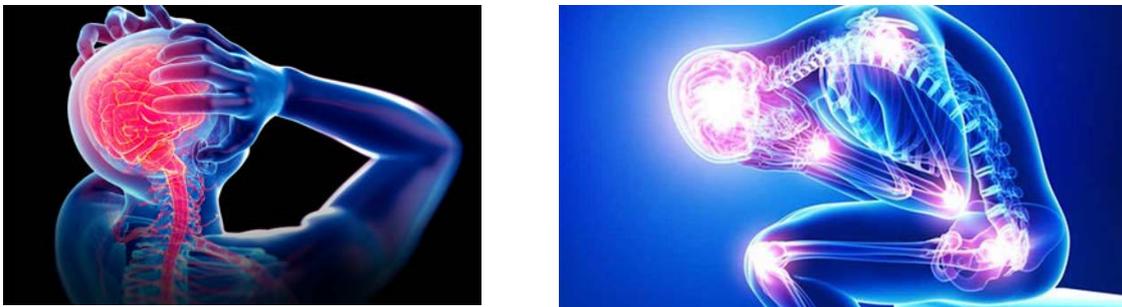


Figure 3: Symptoms and Signs of a migraine and symptoms and signs of Rheumatoid Arthritis, <https://consciousofnews.com/symptoms-signs-rheumatoid-arthritis-can-treat-naturally/11121224/> [last accessed 25/05/2019]
<https://www.painfreelivinglife.com/pain-conditions/migraine/tension-headache-or-migraine-how-to-tell-difference/> [last accessed 25/05/2019]

Compared to the aforementioned public perception of osteoarthritis, which is easily appreciated conceptually as a result of general ‘wear and tear’, which one can relate to everyday items in our possession such as clothing or tools worn out through use over time, attempts to visually explain the

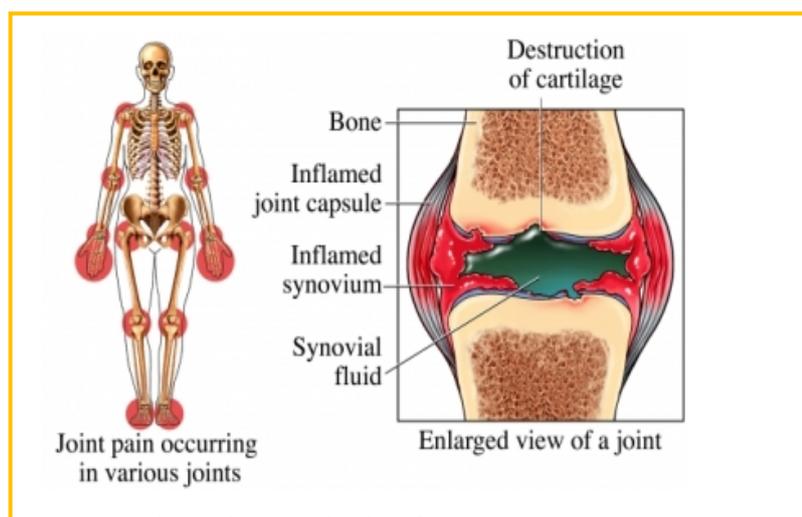


Figure 4: What is Rheumatoid Arthritis? <https://www.hygeia.gr/en/>

complexity of the physical causes and symptoms of auto-immunity in joint structures invariably result in *medicalesque* diagrams.

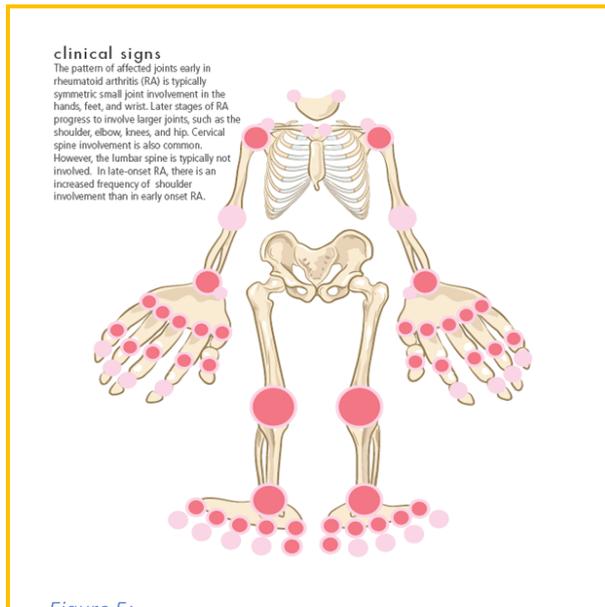


Figure 5:
https://www.medscape.com/viewarticle/546105_2

Such diagrams initially locate the viewer using skeletal structures emphasizing the internal viewpoint and the medical nature of the visual data, as well as drawing connotations to human mortality. Elements of red provide the focus, drawing instinctively on the human connections of blood or to areas of pain, these dots have become commonplace visual metaphors for pain and as in Figure 5 they can be overused to the point where the diagram becomes comical. Used prolifically in the public realm, their meaning has become generic, as has the pain they represent.

These red zones become markers, highlighting points of concern around the body but often resembling combat wounds from bullets. In the infographic below the red dots themselves become targeted within a gun sight reinforcing the ‘attack’ of the disease.

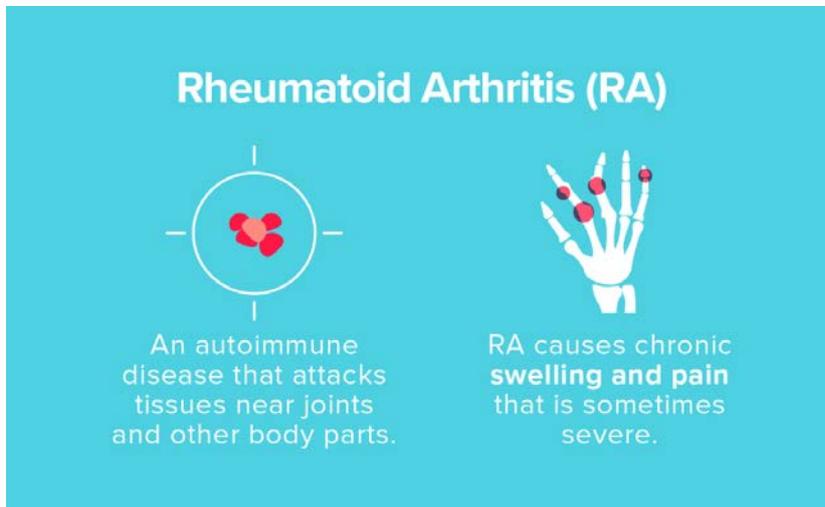


Figure 6: <https://www.healthline.com/health/rheumatoid-arthritis/facts-statistics-infographic#1>

Such militaristic concepts are prevalent in health, used by both patients and the medical community. In 1971, President Nixon declared war on cancer (Penson et al. 2004) and while such narratives have been widely criticised in literature (Sontag 1977; Nie et al. 2016) they continue to be used graphically to capture the public imagination to describe the fighting, surrounding, signalling, detection, and advance of disease, such as with the use of red arrows to suggest the journey of the disease referencing troop movements in military maps, as can be seen in the comparison between the maps below.

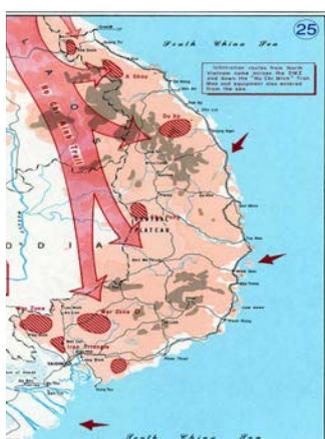


Figure 8: Troop movements
<https://www.patriotspoint.org>

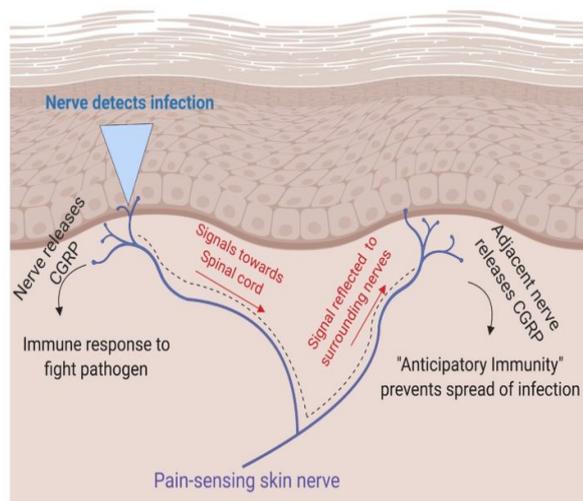


Figure 8:infection movement
Image credit: Jonathan Cohen/Adapted from Cohen et. Al., Cell 2019

The visual connotations of these diagrams lend credence to the perception of illness as something to fight, that can be beaten if one tries hard enough or that in some way the body needs to be cleaned, leading ultimately to the possible conclusions that the person who has RA is a pariah, or someone who is under attack and is therefore a victim (Nie et al. 2016). They provide little relevant context to an awareness of what having RA means to someone's everyday existence.

The effect of RA on the physical structure of the body is traumatic but it also impacts heavily on mental health, resulting in increased stress and social isolation (Belza et.al. 1993; Hewlett et.al. 2005). "Physicians have historically separated the diagnosis and management of psychological health from physical health. We are learning at high cost that this division of care results in suboptimal treatment. By neglecting mental and behavioural health, contemporary medical practice makes it near impossible to succeed in holistic care and improve health outcomes." (Galloway in NRAS 2018a, p.5) Maintaining the mental health and wellbeing of patients is widely accepted as part of the health professional's role but despite the desire to provide such support, they "themselves rate their overall provision as inadequate, which may explain why healthcare professionals are not asking about mental health" (NRAS 2018a, p.27).



Figure 9 Living with chronic pain and living with teenage depression
<https://rheumatoidarthritis.net/living/how-i-manage-my-never-ending-fatigue/>
<http://www.hp-publications.co.uk/products/53>

Other visual routes attempt to conceptualize this issue through metaphoric images such as being trapped alone, a rose, in a nest of thorns but such imagery draws similarities to other awareness campaigns, such as for teenage depression. Although the intent is to highlight the sense of isolation that living with either condition can bring, such a universal visual analogy promotes the 'I know how that feels' commentary and the comparisons that undermine any understanding (CreakyJoints.org 2020)

Most imagery available online through search engines such as Google searching with the keywords 'Rheumatoid Arthritis' [accessed 16/01/2020] link to the most visible and recognizable symptom of RA, the deviation in the hand.

Visualizing RA in this manner contextualizes RA in everyday life, but, although the message is clear, 'RA looks like this', in an image such as the one shown in Figure 10, the suggestion links to misconceptions about the disease that most trouble the leading charities and health professionals, namely that it is a disease of older people, it is caused by over working the joints, or it is affected by climate (NRAS 2013). The botanical reference also draws connections to more settled, older generations with the secateurs nipping the flower another almost casual metaphor of how life can be 'cut short'.



Figure 10 Public perceptions of RA
<https://www.aarp.org/health/conditions-treatments/info-2019/relieve-inflammatory-arthritis.html>



Figure 11:
https://www.roche.com/research_and_development/what_we_are_working_on/immunology/arthritis/rheumatoid-arthritis-through-the-lens-of-an-artist.htm

The visual link between the deviation of the hand as emblematic of RA is reinforced in the approaches of artists where the topic of interest lies with RA. In 'The Art of Living with rheumatic diseases' (2009) Manja Zore, working with the University Medical Centre and Roche Slovenia to raise awareness around importance of access to RA treatments, decided on images of the hands as symptomatic of the lived experience of RA (Figure 11).

Figure 14 shows the artist Francesca Corra's work 'Healing hands: the art and science of arthritis' (2015) at the Kennedy Institute, which investigates the nature and impact of the disease through a series of drawings and paintings that captures arthritic diseases of the hand, whilst in the exhibition 'Interweave' (2017), Deborah Gardner, again through drawings, drew attention to the effects of arthritis and its relationship to the textile industry (Figure 12).



Figure 14: <https://www.leverhulme.ac.uk/former-schemes/healing-hands-art-and-science-arthritis>



Figure 12: 'Interweave' (2017), Deborah Gardner,

This symbolic relationship is also used by leading charities such as EULAR in their 2012 campaign 'waving for awareness' (Figure 13) or, using a more linguistic metaphor approach, their 2018 awareness campaign 'Let's Get a Grip on Arthritis'. Although such approaches have great value in

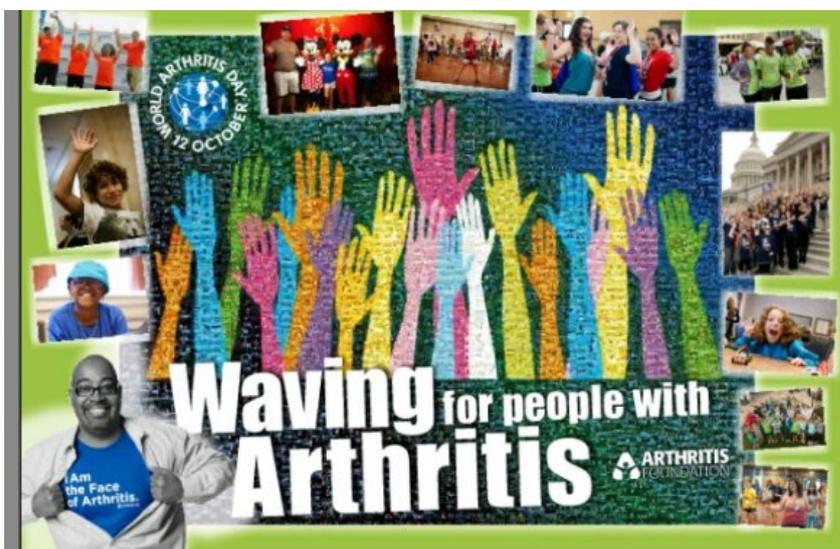


Figure 13: <https://unitedadvocacyaustralia.wordpress.com/2012/10/14/waving-for-people-with-arthritis/>

raising awareness of RA as a disease that people have, they do little nor are they designed to communicate the complexity of the lived experience.

2.4 COMPLICATIONS IN VISUALIZING THE EXPERIENCE OF RA

“RA is... a very individual disease with no universal pattern to the symptoms” (NRAS 2013, p.5) and research has shown that this is also reflected in the idiosyncratic nature of the experience of the disease (Nikolaus et.al. 2010). Therefore, any representations of the experience of RA would be equally idiosyncratic, undeniably a factor in choosing this as the focus for the research.

A second important element was the “hidden” symptoms (NRAS 2014) that define the experience beyond the visual cues that the public eye empathizes with RA. Visualizing such attributes is complex and relies on infographics, simple visual metaphors that describe the complexity rather than the information, which is presented in text. Advertising success relies on a ‘keep it simple’ strategy (Green 2008), conveying a clear yet memorable message accepting that the audience’s attention is fleeting and preoccupied. The idea of the iceberg seen in Figure 15 works well in this context.



Figure 15: Hidden dangers <https://www.myrateam.com>

Rather than undermine or obscure the complexity of the lived experience of RA, by associating RA with an iceberg, the disease is subconsciously semiotically linked with all the iceberg symbol represents in society, cold, danger, much more lying unseen. Such imagery seeks to promote awareness more than understanding; there is more to RA than what you see. The educational simple configuration of the graphics reinforces the message and stops the viewer from feeling threatened or disconnected by the unwelcome topic (Floch 2005). The concept of semiotics as a driver of meaning is further discussed on page 46.

Of the 'hidden' symptoms of RA, pain and fatigue are the two most frequently reported; however, leading charities are duly concerned about the societal appreciation of these symptoms, As Laurie Ferguson, director of education development for CreakyJoints stated, "we live in a culture that is not empathetic to chronic pain, period" (CreakyJoints.org 2019). Despite research into the topic and the appreciation of their impact on quality of life (Stone et.al. 1997), there are still misrepresentations and gaps in the understanding of chronic pain (Phillips 2009; Lister 1996). "Lack of awareness of RA makes it even more isolating. Too often, even doctors doubt how much RA patients endure" (Rheumatoid Patient Foundation 2013). Bury (1988) discussed concerns nearly thirty years ago regarding the perceptions of RA between patients and professionals, and although education about living with RA, specifically in General Practice, has improved, "serious issues remain" (NRAS 2013, p.8). "Despite evidence... there have been no notable calls to action from organizations. Instead, the main calls for action have come from patients" (NRAS 2014, p.19).

2.5 VISUALIZING FATIGUE

In 2014, NRAS conducted a UK-wide survey on fatigue called *Invisible Disease: Rheumatoid Arthritis and Chronic Fatigue* that stated "chronic fatigue is the least publicly understood symptom of RA" (NRAS 2014, p.8). Fatigue, according to Ailsa Bosworth MBE Chief Executive of NRAS is difficult to treat as there is "is no magic pill or instant resolution" resulting in a frustration that leaves this experience often avoided in conversations between professionals and patients (NRAS 2018).

Dr Katie Druce, researching into the lived experience of chronic conditions such as RA, highlighted that this lack of communication alongside the hidden quality of the condition results in feelings that "healthcare providers, friends and family members don't care about their fatigue" (NRAS 2018, p.4). Whereas, the truth, she believed lay in the inability to relate to it, "most of us know what it feels like to be tired, but few of us can understand the overwhelming feeling of physical and mental exhaustion reported by people with RA" (Ibid.).

Without referencing a relationship of cause and effect for fatigue such as having just exercised or carried heavy loads, the concept is hard to present to the public. Graphics rely on the metaphoric link between being literally worn out /run down and a drained battery or a wound down clockwork toy.



Figure 16: no power to work
<https://rheumatoidarthritis.net/infographic/strategies-dealing-ra-fatigue/7/>



Figure 17: a run-down clockwork toy with key and a drained battery included
<https://www.independent.co.uk/life-style/health-and-families/new-recognition-for-chronic-fatigue-a8081751.html>

However, these give a misconstrued and potentially undermining concept of fatigue when one considers phrases like ‘just rest up, you’ll feel better’ or ‘I’m tired too, it’s been a long day’ are considered amongst the top ten as things not to say to people with RA according to the Creakyjoints.org website.

Kelly O’Neill Young, who publishes a successful blog site on RA commented on the frustration she felt with comparisons of fatigue with tiredness. She described her fatigue thus:

“It feels like some *thing* is pulling me backwards. It’s not the stiffness that makes moving extra difficult. Or the ice-pick pain or tenderness I have in every joint. It’s neither depression nor hopelessness, it is something that’s making gravity stronger. *This is not the same as being tired*”.
 (https://rawarrior.com/rheumatoid-arthritis-fatigue-is-not-just-being-tired/ [last accessed 20/01/20])

2.6 UNDERSTANDING PAIN

As with fatigue, pain is also a private experience. If we are unable to see the factors, causes, or any visualization of pain, as is often the case with RA, it becomes suspect; not just in the perception of

others but in our own reflections on our own pain (Csordas 1994). In Western culture³ we have come to accept pain as “a clinical experience that is relegated to medicine for alleviation” (Neilson 2015, p.2). We believe that pain, if describable, is fixable and so we seek readable, quantifiable, and hopefully visual symptoms (Ho and Johnson 2013; Jackson 2005).

If my aim is to translate the lived experience of RA to others, then an understanding of the cultural imagery of pain is considered necessary. The following subchapters will question the concept of pain in more depth, asking how we communicate pain through words and metaphor, which words we choose and why, how we are able to communicate pain without words and how this brings to the fore that pain is intersubjective and an emotive reality as much as a physical entity. The intention is not to highlight pain as the overriding factor in RA but to show that such experiences, described as symptoms, are complex and cannot be easily isolated as a means of communicating how it feels to live with a chronic illness like RA but suggest that a multimodal approach is more fitting in both understanding and communicating.

2.6.1 THE CLINICAL NEED TO UNDERSTAND PAIN

In a study on the perceptions of RA, Studenic et al. (2012) highlighted different perspectives between sufferers and those given the responsibility of easing their pain. The paper shows that “pain is the single most important determinant of the patient's perception of RA disease activity” (p.2814), as opposed to the physician's perception where joint swelling is the best indicator⁴. Such

³ I use the phrase Western culture, not to describe any specific group of people, but rather cultural tendencies and practices that lean toward individualism and a scientific rationality more prevalent amongst European and derivative nations, expressed for example in the desire to capture visual realities through geometric perspectives in the West as opposed to temporal, panoramic visualizations of Eastern art (Kubovy 1986; Tyler and Chen 2011). These ways of seeing gave “different trajectories of abstraction in the Eastern and Western cultural environments [creating] unique conceptual frames” (Bao et al. 2016). It is Western culture that frames my reflections, proposals, and critiques in the work undertaken here.

⁴ One of the reasons for this discrepancy according to Studenic's study lies in the more positive ratings applied by physicians over patient's perceptions due to the physicians more educated awareness of the potential risks

‘discrepancies’ matter as an important aspect in the management of RA is a thorough evaluation and discussion of treatment decisions between the patients and their physicians, often referred to as “shared decision-making” (Studenic et al. 2012).

It is because of the importance of shared decision making that describing pain in the most accurate way has value. Our understanding of pain is based on our ability to use our experience and imagination to communicate. We express pain through imagining and imagery with the tendency to rely on a scientific metaphorical system to enable calculation rather than through our lived experience of a world in which pain is suffering, a ‘sorrow’ (Genesis 3:16) appreciated as an embodied, cultural and intersubjective experience as opposed to a sensed, physical sensation.

2.6.2 DEFINING AND DESCRIBING PAIN

Pain is more than a stimulus and the resulting sensory perception. The International Association for the Study of Pain defined pain as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage” (iasp-pain.org 2021). Pain starts with potential, a realization, leading to a response/vocalization, an attempt at avoidance and continues into the ‘self-soothing’ period that lasts beyond sensory perception (Melzack and Wall 1967). Pain is not in isolation to the circumstances in which it arises. This means that we do not solely experience cause then effect; a stab with a pin causes a wound which then evokes pain.

The most commonly understood pain, damage response pain, is nociceptive. In response to a variety of (noxious) stimuli that cause or threaten to cause damage to normal tissue, nociceptors (sensory receptors of the peripheral somatosensory nervous system that relay information about changes to the norm from the surface or inside the body to the brain) are triggered resulting in either an autonomic response, such as elevated blood pressure, or a behavioural response, for example, motor withdrawal reflexes (flinching) (Freberg 2015). These stimuli can be and are measured, often as a marker/guide to pain and pain thresholds despite the IASP statement that “the stimulus is not pain and cannot be a measure of pain” (iasp-pain.org 2021). Descriptions of pain, in contemporary

involved in any future treatments that would be required for a good disease activity outcome (Studenic, et al. 2012), in a sense, ‘things could be worse’..

Western society are dominated by metaphors based on medical and neuro-scientific discourse formulated around this understanding (Neilson 2015).

Morris, in the *Culture of Pain* (1991, p.4), wrote that “we are the heirs of the transformation in medical thought whereby we think of pain as no more than an electrical impulse speeding along the nerves”; pain is a response travelling along wires and through gateways (Melzack and Wall 1967). However, the IASP defined pain as an experience; pain “is always a psychological state” (iasp-pain.org 2021, p.226), stating that pain “in the absence of tissue damage or any likely pathophysiological cause...should be accepted as pain” (ibid.). Yet, although the IASP definition consciously “avoids tying pain to the stimulus” (ibid.) professional discourse on medicine, and the compliance of society in regards to its authority on the topic, still “decontextualizes experience in order to isolate pain as symptom and sign” (Neilson 2015, p.4); where the experience of pain is a sign of the coming together of the cause and effect of some physical encounter.

Descriptions of pain tend to refer to pain and the body objectively. Pain is conceptualized as separate from the self and does not fit within the projection of self-image (Jackson, 2005). Through language we instinctively seek concrete metaphors to describe the experience and emotion, pain becomes a physical entity that engulfs, sneaks up and attacks us, ‘the pain takes over’ (Couceiro-Bueno 2009). Yet it is also the case that we can often subjectify pain claiming that it is ‘all in my head’ (Couceiro-Bueno 2009; Csordas 1994; Jackson 1994, 2005). Feldges described this dialogue as a negotiation; “a self that relates itself to neuronal stimuli or emergent functional/cognitive states by trying to negotiate a position for itself” (Feldges et al. 2014, p.50). This negotiation can be seen as a desire for control. If the objective perspective sees pain as ‘out there’, real and as an object, pain can be fought off and subdued. Subjective pain isn’t ‘real’ and therefore it can be controlled ‘Zen-like’ from within through mental concentration (Jackson 2005). Indeed, if a pain were to increase beyond a certain point, subjective thinking tends to dominate as the pain becomes all encompassing; no longer separate or unavoidable, such pain becomes integral, we become the pain (ibid.).

Merleau-Ponty stated that, as opposed to seeing our body or pain as objects, this holistic and embodied approach to pain, where we are ‘*in pain*’ (2002, p. 107) is a more phenomenological experience; “while pain maybe cognitively localized, it is overwhelmingly the holistic individual who is involved in experiencing and expressing pain” (Strong et al. 2009, p.8). This appreciation of pain is even familiar to Descartes, whose work is often maligned as the antithesis to the concept of embodiment:

There is nothing that this my nature teaches me more expressly than that I have a body, which is not well when I feel pain...and by this sense of pain...my nature tells me that I am not in my body, as a mariner is in his ship, but that I am most nighly conjoyn'd thereto, and as it were blended therewith; so that I with it make up one thing; for otherwise, when the body were hurt, I, who am only a thinking thing, should not therefore feel pain, but should only perceive the hurt with the eye of my understanding (as a mariner perceives by his sight whatever is broken in his ship).

(Descartes 1680, p.97-8 taken from Gaukroger 2008, p.237)

Gadamer, the philosopher who provides the ontological framework to this study (see p.59), wrote that “pain embraces our life and challenges us constantly”⁵ (Felges 2014, p.47). He saw pain as confronting us with our lives, constantly engaging us in a debate whether to let pain dominate or whether to engage in a conscious reflection with the self on how to live “in the face of [life’s] painful limits and finitude” (ibid). For Gadamer it was through communicating our pain that any understanding of it could be made. We need to be able to communicate with others about our private, unobservable first-person state, our lived experience, in order to understand ourselves in a social context which then allows medical intervention. Simply put, an appreciation of how we feel in relation to those around us allows an assessment of whether seeing a doctor would be a good idea or not.

2.6.3 COMMUNICATING OR CALCULATING PAIN

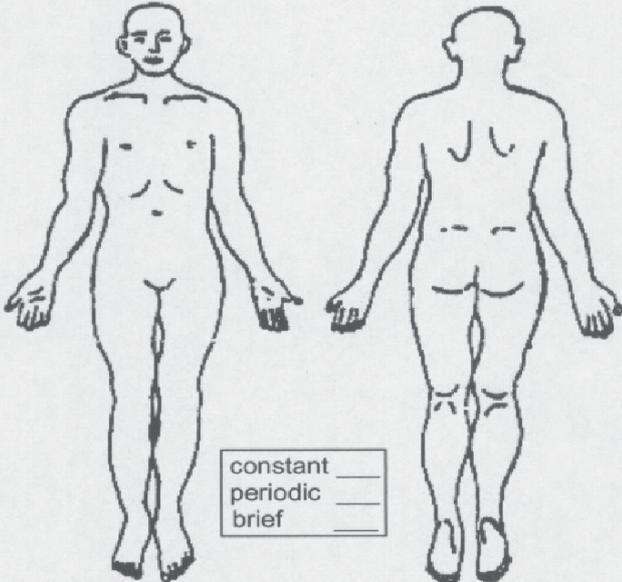
Assessment of pain by health professionals relies to a large degree on ‘self-reporting’ (ebmedicine.net 2021). In being asked questions such as “How do you estimate your disease activity today?” (ibid.) patients are expected to respond as quantitatively as possible using, for example, a 100mm visual analogue scale, marking a ten centimetre line somewhere between not at all severe and extremely severe (see Figure 18); a system which is considered to be reliable and valid (Bijur, Silver and Gallagher 2003) despite requiring some level of abstraction to engage with, i.e.: conceptualizing pain as distance or number, or understanding pain in the light of what past experience offers, or as a value on a social scale, how severe when compared to what others have suffered or may suffer.

5 There are direct similarities to be drawn here with the teachings of Buddha, in particular his first noble truth that we live in suffering (dukkha) and it is only from this perspective that we can grow.

Although “each individual learns the application of the word through experiences related to injury in early life” (IASP 2016, p.226) our understanding of pain is intersubjective (Csordas 1994). We learn pain language through societal and cultural behaviours we see and imitate (Strong et al. 2009).

McGill – Melzack Pain Questionnaire

Patient's name _____ Date _____ Time _____ am/pm
 Analgesic(s) _____ Dosage _____ Time Given _____ am/pm
 Analgesic(s) _____ Dosage _____ Time Given _____ am/pm
 Analgesic Time Difference (hours): +4 +1 +2 +3
 PRI: S _____ A _____ E _____ M(S) _____ M(AE) _____ M(T) _____ PRI (T) _____
 (1-10) (11-15) (16) (17-19) (20) (17-20) (1-20)

1 flickering _____ quivering _____ pulsing _____ throbbing _____ beating _____ pounding _____ 2 jumping _____ flashing _____ shooting _____ 3 pricking _____ boring _____ drilling _____ stabbing _____ lancinating _____ 4 sharp _____ cutting _____ lacerating _____ 5 pinching _____ pressing _____ gnawing _____ cramping _____ crushing _____ 6 tugging _____ pulling _____ wrenching _____ 7 hot _____ burning _____ scalding _____ searing _____ 8 tingling _____ itchy _____ smarting _____ stinging _____ 9 dull _____ sore _____ hurting _____ aching _____ heavy _____ 10 tender _____ taut _____ rasping _____ splitting _____	11 tiring _____ exhausting _____ 12 sickening _____ suffocating _____ 13 fearful _____ frightful _____ terrifying _____ 14 punishing _____ gruelling _____ cruel _____ vicious _____ killing _____ 15 wretched _____ blinding _____ 16 annoying _____ troublesome _____ miserable _____ intense _____ unbearable _____ 17 spreading _____ radiating _____ penetrating _____ piercing _____ 18 tight _____ numb _____ drawing _____ squeezing _____ tearing _____ 19 cool _____ cold _____ freezing _____ 20 nagging _____ nauseating _____ agonizing _____ dreadful _____ torturing _____ PPI _____ 0 no pain _____ 1 mild _____ 2 discomforting _____ 3 distressing _____ 4 horrible _____ 5 excruciating _____	PPI _____ Comments: _____ <div style="text-align: center;">  </div> constant _____ periodic _____ brief _____
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accompanying symptoms: nausea _____ headache _____ dizziness _____ drowsiness _____ constipation _____ diarrhea _____ Comments: _____	Sleep: good _____ fitful _____ can't sleep _____ Comments: _____	Food intake: good _____ some _____ little _____ none _____ Comments: _____
Comments: _____	Activity: good _____ some _____ little _____ none _____	Comments: _____

Figure 19: McGill Pain Questionnaire (Melzack 1975)

Our intersubjective communication of an internal, mental and private state relies on the assumption that our situation is “in principle sharable, and thus other persons could be or could have been in the

same situations” (Schmicking and Gallagher 2009, p.311). We assume that what is true in regard to our understanding of our experience would also be true to others if they were in our position, a principle based on our shared culture, the traditions and authority explained by Gadamer (2004) (see APPENDIX 4) that provide the collective knowledge and correct descriptions of reality alongside the understanding we have “adopted and acquired from others” (Schmicking and Gallagher 2009, p.308).

However, applied linguistic studies in the language of pain (Halliday 1998; Lascaratou et al. 2008) highlight the lack of social and semantic context of the MPQ’s words (Strong et al. 2009). Lascaratou proposes a framework to the understanding of pain which incorporates the MPQ’s adjectives of pain as a quality within a larger context, pain as thing-participant, pain as process and pain understood through metaphor theory.

In Western society we tend to see pain as a sensation described through adjectives as with the MPQ (Melzack 1975) with emotional overlays drawing from affective resonance (an empathy relating to how we respond to pain in its various forms as a society); yet pain as a sensation is both emotion and cognition simultaneously (Freberg 2015). Pain as an experience is not separable into the physical sensation and the meaning it has for us in experience. Any understanding of pain is to be found in context rather than abstraction.



Figure 20: Pain as a physical entity
<http://library.duke.edu/digitalcollections/mma/> [last accessed 17.04.19]

In Western culture, pain is usually understood as a physical entity⁷; pain is experienced by the body, the body is a physical object, therefore pain is physical. We understand the principle of cause and effect, which leads us to the belief that one can see pain, a concept reinforced through the visualization of damage and wounds through technology such as X-rays, Ultrasound imaging, or MRI, etc. We undertake physical acts to *get rid of* pain, often objectifying it as something culturally unsound, alien or monstrous (see Figure 20). We use metaphors describing the body as a container that holds pain, often seeing it as a possession however undesirable (Lascaratou et al. 2008; Strong et al. 2009); the idea of ‘relief’ from pain shows this, being physically relieved of pain as if it were a burden.

2.6.4 METAPHORS OF PAIN

In an attempt to conceptualize the unseen, we use metaphor to communicate pain in a way we imagine and hope others could understand. Metaphors in this context should not be seen as “simply additions or embellishments to more ‘basic’ pain descriptions, but an integral part of the patient’s attempts to provide an insightful and true account of what they are going through” (Sussex in Strong et al. 2009, p.10)

Research into the provenance of metaphors of the phenomenological attributes of pain found that the source domain tended to draw on the most notable agents or origins of pain (Kövecses 2008). This links back to Scarry’s disclosure (1985) that we have the tendency to see pain through metaphors limited to destructive concepts such as weaponry or the damage they cause (*the pain raked down my back*, for example). Metaphors can be understood to comprise two elements, a source, the words used to get the idea across, and the target, from where the idea for the metaphor comes. If we consider the previous example, *pain raked down my back*, pain is the target, the concept hoping to be understood, whilst the raking down is the source, both of the pain in the narrative and a hoped-for explanation of how it feels. Unlike the target domain, in this case *pain*, which is most often abstract if widely appreciated, the source domain tends to be concrete, a grounded, relatable act or object based on sensory experience (Lakoff and Johnson 1980).

⁷ Santangelo (in Boddice 2014, p. 37) notes that in Chinese culture, for many centuries, there is a clear acceptance of the ties between “moral and physical pain, and the reciprocal influence of emotions and bodily sensations”.

The conceiving of pain as its cause rather than an effect helps others understand the experience by giving it logical meaning and, importantly, a relatable narrative; if you imagine this happening to you then you will understand how it hurts. On this basis Semino (2010) developed three main groupings of pain in metaphors, (shown here in capitals to follow the conventions of metaphor studies in linguistics):

- PAIN IS A SHARP OBJECT -for example a stabbing or piercing pain
- PAIN IS FIRE - for example a burning pain
- PAIN IS A TORMENTING ANIMAL - for example, a tearing or gnawing pain.

Semino concluded from this that the primary metaphor of pain, the source from which we draw our means to communicate metaphors and analogies of pain, is PAIN IS CAUSES OF PHYSICAL DAMAGE (Semino 2010; Kövecses 2008). As mentioned, metaphors have a target domain, the thing that they hope to describe, in this case PAIN, and a source domain, the means by which they hope to describe the target, here understood to be any CAUSES OF PHYSICAL DAMAGE. The target domain of pain is abstract because pain is subjective and poorly delineated, unobservable yet universal. The source domain relies on the fact of embodiment and tends to have a strong basis in metonymy, the cause and effect of nociceptive pain (Semino 2010). This can be seen in the adjectives used in any of the pain descriptions displayed in the McGill Pain Questionnaire (Melzack 1975), such as the descriptor 'sharp'. The phrase 'a *sharp* pain in the chest' provides a contextual, emotional, comparative understanding drawn from two points: the physical property of an object such as a *sharp* knife and the transference of this understanding into the action of that object because objects are understood through their actions (Heidegger 1962; Drefus 1991). Our experiences of our day-to-day interaction with the world provide us with the language to describe abstract, unperceivable notions such as pain. In this way metaphors build conceptual understanding multimodally and so allow concepts such as pain to be described verbally but visualized in the same manner.



Figure 22: <https://health.clevelandclinic.org/what-causes-a-sudden-sharp-pain-in-the-chest/>



Figure 21: <https://www.prevention.com/health/a20496472/6-health-problems-that-only-seem-like-back-pain>

This multimodal use of metaphor can be seen in the two images describing sharp pain (in chest and in lower back). Both draw on the same source domain of a lightning bolt as a cause of the pain they wish to describe, a short lived but sharp/shooting pain in a localized area, provided with a focus by the point of the lightning bolts. This visual metaphoric principle can be taken further if we extract the target from the image, i.e.: the person with pain, leaving only the symbol of pain we have the electricity hazard sign as a graphic visualization of the potential of pain. 

Figure 23: Caution hazard of electric shock sign.

However, Shane Neilson described the reliance on visual metaphors to explain complex issues in medicine as potentially misleading if not harmful. He claimed that “visual metaphors are the *sine qua non* of the medical pain discourse of the late 20th century onwards because they are more ‘concrete’ than those channelled by words” (2015, p.6).

Visualizations of how pain works, Neilson went on to explain, have come to dominate what we think of as pain, “we think of pain in terms of nerves” (ibid., p.2) and we think of nerves in terms of circuitry connecting the world to our internal mental state as shown in Neilson’s depicted examples below.

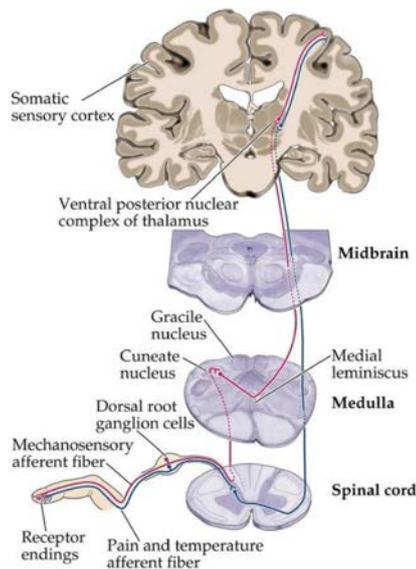


Figure 25: Contemporary depiction of nerves
The spinothalamic pathway. Adapted from *Somatic Sensory System*
(<http://www.rci.rutgers.edu/~uzwiak/AnatPhys/ChemicalSomaticSenses.htm>) accessed 14.02.2016



Figure 24: Descartes' depiction of nerves
(http://en.wikipedia.org/wiki/History_of_pain_theory).
Original illustration appeared in *Descartes' Treatise of Man* (1664).

Neilson explained how such diagrams show how the cause of pain is widely perceived as something *received* through receptors with a message taken through the body to the brain along designated pathways. Neilson’s criticism was that, despite an increase in medical understanding and accuracy over three and a half centuries, there is fundamentally little difference between the diagrammatic

metaphors shown in the contemporary image, Figure 25 and Figure 24 Descartes' description from 1664.

If pain is considered as these diagrams suggest, an event of cause and effect, the body becomes a mere conduit of communication, a receptor and transmitter that passes the message of the outside world to our brain as the seat of consciousness, denying the idea of embodiment. Yet the cause of pain is not the same as the experience of pain (Couceiro-Bueno 2009; Jackson 1994). To see pain in this way decontextualizes it.

To visualize another's pain it needs to be understood in context, an experience as part of the lived experience which phenomenological understanding provides. This relies on our imagination contextualizing within social and cultural situations, projecting our emotions onto the subject (Preston 2007; Goldman and Jordan 2013). The following subchapters outline the integral relationship of our multimodal experience of the world and our ability to understand each other's mental state, building the argument for using materials and forms as a visual language.

2.6.5 EMPATHY

This need for metaphorical context, the desire to visualize pain can be understood through our reliance on our exteroceptive/perceptive field, our ability to engage with the world and see, feel, appreciate its impact on us and those around us (the source domain) whilst the target, the interoceptive's "vocabulary is not as well developed ...[it is] experienced as modulating a single dimension of perception, i.e., 'inner sensation' rather than opening onto distinct perceptual worlds" (Leder 1990, p.40).

Because we are in-the-world we are largely ignorant, or rather not conscious of our own body language/behaviour. Merleau-Ponty describes the body as "the very movement of expression" (2002, p.147), a language, not just communicating but becoming who we are in a given situation. Through our perceptible responses, reactions/reflexes and gestures, our emotional state (happy, tired, stressed, in pain) becomes inferable to others (Couceiro-Bueno 2009), which Merleau-Ponty described as 'intercorporeality' (2002). Indeed, this communication is often more clearly visible to others than ourselves, a concept that Sartre named as my 'body-for-others' (Satre in Stewart 1998, p.130). This body language does not just signify however, it involves others; we respond at a neurological level to the body language of others.

Fuchs described the body in working this way as “a tacitly “felt mirror” of the other” (2005, p.98) with the understanding that we see and understand ourselves, actions and expressions in others, “as if the other person’s intentions inhabited my body and mine his” (Merleau-Ponty 2002, p.185). Scientific validation for this was made in neuroscience when Rizzolatti discovered mirror neurons in macaque monkeys⁸ (Rizzolatti et al. 1996; Gallese et al. 1996).

2.6.6 MIRRORS AND EXPERIENTIAL EMPATHY

Mirror neurons are groups of neurons residing in the ventral premotor cortex. The ventral premotor cortex is believed to integrate proprioceptive, visual, and tactile stimuli into a corresponding event⁹.

Mirror neurons become active:

- when an action is performed.
- when the same action is observed.
- when it is imagined, when a linguistic account of the action is processed for example.
- when the action is communicated through signs or mimicry and not directed to particular objects.
- when the action is understood as a possibility/potential but has not been done before.
- when the action is described to another, say as an explanation.
- during some sensory/emotional experiences such as pain or disgust.

⁸ Neurons in the monkey’s pre-motor cortex were noted to code for a particular type of goal-oriented action, for example, grasping, tearing, or manipulating an object. A subclass of pre-motor neurons were found to fire both when the animal planned to perform an instance of their distinctive type of action and when it observed another animal perform the same action. These neurons were dubbed “mirror neurons” (Rizzolatti et al. 1996) because an action plan in the actor’s brain is mirrored by a similar action plan in the observer’s brain. Evidence for a mirror system in humans was established around the same time (see Fadiga et al. 1995 for an overview).

⁹ Current theoretical frameworks postulate that this multimodal integration is required for a feeling of ownership of the body, and is ultimately accompanied by a sense of self. This might seem trivial; but actually, it is necessary for the discrimination between one’s own body and its surroundings, as well as the distinction between self and other (Bekrater-Bodmann, Foell and Kamping 2011).

(Pineda 2009; Shapiro 2014).

Empathy is traditionally considered a shared emotional experience, an “emotional sharing” (Avenanti et al. 2006a, p.21) arising from perceiving another’s situation and feeling emotionally connected or sympathetic to it¹⁰.

As an act of ‘sharing’ we can see empathy as an unconscious, embodied simulation drawn from similarities between ourselves and others (Semino 2010). For example, the affective qualities of pain in the brain are activated when similar qualities are activated in others close to us (relative to one’s openness, one’s sense of responsibility to others and the closeness of our relationship with them). We see pain and illicit the same mental response as if we were in the same pain; a “comparatively simple form of empathy, based on somatic resonance, primarily concerned with mapping external stimuli onto one’s body” (Avenanti et al. 2006a, p.958). The mirroring effect in sensory-motor areas of the pain matrix¹¹ causes us to physically react empathetically to the pain of others and any

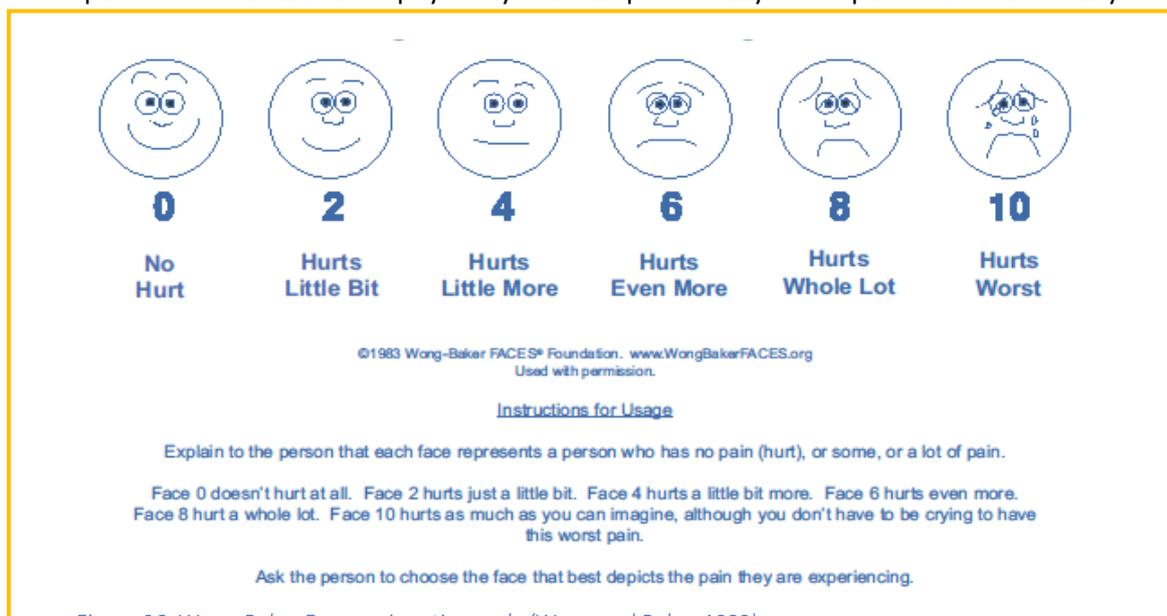


Figure 26: Wong-Baker Faces pain rating scale (Wong and Baker 1983)

10 We do not just empathize with other people however, this also occurs with other forms of life, wilting plants for example and even with inanimate objects, the childish play of the Pixar film company’s desk lamp logo is an excellent catalyst for anthropomorphic empathy.

11 The ‘pain matrix’ is part of the neural network connected to representations of painful experiences. It becomes active when we experience pain but, also, when we observe pain. The sensory-motor area calculates

judgements on that pain are made by the observer in context to their own mirrored response (Avenanti et al. 2006a, 2006b).

An application of this, used to quantify pain, can be seen in the visual prompting approach of the Wong-Baker faces (Berthier et al. 1998) where the patient seeks out a face with an emotional expression similar to their own internal feelings (see Figure 26).

2.6.7 IMAGINING PAIN

The Wong-Baker rating scale is an example of experiential understanding as opposed to conceptual; we feel and empathize with another's pain seen in the faces, however simplified, but we are not drawing an understanding of their painful situation, consciously thinking what it must be like *being* them. Cognitively as much as philosophically, such an act is more akin to sympathy than empathy, and, although often confused and even substituted for each other, in terms of the current research, I will define sympathy as "the heightened awareness of another's plight as something to be alleviated" (Preston and de Waal 2002, p.6)¹².

The distinction here is important as the aim is not to generate a model of sympathy but to convey an experience as truthfully as possible. Drawing on the research of Hoffman in empathy's contribution to social development and the evolution of morality (2001), Preston and de Waal came to define empathy as:

"any process where the attended perception of the object's state generates a state in the subject that is more applicable to the object's state or situation than to the subject's own prior state or situation" (2002, p.4).

In this definition, Preston and de Waal reinstate empathy as a conscious act where the emotional mirroring is conceptualized in the light of one's own and the observed situation. This appreciation of attending to a perceived state of another, re-experiencing it by contextualizing it with one's

how much pain and where the pain is although this is not activated in mirroring responses (Lamm and Majdandžić 2015).

¹² see Wispe 1986, 'The distinction between sympathy and empathy: To call forth a concept, a word is needed' for a full Discussion.

situation, historical and cultural understanding is a form of imagination, which consists of trying to construct in oneself a mental state that isn't generated by action or perception.

In discussing imagining pain, our own or others, it is not meant in a derogatory sense of fantasizing or falsely believing, instead it is using creative, embodied imaging to simulate a believed, if unperceivable state. This unperceivable state becomes tangible when the imagination is contextualized through experience. Rather than entertaining a proposition or concept, entertaining an idea that something *is*, imagining with a “distinctive experiential aspect” (Gaut and Livingston 2003, p.273) entails a sensorial, phenomenal engagement by imagining both what something may be perceived as and what it may be like to feel that something or how that something could make one feel.

Misinterpretation can occur where the mind reader's own genuine beliefs and presumptions become 'entangled' with the pretend states they put forward (Goldman and Jordan 2013). If we try to imagine ourselves feeling the pain, of being in the painful situation of another, it is difficult without making assumptions as to what we think it *should* be like, with the result that we merely hypothesize on being in pain, a concept appreciated as 'the curse of knowledge' (Camerer et al. 1989).

2.6.8 VISUALIZING PAIN

Mirror related cognitive functions are less prone to such misinterpretation; “the strength of activation in imagined empathy is rarely as high as in direct empathy because of the increased difficulty in attending to internal over external stimuli” (Preston 2006, p.429-430), in other words trying to imagine how someone feels without seeing them or hearing about them is harder. However, Zaki et al. (2010) demonstrated that if the mind reader was provided with 'perceptual cues' the imaginative act became more 'grounded' within an embodied understanding with a stronger low level simulation response (Zaki et al. 2010, 2012; Lombardo et al. 2010). In the context of this study the function of the model is to act as this perceptual cue, not to inspire sympathy, a conscious attitude more similar to compassion, but to ignite empathy.

Perceptual cues for pain, as discussed earlier, come from metaphoric relationships to something capable of causing pain (Semino 2010). These can be visualized through objects such as needles, pins or broken glass shards, or from potential signs, narratives of future pain, such as the comic cues of

banana skins, a missing manhole cover in a pavement or a broken ladder rung, for example. These perceptual cues allow us to place ourselves in an imagined situation and conceptualize a scenario of 'what would happen to me if...'. This idea has a foundation in how we cognitively play out how to engage with our surroundings and the things we find in it.

We perceive affordances related to the objects in the environment around us (Gibson 1956; Preston and de Waal 2002) and this triggers the appropriate cognitive motor responses in preparedness for action (Grafton et al. 1997). For example, we see a hammer and we imagine a situation that involves us using it. This perception and relating it to an action or affordance do not just rely on seeing the hammer in an ideal situation with the need to put a nail in something; "even relatively abstract cognitive affordances of objects may be partially coded with respect to their appropriate motor acts" (Preston and de Waal 2002, p.11). In other words, such cognitive responses to stimuli also occur if we see an abstract image of a hammer, hear a hammer in use or even the name 'hammer', as our imagination draws on embodied memories of our experience of hammers evoking the corresponding motor acts alongside the objectification of the hammer.

Generating these mental scenarios has substantial overlaps with our perception in cognitive processing as we 'see' the action in our imagination (Kosslyn and Ochsner 1994; Goldman 2006). It is this imagery that gives experiential imagining (imagining the experience of something) its multi-sensory characteristics (Gaut and Livingston 2003).

Imagery here is not necessarily a mental image as in remembering a past scenario, which would be an asserted thought, but in having an unasserted thought, something that exists as an idea, a possibility, even if not in reality. To visualize the idea of something is to construct a simulation from elements of experience that resembles the visual experience you would undergo *as if* you were actually seeing or had seen it. For example, to visualize a hammer in your imagination is to create a mental framework drawing on your social interactions (people describing hammers to you), historical and situational memories (seeing and learning about hammers) and experience (using hammers) that enacts you seeing the hammer and the simulations you create around hammers.

In 'Perceptions of Pain' Deborah Padfield (Padfield et al. 2003) used the approach of literal visualization to produce photographic images of pain in consultation with sufferers of chronic pain, as can be seen in Figure 27, with the image showing Robert Lomax's metaphoric description of feeling as if ants were crawling through his skin. By visualizing the metaphorical descriptions of Lomax literally, Padfield prompts the viewer to mentally reconstruct the scenario. As a perceptual cue it provides a link to relatable experience; seeing the hand stimulates a low-level simulation response that it could be our hand, alongside the emotive reactions resulting from the idea in our imagination of ants crawling on us. We do not have to have any experience of Lomax or his situation but because of our understanding of our own hand and what we know of insects, we are able to visualize the experience which triggers a multi modal response in our imagination.



Figure 27: Robert Lomax: "my pain feels like ants crawling all over and underneath my skin." (Padfield et al. 2003)

The detail of such a mental simulation is determined by the extent to which it is made conscious, the closer to a reality one gets the more vivid/detailed and easier the mental simulation becomes and, if provided with 'perceptual cues' such as the photograph above, the imaginative act becomes more 'grounded' within an embodied understanding with a stronger low-level simulation response.

However, similarly to the MPQ (Melzack 1978) when we consider adjectives as descriptive actions for pain with words such as prickling or drilling, these images objectify pain sensation, decontextualizing the description from the lived experience. Rather than being an understanding, it is an experiential empathetic response mechanism framing a moment in time. This kind of event is limited and abstract; the concept is exhaustible in terms of what we can learn from it because the

uniqueness of such moments makes them hard to contextualize. We can imagine the uncomfortable feeling of ants on our hand but this does not help us understand how it is to live, work or play with this as a constant sensation or, indeed, if this is the sensation that defines Lomax's situation.

2.7 SUMMARY OF KEY POINTS

Preston notes that for empathy to have relevance "the subject must be able to experience a similar emotional state as the object, and respond appropriately to the object" (2007, p.441). This chapter has shown how in attempting to understand pain as a quantitative symptom or through analogies, its true complexity, that of a lived experience, is overlooked primarily in favour of responding to the idea of the cause of pain.

Pain, being an embodied experience, has the potential to be visualized and a greater understanding of another's pain becomes open to us if the perceptual cues offered are more than symbols but carry in them meaning of their own. In seeking to describe pain in words we fall back on metaphor, which gives it the empathetic understanding that adjective descriptors cannot bring, because it draws on narrative where we are able to simulate our experience to understand. However, singular metaphors, visual or otherwise, are not enough to convey the complexities of a lived experience.

As discussed in this chapter, communicating the subjective, often unseen symptoms and experience of RA is complicated. Imagery regarding RA is often uninformative, at worst it misleads and entrenches beliefs that deny any advancement in the lives of people with RA, isolating them socially and restricting their quality of life. In seeking a more meaningful means of visual communication, one that begins to express the complexity of a lived experience, particularly one with RA, the language used will need to look beyond accepted tropes whilst drawing on concepts that are appreciable to others. The culturally grounded, metaphorical framework of materials and form provide context through the model as the cultural link from subjective expression to generic communication, that diagrammatic symbols cannot reference.

The following chapter will put forward my understanding of models. Before discussing the model as conceived in research and design, and how through a process of categorization and definition in these fields, the potential of models as a medium of expression has been undervalued, I will begin with how the medium of modelmaking, the materials involved, communicate to us through the interactions we have in our environment and the historical relationships we have to them.

3. THE ROLE OF THE MODEL IN THIS RESEARCH

“Until images and iconic models have a defined space within the ontology of social practice, they remain at best the whispering of the gods” (Nellhaus 1998, p.16)

In approaching this research, I have always held a strong conviction to place models and model making centre stage. In doing so I feel it necessary to embed these within my chosen epistemology and in this chapter, I will discuss how people have sought to define models and how these definitions control and potentially limit the possibilities of their application. By questioning these distinctions, I present an understanding of how models perform in this research and how much they have to offer as a mode of communication in general.

In a different context one could describe the findings of this project as sculpture as opposed to models, but this term lays the stress on the object, a visual manifesto, rather than promoting the activity, an invitation to conversation. The models in this research are not an end product but a part of ‘the subjective process of thinking, problem-solving, and theorizing.’ (Chaplin 2002, p.186-7) and in using the terminology *model* as opposed to sculpture or artwork, the intention is to highlight that the object in question has a role to fulfil, a process of both research and design, catalyst and conversation.

Models are rarely considered as the ambition for a project but rather they play out their roles in an undeclared stage during it. Much of the current writing on model making in research has focused on its potential contributions to or efficiency within pedagogy or design, primarily focused through architectural practice (Dunn 2007; Gürsoy 2010; Campbell 2012). I wished to distance model making from creative practices to which it is integral but so often subordinate and instead place the emphasis back on models. In this chapter I question the various attempts at categorization of the model used to control its variety in application. Models are ubiquitous in many practices in both the sciences and the arts. Like all representations, models ‘are thought which has been externalized’ (Chaplin 2002, p.186-7) and in this chapter, I explore the way in which we interact with them as one closely affiliated to understanding and translation in linguistics (see Chapter 5.1)

The model is a slippery concept. Etymologically, to define is to set the boundaries to something, putting to an end any doubt as to its meaning, but the term ‘model’ proves ambiguous with indeterminate facets:

“models situate themselves somewhere between instrument, representation, object and sculpture. They hold the capacity to represent a diversity of intentions in a very direct manner” (OASE 2011, p.23).

One reason for this inconclusiveness is the variety of sources to its etymology; as a noun it lies everywhere between an original and a copy and as a verb it establishes but feigns, traces yet constructs¹³.

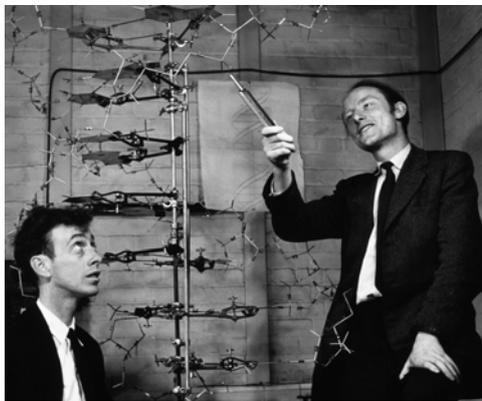


Figure 28: Watson and Crick present their double helix model of DNA (1953)



Figure 29: Gaudí's hanging model for the Colònia Güell church (1889).

13 Etymologically the word model is derived from the Latin with numerous stems for both its application as noun or verb:

model-noun	
exemplar	example, model, copy, pattern, original, ideal
exemplum	example, pattern, copy, instance, precedent, model
exemplare	example, model, copy, pattern, original, ideal
specimen	ideal, example, specimen, sample, pattern, model
regula	rule, standard, norm, canon, lute, model
archetypon	original, pattern, model
exemplaritas	exemplar, model
model-verb	
formo	form, shape, fashion, mould, frame, model
construo	construct, build, arrange, establish, rear, model
exprimo	express, extort, press out, squeeze out, represent, model
fingo	mould, imagine, form, invent, feign, model
delineo	trace, model, portray

My goal is not to raise models to the heights of great literature, although some models do, in my opinion, carry such distinction (consider Watson and Crick's double helix model of DNA (1953) or Gaudí's hanging model for the Colònia Güell church (1889). What I have tried to do here is to question any preconceptions of what a model is. The temptation is to define models. That is to define in the true sense of the word, to fence it within a boundary of limitations, of what it is made for, what it can and cannot represent. Through questioning various understandings of the model, my ambitions for the models in this research are revealed as more discursive than descriptive; the role of the model is not to define the lived experience of the participants but to invite conversations that question such definitions and provide opportunities to learn.

3.1 DEFINING MODELS

In *Truth and Method*, Gadamer describes models as "disappearing schema¹⁴" (2004, p.139). This statement was made in the context of models performing the role of a study, a stand-in for the purposes of examination of details, enabling an understanding for the artist of what is seen before the *actual* work of art is produced. Gadamer saw the model as a partial abstraction from the dialogue of a creative process. In this sense, the model was temporal as its role was never to remain beyond its brief and specific conversation with the artist.

This appreciation of the model is perhaps the most commonplace. When contemplated on as the primary focus within doctoral theses, models are most often considered as representational (Dunn 2005, Gürsoy 2010). Resigned to this role, as 'punctuations' within a design dialogue, the model merely acts to stabilise and reinforce predefined intent. This understanding is taken from the value that models carry in architectural practice and education, where a model is seen as evidence of an idea being structured, a clarifying representation but not the idea itself.

This theoretical approach was first defined by Marcial Echenique who provided a classification of models and their relevance to architectural research alongside the construction industry (1970). He

¹⁴ The concept of schemata in the creative process involves the maker being placed in a cultural and historical context (Gombrich 1977).

proposed three primary forms of model: the descriptive, an explanatory and qualitative form showing an aspect of reality, the evaluative model, which allows for examination of an idea through qualitative data and the predictive model to show conceptual ideas.

This approach was later adopted by Professor of Urban Design, Nick Dunn in his thesis on ‘the ecology of the architectural model’ (2005), ultimately leading to its ready absorption into architectural education (Dunn 2008, 2014; Campbell 2012). By categorizing the model within predefined roles (and also limiting the material palette applicable to each case (Campbell 2012, p.58)), both Dunn and Echenique’s approaches undermine the model’s multivariate capacity for meaning. Such definitions cede the model to a mute documentation of whichever stage of design the maker resides.

However, parallel, if contrary to this, the model has also been seen as something that allows “an idea to function and develop for the thinker while offering the possibility of transfer of an idea or triggering of notions” (Albarn and Smith 1977, p.7).

Mary Hesse, physician, mathematician, and philosopher broached a similar questioning, conceptual path for models as a means of interpreting logic and scientific methods in physics (1963). Based on ‘analogies’ both positive and negative, the principle draws on phenomena existing in the real-world using materials relevant to the question at hand and that could be readily understood in context. In applying analogies to a model, the implication is one of foreknowledge, that the model, as metaphor, has properties that translate observable characteristics based on pre-theoretical understanding. The innovation in Hesse’s approach lay in her ‘neutral analogies’, which sought to *apply* the metaphor, using materials that we understand to investigate new ideas, conceptual models analogously informed by knowledge of a series of known constraints, an understanding placed out of context to aid understanding, a “plausible and lucid rendering of original ideas, at a stage that everyday reality had yet to reach” (OASE 2014, p.23). For example, Hesse used the positive analogies of billiard balls, their motion and impact qualities as positive analogies alongside the molecular theory of gas to propose the use of billiard balls as a means to experiment and make predictions as to the behaviour of gases.

In Gadamer’s terminology, what we see here is a “continuity of meaning” (2004, p.129). All involved in the conversation, the maker, the viewer, the model, all “stand on the same tradition” (ibid.), a foundation in material culture and language that allows the model to hold its own meaning. Hesse’s concept provides both an original modal perspective to model theory framed around observable,

experiential qualities, and importantly, one that directly engages the model in the conversation. Her conceptualization allows for the creative interpretation of the materials involved in the process to speak, to potentially tell us something new about the world. However perceived, “three dimensional models [have] always embodied and displayed knowledge” (de Chadarevian and Hopwood, 2004, p.3). What Hesse’s analogies provide is an appreciation not centred on the maker, that meaning is found in a model and the idea that the model has its own voice.

As with Echenique (1970), Glanville (2012) framed the model within a maker’s intent, seeing the preposition of a model as set by both the maker and the user. Ranulph Glanville, cybernetician and professor of research in design innovation at the RCA, conceptualized models in terms of the actions they afforded. He stated that a model should be understood as an ‘intention’, constructed with purpose to fulfil a purpose. When seen as intentions, he believed that models could be categorized as models *of* or models *for* (2012), a theoretical stance with similarities to Hesse’s positive and neutral analogies.

Models *of* illustrate, demonstrate, even document. Not necessarily looking to question or answer, they are a statement. Ultimately, they are models of something. They can also be understood as descriptive, evaluative, or predictive (see Dunn 2007).

Models *for* are explorative. They are models for finding things out. Here, the model has a voice allowing a dialogue involving the maker/observer asking questions of the model and it asking questions of them in return (Glanville 2012).

But Glanville realized that any definition is purely for the benefit of the maker in establishing their position in the design conversation and not that of the model. There are no obligations for the model. A model designed purely to illustrate a point can enlighten and lead to adaptations and questioning of a process whilst a model *for* can become representational of a moment, a documentation (Glanville 2012).

Models and the intentions we instil in them have a direct relationship to modal experience, what we see, and feel about the things in the world. Interaction with models to understand something comes through models like images through a lens; models do not provide a pure reflection, a perfect copy of reality. In this study I am using models to translate understanding and so an acceptance that they are more than simple abstractions of or signposts to reality is important in establishing any truths in the conclusion. Questioning the existing definitions of the model, the final part of this chapter will explore its role as a communicator and establish my concept of the model.

3.1.1 MODELS DEFINED BY ABSTRACTION

Models, despite their scope and potential in meaning, are most often defined in terms of their abstraction from reality. Although it is appreciated that models bridge the gap between concept and reality, as shown in the visualization of the mathematical equation below. They are not portrayed or considered as real, indeed by definition models are not real (OED 2019), they lie outside of reality, only able to represent it through reproduction.



Figure 30: Photo by Man Ray, Mathematical Object, 1936. Model made by students from Munich Technical College (1910-20) under guidance from Felix Klein and Alexander Brill. Robert Motherwell, the Abstract Expressionist painter was quoted in an interview explaining that abstract isn't "something remote from reality" (Protter 1997, p.256), that in its presentation and effect abstract art is as real as the conversation he was having about it. Mathematical models such as the one pictured provided a possibility to 'realise' what had only been 'abstract' before. The beauty of the forms proved hugely influential to the abstract art movements of the 20th century

This appreciation of a distancing from reality is due to "a certain detachment from the body, a reduction of sensory perception. Architectural models, for example, are small" (OASE 2011, p.37.) Dunn stated in his PhD thesis that a model "could never possibly represent the complexity of reality...by its very definition it should not aspire to since the entire purpose of a model is to focus on a particular area of inquiry" (2005, p.67).

This sense of scale, the smallness of a model may evoke embodied responses from an onlooker. "God-like" feelings of power from a bird's eye perspective for example (Knott 2015, p.109) but these are real responses not reduced, 'concentrated' perceptions. In attempting to simplify the process

and theory of models in this definition, the roles, and responses of both the maker and the model are being subverted.



Figure 31: Iguanodon sculptures in Crystal Palace Park, 1854. The models were designed and sculpted by Benjamin Waterhouse Hawkins under the scientific direction of Sir Richard Owen. Photograph courtesy of Ian Wright 2014. Designed to highlight the advancements made in palaeontology, these models, drawing on the data taken from fossil studies, were the first of their kind. Built at 1-to-1 scale they evoke the very real response of awe, whilst providing the opportunity to scientifically examine the potential muscle structures and gait of the dinosaur. Since proven to be scientifically inaccurate, the models have been listed as Grade I monuments and continue to offer new knowledge to social history and the possibility of other worlds to children (McCarthy and Gilbert 1994).

In an educational guide for architecture students that drew heavily on Dunn's perspective this simplification was described as "a process of elimination", where "the purpose of the model becomes clearly defined and information taken from the study becomes concentrated and clear" (Campbell 2012, p. 57).

However, "it is not the genuineness of the experience or the intensity of its expression, but the ingenious manipulation of fixed forms and modes of statement that makes something a work of art" (Gadamer, 2004, p.62). Here Gadamer is reasserting the emphasis of art's ability to influence understanding onto the physicality of the piece, as it stands before us, rather than any intention of the maker. A model cannot be detached from reality, indeed in architectural practice, the model is often accepted as the only reality of a design never to be built. Edwin Lutyens' scheme of the Metropolitan Cathedral of Christ the King, Liverpool was only ever fully realised in model form (Figure 31) and as with the dinosaurs of Crystal Palace, the size and intricacy of the model were not accidental. Referencing the 'Great model' by the Cleere brothers (1674) of Wren's design for St. Paul's Cathedral, it was built to a scale that could only invite a deeply physical response from the onlooker. Also as with the 'Great Model', Lutyens' model was not designed to point to any representation of a fixed reality, (Wren's design was already being questioned and changed as the

model was being constructed). Both models looked to capture a sense of what the buildings could make you feel.

As discussed, Dunn's (2007), Gürsoy's, (2010) and Campbell's (2012) conception of the model as a



Figure 33: The Great Model, 1674, by William and Richard Cleere, at a cost of £500. The polished, carved joinery that now characterises the grandeur of the model was originally painted to represent the stone and leadwork of the 'real' building

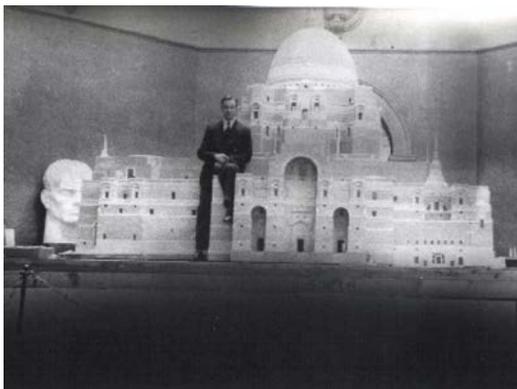


Figure 32: Edwin Lutyens' scheme of the Metropolitan Cathedral of Christ the King, Liverpool was only ever fully realised in model form. The model on show with Lutyens at the Royal Academy exhibition in 1934 and after restoration 2007. Images courtesy of National Museum Liverpool.

focus drew from Echenique (1970). However, Echenique's choice of language denies the oversimplification they apply to him. He does not describe the process in a reductive manner, 'eliminating' and 'concentrating' as is suggested in the later works that reference him, rather his words suggest an interpretive approach, 'abstracting' and 'refining' and 'translating' (ibid.).

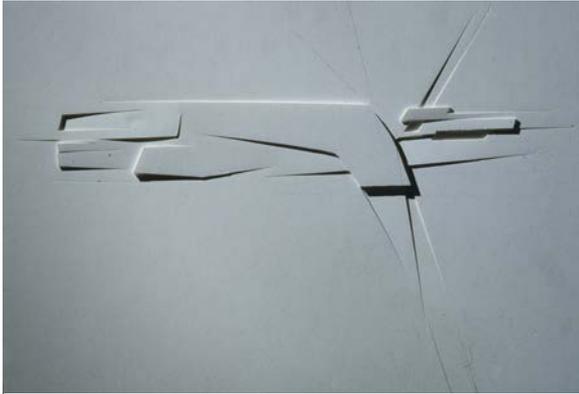


Figure 34: Zaha Hadid, paper cut Illinois institute of technology 2010

Zaha Hadid's model of a proposal for the Illinois Institute of Technology highlights the limitations of considering models as simplification. In abstracting and refining the concept behind the design of this building project Hadid was able to express the complex merging and folding of the building's layers, whilst allowing a material pun on the client's *cutting-edge* approach to technology.

It is without question that models involve abstraction, and that this is often taken to be an act of simplification. But these acts are not a process of elimination, they are translations and interpretations, understood as 'the expression of certain relevant characteristics of the observed reality and where reality consists of the objects or systems that exist, have existed or may exist' (Echenique 1970). Revisiting Echenique's description frees models from the taint of being considered *just a copy*. In using the term 'expression', Echenique appreciates and places forefront the interpretive layer that a model brings as an 'observed reality'.

In describing the action of models as an expression of observed reality, Echenique showed an awareness of Gombrich's belief that one cannot draw or make what one sees (Gombrich 1977), a point poetically explained by Scott Root-Bernstein: "perceiving (that is, the use of the 'eye of the mind' to interpret observation) is not the same as seeing (that is, the uninterpreted images on the 'eye of the forehead')" (1985, p.53). According to Gombrich, perception is a skill to be learnt involving an "active construction of the world" (Wood 2009, p.836). In trying to convey what their interpretation of the world is¹⁵, the artist draws on culturally determined, visual conventions

¹⁵ Merleau-Ponty in his essay 'Eye and Mind' (1964) discussing Cezanne, explains how this is a phenomenological exercise, 'reconstructing what is 'seen' through experimenting with shifting and fragmented forms. Not learning how to see... but learning how to make visible those invisible structures of perception' (Paterson, 2007).

(schemata) (Gombrich 1977) and the model enables this perception to be seen (Gadamer 2004, p.139). The model is not merely a reduced quality copy of a reality. What one understands in seeing is “never a mere mirroring of what is there” (2004, p.79); perception is bound by our prejudices as much as the immediacy of existential engagement.

The model is a ‘physical point of translation’ (Paterson 2007) between maker and viewer and does not sit outside of reality. In the act of translation, the model plays an active role in making reality. Not only does the model influence as much as reflect the perception and reality of the maker, but any reception of the model could never be a neutral acceptance of its maker’s intent.

Even if we were to consider the model as a symbolic gesture or illustrative signpost to an unseen reality, it would not be an expressionless nonentity. Peirce defined in his theory of signs, as “something which stands to somebody for something in some respect or capacity. It addresses somebody, that is, creates in the mind of that person an equivalent sign” (1903, p.228). This equivalent sign is known as an interpretant (ibid.), It is an interpretation of the sign by the receiver, it is not a direct link to understanding. As Zeman points out “a sign does not communicate *in vacuo*, but in a context, in relationship to other signs” (Zeman 2019); a model is not a concentrated abstraction of reality, there are “a memorandum of conditions in their appearance, concerned with sequences, coexistences, relations”. (Dewey 1958, p.85). The model can only ever be understood in the broader context of the relationship it has with the perceiver in the light of their beliefs.

In appreciating the model as a means of conveying information this study now has to consider the idea of the model as a sign in greater depth. Peirce saw the sign as an as an interpreted act of communication, an ‘operation or process aiming towards some effect or goal’ (1903, p.272-3), which has distinct similarities to Glanville’s appreciation of intention (2012) as an action that defines the model. Although these align with this project’s understanding of the model, there are epistemological disparities between Gadamer’s passive and Peirce’s more active appreciation of the value of the sign in communication. To be able to consider the model as a sign of lived experience then we need to understand to what extent, if at all, the model contributes in the process.

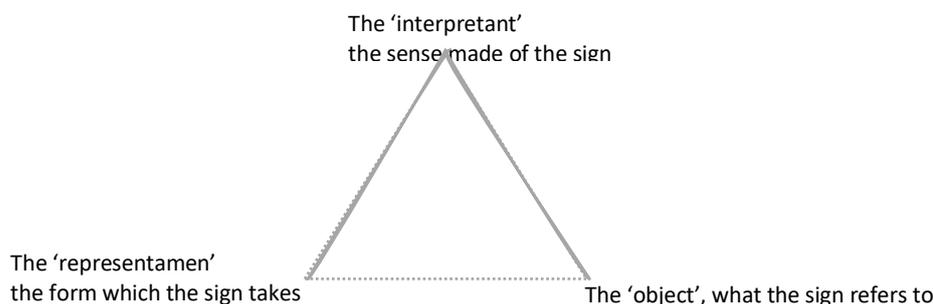
3.1.2 MODELS DEFINED AS A SIGN

Although the study of signs offers two routes, semiology following the work of the linguist Ferdinand de Saussure or semiotics formulated by the philosopher Peirce, this project will follow the latter.

Saussure's model recognizes language as something we are born into and which becomes invisible and 'natural' to us (Saussure 2011, p.71), which is wholly in line with Gadamerian thinking. However, Saussure saw a sign equating to a two-fold structure of signifier, the form of the sign, and signified, the meaning contained within it. Saussure stressed the arbitrary nature of the relationship between these two with recognition of the sign and understanding based on collective habit, that is social and cultural conventions, tradition.

Saussure's model is best, and most convincingly explained using words as the sign structure. If we consider the word APPLE, pronounced 'æp.əl, we can appreciate that there are no natural connections between the word or sound with the fruit we know it to mean. It is tradition that dictates we call it thus and would not understand it called anything else, but it could have been known by any other sound/symbol, 'that which we call a rose, by any other name would smell as sweet' (Romeo and Juliet, Act-II, Scene-II. Shakespeare). Saussure did accept some flexibility in the principle. Lévi-Strauss (2008) explained that a sign was arbitrary a priori but could not be considered so *a posteriori*. If we continue the example of the apple, the logo of the company Apple Inc. 🍏 relies on a meaningful combination of signs and historical understanding (the apple and Eve or Alan Turing, for example) and therefore is not arbitrary (Floch 2005).

Peirce's model of signs focuses more on the process of appreciating signs over the concept of signs as a structure (Chandler 1994). It is Peirce's emphasis on the importance of interpretation in processing signs which holds value for models in this study. Signs do not contain meaning; the meaning is found in the dialogue with things around us. This approach is expressed as a triadic model:



It is the relationship of the three aspects together, what we physically experience, perceive or hear (the 'representamen'), what that stands for (the 'object') and how we interpret these and their

relationship (the 'interpretant'), that collectively make a sign. Any understanding or meaning making from either the representamen or the object of the sign involves the essential process of interpretation, with no one point able to stand isolated from another (Sless 1986).

If we consider models as interpretable, either as a sign or at least comparable in principle, we can draw on Peirce's approach to understanding signs being based on degrees of conventionality and their relationship to direct perception. Peirce described these gradations of a sign through three main variants, the index, the symbol and the icon.

The symbol requires a deeper understanding of conventions to be understood than an icon. For

example, understanding what the symbol  means requires learning, it offers no visual clue to the user's aversion to nuclear warfare, whilst an iconic sign with an embedded likeness of what it

means such as  requires very little prior knowledge.

To appreciate models in a semiotic context, how they communicate and how we interpret them in based on their relationship to conventions and perceived realities I will now explore the idea of the model as index, symbol and icon in greater depth.

3.1.3 INDEXICAL SIGNS



Figure 35: Models on the shelf of Henry Moore's studio at Perry Green in Hertfordshire as found on his death 1986 act as an indexical link to the creative output of the owner. Curated by the Henry Moore Foundation 2007. Photograph courtesy of Jonty Wilde

An index is defined by a connection; some sensory feature, **B**, (something directly visible, audible, smellable, etc.) that correlates with and thus implies or 'points to' **A**. Therefore, an index has a correlation in space and time with its meaning, **A** always comes before **B**. A classic example of this could be footprints in the sand as an indexical sign that someone had walked there previously. A model could only be considered as an index if it were not engaged with directly. For example, seeing

a varied array of models displayed on a shelf in a room could imply that that room or a person who uses that room is engaged in some act of creativity or education¹⁶.

3.1.4 SYMBOLIC SIGNS

A symbol is an arbitrary pattern that gets its meaning primarily from its mental association with other symbols and only secondarily from its correlation with environmentally relevant properties; the word dog when spoken creates images of the written word dog and of our understanding of dogs, all leading to an actual dog as an object. As Gadamer noted, the meaning of symbols “does not consist in external appearance...but in a significance that lies beyond it” (2004, p.63).

“To make a model is to establish a meaning in a set of new objects (drawings, blocks of wood, mathematical functions) by posing a systematic relationship between these and a certain set of events in the world (the structure of a building, geometry of a city, changing population size)” (Hanna 2012, p.97).

This statement places models in a different context to those discussed previously. Here models have completely lost their power to speak, rather they simply point to a relationship between a pre-established concept and a reality which lies elsewhere; the model has become symbolic, a sign.



Figure 36: Jørn Utzon, Spherical solution model 1962.

Utzon’s model, the ‘spherical solution’, is the perfect expression of Hanna’s statement. The model of the inspiration for the Sydney Opera House stemmed from a critique that the design could not be built as the proposed arches required individual, complex, and therefore expensive calculations. Utzon’s model demonstrated how all the forms derived from the same geometry, whilst providing a

¹⁶ For an interesting example of this see Mehrtens in de Chadarevian and Hopwood (2004, p.281) analyzing the role of the model in the photograph of the mathematician August Gutzmer.

signature to the city's skyline, symbolically generated from a unified, natural whole (also note the use of triptych, a format of devotional

The systematic relationship implied in Hanna's statement contextualizes the model as a symbol of what it represents; the onlooker understands the small wooden blocks as symbolic of unbuilt building proposals because they understand the reason for their existence lying in the cultural role of the architectural model as a process of construction and urban design.



Figure 37: 1:500 scale architectural massing model detail. Organised, small blocks of timber mean buildings only because we accept the cultural system of architectural modelmaking. Photograph courtesy of www.Yellowtrace.com.au and make-models.com.

This connects strongly with Gadamer's understanding of a model as a thing that "enables something else that cannot be perceived to become visible" (2004, p.139). Symbols, in and of themselves, "say nothing of what they symbolize...the representational function of a symbol is not merely to point to something that is not present [as with a sign¹⁷], a symbol manifests the presence of something that really is present" (Gadamer 2004, p.147); for example, the symbol of a crucifix on a necklace does not tell you anything more or less than who stands before you wearing it are Christian. It is not to our advantage to describe models in the same light because If we were to do so, we would need to

¹⁷ "A sign is nothing but what its function requires; and that is to point away from itself" (Gadamer, 2004, p.145). This can be simply understood in the way we see warning signs. Their purpose is not to attract our attention to them but to point to the danger approaching; if the sign held more attention than that it would become a danger in its own right.

understand that they would present a meaning only through what they represent, the blocks of wood in Hanna's description *mean* a building, for example. This approach negates the model being able to contribute to any discussion, resigned to roles of *description of, evidence of, showing clarification of* as noted in the definitions of Dunn (2008) and Campbell (2012) discussed at the beginning of the chapter.

3.1.5 ICONIC SIGNS

As a three-dimensional representation, a thing used as an example, or a simplified description, a model is defined in the Oxford English Dictionary (2019) as having "a relationship of similarity, analogy or other comparably shared quality", a statement which correlates with the definition of an icon.

An icon's direct relationship to its object is a mental representation, how we perceive the understood object. In other words, "interlinking the reality of the model as a concrete and material object on the one hand and the reality that the model denotes on the other" (OASE 2013, p.20).

But the fact that such models often mimic reality should not deny their ontological status. "The 'ideality' of the work of art does not consist in its imitating and reproducing an idea but...in the 'appearing' of the idea itself" (Gadamer 2004, p.138). The fact that the model, even if manufactured to be representational, holds a truth within itself elevates it from the status of a copy. "The quality of being an original is...not limited to the 'copying' function ...rather [it] is an essential element founded in the fact that art is by nature presentational" (ibid.).



Figure 38: 1:600 scale plan relief model for Louis XIV of Lille, 1688. Image courtesy of Musée des Plans-Reliefs

The role of the model is to communicate, but it is not a mere conduit, conveying truth from maker to observer. The relief model of the city of Lille, part of a collection of a great many models of cities, coastal and border landscapes, mimicking the topography of the fortified city as accurately as possible, was originally designed as a military aid in the defence of the realm. However, the perspective the models offered distorted from a protective overview to a possessive ‘god-like’ view, a visual flattering to the ‘lord of all he surveys’. This example shows that although a model may be made to represent something, its meaning is to be found in the act of presentation, through interaction with it, and not in the realization of something to which it referred.

An appreciation of the role of the model as representational is, perhaps, most often seen in the context of anatomical studies where “the main characteristics that make a model ... are: (a) realism and fidelity to the original; (b) proportionality in topological and spatial relationships; (c) detail and resolution” (Valdecasas et al. 2009, p.837-8). In other words, the model should ‘copy’ the real as closely as possible. In doing so the model could be appreciated as a sign, connecting, or rather directing the onlooker to an un-present reality, with any interference from the model seen as a distraction. To ‘work’, the model needs to seem as real as possible to the user, making any suspension of disbelief as easy as possible.



Figure 39: Ivory manikin of pregnant woman used by physicians or midwives for instruction, circa: 1690. David M. Rubenstein Rare Book and Manuscript Library, Duke University, Durham, North Carolina

The ivory section model of the pregnant woman shown here exemplifies Valdecasas’ principles, representing a roadmap in anatomical understanding. However, now that the science has outstripped the representation, the symbolism of the model has come to represent the performance value over the professional interest.

Messerschmidt’s ‘character head’ models were made as examples of the human emotional condition reflected through physical proportion. Originally displayed for professional medical consideration at the Citizen’s Hospital, Vienna, in proportion, detail, resolution and fidelity to the original they are masterful works of anatomical study. Yet they fail as models if one considers them through Valdecasas’ lens as signs or copies. The heads literally face us, demanding recognition as objects in their own right. Indeed, their capacity to speak was so extraordinary that they were soon displayed to the wider public as curiosities at the Prater amusement park in Vienna.



Figure 40: *The Intentional Wag, Childish Weeper, the Yawner, and the Hypocrite and Slanderer. 4 of 69 heads that seek to define the human character by Franz Xaver Messerschmidt (c. 1770–83), Museum of Fine Arts, Budapest.*

However, the heads do still ‘work’. In their powerful and constant contemporality, they speak to us of our own humanity, the faces we see are the ones we know and because of this Messerschmidt’s models can be appreciated as signs, pointing at us, and reminding us that our own faces signal to the world.

“Art is knowledge and experiencing an artwork means sharing in that knowledge” (Gadamer 2004, p.84). Although it may be considered that the primary requirement of models, and in particular anatomical models, is to represent reality as closely as possible, it would perhaps be better to say that their primary function is to educate, offering a “transmission of knowledge and experience” (Valdecasas et al. 2009, p.837-8). Where the *reformulation, reinterpretation, or reintegration* of previous knowledge is “no mere *reproduction* but a creative process” (de Chadarevian and Hopwood 2004, p.196. *Researcher’s italics*). Models as a genre may be symbolic, anatomical models or building scheme presentation models for example. Yet models do more than “merely take [the] place” (ibid.) of an original. As objects, models exist in their own right; they ask questions, and they communicate new knowledge. In short, they are more than their original intent. In describing the role played by models in the advancement of molecular chemistry, Christoph Meinel stated that:

“models have a life of their own. They are neither mere representations of scientific theories or data, nor are they purely practical tools. This partial autonomy, which is partly embedded in their physical structure, is a tricky thing, for it may give birth to developments not intended by those who made these models” (de Chadarevian and Hopwood 2004, p.269).



Figure 42 An unusual variant of the ball and stick chemical model by Ava Helen and Linus Pauling, 1963. Using such models, they were able to advance understanding of how blood works at the molecular level, which led to discoveries about immunology, sickle-cell anaemia, and genetics, amongst others. Image courtesy of Special Collections, Oregon State University Libraries

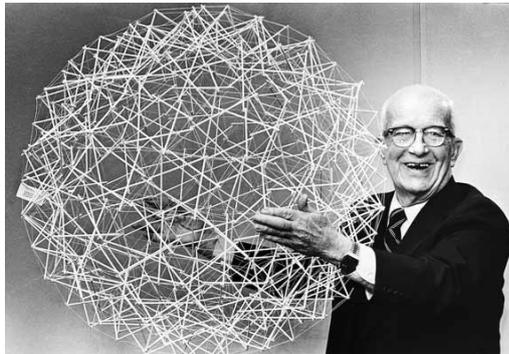


Figure 41: This approach to models provided “a material link between theoretical notions and the body and gestures” (de Chadarevian and Hopwood 2004, p.269). Richard Buckminster Fuller seen here holding a Tensegrity sphere (1979) was to realise this principle on a larger-than-life scale, using the ball and stick models of chemistry to explore the physics of tensile structures in architecture.

Hanna also noted that models require a level of autonomy but in his case, it was to maintain a contemporaneity, a relevance to the moment beyond their initial creation. He believed this to be found in the constant refreshing of data within the system (Hanna, 2012) In other words, what the symbol symbolized was renewed thus giving the model new life and meaning; however, this is not so much autonomy than flexibility in implication. A model’s autonomy stems from their meaning

inherent within, “embedded in their physical structure” (ibid. p.138). These are acts that a symbol is incapable of performing (Gadamer 2004).

What I am proposing here is that models fulfil Gadamer’s requirements of a work of art,

“the essence of the [model]¹⁸ is situated...halfway between two extremes: these extremes of representation are *pure indication*, which is the essence of the sign, and *pure substitution*, which is the essence of the symbol. There is something of both in a [model]” (Gadamer, 2004, p.145).

As well as “implying the existence of something else... models...always refer onwards” (de Chadarevian and Hopwood 2004, p.447). Models provide perspectives of the context they were created for, but they also offer different views which their makers had no conception of.

3.2 SUMMARY OF KEY POINTS

In this chapter I have shifted the understanding of the model from a passive copy to a creative and interactive mode of expression. In one respect this chapter has sought to undefine the model, removing, as far as possible, the preconceived barriers to its potential, expressed in the examples I have shown that begin to convey the wealth and possibility of the language.

Models are not dumb vessels, a mere link to the maker’s intention; they have something to say. Even if they had been made simply ‘to show’, a copy or representation, once the model is engaged with, Gadamer’s act of presentation, the idea behind that copy is understood only through a conversation *with* the copy. In this engagement the model and viewer are changed, the model will never appear in the same way to the viewer and the viewer’s perspective has shifted and their horizons have widened (see APPENDIX 11.4).

In Merleau-Ponty’s phenomenological account of perception, human beings are not isolated subjects, who determine and define the objects when they appear before them. Neither are those objects mute, fully determinate things, only imposing themselves upon those who choose to experience them (Evans, 2008, p.185). Instead, as the philosopher Fred Evans explains, we

18 I have used [model] here as a substitute for the word [picture] that was used in the original text.

immediately engage with and are aware of the things around us through bodily perception because they immediately and mutually engage with us to offer a reciprocating, pre-reflective sensibility and signification, “this simultaneous entwining is the only way we and these objects exist for one another” (ibid. p.186).

Merleau-Ponty’s phenomenological understanding of perception and embodied experience similarly explained that “when we try to seize ‘sensation’ ...we find ... a formation already bound up with a larger whole, already endowed with a meaning” (2002, p.9). Even the most rudimentary of sense-experiences already has some articulate or articulable structure and involves a perception of something, a perception that already has some conceptual content. For example, if we consider colour as something perceived, Merleau-Ponty (ibid.) stated that a particular ‘red is what it is only by connecting it up from its place with other reds about it, with which it forms a constellation’. More than this our experience of a thing’s colour cannot be even confined to visual experience but has a texture that includes other perceptions of the thing, for example dimensions of tactility, sounds or smells. Also, often seen in different contexts the same material/thing/colour will appear/feel different, yet we appreciate it for the same, relying on our cognitive environment, evoking a sensory memory- substituting memory for actuality (Zeki, 1993).

Perceiving, and rationalizing everything in our environment are actions framed in terms “derived from previous cultural-historical experience and reflective contemporary social values, relationships, and conditions” (Smedley 2007, p.75-76)¹⁹. To understand a model, to be able to both make and interpret its meaning, is to see it in context to our cultural and historical horizons.

As such, models can be understood as contributing to a cognitive process of evaluation, interpretation, and comparison akin to Sperber and Wilson’s ‘principle of relevance’ (1986), a phonetic/linguistic theory of communication. Sperber and Wilson, instead of seeing any informative intention as an attempt to directly modify a hearer’s thoughts, saw this as an intention to modify their cognitive environment-a manifestation of memories, facts, associations, and assumptions we are already aware of alongside those which we are capable of becoming aware of due to our

¹⁹ Although potentially this quote may be considered as being taken out of context because Smedley wrote it about the concept of ‘race’ in North American culture, the definition of a knowledge system is without doubt cross disciplinary.

cognitive abilities and the environment we reside in. This is a theory which sits comfortably within hermeneutic philosophy where understanding is not a blind acceptance of information but is always to be found in context to our own prejudice, history, and culture (a more detailed explanation of this concept is given in APPENDIX 11.4).

To appreciate these two principles, firstly that our interactions with the world and how we think about these are framed by our history, and secondly, that models, as visual objects, are able to communicate and be understood, the following chapter will provide a theoretical framework. I will discuss the context of employing art in academic research and define language and its relationship to experience. I will explain these within the ontological framework of hermeneutic study, which I also see intimately aligned to the cognitive processes of evaluation, interpretation, and comparison.

4. THEORETICAL FRAMEWORK TO THE STUDY

Having described concerns over the way in which RA is perceived by and presented to the public as a motivation for the study and also discussed the value that models have in pursuing solutions to this, I will now describe a theoretical framework that provides the conditions for the ambition of the research, that models can provide a novel and engaging perspective of the lived experience of RA.

It is not contentious to suggest that visual media could offer descriptive clarity over and above that already offered by more conventional paths. To quote Aldous Huxley,

“words are few and can only be arranged in certain conventionally fixed ways; the counterpoint of unique events is infinitely wide and their succession indefinitely long. That the purified language of science, or even the richer purified language of literature should ever be adequate to the givenness of the world and of our experience is, in the nature of things, impossible” (1991, p.118)

This chapter initially describes the merits of visual media in expressing lived experience put forward by Huxley and in doing so establishes the value of truth in this research where models represent the conclusion of the investigation.

Here I will also lay out my ontological perspective, the underpinning to the whole thesis, framed around the thoughts of Hans Georg Gadamer. Gadamer studied under both Heidegger and Husserl, the pillars of modern phenomenology, before developing his own philosophy, which was published in 1960 as *Truth and Method*. When he died in 2002, he was considered “one of the outstanding figures of 20th-century philosophy” (Roberts 2002, para. 1). Gadamer’s philosophy argues for a greater appreciation and application of phenomenology in methodological approaches to understanding our world and provides a foundation for practice-based combined Arts and Health study such as this.

In relation to this, I will outline why other ontological approaches to the theoretical framework were not employed. I will also introduce the relationship of Gadamer’s understanding of Hermeneutics to Situated Cognitive theory that allows this study to move between philosophical understanding and practical application, which will be outlined as this study’s methodology in the coming chapters.

The opportunity to establish this theoretical position is encompassed in the value of language to understanding. This chapter will define what language means in this study and how it finds value in embodiment, the experiential appreciation of ourselves as part of our environment.

There are further elements to Gadamer's philosophy that have relevance to this study. However, as these relate more to the establishment of my approach than any designated application within it, I have included them in the appendices rather than as part of the overall narrative so as not to divert the reader too far from the path. These include Gadamer's concept of play and his concept of understanding, known as a fusion of horizons, which both outline approaches to thinking and how, phenomenologically, we undertake any engagements with situations to gain new knowledge; whilst the discussion around hypotheses and the concept of design as a puzzle stem from conversations with the reviewers of my ethics submission which also helped establish my position for this study.

4.1 THE VALIDITY OF ART IN RESEARCH

The sociologist, Elizabeth Chaplin, explaining the value and increasing prevalence of visual imagery in Sociology research, stated that 'looking at a picture is as much reading as is engaging with a text' (2002, p.177). The hypothesis to this study is that this statement applies to all visual media, 2D and 3D, and that models too can be read just as a picture can be. Just as one appreciates text as a medium of communication, with the consummation not the writing on a page but the comprehension of it, models are made to be interpreted, and in the context of this study provide the opportunity to understand descriptions of experience. Although the summary findings to this project will be 'invaded by language' (ibid., p.88) as part of the process of analysis and reflection, the intention has always been for the models to be read.

I have always appreciated the role of models as a communicative one, a means of conveying information to a third party which it would be difficult to describe, or to use the American philosopher Susanne Langer's terminology "verbally ineffable" (Langer 1957, p.26). In architectural practice models are often employed to bridge the conceptual gap between a designer's and client's understanding in describing the emotive intentions of a design. It is my conjecture that lived experience, "the feeling not simply of emotion or effect, but of life itself" (Hagman, 2011, p.70) is one such example of an intricate and multi layered context that the model is well suited to

describing. In a paper affirming the role of art as knowledge, Eisner stated that the lived experiences of others are beyond the capability of ordinary discourse:

“The reason for this ineffability is not that the ideas to be expressed are too high, too spiritual or too anything else, but that the forms of feeling and the forms of discursive expression are logically incommensurate” (Eisner 2008, p.7)

Engaging with the visual evokes a sensory response; a response that since Plato has been believed to mislead those seeking truth, distracting from the forms of critical rationality upon which truth depends (Eisner, 2008, p 4). As a result, visual media has slumped into a dubious position in academic research. However, historically, and culturally, it is the arts that address the task of evoking emotion appreciating the value of subjective experience in our understanding of reality. Langer, theorizing on the influence of art in society, believed art expressed our concepts of life in concrete form, opening subjective, emotive, inner realities to the observer’s gaze (Langer 1957).



Figure 43: Roch-Cuerrier, *The Lived Experience of Time*, 2018
(<https://www.julierochcuerrier.com>, last accessed 02/2020)



Figure 44: Do Ho Suh, *New York City Apartment Corridor*, 2015
(<https://michaelgimberblog.com/2018/03/23/do-ho-suh-remembers-home/> [last accessed 02/2020])

This can be seen in the works above by Julie Roch-Cuerrier and Do Ho Suh, where both artists engage in material practice to explore and convey the complex, universal but subjective emotions Langer describes. The bronze casting of the roots of an apple tree by Roch-Currier is a reflection on memory and the lived experience of her relationship with her Grandmother framed around an apple tree from the family garden, whose life span matched that of their relationship, whilst Do Ho Suh’s work, representations of the places he has lived, sewn in fine, translucent fabrics express his feelings of homesickness and the raises questions about our relationship to the idea of home. Works such as these do not explicitly define the human condition of loss or displacement, distilling them into an essence so that they can be simply spoken or rated. There is a complexity revolving around the

perception of the work, the processes involved in manufacture, the materials used, personal memories and cultural connotations. Roch-Cuerrier's use of bronze suggests an artistic heritage, a classical weight, physical and metaphorical, though the work levitates factually above the floor; a memorial based on shifting memory designed to last beyond any fragile and flitting experience had; whilst Do Ho Suh's use of a fine, translucent fabric mesh evokes the opposite response, emphasising the delicacy and vaguery of memory and its value in constructing our realities. Artwork such as these do not provide an easy answer, suggesting a black and white stance to the experience that would negate any need for such work in the first place. Their material presence invites consideration and discussion, allowing understanding to evolve rather than be claimed.

Gadamer was aware of this and sought to explain such art as a revealer of reality rather than a distraction from it (2004). His philosophy on the concept of truth and how understanding is found in dialogue focuses on our engagement with the arts. To appreciate his stance, which reads as the thesis to my work, it is worth quoting his words at length:

“Does not the experience of art contain a claim to truth which is certainly different from that of science, but just as certainly is not inferior to it? And is not the task of aesthetics precisely to ground the fact that the experience of art is a mode of knowledge of a unique kind, certainly different from the sensory knowledge which provides science with the ultimate data from which it constructs the knowledge of nature, and certainly different from all moral rational knowledge, and indeed from conceptual knowledge-but still knowledge, i.e., conveying truth” (Gadamer, 2004, p.84).

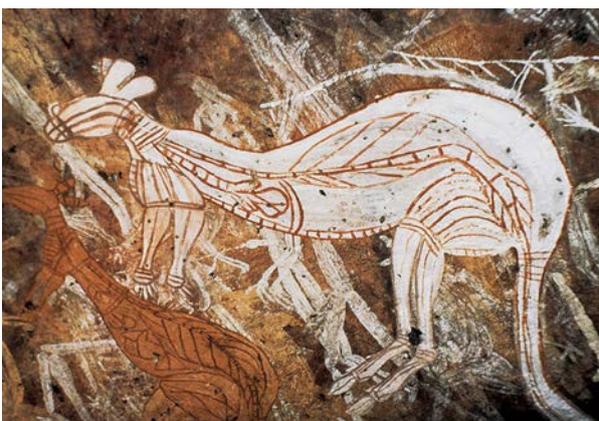


Figure 45: Aboriginal cave painting, circa 13 000BC. Thought to be a visual description to teach others the internal structure of a wallaby
<https://www.theguardian.com/environment/2013/mar/08/australian-uranium-discovery-art>

For Gadamer, the basis of understanding, how we acquire and pass on knowledge, was language *in all its forms*, determining who we are and how we perceive our world. Visual, depictive information

has always played a role in shaping these perspectives (Chaplin, 2002) conveying truths and consequently how we interpret the world and act accordingly (see Figure 45).

Visual, practice-focused approaches not only provide new ways to describe and understand our world but in doing so they offer the potential of a voice for those previously unheard. The variety and creativity of these research outputs, producing knowledge inspired by and learnt from participants, or shaped with the participants, has been explored through a whole diaspora of our visual culture, from performance (Richardson 2015), photography (Padfield 2003), interpretive dance, (Krantz 2015) to musical arrangement or composition (Gouzouasis 2013).

The focus of such approaches is always to “help ...express what is so difficult to talk about” (Libby et al. 2018 p.21) to create new “forms of knowing that go beyond descriptive text.” (Byrne, Elliott and Williams 2016 p.1).

These approaches not only “enliven the analysis of otherwise dry and detached interview data” (Gerstenblatt 2013, p. 294), but they importantly provide a more accessible platform (Knowles and Cole, 2008) where the participants no longer need to be understood as passive data providers and subjects of research but rather producers (Byrne, Elliott and Williams 2016).

In *An Introduction to Visual Culture*, Mirzoeff (1999) considered that these ‘disjunctured and fragmented’ voices in research were indeed ‘best imagined and understood visually’ (p.5). As our appreciation of the value of knowledge to be explored in visual culture grows so too will the diversity of approaches and, hopefully the diversity of voices heard. I see this project as a contribution to this path.

Language is a product of history and culture, as is art; and art, as a language, provides the means to communicate and asks questions that we can interpret, even if not appreciated as distinct or direct as the spoken word. While the role of models in this research is to communicate and provoke interpretations that generate interest, awareness, and further study, it is important to acknowledge that the models are not essentially, intrinsically meaningful. Although the concept of reading may suggest meaning is to be ‘found’ within the models, this is a misguided assumption (Banks 2001; Mannay 2016). The methods and analysis in this thesis aim to explore how material and form can be applied within a cultural context to *convey* meaning, that is carrying not containing. The analysis described later is an act of translation, one that should be appreciated as a process of interpretation not a revelation of truth.

Whilst this research is participant focused, the understanding of the visual information, the models, will be mine. In this context, the provocations or visual cues will stem from my cultural understanding. In seeking to understand how we find meaning in the visual arts, it is made clear that “the most salient aspect in understanding a visual image is what the creator intended to show” (Mannay 2017, p.347). This principle, known as auteur theory (Rose 2001; Mannay 2010) makes clear the need to acknowledge the image-maker in establishing the intent, or internal narratives of the work for the reader. I am the modelmaker, although every attempt will be made through an in-depth and clearly explained analysis to expand and translate the participant’s intentions, I do not hide from the fact that translations are interpretations, always to be appreciated within a context, framed here within the aims and objectives of the study, and my history, outlined at the start of the project in the biography.

The models shown at the conclusion of this research are a creative act, and for this reason I have been able to consider them as art in the light of Gadamer’s philosophy and yet, importantly, I do not see them as ‘picturesque’ or pejoratively illustrative tools of this study, any more than someone writing an interpretive analysis of a lived experience would consider their findings in need of decoration or illustration. Any interpretation of the models has drawn on the same level of consciousness as the more currently conventional written statement. Any such reading would not presume that it is the words that speak but the writer, so it is with the models.

4.2 ONTOLOGICAL PERSPECTIVE

As discussed above, the approach that this research will follow is taken from Gadamer, in particular his writings in *Truth and Method* (2004). This section will lay out Gadamer’s hermeneutic principles in greater depth, how the notion of embodiment, that our mind and body are one, is intrinsically woven into the concepts of society, culture and history that allow us to be human. This understanding allows the research to link making with language and communicating abstract, emotive concepts.

The result of the analysis in this research are models; they are a subjective response and open to interpretation. The process of analysis, however, which is outlined in the Methodology, is defined by the idea that embodiment is the foundation to our understanding and how we communicate this

and therefore this chapter holds a distinct relevance to the creative expression and output of the research.

Gadamer's approach to hermeneutics was ontological. Rather than seeking answers his interest lay in how we approach them; how do we understand and how do we go about finding truth? His contribution to hermeneutic research was purely philosophical. He left no actual methodology to follow, and the practice-based, visual languages approach undertaken in this research project has no precedents to draw on. Traditionally, hermeneutics has been applied to verbal or linguistic concerns (see Austgard, 2012; Fleming, Gaidys and Robb 2003), however, as discussed, Gadamer's philosophy goes to some length to convey an appreciation that art should be understood as language as much as the written word (Gadamer 2004) and it is entirely relevant to apply his philosophy with research structured around visual media.

4.2.1 ALTERNATIVE APPROACHES

In qualitative research, when describing the lived experience of others, phenomenology is outlined as the most common methodological path (Cresswell 2013). However, I struggled with the philosophical commitment to the concept of bracketing, a suspending of critical judgment and a temporary refusal of critical engagement, designed to allow the researcher to come "face to face with the ultimate structures of consciousness" (Lavery 2008, p.22) enabling a clear description of the reality in question (Spinelli 2005).

The idea of being able to separate oneself from any personal bias or experience clashed with the way I intend to use my appreciation of materials and forms through modelmaking as a medium of expression.

Although seductive to science as a rigorous method (Giorgi 2009), I felt that phenomenology as a research methodology attaches less importance to the social, cultural, and historical context integral to hermeneutic understanding (Gadamer 2004), to embodied cognition's appreciation of the way in which society and our environment mould our consciousness (Shapiro 2014), and to the cognitive linguistic understanding of the generation of language and the role it plays (Murray and Goldbart 2009).

This research, rather than applying the method of phenomenological bracketing to further cognitive understanding, applies cognitive theories as methods to express phenomenological experience. This approach will be discussed at greater length in the following chapters.

Despite the claim of subjectivity in the findings, my ontological position is not simply relativist; I have difficulty in accepting that there is no objectivity and therefore a purely relative nature to truth systems. One approach that I considered, similar to Gadamer's philosophy in its shift of focus towards ontology, was critical realism. Critical realism has at its heart the guiding principles of understanding through application in any investigation of causality. It is a 'philosophy [of] process' (Pratt 2010, p.21) not designed to provide irrefutable truth but to explain and describe the perceivable events resulting from such. It is best understood as three interconnected worlds of understanding:

- a real world (or intransitive dimension) that exists independently of human thought and our knowledge of it is socially constructed and fallible.
- the actual world (transitive dimension) in which we reside and enact, from which we attempt to transcend "the limitations of human knowledge and approximate the truth" (Bygstad and Munkvold 2011, p.20).
- the empirical world –our understanding of the real as factual truths that we draw on to hypothesize on what we cannot know because they lie beyond the limitations of human experience.

Although sharing the understanding that knowledge exists as a real, social object (Roberts 2014) hermeneutics differs from critical realism in that one does not detect reality through hypothesizing on observations of its effects; the actual world, the real world, and the empirical world need to be understood as one, our experienced life world. In hermeneutics one does not detect reality so much as experience it.

Through a critical realist methodology, this research would have involved a description of the researcher's observations of RA in another person, leading to an explanatory hypothesis as to why these events occur based on already expounded empirical positions. Instead, as with Gadamer, my stance can be described as that of a "perspectival realist" (Wachterhauser 1994, p.154) where, in following a hermeneutic path, although I accept my interpretations as reality, this is within the constraints of culture and history. This point is important as it allows material culture to be intersubjective as with language, the application of materials in the models although subjective as a response to be understood linguistically, like descriptive words chosen in text.

The following sections will expand on the idea of perspectives in understanding, showing the underlying currents flowing through the research forging the links between interpretation, experience and language that tie material culture, model making and communication together.

4.2.2 PERSPECTIVAL REALISM

The truths I claim in this research are historical and local. Historical because we cannot be separate from this time and the context that brings; local in the sense that we cannot be anywhere but the place where we stand. This context brings our point of view, our interpretation of what we experience and perceive. Although we accept that there is a world outside of our culturally conditioned perception of it, we are unable mentally, as we are unable physically or literally, to see the whole picture of the world and therefore can never have more than this perspective.

Gadamer's contention was that this perspective, one's point of view, is derived from and developed through the environment of family, society, state, our culture and its history, collectively the "soil where our judgment is grown" (Dobrosavljev 2002, p.608). Gadamer referred to it as our prejudice. Rather than the negative connotation of bias leading to disingenuous facts that we apply to it in conventional research terminology, in Hermeneutics, the understanding of prejudice stems from its etymological base, *prae-judicium* meaning in advance of or *before* judgment (Gadamer 2004, p. 283). It is the knowledge we bring with us, providing the context for questioning new experiences.

Although foundational in the sense that it underlies our knowledge and what we accept as truth, this prejudice is not fixed and can change. It is influenced not only by what we encounter but also by what others tell us as we search for a common ground in a social and cultural framework.

Understanding has a dialogical basis; we build an understanding of our world, what we know and accept as truth, through our interaction with others, sharing knowledge through learning and teaching.

By appreciating that we have a point of view, we accept that others have their own perspectives and beliefs. It is the combination of an interpretation of our own experiences alongside what we take (or reject) from our interaction with others and their experiences that brings our understanding. In this sense our understood reality is multiple with many truths; the world exists between individuals and the world and our experience creates a shared understanding (Gadamer, 2004). Our knowledge could be better seen as agreements, a process of mediation between individuals unfolding through discussion rather than an accumulation of information.

Our individuality is an interpretation of our relationship with our surrounding environment, which includes other people, but this is not to deny that we are private; we are individuals. This is not because we *think*, as everyone else thinks too, but because of a growing understanding of a

difference in our point of view in being amongst others in society (see McGuire and Raleigh 1986; Ybarra et al. 2008, for more on how intersubjective experience is integral to normal development).

This shared understanding, our growing appreciation of our existence and the world around us, individuals amongst individuals, takes place in a broader context of a shared history, what we know of what has gone on, been learnt, rejected, accepted, or denied before. It is this historical context that restrains our subjectivity from assuming supremacy and asserting a subjective construction of reality over others, that my reality is the 'real' one. In following Gadamer, my position is that reality is not subjectively constructed but is intersubjective. I have my perspective on reality but any understanding of this comes from being open to new perspectives, different points of view whether that stems from the spoken or the written word, or from visual communication such as photographs used as evidence, fine art paintings as interpretations of experience or models.

4.2.3 AUTHORITY AND TRADITION AS SOURCES OF KNOWLEDGE

Gadamer offered a framework to this intersubjective knowledge construction that allowed for certain truths to be accepted, acknowledged points of reference from which we could begin to question and develop. He termed these sources as authority and tradition (Gadamer 2004, p.273-4).

Authority represents sources of knowledge we trust, often without question, such as our parents, teachers, or books. Gadamer knew that the acceptance of authority, coming with the act of trust, had both positive and negative connotations; in the moment of learning we cannot know whether what we have accepted or learnt is correct. Gadamer appreciated that authority as a concept suggested submission, but he stressed that authority should not demand obedience because understanding must always be open to question because understanding can only come from discussion, interpreting someone else's perspective through our prejudice.

Tradition, for Gadamer, was the "mediator [of] the original structure of our understanding" (2004, p.298). Tradition, rather than being derived from an authority or actively learnt, is accepted merely by existing in a place absorbed into and scaffolding our prejudice:

"we do not conceive of what tradition says as something other, something alien. It is always part of us, a kind of cognizance that our later historical judgment would hardly regard as a kind of knowledge but as the most ingenuous affinity with tradition" (2004, p.294)

This approach can be appreciated in the light of Bourdieu's concept of habitus, which he described as "society written into the body" (1990, p. 63), understanding acquired through a sense of home, a subconscious but aware state of being-in-the-world that evolves as we exist within the framework of family within society within a state, all bound by culture. However, as with authority, Gadamer warned that tradition needs to be questionable to remain vibrant and flexible. If traditions are not constantly re-affirmed, re-evaluated or reflected upon, we jeopardize our individuality within the state or stagnate as a society.

Tradition provides a cultural lexicon that allows a designer to emotively influence us and how we appreciate our surroundings through the materials they choose. Our acceptance of materials, culturally fashionable or not, draws on long-established conventions originating in physical attributes or availability. This concept will be discussed at greater length in the following chapter (4.4). However, before expounding on this point, it is necessary to explain Gadamer's understanding of language and how it is integrally linked to the principle of embodiment. The aim here is to highlight how the relationship between a material, the traditions affiliated with it, and its application, is an unspoken but influential language.

4.3 DEFINING LANGUAGE, the medium of hermeneutic experience

In the following pages I will lay out the philosophical argument that language is a culturally framed, multimodal experience and that we are offered communication in every aspect of our lives through the materials and forms of the world around us. It is through this environmental discourse that our own ability to conceptualize and communicate stems.

It is important to emphasize that in this study I appreciate language as more than the classic view of an instrument of thought communication such as the spoken word, a tool which is shaped and controlled by an individual. Nor do I see it as just based on a pure information system of symbols and signs such as writing, "a codified cultural artefact for the purpose of creating records" (Li and Hombert 2002, p.196).

Rather, this study will understand language as our means of connection; it is expressive and outward facing, drawing from our environment, our situation, as much as from our embodied sense of self. Gadamer explained that language is not subjective, rather for language to exist at all it needs to be shared. Sharing with Gadamer a belief in the relationship of language to reality and the integral role

of intersubjectivity to understanding (Başaran 2014; Lawn 2007), the philosopher Ludwig Wittgenstein put forward the concept that when we engage in dialogue, we become involved in a social and situational game. He described communicating as participating *in* language, living it rather than using it (Costache 2011). One does not learn language; we learn the rules of the game in which language operates. These rules apply to the situation in which we and the language reside, when this differs so do we, resulting in changes in how we participate in language. We are born into and grow with language (Gadamer 2004) because we are born into and grow with our traditions, society and culture.

Language meanings are contextual to the situation. We can only understand based on what we are, where we are and what we can do or are capable of doing in the time and place we exist. Vice versa, this appreciation of being-in-the-world is never before our understanding of language because our sense of self is the communication with everything around us.

As with social interaction, we also communicate with and through the spaces we live in. Learning how to behave and interact with our environment, is an engagement with it; our body *combines* with the world around us (Merleau-Pony 2002 p.140). Drawing on this, Marshall McLuhan's concept in '*Understanding Media: The Extensions of Man*' (1964), that the "medium is the message" (p.1) also sees our environment as intrinsic in our thoughts and beliefs. This intimate connection where our physical-sensual sense of space is also an extension of the self (Deplazes 2005; Paterson 2007) means that "all media are extensions" (p.11) of ourselves in experience. McLuhan explained that "any extension, whether of skin, hand, or foot, affects the whole psychic and social complex" (p.2); an echo of Evans' reciprocating, pre-reflective sensibility when interacting with objects.

4.3.1 THE RELATIONSHIP OF LANGUAGE AND EXPERIENCE

As discussed, in Hermeneutics, language is integrally connected to our sensual engagement with the environment; language is how the world becomes open to us because our experience occurs in and through it.

Experience can be understood as the combination of understanding, interpretation, and application, both a record of past situations and the condition for future action. No matter how singular an event, any experience is understood, interpreted, and applied differently by all involved; experiences are unique to the individual. "There are no 'experiences' as an already separated multiplicity like stamps in an album or marbles in a bag ... experience is variously and endlessly differentiable" (Gendlin 1992, p.144). Experience constantly changes through discourse and action, attention, and

reflection. As our situation adapts with new understandings we reinterpret and reapply our past experiences.

Our self-consciousness, the way we experience the world, such as the considerations that guide future action and our ability to conceptualize, are all framed through experience. However, to think or reflect on experience, in other words, to give experience meaning, we have to go *into* language; which is why Gadamer described language as the “universal medium in which understanding occurs” (2004, p.390).

Gadamer argued that it should be understood that socialization and acculturation come before self-reflection (2004). In other words, intersubjectivity (language) and tradition (our historical and cultural context) dictate to our experience of an engagement with the world.

Walter Benjamin (2008), followed a similar path, relating our appreciation of our surroundings to collective memory. Benjamin saw that our perception of the (primarily built) environment was accomplished more by habit than by any attended physical and sensual engagement, that habit determined how we see spaces, that our perception of the places we live in and the materials that they are made of are moulded by our culture and history.

4.3.2 SITUATION: THE CONTEXT OF OUR EXPERIENCE

Our responses to this complex relationship of influence and experience take place in our ‘lifeworld’ (Husserl and Carr 1970), a perceptual *involvement* of reflection and questioning, understanding and interpreting in the environment (Jvonu 2001).

Because it is the situation in which we sense our own existence, a merging of past events, future possibilities, emotions, perceptions and involvement, our ‘lifeworld’ is inseparable from us. The basis to this lies in our inherent, pre-reflective self-consciousness, the phenomenological understanding that if we focus on experience, experiencing, or our existence, we find ourselves already in a situation to be able to do that; we always sense ourselves being somewhere in sensing anything else. (Merleau-Ponty 2002; Dreyfus 1996).

In denial of any Cartesian dualism, situational refers to the concept that we, as a consciousness, are embodied and enacting. Our consciousness is bound up with our body and world experiences²⁰. In other words, we are as inseparable from our situation as our mind is from our body. This entwined and reliant relationship is how this research defines the term embodiment.

4.3.3 COGNITIVE PERSPECTIVES ON EMBODIMENT

Deeply rooted in phenomenology, embodiment has come to play a formative role in many of the theories investigated within the fields of cognitive science. I have chosen to entwine this field within the philosophical stance of the research as a part of the ontological perspective, as it will go on to define the practical element as well as underscore and compliment the philosophical framework. My desire was to ground my ontological approach within a landscape that would allow me to apply scientific theories in practice as a methodology. Gadamer's thoughts on our engagement with the arts lends itself to the way in which this creative enterprise could work in research practice.

Theoretical approaches, such as embodied cognition, alongside dynamic, ecological, embedded, enactive and extended cognitive theories, have been collectively grouped under the umbrella of situated cognitive theory (Shapiro 2014).

Whilst the term embodiment in cognition unites the body (outside of the skull) with our brain as the system which allows intelligent action, situated cognition extends this system and more specifically dictates that the environment (outside of our skin) not only has an influence on, but is an integral part of cognitive processes. This approach shows a mutuality between us and our surroundings, we are a system that should not, logically, be seen dualistically as two separate domains (Shapiro 2014).

It is important to note that this concept of embodiment runs counter to much accepted thinking in cognitive science. The alternative lies in the understanding that our perceptions are impoverished requiring our brain to engage in a computational process that draws on a lexicon of memorial representations to "embellish the input" (Michaels and Palatinus in Shapiro 2014, p.22). This process

²⁰ This intrinsic relationship can be seen in the Japanese word for human being 人間, ningen, which consists of two symbols: *human* 人 and *space* (or more precisely *in-between space*) 間 (which itself derives from two signs that of a gate or gateway and the sky). To understand the meaning of the concept of a human being the two signs need to be read and understood together.

is known as a sense-think-act cycle (Hurley 1998) that places the brain as a mediator, literally at the centre of our existence and experience, and so stands opposed to the principles of embodied cognition, which instead supports the concept of a sense-act process (Clark 1997) where our engagement with the world is a bodily response.

Dawson (Shapiro 2014) highlighted three key points, which, taken together, are definitive of the cognition of embodiment: conceptualization, replacement, and constitution.

Constitution is explained as when “an agent’s world and body are constituents of (and not merely causally related to) the agent’s mind” (Dawson in Shapiro 2014, p.59). Our consciousness isn’t passive, nor is it purely receptive, creating or constructing content out of experience. Our consciousness is the engagement with the world. Our bodies are not a conduit for our consciousness, merely a body we sense as ours among other sensed things. Our reflexes and responses “[do] not result from objective stimuli, [but turn] toward them” (Merleau-Ponty 2002, p.87); in other words, we are intrinsically engaged, sensing, experiencing and expressing our bodies as part of the environment rather than standing remote and observing it before acting.

Replacement, the understanding that an “agent’s interactions with their world replace the need for internal mental representations” (Dawson in Shapiro 2014, p.59) highlights that understanding can only come through interpretation *and* application, our prejudice is exposed and re-evaluated through experience. Through replacement, our knowledge provides us with the understanding of past events and potential for future action, integral to our understanding of ourselves in being-in-the-world (Oh 1986).

Conceptualization refers to the principle that “the agent’s understanding of the world depends critically upon the nature of the agent’s body” (Dawson in Shapiro 2014, p.59). We perceive the potentials of our environment based on our appreciation of our own capabilities and experiences. This appreciation framed around our self-awareness, is reflected back by our environment. “Objects inherently suggest” spatial, sensual, functional and applicable possibilities to us (Davis 2009, p.8); a concept which draws inspiration from Gibson’s Theory of Affordances (1957), which will be discussed in more depth in the following chapter. In phenomenological terms, we can draw parallels with Merleau-Ponty’s understanding of operative intentionality, “apparent in our desires, our evaluations and the landscape we see” (Merleau-Ponty 2002, p.xviii), a phenomenological comprehension of our embodied self with our surroundings (Reuter 1999).

Constitution and replacement have relevance to this study as the foundation to the principle that language, as a means of understanding and responding to and in our environment, draws on this environment. This means that models are not passive but communicative objects. Replacement takes this understanding further and, alongside conceptualization, allows us to put language into context, allowing us to interpret the models and so find relevance in what they are trying to communicate.

4.4 THE CONCEPT OF MATERIALS AS A LANGUAGE OF SENSATION

An engagement in dialogue with materials builds the cultural relationships we draw on when we make decisions as to their use, forming metaphorical connections, threaded together by history²¹. We can see it in our relationship to wood, for example. We associate wood with tradition, quality, craft, we put small pieces of it into cars to add a sense of luxury we link it to our heritage, venerating and protecting ancient trees as national monuments and tie it to our sense of nationhood, with a heart of oak, and yet we also take it for granted, wedging it under doors to prop them open, and accept it as the ultimate disposable item, matches or stirrers for coffee. We accept the affordances of wood almost intuitively, trusting it with our children without the need of a carpenter's or woodman's expertise. It is part of our cultural DNA.

Manzini described the process of how this cultural memory develops:

²¹ Professor Carey Jewitt's work, working with 3D printing models and drawing on social semiotics, also frames itself around the concept that our responses to objects are multimodal and based on intersubjective language (Halliday 1978; Kress and Van Leeuwen 2001). While her research primarily focuses on the digital realm, understanding the notion of touch in VR for example (Price, Jewitt and Yiannoutsou 2021), her understanding of how our senses are realised, conceptualised and shared, highlight the value of design in our environment, and is an invaluable contribution to the research of multimodal and sensory experiences of materials and objects.

“once a material was considered to be ‘known’, reference to that material became a handy abbreviation for the set of relations between considerations of use and performance that typified that material. A material’s identity was constructed on the basis of knowledge taken as predictable behaviour” (Manzini 1986, p32).

Assigning meanings to materials has a deeply rooted practical basis. Historically materials were chosen either pragmatically – for their utility and availability – or they were chosen formally– for their appearance and ornamental qualities (Addington 2004). In this way, the application of a material relies on its quantitative and tangible qualities (stiffness, strength, porosity, density, etc.) alongside the modal qualities, appearance, texture, colour, tactility, etc.

Yet, it is recognized that we have an interaction with materials beyond their appearance “where material ends and sensation begins” (Paterson 2007, p.96). Architectural practice makes a clear distinction between these tangible and non-tangible qualities, a distinction between utility and modality seen in Wastiels and Wouter’s *‘Study of the Aspects Identified by Architects for Selecting Materials’* (2009). They defined a material’s properties into two main groups or ‘aspects’, one relating to technical capabilities, corresponding to ‘physical aspects’ discussed above, and those relating to our senses, ‘sensorial aspects’, which derive from experience, our perceptions (materials feeling inviting or spaces feeling cold, etc.), associations (materials and memories), and emotional reactions (idiosyncratic responses based on persona, mood, etc.) (Karana and van Kesteren 2006; Wastiels and Wouters 2009).

However, it is often the case that a material’s meaning is considered to stem from affordances prescribed by the object the material forms (Karana 2010); any emotive response to the material plially dictated by the function, shape, or manufacturing process to which it was applied. Materials become “like an actor, assuming many different personalities, depending on the role it is asked to play” (Johnson et al. 2002, p.73). The cultural and historical context that Gadamer and Benjamin saw as the root of sensual engagement is resigned to a categorizing attribute, “materials have a history, which helps us to assign meanings to them” (Karana 2010 p.274).

In my career as a model maker within architectural practice the understanding that materials can be used as language and the model as the means of discourse stems from the initial stages of the design process. This often involves a model being made as a concept, a visual representation of a set of emotive, abstract ideas. These models use materials, form and light, to capture the essence of a designer’s idea; a sense rather than a representation of any reality involving environmental

conditions or human factors such as ergonomics, accessibility or programme. This engagement with materials belies the idea that materials are ‘actors’; as concept models, the materials become an act of embodiment, a systematic arrangement in response to haptic experience and cultural understanding. Explaining how such models are capable to engage in this way Manzini concludes his description of the evolution of material language:

“thus memory deposited upon the material itself a sediment of cultural values, which in turn becomes part of conventional communication — qualities such as ‘precious’, ‘warm’ and ‘homelike’” (Manzini 1986, p32).

Linguistically speaking, the more involved our engagement with a material, the more adjectives we are able to find for it. However, these adjectives are merely translations of the language of sensation with which materials talk to us. Phenomenologically, we accept our relationship and interaction with the world around us so readily that “it is difficult to say where in fact the material ends and sensation begins” (Deleuze and Guattari 1994, p.166).

If we accept a medium as a means by which something is communicated or expressed, the material’s ability to express sensation is because meaning is inherent within material. Material is like language, more flexible semiotically, but as a thing in the world it comes before our prescribed understanding, before reflection, in an already formed socio-cultural grounding; as with Gadamer’s claim that we are born into language (2004) we are also born into a material culture.

4.5 SUMMARY OF KEY POINTS

This outline of Gadamer’s philosophical perspective and situated cognitive theory has focused on the embodied principles of intersubjective, situational understanding. The conceptual basis of this thesis, the idea that models can convey an appreciation of lived experience, lies in an acceptance that part of our intersubjectivity, social, cultural, and historical, stems from the connections made through material experiences in a shared world.

In this way we communicate with and through materials all the time. The language is all around us, and we, subconsciously responding, move through the world in relation to what the materials in our environment say. However, the intent to communicate through materials in this research is more direct. I see the knowledge that models can offer in research akin to poetry. This is not a new

concept for visual media, Horace, writing 2000 years ago, was noted as saying that pictures are poems without words. The Oxford dictionary defines a poem as “a piece of writing in which the expression of feelings and ideas is given intensity by particular attention to diction, rhythm, and imagery” (OED 2019). The models in this research provide the platform for just such an intensity in the expression of feelings and ideas through their particular attention to material and form.

My approach to using materials to communicate lived experience over using digital media, 3D computer modelling or virtual reality for example, was partly in response to *‘The material of invention: materials and design’* by Ezio Manzini (1986). Manzini’s book was essential reading during my studies at degree level, whilst my vocational training and continuing career path has always focused on a relationship with materials. How we interpret materials is a cultural and social issue (Sennett 2008) and in a world dominated by plastics that have the capacity for almost any form, colour, or texture, culturally the appreciation of materials is becoming commoditized, their attributes subservient to the concept to which they are applied or often merely referenced.

“A world of nameless materials is taking shape In this new world, we seem to perceive only surface, only local and momentary relationships. In a word, we perceive only appearances” (Manzini 1986, p31).

Although written before the technology of interactive computer-generated experiences within simulated environments became viable as tools, Manzini’s concern that we now ‘perceive only appearances’ (ibid.) reflects virtual reality’s limitations in conveying lived experience.

There is a growing prevalence of digital technology in the architectural design process providing “unique architectural expression and a new aesthetic” (Gramazio and Kohler 2016, online para 1) where even the freehand sketch is becoming secondary in communicating conceptual ideas (Oh et al. 2006).

But, even though such technology brings the advantages of ease of application, immediacy, and uniformity, I have put forward the case here that we should not disregard physical models as anachronistic in our drive to explore the digital version of our world. The infinite potential in the emotive, embodied understanding found in the perception of and haptic interaction with materials should not be ignored in research.

The use and potential of digital technology in model making is increasing exponentially (for example see Jewitt et al. 2022). I have avoided any engagement with such processes here, not through any

Luddite act of denial but to emphasize my understanding that digital processes are tools to generate, not replacements of any understanding of material and form. The forms resulting from digital processes such as 3D printing, similarly to drawing, are expressions of intent, but historically they are conceptually divorced, lacking the “sediment of cultural values” (Manzini 1986, p.28) that bring an intersubjective connection. Benjamin described this in *The Work of Art in the Age of Mechanical Reproduction* as an “aura” (2008, p.7), an emotive yet subconscious relationship between us and crafted objects; a concept closely related to his awareness of the habitual sensuality of our engagement with the built environment²² recounted earlier that I have sought to apply and amplify as language in this study.

There is also an emerging reliance on digital technology to provide perceived realities in therapy (Krijin et al. 2004). “Virtual reality generates a convincing interface, so that users believe they actually perceive sensory information that is similar to that of the real world” (Broeren et al. 2002, p. 2). Virtual-reality experience is considered “a powerful way to evoke and stretch empathic capabilities” (Svoboda et al. 2005 p.422). However, it is only relevant to physical perceptual changes for the participant. Virtual realities provide a perceptual cue to how one could feel under set conditions. The details of virtual simulations are determined by the closeness to a reality one gets being provided with ‘perceptual cues’ (including visual, haptic, and olfactory). The more vivid and detailed, the easier generating actual mental simulations becomes, bringing the emotional understanding with it, hence their value in creating awareness of medical conditions.

In a study exploring whether perspective taking through virtual reality is driven by increased empathy, van Loon et al. stated that:

“The VRPT [virtual reality perspective taking] experience successfully increased participants’ subsequent propensity to take the perspective of their partner (a facet of empathy), but only if the partner was the same person whose perspective participants assumed in the virtual reality simulation” (2018, p.1).

²² It is worth noting, however, that Jewitt’s work on touch (Jewitt, van der Vlugt, and Hübner 2021) and its central role in interaction, stems from engaging research in virtual reality and social experience.

This 'facet of empathy' the participant felt was however "not strong enough to induce an increase in prosocial behaviour" (ibid.), implying that it does not produce a response that inclines the perspective taker towards a behaviour that would benefit others. They also noted that in the experience of the process, the "participants' reported feeling of immersion in the virtual environment" (ibid.) as an experience in and of itself, detracted from and confused the message. The participants knew they were experiencing the experience, and, however immersive the experience, "understanding is always more than merely re-creating someone else's meaning" (Gadamer 2004, p. 375). As a fleeting experience of physical data, a one off *erlebnis*, such experiences lack context; they provide 'an unpleasant sensory experience' but lack the emotional context of living with it, which the International Association for the Study of Pain sees as a major aspect to the definition of pain (iasp-pain.org. 2021). This concept of experiencing aimed at exposing hidden symptoms to the common gaze and bringing insight to subjective conditions that were previously only describable, if considered without due care, has the potential to diminish the experience of someone actually living daily with a condition. What the translation into models in this thesis tried to capture was not the immediate sensation of one of the symptoms of RA but the whole experience as lived.

The following chapter will discuss the way that words in this research will be dislodged as the primary source of meaning, through an appreciation of the role of experience in how we understand language, whilst the final chapter, the Methodology, explains how such particular attention to the use of materials as descriptors takes place in this research.

5. THE PATH TO TRANSLATION, HOW WE FIND MEANING IN MATERIAL AND FORM

“A purely linguistic approach to thought seems to me to be misguided. Neither our experience of nature nor our ability to think about it are limited to, or are even mainly confined to verbal forms. Thoughts may, in fact, be translated into language only for communicating. But pictures, music, and other nonverbal forms of thought also communicate and can be manipulated logically”

(S. Root-Bernstein, 1985, p62).

The previous chapter, in establishing art as a valid construct in research, saw language as the social, historical and cultural connection *and* foundation to our understanding and experience. I have also tied this research to the concept of embodiment, the idea that our existential, physical engagement with the world provides us with the means to understand and describe this language. In this, materials provide a rich and vital source of knowledge, tacit and explicit, that we draw on to appreciate our environment; a concept that we have, quite literally, manipulated throughout our history in the design of our environment.

The work so far has provided a pathway that allows models to be considered as a language. The following chapters lay down the practical framework to the research, theories that explain the non-verbal synthesis of meanings as a method I will apply. The focus will be on explaining how language is appreciated multi modally. I will explore the importance of metaphors as the basis to conceptual understanding across languages, and further consider sign language, with its emphasis on iconic gesture and form, as a medium for cross modal translation. I will also discuss and seek to allay concerns held by theories I am engaged with about the value of images in conceptual metaphors. In doing so I provide a case study for the analytic approach used in this research.

Individually, some of the work discussed, for example the appreciation of the role of metaphor in design (Van Rompay and Ludden 2015, see chapter 4.4) has become increasingly accepted in the field (Cila 2013) and is not new to research. Although incredibly valuable, I feel such approaches are increasingly considered in isolation, abstracting the complexity of how we find meaning through objects. In seeking a guiding structure describing how models could translate linguistically codified emotion, to be able to hold and convey an intentional meaning, this chapter proposes that it is

through *context* and the connections between theories, with the concept of embodiment running throughout, that begins to explain the complexity underlying such tacit, everyday interactions, nonverbal communication through material and form.

5.1 TRANSLATION

In the previous chapter (p.46) I described models as ‘a physical point of translation’ drawing from Paterson’s appreciation of the value of touch in the arts (2007). He argued that the artwork provides a language appreciable to others, providing a platform where unclear sensational expression becomes focused, translated into form.

Translation should not be thought of here as a simple transposition of meaning, as in a word for a word, but an act of interpretation, sense for sense.

Sense for sense is “a term for a translation approach by means of which the content, i.e., the sense of a source text, is translated. The meanings of the source words are translated *within their context*” (Munday 2009, p.224, my italics). This approach, first devised by Seleskovitch and Lederer (1995), was applied by Betty Colonomos in seeking a way to transfer language meaning cross modally as an interpreter for the deaf. She developed the Integrated Model of Interpreting (1989), a theoretical framework of comprehension that spotlighted the key to translation as experiencing a message, rather than fixating on the language used; an approach that sought to gain an “equivalence of meaning” (Munday 2009, p.224) rather than an algorithmic rendering. With any re-expression of a source by an interpreter, organizing it into the structure and the culture of the target language, Colonomos emphasized the need to retain the feelings of the message (1989, 2015), focusing on this ‘sense’, the intended meaning, rather than the source’s original linguistic form (Seleskovitch and Lederer 1995).

In this interpretive approach to translation, making ‘sense’ of a communication is a “non-verbal synthesis” an unfolding of understanding (Munday 2009, p.224) that comes through the appreciation of the context. De-verbalizing the communication prevented it decontextualizing, which would abstract the meanings (Munday 2009). Translated words always have meaning, but the concern is that the intended one becomes only one of many. These fears can be seen if we just consider the word ‘model’ with its multiple applications in English and equivalent credible meanings if translated literally into French.

5.2 THE METAPHOR AS THE MEDIUM FOR CROSS MODAL TRANSLATION

5.2.1 CONCEPTUAL METAPHORS

Our “conceptual system is grounded in, neurally makes use of, and is crucially shaped by our perceptual and motor systems” (Lakoff and Johnson 1999, p.555). The basis of Lakoff and Johnson’s argument, “built on centuries of scholarship” (Kövecses 2017) was simple, our bodies shape every understanding that we have of our environment and those around us, and our interactions are constrained by the structure of our body. The conclusion that followed, that conceptualization is embodied led to the establishment of metaphor as the crux axis when making sense of concept from experience.

In the ‘Philosophy in the Flesh’ (1999), Lakoff and Johnson claim that recurrent patterns of pre-conceptual, embodied, sensory experience become understood as image schema. Image schemas are the foundation of our conceptual system even though they are unconscious thought. As concepts they are very broad; linguistically you should not see them as say, pencil or teacup but thing or container (de Mendoza Ibáñez and Velasco 2002). For example, we are vertically asymmetrical with head-top, feet-bottom and we live in a system where light comes from above and things fall to the ground through gravity. These factors give rise to our understanding of the UP/DOWN schema. Another example comes as we learn to move, building a stability and balance to engage more freely in our environment which gives rise to the BALANCE schema. This sense of stability is expressed in how we feel the world should feel, ‘a fair and balanced perspective’, someone who does not fit in this view could be described as ‘unbalanced’.

It is important not to see image schemas as mental images, which are a conscious recall of visual memories. Rather they are an unconscious holistic feeling and are multi-modal (relating to different types of sensory experience). Sensory experience leads to the development of image schema allowing conceptual representation. This process of metaphorical reasoning as a cognitive mechanism, proposed by Lakoff and Johnson is known as Conceptual Metaphor Theory (CMT) (1980, 1999).

A metaphor is a means of conveying or mapping a concept from one domain, the source, onto a different one, the target, where “one thing stands for another” (Gadamer 2004, p.63). Grady (1997) differentiated between two types of mapping processes in CMT, resemblance metaphors and correlation-based metaphors. The former based on shared characteristics of target and source domains that Gadamer saw as a “procedure of interpretation” rather than one of knowledge (2004,

p.64). The latter, correlation metaphors, are based on abstract target domains and experience-based source domains. According to Grady (1997) correlation metaphors are made up of smaller metaphorical parts called primary metaphors that consist of a “minimal structure [based around image schema], which we acquire naturally, automatically and unconsciously by our immediate interaction with the physical world” (Van Weelden et al. 2011, p.1). We can describe them in words or pictures but experience them holistically (a feeling). As primary metaphors are embodied and conceptual, they are not restricted to verbal language, also occurring in images and in gestural actions (Lakoff and Johnson 1999; McNeill 2008).²³

An example of a primary metaphor is “MORE IS UP, LESS IS DOWN”. According to Lakoff and Johnson (1980) some metaphorical notions (good, virtue, happiness, consciousness, health, wealth, high status, power, etc.) are mapped onto the “up” pole of the vertical dimension, whereas the opposite notions (evil, vice, sadness, unconsciousness, illness, poverty, etc.) are mapped onto the “down” pole of the vertical dimension. Our conceptualization of this is directly linked to our physical experience²⁴ (Schubert 2005; Moeller et al. 2008); linguistically we express this as ‘I’m feeling a bit down’ or respectfully ‘looking up to’ someone.

In stating that image schemas emerge out of embodied interactions with the world, Lakoff and Johnson (1999) were able to argue that conceptualization varies with the individual and that our perceptions are framed by our social and cultural understanding.

5.2.2 AFFORDANCES AND THE PERCEPTION OF FORM

We understand our world through our perception of it.

²³ Further evidence for this can be found in investigation of metaphors such as “TIME IS SPACE” (Boroditsky and Ramscar 2002), “POWER IS VERTICALITY” (Schubert 2005) or “CATEGORIES ARE CONTAINERS” (Pecher and van Danzig 2011).

²⁴ Binder and Desai importantly note that “emotion is as much a modality of experience as sensory and motor processing. Words and concepts vary in the magnitude and specific type of emotional response they evoke, and these emotional responses are a large part of the meaning of many concepts” (2011, p.3).

The idea that we perceive our world through basic general skills (reachability, size, potential for use based on our understanding of our capabilities, etc.) and through an innate understanding of being (that we have arms, legs, can move in certain ways) has a phenomenological basis (Drefus 1996; Merleau-Ponty 2002). The psychologist James Gibson developed this concept (1954), seeing perception as a system picking up information to support the coordination of our actions with the systems that the environment provides (Greeno 1994). In other words, we conceive our surroundings and the objects within it, in terms of the functions they offer, their affordances. These properties are correlative with our bodily capacities and acquired skills and, because our interactions are constrained by the structure of our body, our conceptualization of our world is embodied. We conceptualize objects in terms of the actions they afford and this affordance has functional as well as spatial meaning. Although in this sense affordance is subjective, our appreciation of what our environment affords us also draws on objective properties established in society (Gibson 1954, p.129).

Gibson also considered that the cultural world through our acquired cultural skills is also correlative with our body. He uses the example of mailboxes “Mailing-letters is clearly not a cross-cultural phenomenon based solely on body structure, nor a body structure plus a skill all normal human beings acquire. It is an affordance that comes from experience with mail boxes and the acquisition of letter-mailing skills” (Dreyfus 1996). This appreciation leads the physical appearance and material choice in the perceived object to align themselves to the concepts or affordances of the object in question. The original colour of mailboxes, for example, was green; our acceptance of them as red within the UK was originally a health and safety issue to highlight their presence to traffic, not the concept of imperial royalty we associate to their colour now.

Tsur (1992) claimed that in understanding resemblance (image) metaphors we prefer to interpret based on what things *do* rather than what they are like (this is thought to come from an instinct for survival based on what things could do *to us*). However, Keil (1989) proposed that we use shape and shape’s similarity between objects to firstly identify and then categorize an object. Van Weelden et al. after experimenting with the role of shape in comparing objects, stated that “an essential component of visual metaphor processing-comparing objects stemming from disparate conceptual domains-is affected by shape” (2011, p.292)

Therefore, although through experience we develop causal theories to distinguish and categorize things based on how we have or could use them (whether we can cook with them or wear them, etc.), it is a combination of this functional affordance with an awareness of shape which then

generates the basis of these categories. In other words, if something looks similar to something else it will probably function in the same sort of way (Glenberg 1997). Grady expressed this as a primary metaphor²⁵ “THE NATURE OF AN ENTITY IS ITS SHAPE” (1997) or as refined by Ortiz (2010) “SHAPE IS FUNCTION” after an analysis of the relationships between shape and function in pictorial advertisements.

Metaphor is an important if not essential vehicle in cross-media transmutation, especially to the visual but it tends to rely on properties of resemblance that allow simpler cognitive processes (Littlemore et al. 2018). In their paper ‘What makes a good metaphor’ (2018) Littlemore et al. felt that metaphor quality was largely based on the speed in finding meaning, and that the more creative the metaphor the more poorly it was received. Therefore, in the field of design, visual language tends to focus on the clearest, most direct perceptual cues to convey meaning in order to reduce the potential of any context-irrelevant simulations from the target audience. In choosing metaphorical bridges for communicating in three dimensions, designers also tend towards the source with the most intended meaning and the one most highly related to the target.

Van Rompay and Ludden (2015), investigating how designed products convey emotional or animalistic traits, approached their analysis of metaphor in design to “create awareness of the bodily bases of product experience” (2015, p.9). The connection between the designer’s intent with the form and choice of materials of the final product for them comes through image schema. However, rather than the multi modal concept implied by Lakoff and Johnson above (1980, 1999) they saw image schemas as “visual-spatial” in nature, and so an effective means of literally “characterizing experiential qualities...creating a bridge between the abstract (e.g., an idea as to what a product should express) and the concrete (e.g., product shape and materials)” (Van Rompay and Ludden 2015, p.9).

25 In current literature image schemas and metaphors are presented in capitals (e.g.: CAPITALS ARE METAPHORS) and to avoid confusion I will hold with that convention here.

In response to what they felt was the lack of any “comprehensive framework for understanding embodiment in relation to design experience” (2015, p.1) Van Rompay and Ludden defined four key aspects:

- Anthropomorphism, a natural tendency to see human traits and features in objects (Aggarwal and McGill 2007; Guthrie 1997) which Van Rompay and Ludden saw as literal resemblance or familiarity to the human form/face/expression (2015).
- Image schemas and symbolic meaning: similar to Arnheim’s Gestalt theory of expression (2004), but more heavily based on CMT (Lakoff and Johnson 1980, 1999). It is used here as a means of seeing the world/objects in terms of visual and spatial relationships (metaphors) drawing on our own embodied understanding.
- Multi modal concepts and the experience of materials through sense.
- Meaning portrayal through action and movement.

However, Chang and Wu (2007) considered that apart from the multi modal experience of interaction, all of these points were anthropomorphic, deconstructed into three components, literal anthropomorphism, similarity in things such as in movement and finally, abstract, for example image based metaphors of sensual awareness.

5.2.3 ICONICITY

This concept of anthropomorphism in design draws similarities with the understanding of iconicity in language use. Iconicity in language is the non-arbitrary relationships of linguistic structures and the meanings they convey based on similarities found in physical experience (Lakoff and Turner 1989; Taub 2001). Onomatopoeia is the most obvious example of this in spoken language, although iconicity also references other less distinct embodied concepts such as time based action, where “the order of elements in language parallels that in physical experience or the order of knowledge” (Greenberg 1966, p.103) as in Caesar’s dictum ‘veni vidi veci’ (Jakobson 1965), or semantic relationships like the connection between an element of the body such as an eye or foot and a comparable element of an object such as the base of a mountain or a hole in a needle (Fischer 1997).

Iconicity can be seen at its most prevalent in sign language (Taub 2001) because “iconic (i.e. visual-visual) correspondences between the form and the referent are the most natural and convenient way of representing the world” (Kaneko and Sutton-Spence 2012, p.4).

In arguing for a cognitive basis to linguistic form and meaning, Sarah Taub (2001) drew on sign language to propose a three step, ‘analogue building model’ to explain how embodied awareness and perception are mapped into linguistic form (see Figure 47).

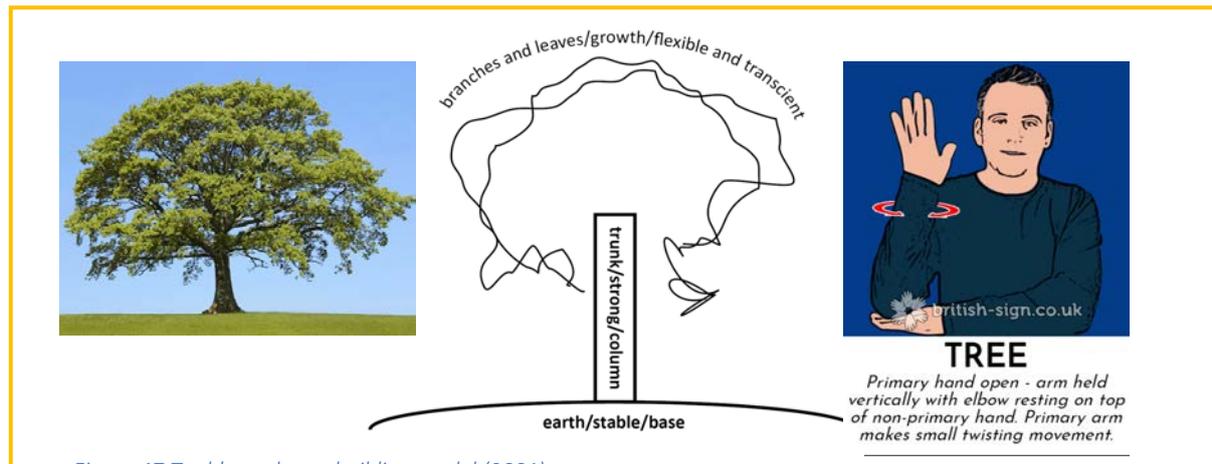


Figure 47: Taub's analogue building model (2001)

Images from: <https://www.fast-growing-trees.com/SawtoothOak.htm> and <http://www.british-sign.co.uk/british-sign-language/how-to-sign/tree/>

The first step is the selection of a mental image associated with the original concept. The core elements of this are then schematized. These could involve key visuals but could be any embodied experience that comes to define the concept, a particular action (like a lion's roar), trait (like a penguin's wobble) or participatory involvement known as motor iconicity (such as using your fingers to type in the air). The third step is the encoding of the schema through gesture using the appropriate parts of the sign language (Kaneko and Sutton-Spence 2012, p.6-7). The iconic sign for 'tree' relates to the social and cultural knowledge of a tree, but in display it also relies on embodied experience for comprehension.

5.2.4 THE GESTALT APPROACH

In many respects this process links to Gestalt psychology where "any stimulus pattern tends to be seen in such a way that the resulting structure is as simple as the given conditions permit" (Arnheim 2004, p44). Much of Arnheim's work explored the ability to perceive complex structures through

only the simplest of parts and their relationships to each other²⁶ although he was also concerned with the question, when providing minimal means, how the effect of the phenomenon on subjective experience could also be defined; did the meaning carry? (Arnheim, 2004, p. 32-81)

Van Rompay and Ludden's approach to the emotional engagement with objects relies on the same conventions (2015). For example, a voluminous jug is metaphoric as it anthropomorphises the target of (for example), an overweight, jolly butcher, or a laughing cavalier or Bacchus who enjoys life to excess onto the source, the jug that can hold a lot; therefore, this jug is a happy, generous jug.



Figure 48: a happy jug

For Arnheim, what we perceived was not just the object, “when objects are nothing but objects, then shapes, colours and sounds are nothing but shapes, colours and sounds” (Arnheim 1959, p5-6). The attributes of what we perceive in objects were part of a narrative, a story we are able to create through an empathetic leap of imagination based on the composition we see. The shapes, colours, and sounds we perceive are collectively more than merely relatable to our subjective state but also to a historical consciousness, one that allows interpretation over assimilation.

When Gadamer claimed that tradition comes before reflection, he was aware that our perceptions are framed by our social and cultural understanding (Gadamer 2004) and Arnheim's approach agreed with this. We perceive things in context to our situation, looking for ‘relevance’ (Sperber and Wilson, 1986) and if what we see appears as an expression (whether that be speech, art, music, gesture, etc.) we look for ways to translate and understand it.

This means that what we perceive is capable of telling us something new, adding to our experience rather than mirroring it.

²⁶ Arnheim (2004) was one of the leading exponents of the concept that an object projects an embodied understanding through its composition. Known as the principles of grouping, they are: Proximity (close together=grouped together), Similarity (look-a-like linked together), Continuity (crossed keys), Closure (joining up the dots), and Connectedness (common fate=moving in the same direction so grouped like swarm/flock/shoal).

5.2.5 THE PROBLEM OF IMAGES AS METAPHORS

However, in Lakoff and Johnson's Conceptual Metaphor Theory (CMT) (1980, 1999) it is understood that image metaphors do not map knowledge. Instead it is thought that they map "conventional mental images onto other conventional mental images by virtue of their internal structure" (Lakoff 1987, p.219). An example used by Lakoff and Johnson is quoted from a poem by André Breton, "My wife...whose waist is an hourglass" (1989, p.90). The form of an hour glass is mapped onto that of Breton's wife's waist, leading to both the visualization and assumption that she has a small waist.

Image metaphors are considered to lack "the inferential richness attributed to various [other] types of metaphor" (Caballero 2001, p.98). Due to their seeming reliance on resemblance, this form of metaphor is considered incapable of abstract visualization (Grady, 1999). In fact, the more abstract the concept, the lower its "imageability" was considered possible (Gleason 2009, p.441); truth, for example, as a concept cannot be visualized without recourse to metaphor. Therefore, whilst correlation metaphors seek to map more abstract target domains such as emotions, image metaphors are considered only capable of mapping concrete objects, things which are directly accessible to the senses (Coëgnarts and Kravanja 2012).

Lakoff and Johnson (1999) stated that the difference between abstract and concrete is determined by whether it is something that we are able to perceive directly or experience through bodily actions. One characteristic of this reliance on similarity, being "grounded in a single resemblance between source and target" (Coëgnarts and Kravanja 2012, p.99-100) is that image metaphors are considered a "one shot"; they can only map that specific concept and have no reference to knowledge nor can they infer anything further (Lakoff and Turner 1989, p. 90). André Breton's wife's waist was implied only by the form of the hourglass, which we have experienced. The function, materials, the movement of the sand were all superfluous to the inference.

According to Lakoff, image metaphors are made with conventional, commonplace, and orthodox, images that we unconsciously acquire throughout our lives (Lakoff 1987, p.220), a process analogous to finding similarities to pictures by flicking through a photograph album. In this context, mental images form frozen moments when mapped as metaphors. Any conceptualization stems from the knowledge of the image rather than any embodied experience of the represented thing in itself.

Metaphorical images are considered to follow three types:

1. symmetrical image alignment (for example, a pictorial simile looking for similarities or



Figure 49: a pictorial simile <https://adsoftheworld.com>

resemblance),

2. a perceptual echo-involving two completely different things but one strongly evoking a memory of the other in some way



Figure 50: perceptual echo, white cliffs of Dover (www.whitecliffsofdoover.com) and the Battle of Britain (www.raf.mod.uk)

3. and the hybrid-a forced juxtaposition, superimposition of images (Lakoff and Turner, 1989).



Figure 51: example of a hybrid image metaphor adsoftheworld.com

In these ways the cognitive act of visualizing is confined to the visual-visual format of iconic signs. The work of Keil (1989), Van Weelden et al. (2011), Grady (1997) and Ortiz (2010), discussing how we draw on similarity of shape between objects to categorize them, further entrenches this position (74).

However, the following pages describe how in linguistic studies the understanding of meaning making from perception to conceptualization shows a more phenomenological, embodied appreciation that belies the simplicity of this approach to images used as metaphors. Here I employ

Barsalou's perceptual simulation theory (1999), which explains that we make these visual connections and concepts based on simulations of embodied experience and not just similarity. As Merleau-Ponty stated, when we try "to seize 'sensation'...we find a formation already bound up with a larger whole, already endowed with a meaning" (2002, p.9). Our experience, our memory informs all of our senses.

5.2.6 EMBODIED UNDERSTANDING IN LINGUISTICS

In 1947 Kohler (1970), conducted tests showing that signs and discourse were often perceived figuratively²⁷ by showing that a high proportion of participants in the research connected fabricated words such as "maluma" with bulbous, curvy abstract forms or "takete" with angular.

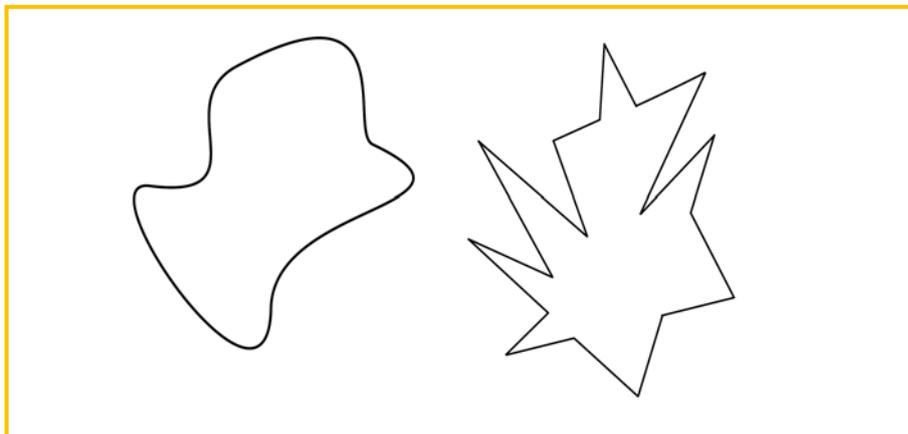


Figure 52: Researcher's interpretation of 'maluma' (on the left) and 'takete' forms

Scheerer and Lyons (1957) proposed the embodied process involved in perceiving abstract concepts in terms of visual imagery and also the other way around, that visual imagery leads to conceptual expression. Koriat and Levy (1979) later showed that these phenomena crossed cultural boundaries, which suggested that the appreciation was based on a human, physical rather than any social trigger. Cognitive research has since reinforced this position that the understanding of language is

²⁷ Literal language means exactly what it says, while figurative language uses similes, metaphors, hyperbole, and personification to describe something often through comparison with something different. Figurative language is language that uses words or expressions with a meaning that is different from the literal interpretation. When a writer uses literal language, he or she is simply stating the facts as they are. Within the Arts, however, figurative describes art that is clearly derived from real object sources and are therefore by definition representational.

embodied and modally based with spatial connotations (Richardson et al. 2001). In 2012, in a continuation of Kohler's study (1970), Crisnell et al. (2012), provided evidence of associations with the words 'maluma' and the sensation of sweet in the mouth, showing how cross modal connections are deeply entwined in how we communicate and understand our environment.

Exploring this relationship to taste further, Paradis and Eeg-Olofsson in a study analysing the genre of wine reviews noted that conceptually, both cognitively and when verbalizing thought or sensation, the use of descriptive terms is experientially 'flexible' (2013, p.38). They confirmed that the

"conceptual structure in the domain of sensory perceptions seems to be supramodal representations, expressed through syncretic word forms that do not pertain to a single modality of experience but to an overarching representation capable of capturing modal convergences" (ibid.).

This suggests that words (descriptors) such as *sharp* do not automatically trigger the modality of touch but also taste, vision and smell; for example, gooseberries are sharp, light pierces into dark spaces and the smell of ammonia cuts through. The implication is that words do not automatically evoke singular sensory responses, just as our engagement with the world does not stem from singular modal responses to interactions.

In the context of this study the relevance of this information cannot be underestimated, championing the phenomenological position that language is experiential in nature.

David Seamon (2010) references how Merleau-Ponty in the *Phenomenology of Perception* (2002) describes the relationship between our consciousness and situation as a multi modal experience, where "the senses intercommunicate by opening on to the structure of the thing" (Merleau-Ponty, 2002, p.229). Seamon (2010) explained that rather than experience resulting in a mental linear description it creates a synaesthetic response to our encounters. What we verbally describe though the seemingly most relevant sense as a singular modal experience is in truth far more encompassing, for example, Merleau-Ponty notes that "we can *see* the softness of wood shavings... we can *hear* the hard brittleness of breaking glass" (2002, p.229).

5.2.7 PERCEPTUAL SIMULATION THEORY 'As every artist knows, there are thoughts that can be visualized without being verbalized' (Gibson 1971).

The appreciation of multi modal over a lineal modal experience can be seen in El Refaie's (2015) paper disputing Lakoff's simplified role for images in conceptual thought. She applied an understanding of Perceptual Simulation Theory (Barsalou 1999, Barsalou et al. 2003) to highlight the role of visualization in conceptualizing our experience, stating that "all language is understood partially by simulating in our minds what it would be like to actually perceive the things that are being described, which suggests that visualization is not unique to image metaphor" (2015, p.1).

Barsalou's Perceptual Simulation Theory (1999) claimed that "the processing of all language, whether literal or nonliteral, is accomplished through the partial simulation of associated bodily states, actions, and sensory perceptions" (El Refaie 2015, p. 64). In other words, we conceptualize visual images by simulating embodied experience in a sense for sense manner as opposed to word for word in the same manner as is understood in Sign Language translation discussed earlier (Seleskovitch and Lederer 1995).

Barsalou (1999) stated that when we act or engage with the world symbols are activated. These symbols here can be understood as schematic neural representations of embodied action (Barsalou 1999) rather than any form of semiosis. We employ them to create simulations that allow us to judge, act and reflect on our interactions.

Barsalou used our relationship to cars as an example. When we approach a car, a simulator, **car+me**, is activated in which perceptual symbols combine to form groups relating to each other. These symbols are multi-modal but are not holistic, they are parts of a whole not a representation of the whole experience of a thing; they can have a representation of the smell of a car, the feeling of excitement of getting into a car, a gear stick, faded and worn, or the dust stuck in the air vent, any and all sorts of feelings or perceptions that are associated with a car to us.

A simulation is a physical or imagined experience of a simulator, an action such as the physical encounter with the car (**car+me**) or thinking about the car. We draw upon our base of perceptual symbols, anything we know about, or is similar to **car+me** to interpret this encounter.

Simulators are dynamic concepts constantly evolving with new knowledge. New perceptual symbols are created upon closer inspection of the car or on seeing another car and then our simulator for **car+me** is updated. The collection of these symbols develops through our selective attention to an

action, the more involved our usage of a thing or the more time spent in a situation the more specific the symbols that develop. Although this is an unconscious process, through introspection, we can run conscious simulations after an event; for example, when we think about the car ride we had earlier (Barsalou 1999).

Our perception of any given environment is a combined understanding of each and all its parts—the dust on the bookcase, the chipped mug, the colour of the painted walls, the smell of a fading hyacinth, etc. etc., and each of these parts have their own perceptual symbols drawing on historical and social understanding informing our embodied experience. In mentally proposing simulations we draw on these symbols to create theoretical models to understand, hypothesize or compare. We can mentally manipulate the way in which objects are brought together to create new simulations—to abstract conceptual information metaphorically to seek new perspectives, new experience which inform us through interpretation.

What Barsalou's theory makes clear is that, in all conscious simulations, visualization is a very important process in holistically appreciating any experience. Indeed, when we concentrate on an event, when temporal aspects²⁸ of a thing are purposefully mentally simulated, perception becomes 'semiotically inclined' (Davis 2009). This semiosis incorporates a shift from mono-modal, as in what we see, developing into a multi-modal simulation of what we remember through embodied experience. Visualization is not exclusive to image metaphor processing and, although closely related cognitively, it isn't a conjuring up of mental images nor is it just a regurgitation of memory and associations (Barsalou 1999).

²⁸ Temporal in the sense that we cognitively draw on both the past, our memory, alongside the present moment, as well as imagining potential simulations.



Figure 54: visual metaphor through shape and colour (Tokyo at night (image courtesy of NASA from <http://www.nationalgeographic.rs> [last accessed 25.04.16] and insect chewed leaf (image courtesy of Brett Cole photography from <http://www.brettcolephotography.com/> [last accessed 25.04.16

Images such as those shown above, can be superficially seen as solely grounded in resemblance; one-shot, image metaphors defined as a “correspondence [between] two rich images for a temporary purpose on a particular occasion” (Todolí 2007, p.55). Yet this example, although chosen specifically for their visual resemblance are “no less significant and influential to the way we perceive and understand the world than correlation metaphors” (El Refaie 2014, p.19).

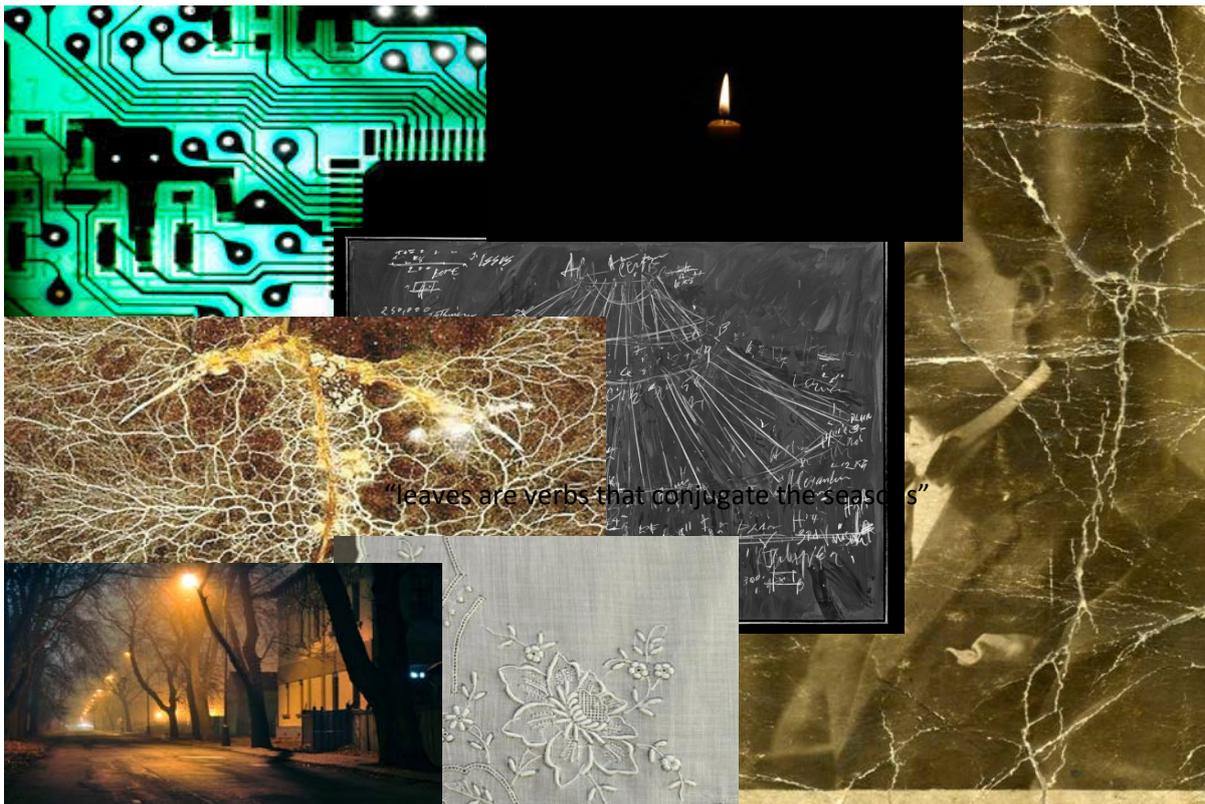


Figure 53: fragments of relevance drawn from image metaphor in figure.

They evoke deeper abstract sensibilities than just visual impression. The leaf’s veins draw visual analogies to aerial photographs of street plans, and through that its decay and fragility question the

seemingly permanent nature of a city, the idea of urban development and natural cycles of growth and decay that comply with the primary metaphor CITY AS A LIVING ORGANISM (Landry 2012). Yet they evoke so much more: haptic, material responses, the delicacy of lacework, creased and friable antique photographs, the image fading with wear, a sense of isolation, a light in the dark, memories of streetlights on a cold, dark night, information networks and electrical pathways, the smell of Autumn, decay and the forest floor, poems and phrases that speak of the passing of time.

In discussing the 'Information Available in Pictures' Gibson noted that "visual thinking is freer and less stereotyped than verbal thinking; there is no vocabulary of picturing as there is of saying" (1971, p.28). The images and thoughts mentioned here are my own juxtaposed, collaged merged corresponding thoughts to the original visual metaphor above (Figure 54). These images consist of "more than a set of symbols" (ibid.) There is no straightforward transfer of 'image to image', each image conveys information about the world that holds a complexity of relevance unique to the beholder. These concepts are structured through our perceptual simulation system, our memory. Visualization may be the recollection/creation of imagery in a search for relevance to our current interest based in our experience (Sperber and Wilson 1986) but it is not merely an understanding of the visible. Such images as shown here can create a connection between concrete, imageable experience and abstract experience through the selection, discarding and reshaping of elements of multi-modal experience, they are not just analogies that invite a meaning through momentary similarity. If we are able to accept that, then image metaphors comply with Grady's definition of primary metaphor (1997).

I have argued that visuals can be used metaphorically, using form, material, and texture, the attributes that makes them real, to evoke complex, abstract concepts by sourcing them from fragments of relevant experience. I have also discussed how we respond to the things we encounter on an embodied meaningful level. Research in linguistics studies (for example Crisnell et al. 2012 or Paradis and Eeg-Olofsson 2013), and Arnheim's work in Gestalt psychology (2004) has shown that abstract arrangements of form or image can dictate, to a degree, certain embodied responses. Yet the idea that such compositions act "more or less like words, [that] the perceiver must learn to 'read'" (Gibson, 1971, p.27) however beguiling is unrealistic. I have discussed how meaning is to be found in visuals as an embodied experience (Van Rompay and Ludden 2015), and how this is fluid and subjective, denying a direct understanding that the written word demands. The final section of this chapter will outline how this meaning can be focused, explaining how metaphoric intent is conducted by a modelmaker to encourage a desired understanding from the observer.

5.2.8 ARCHITECTURAL MODELS AS EXAMPLE OF VISUAL METAPHOR

The intention to use materials and forms to convey conceptual understanding relies on the same metaphoric bridges as other image-based metaphors. In Figure 55 two architectural models made as part of project called the Slow House by the interdisciplinary architectural practice Diller, Scofidio+Renfro (1990) show a range of metaphors in the materials, forms, and colours, using perceptual symbols, such as the image of a car's windscreen mirror, to convey both the narrative of the design and build an atmospheric connection between the future home and the intended client. The models are the only reality of the project, as the house was never built.

Although they were not made specifically following the principles of CMT and were finished long before Barsalou created his theory of partial simulation, I will treat these two models as a case study, critiquing them in the light of the theories I have discussed, providing an example of how the models made in this study will be read. In doing so I highlight the relevance of context when translating meanings cross modally, which provides the final stage to this chapter.

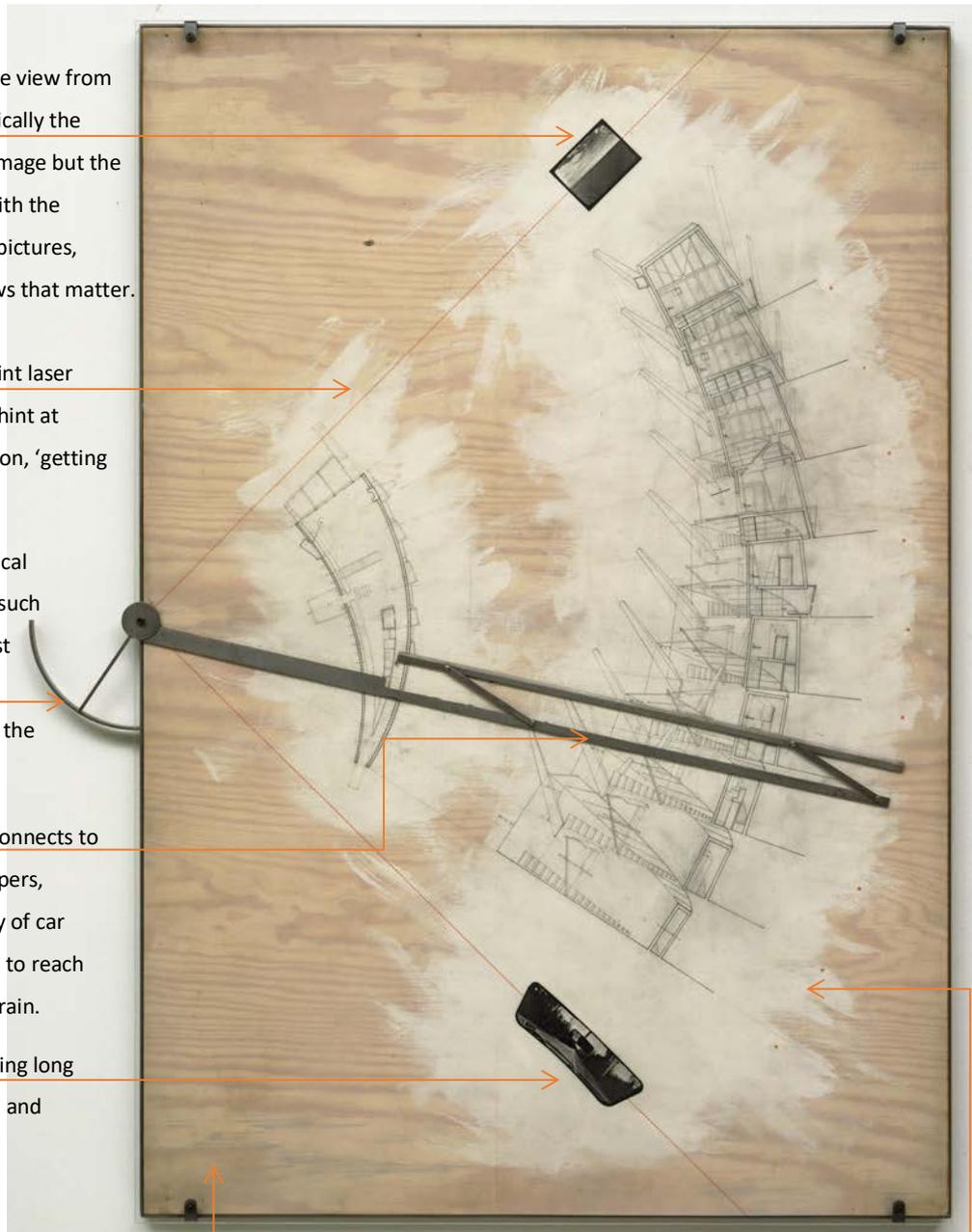
The photograph is of the view from the window. Metaphorically the source here is not the image but the object, a photograph with the connotations of taking pictures, holidays, capturing views that matter.

Red lines link to pin-point laser accuracy but they also hint at bureaucratic organisation, 'getting things right'.

Shapes mimicking nautical measuring equipment, such as a sextant that suggest that the architectural design has control over the sea (view).

The armature's shape connects to those of windscreen wipers, stimulating the memory of car journeys and the desire to reach home to get out of the rain.

Rear view mirror suggesting long drives, the journey home and what you've left behind



The manufactured timber backing references natural materials, implying a certain honesty in the making and craft.

The roughly painted white suggests trying out paint colours and mood boards for decoration in new houses

Figure 55: Slow House concept model, Diller + Scofidio 1990. the captions note several of the perceptual cues and metaphors the model engages with to get its message across.

The metaphors engage with historical and cultural sources such as the reference to the form of the sextant and nautical heritage, or the use of materials such as the plywood back-board with the paint casually rolled over suggesting paint sampling in a new home and DIY. There are direct similarities, seen in the use of armatures referencing wiper blades, a toy car, or the image from a rear-view

mirror, but these are designed to simulate the experience of driving home, reaching your desired destination, which is the home, an idealized concept but one that the architects are building for you. There are also abstract metaphors such as the use of the newspaper (a source of information) collaged to represent the sea as visual data (important, always changing, visually rich), pointing to the idea of the house as a room with a view worth seeing. None of the materials used in the models are expensive, timber, newsprint, machine parts, simple clamps, all reference the project as down-to-Earth, affordable and achievable. They are contrasted against the delicate, fine drawn lines of the Architect reminding the viewer of the accuracy and calculation involved reaffirming the trust in the professionalism of the overall design. Together these elements create the impression of an accomplished project in capable hands.

Newspaper is used here as representative of the sea, conceptualised as information, the sea view as data

The curved plywood sheet is held in a shape that suggests wind breaks on a beach or sails on a yacht. From its starting position it opens up like a flower petal, this with the use of steel clips to hold the position links to biology, detailed examination and the control of nature. The form opens up symbolizing the building opening up

The pin board used here as a base references offices, organisation, maps and planning

The markings evoke concepts of accuracy and navigation.

A small toy car showing the drive to entrance of the design reminds the viewer of the sense of retreat that the house will become but also has childhood memories, family board games and nostalgia for home

The use of visible fixings shows that there is nothing to hide. They also suggest a scientific careful process.

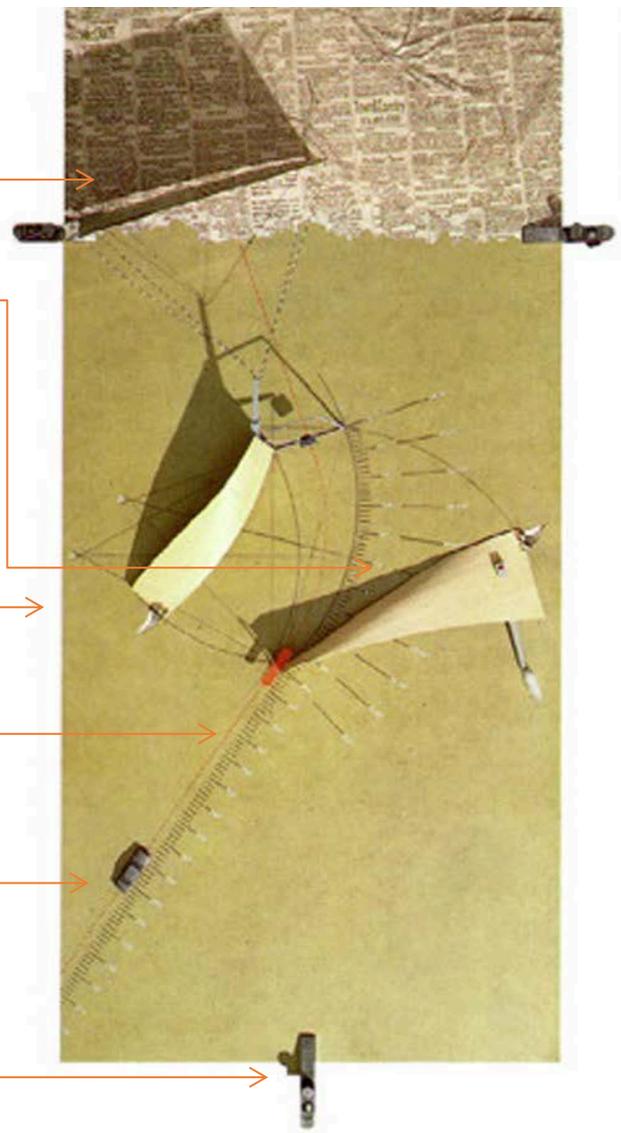


Figure 56: Slow House concept model, Diller + Scofidio 1990. the themes found in the first model continue as a link into this model, the two both made for the same client, the same design.

5.2.9 THE VALUE OF THE ICONIC SUPERSTRUCTURE IN MODELS

The two models above show how perceptual cues and metaphors can convey often subliminal messages. The image metaphors can be very literal, such as the toy car, pointing to where your car goes, but even these references carry deeper, abstract intentions, the toy car referencing the concept of home, family games, childhood and nostalgia, for example. How these analogies are drawn out and what ties them together as a narrative so that the metaphoric intention does not become lost in competing symbolic meanings is what I discuss in this final section of the chapter.

Discussing the role of image metaphor in architectural practice, Rodríguez Caballero stated that “our ability to understand what is both explicitly and implicitly conveyed is only activated when metaphors are seen in context – regardless of whether they map abstract knowledge or images” (2001, p. 99). This relevance of context in making sense of language is mirrored in the approach to translation discussed earlier (Munday 2009; Seleskovitch and Lederer 1995, see p81) where the appreciation of the meaning of a word stems from the understanding of the *overall* intent of the speaker. Its importance is also raised in how we appreciate communication in other modalities, how contextualizing signs used in Sign Language can shift literal meaning to metaphoric or the appreciation of something as music rather than a collection of sounds. In music, Adorno saw context deriving from the intention of the composer, ‘music bereft of all intentionality, the merely phenomenal linking of sounds, would be an acoustic parallel to the kaleidoscope’ (1992, p.3).

For Adorno a piece of work considered as a whole follows a “tendency” (ibid., p.4). It is this tendency that provides the underlying thematic structure of the work, from where the creator of the piece can express their intent in the various elements. Each note works in context to the whole whilst the context itself becomes refined and defined by each note that passes.

If we continue with the Slow House models as an example, we see that they are based on a design which is essentially a retreat with a view. The house is simply a passage, door to window, physical entry to optical departure, although it does include certain necessities (like a kitchen and guestrooms). The whole design is based around the narrative of a journey, escaping to a holiday home. On arrival a long driveway leads up to a narrow facade, comprising only a doorway. Once inside, the building’s curved shape continually pulls you around the corner, further inside, until you are finally presented with the window that dominates the rear of the building. This offers a framed

view of the ocean, but this is itself obstructed by a video monitor, playing recordings of the same vista recorded at an earlier time of the day or night.

This narrative of journey, with arrival being rewarded, provide the tendency, the context that Caballero discussed as key to the accurate translation of metaphor. If we have ever travelled with the hope and excitement of arrival, maybe appreciating the anticipation of a destination being ‘just around the corner’, then we are able to relate to this abstract and conceptual target domain. All the various materials and parts in the model, discussed earlier alongside Figure 31, align to this tendency, shifting from a lexicon of broad potential meanings to iconic gestures and perceptual cues that stir memories and trigger modal responses in us based on relatable/relevant experience intended by the maker.

It is also seen in how contextualizing signs used in Sign Language can shift literal meaning to metaphoric. In British Sign Language (BSL) and linguistic theory this appreciation of thematic tendency is known as the iconic superstructure. Fundamentally hermeneutic in its conception, the iconic elements are seen in a framework defined by the context, “the overall poetic effect of the whole, built up by careful selection of smaller units” (Kaneko and Sutton-Spence 2012, p.12), whilst they in turn help to define it; each element affected by and affecting the meaning of the other, yet each element remaining appreciable on their own merits.

The iconic superstructure is not inherent in the form of the language but is called into play by the language users, “activated at the level of syntax or discourse” (Demey et al. 2008, p.207). In their research Kaneko and Sutton-Spence explored how BSL poets use the iconic superstructure as a basis for metaphorical extension and the way in which it dictates how iconic signs are interpreted.

“In creative sign language, carefully-selected parameters of the sign (handshape, location, movement, and palm orientation) generate an iconic superstructure, which serves as the basis for metaphorical interpretations” (Kaneko and Sutton-Spence 2012, p.4). This is not to exclude the essential embodied aspects of communication in sign language such as the overall posture of the signer or their facial expression. These non-manual markers influence the signs' meaning affecting both grammatical information and emotional intent. Kimmelman (2020) for example, has shown how simple eyebrow gesture can influence meaning, between anger, surprise, or uncertainty, or whether a sign is assertive or questioning.

While in relation to hand forms, Kaneko and Sutton-Spence discuss how bent fingers are more often associated in signing with negative concepts such as ‘anger’ or ‘misery’ although they also are used in other signs that have completely neutral connotations, such as ‘apple’. They explain that when placed in a certain poetic context, although the actual sign for apple does not change, the interpretation of it by the audience takes on the metaphoric connotations. Even though the handshape for the sign used is not negative, (the sign for ‘apple’ is holding the hand in a C shape as if grasping an imaginary apple and taking a bite), by performing this action alongside a succession of bent finger

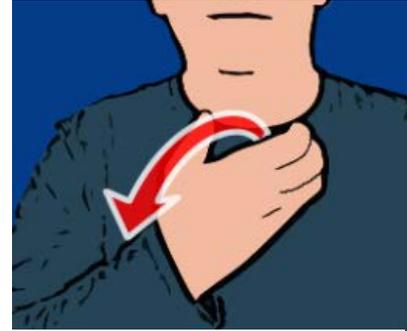


Figure 58:BSL sign for apple
<https://www.british-sign.co.uk>



Figure 57: From the top, BSL signs for 'animal', 'beckon', and 'worm'. Each sign incorporates the bent finger, collectively stressing the associated emotions of anger, wickedness and misery. (The embodied sense of these signs would be better appreciated if you actually make the shapes with your hand).

Image courtesy of <https://www.british-sign.co.uk> and babysignlanguage.com

signs (‘animal’, ‘beckon’, or ‘worm’, shown below) the repetition produced a negative impression to the narrative, giving the poem expressive meaning. The clawing hand gesture, with the embodied connotations the action evokes, provides the perceptual cue to understand the apple, in this context, as something bad or malign.

This appreciation of perceiving shapes in a set context to give them meaning is of great value in modelmaking. How a material element is composed, whether it is in appearance (thin, thick, heavy, its colour, dark, light, translucent, vibrant, etc.), or in its physical attributes (hard, springy, flexible, brittle, absorbent, liquid, etc.), is a syntactic difference, yet how that object is understood or labelled, its cultural connotations (luxurious, industrial, medical, unclean, everyday, etc.), are semantic. It is in the application, and our enactment with the syntactic qualities that lead to a material's semantic appreciation; "meaning is not a fixed property of an object, but ... an emergent product of a relational process of interaction" (Iliopoulos, 2016, p.116).

Material affinities are not, on the whole, 'perceived as belonging to a thing' to misquote Descartes (1993) but because they are deeply rooted in our collective, cultural memory. Used in conversation, or as a conversation, they hold rich, tacit meaning as metaphors when we contextualize them within a larger meaning structure.

5.2.10 SUMMARY OF KEY POINTS

Translating information is an embodied act where we draw on all the resources we have at our command to understand. Even words we appreciate multi modally, describing our world and actions in line with the sensual experiences we relate to them. This chapter has shown how our experience provides the structure to our understanding and expression and how we manipulate that in language taking advantage of our common humanity. The material language I have discussed here emanates from this collective experience in the same manner as the BSL sign for apple.

I have spent some effort in defending image-based metaphors, which in many respects is the same defensive argument as the appreciation of models as a design tool or the role of art in research that I discussed in earlier chapters; because words, images and models are communicative tools they draw on the same emotive and experiential base and that can be expressed either through words or images or models. These arguments are central to the methodology I outline in the following chapter offering a creative path of analysis.

6. METHODOLOGY

6.1 AIMS AND OBJECTIVES

The aims of this research have been to:

- To find a way of communicating the lived experience of rheumatoid arthritis that gives a more subjective and holistic perspective to the general public than current practice allows, making a positive contribution towards the wellbeing of people who live with RA.
- To explore the potential of materials as a means of language, evoking subjective experience.

The formulation from transcription to visualization and model making has been a live and evolving process seeking ways to show the validity of the analysis and the honesty in the translation as it shifts from the transcript to a non-verbalized interpretation, which can be seen in the objectives of the research:

- Propose a philosophical approach that promotes the creative use of modelmaking in research.
- Devise a methodology that allows the translation of text to form.
- Make a series of models that convey the experience of life with rheumatoid arthritis.

6.2 THE HERMENEUTIC CIRCLE AS ETHICAL APPROACH TO METHODOLOGY

Hermeneutics was chosen as the philosophical structure to this project primarily because of Gadamer's extensive reasoning on the value of art as a form of truth and the central role of language in pursuing that truth (2004). However, Gadamer's contribution to hermeneutic research was purely philosophical and he left no methodological approach to follow. In addition to this, because of the physical nature of the findings, the approach undertaken in this research project has no precedents to draw on. I have made every effort to hold to the principles of Gadamer's philosophy and throughout the thesis I have made sure to note Gadamer's perspectives as part of the discussion in the arguments raised.

I have drawn on the approaches prescribed by Austgard (2012) and Fleming, Gaidys and Robb (2003) for linguistic studies in hermeneutics. Their approach provided a tested platform to the early stages of analysis in this project, but also, an ethical stance that has guided the development of the methodology as a whole. Their recommendations break down into five main points:

- The initial area of interest needs to be congruent with the aims of hermeneutic study, that is the phenomena in question needs to be open to new perspectives, the potential of discussion and interpretation.
- The researcher needs to show his prejudice. This is often known as ‘fore-grounding’ and requires the researcher to make his position known both epistemologically and in regard to his understanding of the research topic itself.
- ‘Gaining understanding with the participants’ (Fleming et al. 2003). This process is done through conversation and dialogue; it is not a question and answer session but an attempt to reach a mutual understanding by working together. It is important to remember on this point that in hermeneutic philosophy it isn’t possible to see from another’s point of view and that one can never fully understand how it feels to be someone else. Fleming et al. (2003) note that the researcher should also be aware that meaning and conversational understandings are transient, being situational and historical, meanings can change. It is therefore necessary to reaffirm meanings with the participant at different junctures in the process.
- ‘Gaining understanding through text’ (Fleming et al. 2003). Using thematic analysis to develop basic patterns in the text (Van Manen 1997) allows the researcher to provide the required accuracy and structure to the text-based analysis. The researcher should be aware of the hermeneutic process and look for changes of understanding within the text as larger themes develop and document any interpretative acts clearly.
- Establishing trustworthiness. Trustworthiness in hermeneutics is established by maintaining honesty to the participant’s voice (being faithful to the text). The researcher needs to provide a clear structure to the research and during its progress provide explanations to all decisions/interpretations made. As any conclusion to hermeneutic research is going to be the interpretation of the researcher it is only by showing the process as transparently as possible that the integrity of the research can be maintained.

These methodologies sought an accepted conclusion for hermeneutic research of interpretation of text into text, whilst the purpose here was to take this further by de-verbalising the meaning

(Munday 2009), translating the interpretations into models. However, this is not a concept unfamiliar to hermeneutic philosophy. Gadamer explains text as meaning that has undergone a kind of self-alienation, something that had been de-contextualized through being written down (2004). It was the transformation back into meaning that he considered to be hermeneutic. It has been my intention to gain this understanding through the text but then, still involved in the dialectic movement between the text, participant, and myself, to show an alternative medium for interpretation.

Gadamer described this action of dialectic movement and transformation as 'play'. It is in this sense of involved, interested, imaginative participation that the research has been undertaken following a hermeneutic methodological path adhering to Gadamer's philosophy and his writing on the arts and aesthetic understanding (2004) discussed APPENDIX 4, 11.4.

In applying a hermeneutic philosophy, this research followed a process of assessment, reassessment and reflection on information collected, a hermeneutic cycle (see Figure 59 below). This enabled me to maintain the principles of analytical rigour and persuasive account based on participant engagement as prescribed by Laverly (2008) integral to any validity in hermeneutic research.

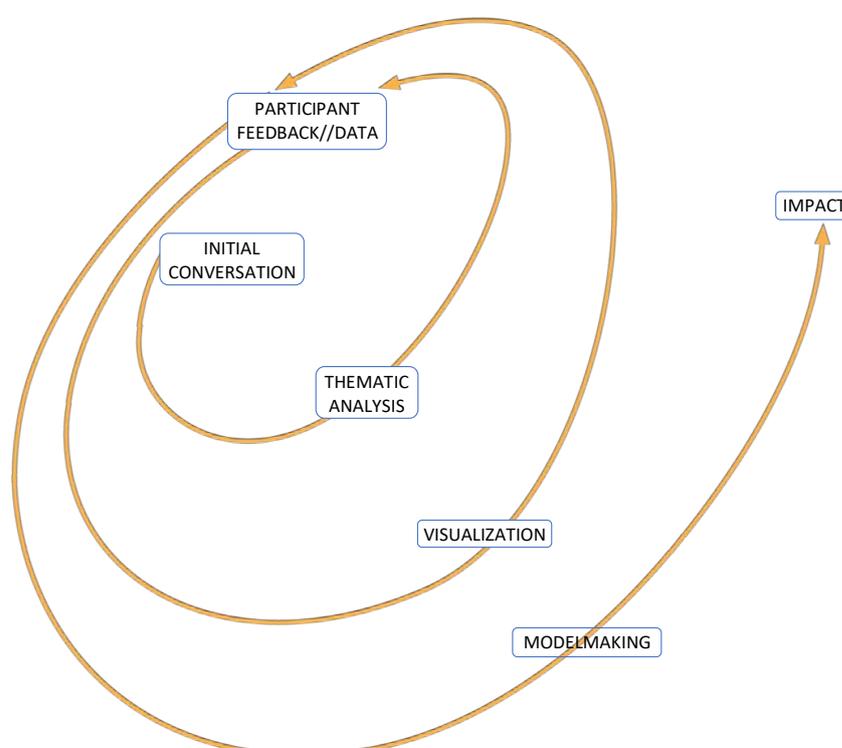


Figure 59: The hermeneutic circle shown in the context of the current research; beginning with the initial data, the process moves through a series of reflective and interpretive stages returning to the data as previously understood with new insight.

Following Gadamer's philosophy (2004) I see understanding not as collecting knowledge with conclusive answers, but a process of shared meanings that open horizons and changes perspectives. Hermeneutics proposes that what we *know* isn't a fixed entity; there is no "natural terminus to the process of understanding...a level at which we have dug down so deep that our spade is turned" (Rorty 2004, p.24). Every understanding comes in relation to what we already know; in other words, it is seen in a context with experience. This context brings pre-conceptual limitations, our prejudice, a boundary that changes with each new experience we encounter and apply.

Entered through our prejudice, this cycle of UNDERSTANDING-INTERPRETATION-APPLICATION-UNDERSTANDING, is our experience and our understanding both renewed by the other²⁹. We align ourselves to a network of prejudice, then apply it to the practical world, literally putting what we know to the test. It is this application that provides us with context, asking questions of our beliefs and defying our prejudice as rigid edicts, instead, showing them to be malleable and flexible.

It is the ability to contextualize that allows hermeneutic research to distance itself from the search for a core truth, a Phenomenological 'essence'. Eidetic reduction (from the word 'eido' or 'form') is the process applied in phenomenological research of going beyond the conventional surface qualities to expose the phenomenon's meaning, revealing its "core" (Moustakas 1994). Brooks made an analogy for eidetic reduction as extracting the attar of a rose:

"as each petal of the blossom is removed, another is fully revealed. The layers of the petals, blended one with the other into a potpourri, yield the attar—the essence of the rose. Each layer revealed by the eidetic reduction successively yields experience, the reflection of experience, until the invariants of experience yield the essence of meaning, that which is constant." (Brooks 1980, p.62-63).

However, this analogy highlights hermeneutic concerns, not least the idea that an understanding of something can be 'constant'. Gadamer observed that interpretations are "never completely definitive. Interpretation is always on the way" (1981, p.56). The eidetic process of removal to reveal something that lies beyond our experience of that thing, in hermeneutic thinking leaves you not with

²⁹ The concept of this circular path of knowledge, known as the hermeneutic circle, was inspired by the linguistic studies of Biblical texts. Reflections on a text or even a word within the book change in context to an appreciation of the book as a whole; but with this new interpretation, the perception of these words become open to questioning in a new light bringing further, deeper understanding.

the thing laid bare but, with a different thing altogether. The ability to see the part in relation to the whole and the whole to its parts and then apply these on reflection, makes learning a dynamic engagement. Rather than an abstract concept, the process of understanding through interpretation is itself part of the experience of understanding. Considered in the light of Brook's analogy, this implies that removing the layers of rose petals to a potpourri brings with it the understanding of making an attar of rose, offering new perspectives as to what roses offer but not a baseline understanding of the 'rose'.

My understanding of the experience of rheumatoid arthritis developed through the analysis in a process that involved re-evaluating my prejudice and a constant reflection of the source material and information considering that. This is not an endless cycle of re-evaluation and uncertainty but a path of continuous growth as the diagram in Figure 59 shows; the hermeneutic 'circle' is somewhat a misnomer as we do not return to the same spot unchanged from the journey we have just made.

The following subchapters outline the methodological path I followed. After providing a visual roadmap to the study I will begin by outlining the participants' involvement, including the recruitment and interview process. I will explain in detail the analytical approach to the conversation, and finally, the practical engagement of drawing and making by the researcher, leading to the translation of an understanding of a conversation into 3D abstract form.

6.3 STAGES OF ANALYSIS

To be able to clearly describe the analysis as a series of stages of translation, from conversation to model, I have artificially grouped the process into two phases. Although in reality these are not so distinct but much more interwoven and reciprocal, the hope was to provide a clear explanation of the process with the reliance on the written word. Firstly, I will discuss the thematic analysis of the transcription, the method used to garner and reflect on that information and how it directly engaged with the text from the transcription following three stages: refining and coding a subjective understanding, appreciating this within a wider social and cultural context, then organizing this into embodied, fundamental concepts. The second major phase of the project I will discuss is the translation into models, where the analysis involves artistic practice, drawing and modelmaking in

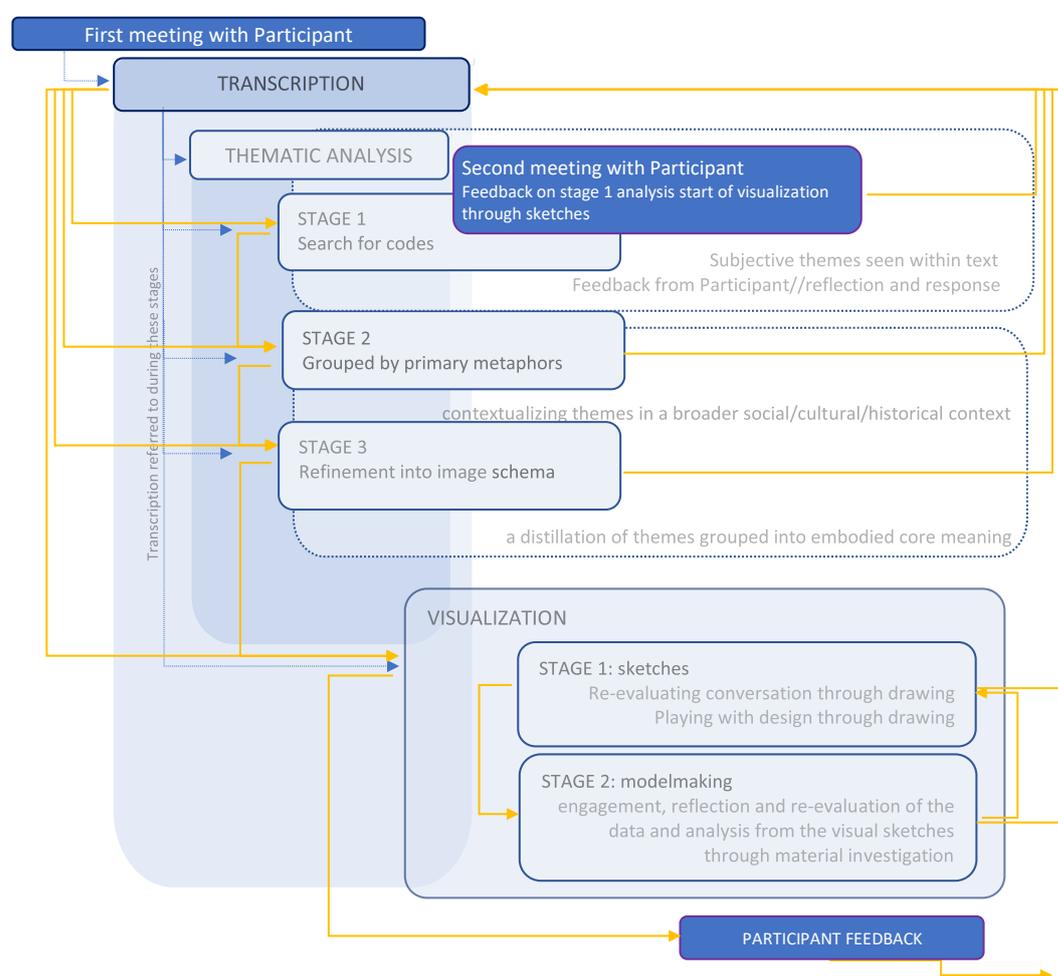


Figure 60: Roadmap showing the various stages of analysis, points of participant engagement and influence of transcription.

interpreting the information, a process I describe as visualization.

Figure 60 visually presents the stages of analysis as a ‘roadmap’ from the first meeting with the participant to their final feedback on the models. Although describing a step-by-step process, the

map also shows the relationships of reflection and re-evaluation to the different stages in the analysis. The yellow arrows are used to map how each stage revisits the initial information, the transcribed conversation with the participants, in an act of reflection that invites both a more nuanced understanding as one furthers the analysis and provides a rigour to the validity of the process.

This relationship between the paths of analysis and reflection can also be seen in Figure 61, which overlays the roadmap with the diagram describing the hermeneutic circle from Figure 59.

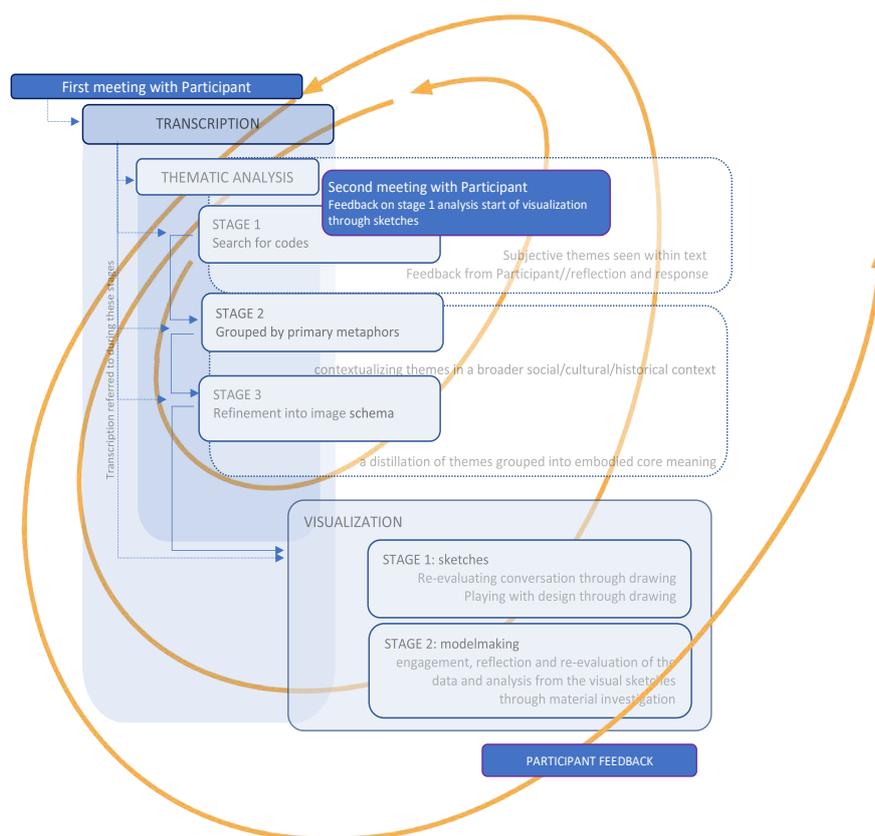


Figure 61: The roadmap overlaid with the hermeneutic circle from Figure 59 shows graphically how the path of analysis follows the philosophical requirements for hermeneutic study.

This graphic shows how, from the initial stages of analysis through to the production of the models, the study follows the philosophical requirements for hermeneutic research consistently returning to re-examine any understanding in the light of the transcription.

This chapter will describe the stages shown in the roadmap above in detail. I will begin with the participants’ involvement in the research, laying down the ethical approach to their engagement in the study, including the meetings and the transcription.

6.4 PARTICIPANT INVOLVEMENT

Figure 62 shows the key stages of participant involvement in the project, highlighted in yellow, which come at the beginning, providing the authoritative source material for the study, in the middle, offering feedback and guidance, and at the end providing an expert opinion.

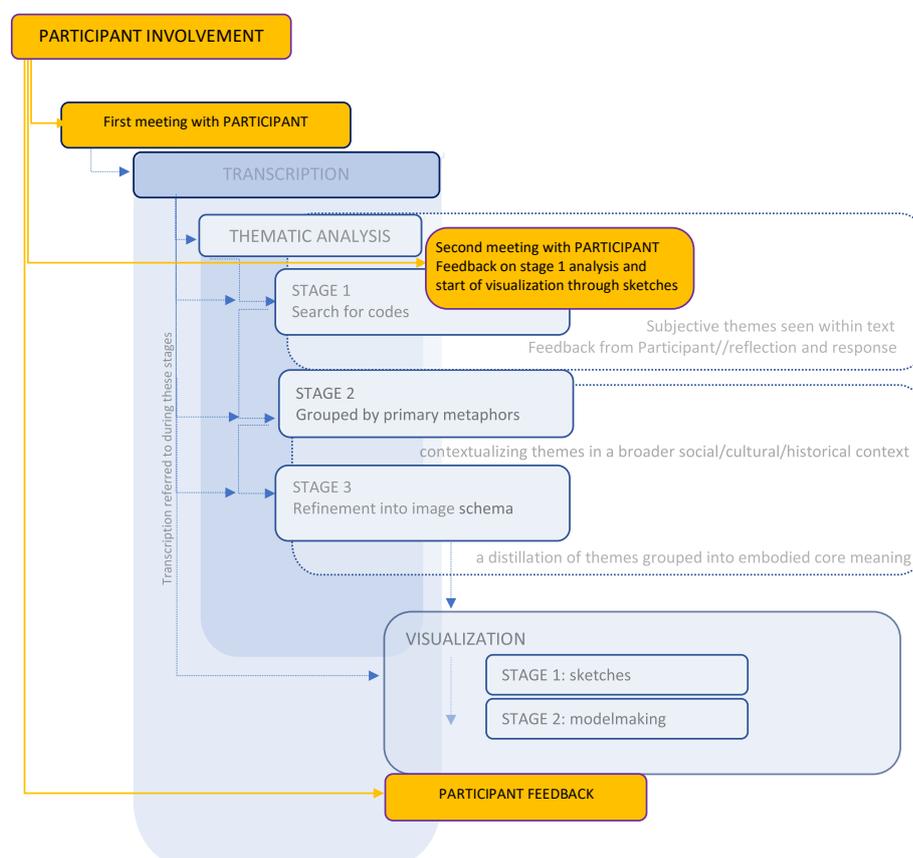


Figure 62: key moments of direct participant engagement in the project, highlighted in yellow.

For the project, I sought three participants through an open request via the University’s Uni-Info system as a method of recruitment (see APPENDIX 2). As the aim and focus of this research is to explore in detail whether models could translate the complexity of dialogue, to aid an understanding of the human experience of RA through material culture, a purposive sample was sought. Although there is no ideal number of participants (Englander 2012; Kvale 1994), Englander recommended at least three participants with the phenomenological method (2012). As well as considering the theoretical and practical commitments of the study, the decision on the number of participants was also based on the development of the models as the intended outcome rather than any concern ‘with the repeatability of an explanation’ (Darke et al. 1998). The value of any explanation was judged in terms of the extent to which it allowed others to understand the phenomena of RA and made sense to those being studied (Walsham 1995).

This research focused on participants in employment from the age of 40 upwards. The rationale for this lay in the “major impact [RA has] on economically active patients” (Godwin et al. 2009, p.24) and the fact that the “age of onset [of the disease] is generally between 40-60 years” (ibid. p.4). (Further details regarding the recruitment process are shown in the Ethics document in APPENDIX 3).

I received five responses to the open call. One came from an elderly male, who was not a member of the University and lived in a different county (two hours drive). They were told of the call by a member of staff who was their relative. I made email contact with the relative who informed me that their father was housebound but very aware and would be more than willing to participate. Unfortunately, I was not able to accept this offer; in a period before video conferencing, I worked full-time and had family commitments that restricted opportunities to engage with the travel at that time.

One other respondent was a male University employee, who contacted me to ask if they could participate as they had arthritis in the foot although this was medically undiagnosed. Although I was keen to include them, partly fearing rejecting anyone from the study, I sought the opinion of my supervisors and the School’s Ethics committee chairperson, who advised against.

I responded apologetically to both respondents. At the end of recruitment, I had three volunteers, female employees of the University, diagnosed with RA.

PARTICIPANT DEMOGRAPHICS							
PARTICIPANT	AGE	SEX	EMPLOYMENT within UNIVERSITY	FAMILY CONTEXT	TIME SINCE DIAGNOSIS	length of INTERVIEW (mins)	No. words transcribed
1	Mid 60s	female	F/T academic	Single +dog	More than 20 yrs	58.05	6191
2	Early 40s	female	P/T administrator	Single +1 child +cat	Less than 10 yrs	58.06	7480
3	Late 40s	female	F/T non-academic professional	Married +2children +2 dogs	More than 30 yrs	44.16	6113

The initial aim was for the participants to have longer-term experience of dealing with their disease, therefore being in a better position to both explain their understanding and be comfortable with any discussions. The King’s Fund, a commissioned inquiry into general medical practice in the UK, noted that “patients reported that they had a low awareness of RA at the point of first contact but that ... they would become experts in the management of their own condition” (Steward and Land 2009,

p.19). This proved to be the case with my participants, two who had experience of RA for many years of their lives, while the third participant, who had only been diagnosed three years previously, also could claim a clear understanding of her illness, its trajectory, and her relationship to it. However, this participant, Participant 2, for reasons she claimed fell outside of the research, decided she could no longer take part after her interview and dropped out of the study. With permission her conversation and the analysis of it was used and continued to be included in the research. The participants involved in the research were all women, white, all working in academia although each in different fields of health, sport, and administration, and aged between 45 and 65.

6.4.1 INTERVIEW/MEETING

The reason for meeting was to meet people with RA face to face and discuss their experience of living with RA with them. The aim was to build an understanding from perspectives offered by the experts, the participants themselves, as opposed to making a general claim regarding the subject and, in doing so, gather the source material regarding first-hand experience of living with RA from which to interpret conceptual themes through analysis. Although, noted that I have no relationship or fore-knowledge of RA, and so potentially could be as somewhat alienated from the participants, it is important to note that commonality or difference between researcher and participants on the basis of “gender, language, physical appearance and personal relationships” (Song and Parker 1995, p.254) undoubtably plays a role in what is said or understood during conversations. Although a male in my 40s, I approached all the participants from a context of student seeking knowledge, not a University employee/equal. By housing the conversations in familiar and academic territory to make the process as comfortable as possible for the participants, I was also providing a point of connection and trust (Richardson 2015). Whilst the relationship with Participant 1 was clearly familiar to her as one of authority (teacher/student) reinforced by using her office for the meeting, held in the library the meetings with Participant 2 and 3 felt much more equitable.

I was not looking to create narratives around personal experience or to use specific personalities as witnesses to their own understanding. However, RA is a very subjective experience, and in any analysis I needed to be aware of maintaining a sufficient degree of mutual understanding with the people who participated, keeping the individual’s understanding in context and not generalizing any information purely to make the analysis simpler.

Gathering information involved one-on-one conversations with the participants, within a two-hour time slot to engage with the participants face to face, allowing them every opportunity to

communicate their experience and, through dialogue, to build for myself a meaningful understanding of their perspectives, interests and concerns.

Two hours was offered as a timeframe for the conversation to allow the participants to structure their calendar. As all of the participants were working, the meetings taking place during the working week on University grounds, I did not want to take advantage of the participant's generosity, I felt the two hours provided enough space to introduce ourselves and talk at length. I explained that the time frame was not defined and if the conversation was shorter or carried over the allotted time it was not a problem. The venues for the conversation had been allotted for as long as I needed them.

In order to involve any participants in this study I was required to submit an ethics report outlining the approaches and responsibilities of the research to show that they conformed to the University of Brighton's research ethics and integrity policy. This document is included in full in APPENDIX 3. After responding to the open call email, each participant was provided with a more detailed breakdown of the study, the requirements of their involvement and what they hoped for outcomes of the study would be. This letter is attached in APPENDIX 2. Although an offer was made to discuss any questions none were raised, allowing times and dates for meeting to be made. Each participant was supplied digitally with a consent form (see APPENDIX 2) before meeting up and asked to sign a physical copy of the same when we met. The consent form outlined my responsibilities to protect the privacy and integrity of the participants, their rights as participants in the research and their agreement to allow me to use their words anonymously in the study and in the public realm.

Rooms on University of Brighton premises were used for the meetings with the participants.

Finding space to discuss research or private conversations in the University grounds is not difficult. Supported by the library, private rooms can be booked for lengths of time for the specific purpose of research interviews.

However, Participant 1 had her own office set within a busy open plan floor of academic and administrative staff. She was confident, both in her role, the topic of conversation and her environment. She had refreshments already available and had prepared her desk for interview, tidying up so I could lay out my recorder and notepad. Although the participant made every effort to make me as comfortable as possible, it was unquestionably intimidating for me, and I was extremely nervous.

I met Participant 2 in a small backroom set aside by library staff for interviews. The room was small, enough space for two chairs and a table and, although it had a window and was light, it felt like a

hastily converted broom cupboard. The participant made no complaints about the space, or my inability to provide refreshments (I brought two bottles of water, teabags, and mugs but no kettle was available). The sense of the conversation was that of a stolen conversation, a feeling of 'meeting behind the bike sheds at breaktime to share secrets'.

I also met participant 3 at a prebooked library venue. Although we had a room, the participant preferred to sit in the large open space of the library. We sat at one end of a large twenty seating table and were completely alone in the library.

The conversations with them were recorded using a digital voice recorder³⁰. This information was transferred to my home computer and protected in compliance with with data handling, storage and integrity requirements set out in the University's ethical policy.

The term 'interview' was used when first approaching the participants, as I felt that this was an easily understood concept, but I explained that my hope was for the meeting to be more of a conversation with a purpose. Interviews presume a hierarchy and a desire from the interviewer to extract from the interviewee something they want. My approach to the meeting tried to follow a feminist interview methodology (Reinharz and Davidman 1992) where the participants were invited to recount their experiences in their own way, with any questions I raised serving only as a guide to their account. An approach that rejects any positivistic ideal of producing an impersonal, value-free and objective account of experience (ibid.).

I instigated the conversation by my stating my interest in:

- The participant's understanding of what RA meant to them (physically, emotionally, or medically)
- How their daily routine was affected by RA and what, if any, adjustments have they made.
- How the participant's felt others perceived their RA.

³⁰ I initially believed that the use of video recording equipment had the potential to greatly increase the understanding of the information gained during interviews because I felt that physical gestures, any movement that expressed or emphasized an idea, sentiment, or attitude, were a form of articulation (Krauss et al. 1996), 'the outward expression of a certain manner of Being-in-the-world' (Merleau-Ponty 2002, p.55) and considered as a language open to interpretation (Merleau-Ponty 2002). This approach to information gathering was only used on the first interview as I found that rather than benefit the process, this information detracted from the analysis of the text, enforcing literal and human gestures that in visual form already held established iconic meanings that restricted the abstract pliability of the materials and forms in the models.

However, I invited the participants to talk about what they considered as relevant, in the knowledge that they had agreed to meet and discuss their experience of RA. The participants then took the lead, interventions from me only came if I needed some clarification or greater detail on points of interest. I outlined my ignorance as opposed to the participant's expertise in an effort that my prejudice would not bias the direction of the conversation, resulting in richer, more diverse and personalized account.

Within hermeneutics, it is important that the researcher and participants work together if there is to be any validity in the researcher's interpretation of the participant's experience. With this level of engagement, I felt it was important ethically for the participants to understand my aims and objectives for the research, and to an extent the philosophy behind it³¹, so that they could understand their contribution and not feel that they have been taken advantage of or misrepresented in any way. I also considered it important for the participant to appreciate that the analysis of the conversation would focus on *my* interpretation and that this research was not an attempt to create a 'portrait' of the participant. These points were raised with the participants before they agreed to be involved and prior to the conversations being recorded.

6.5 THEMATIC ANALYSIS

Using a latent, theoretical, thematic analysis (Braun and Clarke 2006) provided the means to analyse the structure and content of the conversations without 'disembodying' the data from the source by categorizing it (Braun and Clarke 2006; Biggerstaff and Thompson 2008). It is considered the most viable approach for hermeneutic research (Fleming et al. 2002; Austgard 2012)

This approach is defined as a "method for identifying, analysing, and reporting patterns (themes) within data" (Braun and Clarke, 2006, p.6). Theme development is based on the interpretation of the data by the researcher and is therefore not quantifiable and does not conform to any rigid instruction. A "theme captures something important about the data in relation to the research

³¹ Mainly focused on the notion of embodiment as intrinsic to meaning making and language creation, and the appreciation of art as language

question and represents some level of patterned response or meaning within the data set” (ibid., p.10).

I understood themes as the ‘what’ the text was trying to say rather than what the words meant. As Munday (2009) emphasized (see p.81) it is the sense of a source, upheld through the context it is in, where meaning is to be found in translating and not the defined meaning of the words. It was with this understanding that I interpreted the transcript, refining the meaning into a more essential statement of themes and, ultimately, schemas. Any understanding of the conversation was described through concepts justified through examples from the transcript.

The transcription was the source material and focus of the thematic analysis, constantly referred to throughout the three stages of understanding discussed below. It was also referred to throughout the second phase of the study, the non-verbal translation into materials, sketching and modelmaking, to ensure the sense of meaning was not lost. Its relevance and influence on the stages is noted in the roadmap (see Figure 63).

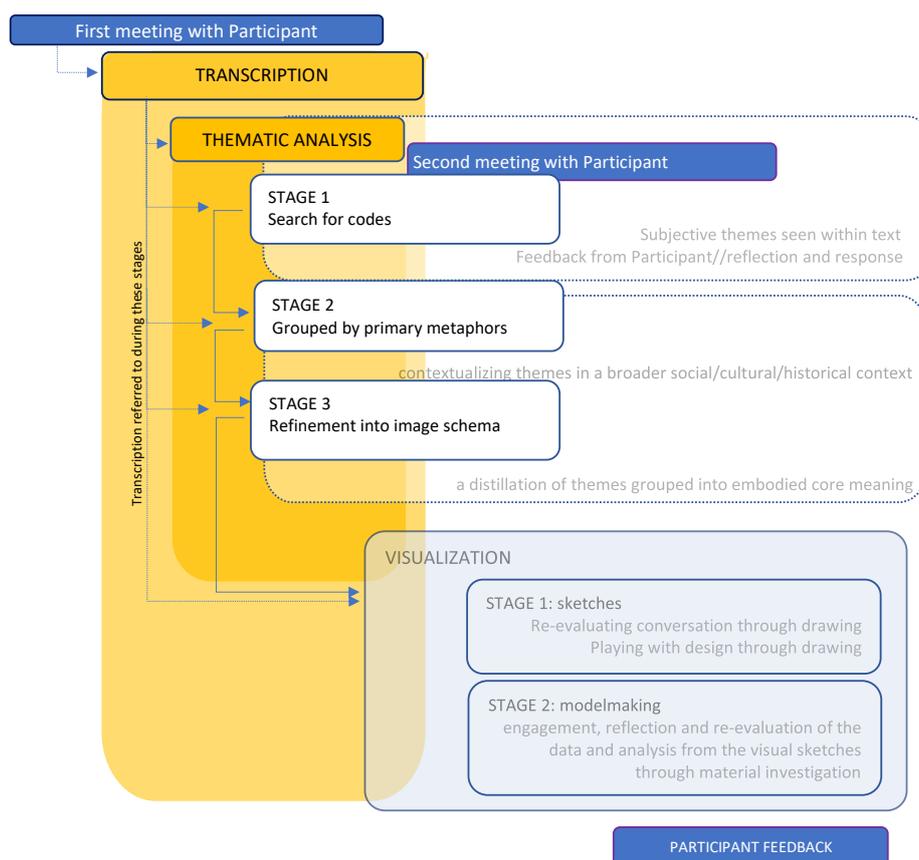


Figure 63: Thematic analysis in context to the study and the relevance of the transcript to the stages of analysis

6.5.1 STAGE 1 a search for themes

Fleming, et al. described this first stage as “gaining understanding through dialogue with text” (2003, p. 118) stating that “the notion of dialogue does not only mean a conversation between two people, it is also possible to have a dialogue between reader and text” (ibid.), where the researcher hypothesizes and questions the text and the text questions the researcher’s interpretation in a “search for meaning” (Austgard 2012, p.832).

Post interview, each recording was listened to on multiple occasions over a period of several weeks so that I could familiarize and immerse myself in the source material. This process allowed me to actively seek out initial thematic hypotheses whilst building an overall feeling for the conversation’s flow. The recording was then transcribed verbatim, including indications of pauses, mis-hearings and mistakes, and even speech dynamics where these were in any way remarkable. The transcripts were then read through with the original recording to ensure accuracy³².

PROSODY

This was not an attempt to see the lived experience of the participant through their eyes, a process that Gadamer felt to be impossible, but to understand it through analysis of the conversation in the light of what I took emotionally from the meeting with the Participant.

The meanings within the transcript are integrally linked to the perlocutionary stage of the conversation (the empathetic and emotional response I had to it). For this reason, I included a prosodic transcription, highlighting the patterns of stress and intonation of the language used as a gauge of my response.

³² The full, transcribed dialogues are provided in the Appendix.

Cole and Shattuck-Hufnagel (2016) explained the purpose of any prosodic transcription system was “to specify (a) the contrastive phonological elements that define the grammatical prosody of the utterance, (b) the acoustic cues to the contrastive features of those prosodic elements, and (c) the values of those cues”.

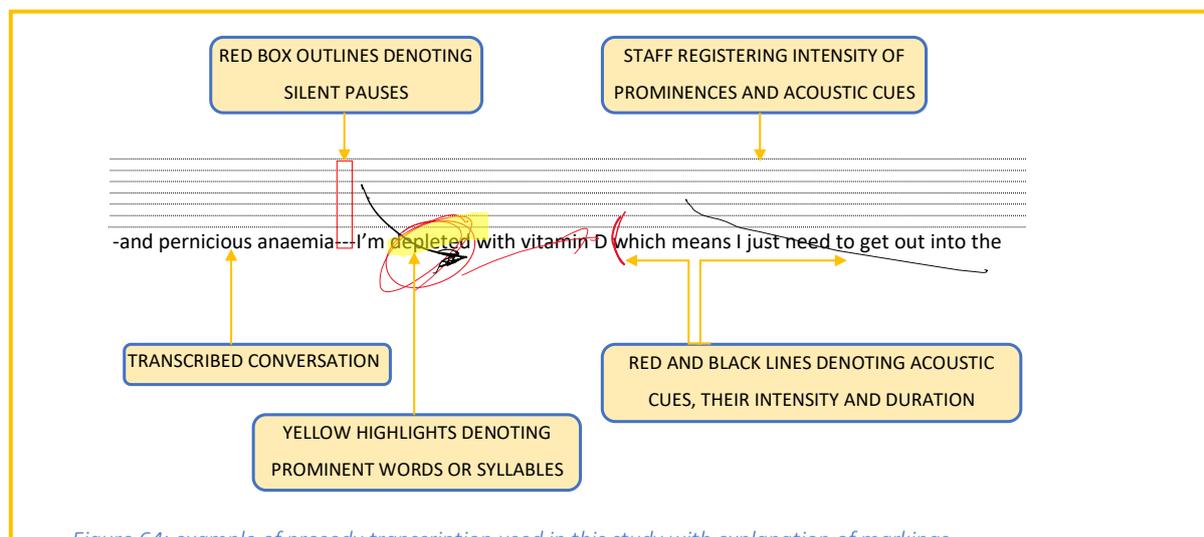


Figure 64: example of prosody transcription used in this study with explanation of markings

In line with this, as part of the transcription, I made a visual record of the silent pauses, the prominences and intensities of certain words or syllables, and acoustic cues³³ (see Figure 64 above). Cole and Shattuck-Hufnagel (2016) suggested that, although impressions of prosodic elements by a transcriber are essentially subjective, a value system that allows a comparison between the perceptual saliences of the various elements would benefit analysis. In compliance, rather than a numerical system I applied a stave³⁴ inspired by musical score sheets, with seven bars above each sentence, marking higher up the stave the more intense, louder, or emphasized an acoustic cue.

Crystal (1985) described “many levels and kinds of speech transcription, ranging from a rough jotting down of the essential words to a meticulous description of everything that can be heard” (p.239). The visual appearance of this study was in part due to the immediacy of the process, where I marked and scored the transcription whilst listening to the audio recording of the conversation in real time

³³ Acoustic cues can be considered as small variations in pronunciation that bring meaning through their intensity, duration, and other various measures of voice quality.

³⁴ A stave is a set of five horizontal lines with spaces which represent different musical pitches in a visual format.

so that I maintained an emotive response to what was spoken. This was a response to and a means of recording the emotion context of the participant's descriptions of their lived experiences and the moments that affected them the most (during the conversation), however seemingly trivial. Making these elements manifest, as visual accents, began to feed the translation into three dimensions, offering literal highs and lows, weight, and distance in the drawn lines. This is not to say that the actual form of the line was copied over into any final design but rather the memory of it, of the mark as a gesture.

The goal of the models is to convey these feelings to third parties, potentially a general audience engaging with this subject matter in a relevant contextual setting, an exhibition or conference on RA, for example. Committing to visual cues from these early stages, closest to the actual moment provide nuances that help convey the intricacies of conversation, adding depth and an openness for interpretations that may otherwise become blurred or subdued in the development of more general themes, making the models more resilient when communicating in the public realm.

ESTABLISHING THEMES

In the analysis, although seeking to understand the lived experience of the participant and conscious of the primary aim of the research (to build models of this), I began by searching for *any* aspects within the source material that appeared most prevalent. These points of interest were basic components of the overall transcription described by Braun and Clarke as 'codes' (2006). This first stage, an inductive process of coding, was data-driven in that it was the source material that led to a development of the future themes, as opposed to a 'theory driven' examination of the source material asking specific questions of it relating to any preconceived notions.

In the conversation, I presumed no fore-knowledge of how the participant felt in regard to their experience of RA, and this stage of the analysis was conducted in the same vein.

Although I was seeking to visualize their understanding, I made no attempt to force this process and bias any information during the conversation. Whether or not the codes and themes had any physical or visual value at this stage was not important. What was important, however, was that the interpretation grasped the intended meaning and that it made sense in context.

All the participants were aware of the concept and aim of the research and this may have unconsciously inclined both of us towards more 'perceivable' metaphors and analogies. However, in hermeneutic research this awareness should not be considered negative in terms of rigour or validation. Understanding 'involves something like applying the text to be understood to the

interpreter's present situation' (Gadamer 2004, p.308), as long as the interpreter's 'present situation', prejudice, and epistemology, have been clearly stated.

6.5.2 SECOND MEETING feedback on themes

The findings from this stage of the analysis were given to the participants before meeting them again for a second time and discussed with them at the beginning of that meeting. In this way the process was validated in line with the prescribed approaches to Gadamerian research of both Fleming, et al. (2003) and Austgard (2012).

Although validation with the participants was important at this stage, truth cannot be finalized in this process because there is a "temporality of every remark within a conversation" (Fleming et al. 2003, p.118) where only the two members of the conversation can confirm any intended meaning, any third party would struggle to "assume the same understanding of the statements of that conversation" (ibid.).

The analysis was presented as a narrative, with the participant presented in the text as a third person, 'the participant'. The analysis was discussed in the present tense from the perspective of an unbiased observer. This is a written format that is common in journalism and literature and was used both to help the participants relate to it and to allow them to engage objectively (McIntyre 2006).

By not directly referencing the participants in the document except as 'the participant', I hoped to prevent any allusions to personal criticism. I also wished to promote the understanding that any analysis or criticism should be directed at the interpretation rather than concerns over how the participant wished to be viewed³⁵. None of the Participants raised any concerns about how they

35 Names insinuate personality by association. I wished to avoid pseudonyms partly for this reason. In the early developmental stages of this research, I was advised to maintain an anonymity in the writing, referring to myself as 'the researcher', a concept that led to the participant included in the initial ethical submission of the project referred to as 'the participant'. Although, as my awareness of my philosophical stance became clearer and I began to discuss my role in the first person, losing the outside, observing principle of 'the researcher', the Participant remained as such, partly to continue to protect their privacy, but also the name 'participant' no longer held the divorced terminology of a research project, but became representative of the personalities I hoped to evoke. I see the individual and conversation, the emotions, the office, and the hand gestures in Participant 1 as much as if they were 'named'. Participant 1, Participant 2, and Participant 3 are individuals and the use of this terminology, for me in writing, is in no way intended to be derogatory.

were presented. Interestingly, both Participants who engaged in the reflective conversation³⁶ on the analysis did so as an analysis of the text, not on what they had said or how they had said it. This almost abstract response suggests that the explanation of the research had been successful.

I explained my decisions and interpretations in the analysis as clearly as possible being aware that “meaningful assumptions should be underpinned by direct quotations from the texts that are being studied” (Austgard 2012, p.833). Austgard also stated that “it is important at all times to make clear what is the content of the original text and what is a presentation of my interpretation of its meaning” (2012, p.832). I therefore chose the following format to help distinguish between the participant’s words and the analysis:

- All original text taken from the transcription of the interview is shown in **bold** placed between ‘**inverted commas**’, font size 11, followed by a reference in superscript, given as line numbers from the transcript. E.g.: ‘**I took him chocolates even though his bedside manner was shocking**’⁶³⁻⁶⁴. Where the focus of the thesis is on more than one Participant they are referenced in the superscript, e.g.:^{456 (Participant 2)}
- The themes proposed are presented in capitals and underlined (e.g.: THEMES ARE INTERPRETATIONS).
- following current literature conventions, primary metaphors are presented in small font capitals (e.g.: CAPITALS ARE METAPHORS) and image schemas are shown in bold capitals (e.g.: **IMAGE SCHEMA**).

A second conversation was instigated to question my interpretations in light of the participant’s critique. This meeting with the participants revolved around a document outlining the themes and an explanation of where they came from, which had been sent digitally to each participant in advance and was also presented at the start of the second meeting as a physical document (see FINDINGS).

Each participant was contacted individually with an attachment containing my written analysis of the conversation we had. I asked them to read through and suggested times we could meet to discuss

³⁶ Participant 1 and 3 engaged with this. Participant 2 had left the research at this point

and critique this analysis as the next stage of the process. The second meetings were to be held in the same format as the first, with myself and each participant meeting privately.

Although I was nervous about the response to the analysis. Despite the attempt to abstract the person from the 'data' using semantics such as naming them 'participant', I was conscious of the intrusive nature in offering a breakdown of someone else's persona to them for critique. This could have been embarrassing or even insulting if misconstrued. However, I feel that the approach to separate the analysis of the conversation to establish the perception of somebody and the need to maintain the humanity in the story, were balanced and accepted by the participants.

Via email, Participant 3 responded with "Wow, I've just read your analysis and it all makes sense to me, most enlightening and very well done".

I thanked her for the vote of confidence and we agreed to meet at the same venue.

Also via email, Participant 1 responded but didn't comment on the analysis:

"I'll see you in my office.

Easter was a bit horrid. My beautiful [dog] died and I am absolutely lost.

Just about got it together so please say nothing tomorrow as I am in an extreme labile emotional state and triggered by the slightest kindness!"

Participant 2 did not respond. I contacted her again to ask if she had received the email and analysis and if she had any questions. After a week delay the participant then contacted me via text to say that she wished to withdraw from the study.

Losing Participant 2 felt like a defeat on several levels. I could not help considering if it was my fault, I had the selfish fear that my research would be flawed, perhaps becoming unachievable and admittedly, I also was annoyed when I worried about losing all the hard work to date.

But these perfectly normal responses were tempered by the humility of other's in literally giving themselves to research. On an abstract level, Participant 2 offered exciting opportunities in the project with a rich and unique analysis, but, as was true with all the participants, whilst Participant 2 was no longer in a position to continue, for whatever reason, the story was hers and if she no longer wanted it heard then so be it.

I contacted her again to ask if it had anything to do with my analysis or the way the study had developed, but she responded that it was to do with other aspects of her life and that she wished the project success.

PROVIDING PEN AND PAPER

To develop a visual language the metaphorical meanings of the themes were hypothesized, and suggestions made and questioned regarding material, form and colour. This meeting was also recorded using a digital voice recorder and A4 photocopy paper and BIC ballpoint pens were offered for sketching.

Another purpose of this meeting was to begin creating visual analogies of the source material, which I could then consolidate later through further drawing into designs to aid the model making process.

For this reason, the potential to make sketches was offered throughout the discussion with the intention of anchoring the conversation in a visual domain. A4 photocopy paper and BIC ballpoint pens were offered for sketching specifically to avoid any feelings of insecurity about 'being able to draw' or 'being precious' about image creation and accuracy. I felt that the conceptual leap from idea to image/drawing would be, at first, easier to grasp than trying to directly visualize materials or objects into anything other than what they are. However, only Participant 1 directly engaged with drawing during any of the meetings.

My approach to the analysis was to draw on the field of architectural design education to explore the embodied, modal relationships of metaphor, rather than engage with other examples of arts-based research methods (Visual art through drawing, painting, photography, collage making, video-making (Mannay 2015)).

Finding expression through artistic media or the objects around me is something wholly natural to me. I classically 'think better with a pencil in my hand', and while there are excellent, successful examples of arts-based data collection methods documented (see Kara 2021; Lyon 2020; Mannay 2015); my aim, with the A4 office pad and Bic biro was to provide the opportunity to draw but within an unpressured and natural environment most akin to one that I would encounter if the participants and myself had met on any other occasion within the institution.

The goal was to translate from the spoken word into models, drawing is a medium I have used to elaborate on the process of analysis and abstraction. For myself, the conversation was the elemental data source, and involving further approaches to clarify, draw out or expose meaning held a possibility of distraction. I wished to find meaning from conversation, with the spoken word as medium.

On reflection, if I had set a task to draw, as part of the conversation, the participants may have complied. But I appreciated the ease with which each participant discussed their story, and I

approached the topic as openly as possible, inviting the participants to give the frame of reference, where to start the story and what was important. This 'free association narrative' approach (Hollway and Jefferson 2008) invited 'a largely uninterrupted flow of talk...opening up opportunities to gain a more nuanced understanding of participant's lived subjectivities' (Mannay 2015, p.111).

While approaches such as sandboxing offer the participant the authority to be in control of what is understood as seen, I was concerned, that any engagement with ready-made/found objects could 'tie' visual metaphors and their forms directly to experience, potentially determining meaning either for the participants or myself.

Knowingly finding expression in abstract form is a skill, something which can be learnt (Mace and Ward 2002). Ideally, I wanted the participants to focus on finding the words, narrating their stories without interruption, using a language that they were culturally attuned to but also one that they engaged with in the medical aspect of their lives when relating experiences to doctors and health professionals.

My experience in analysis was limited and I was aware of my fears exposing the participants to an attempted psychoanalytic commentary and failures based on my ignorance and lack of confidence. I had attended workshops on creative methods (Nicole Browne, '**Using creative methods in qualitative data collection**'; Dr Karen Lumsden, '**exploring the power of stories in social research**'; Social Research Associations annual conference in 2019, 'Blurring boundaries and crossing frontiers in social research')

It would be valuable to explore the process of analysis of something like 'sandboxing', abstracting the analogies the participants make in real time³⁷; developing the scenes they create from narratives with found objects as characters into subjective, schematic forms. In the light of this project, an exploration of cultural appropriations of found objects, abstracted through schema is extremely

³⁷ The concept of visualising scenes, architectural spaces and concepts in real time is an approach to modelmaking I have used with clients in my past. Using card, plasticene and other easily manipulable materials, I would make set design models that visualized the world the clients are verbally describing.

interesting but I see this as a development of the translation process rather than an aid to understanding the current investigation.

6.5.3 STAGE 2 contextualizing themes in a broader social context

The themes developed to this point were “the means to get at the notion” (van Manen 1997, p.88). The themes developed needed to be to be questioned in the light of other understanding and open to application. This is what Gadamer termed historical consciousness, providing a frame of reference in a wider human context to the present stage of understanding (see APPENDIX 4).

In applying a latent approach to the analysis, my aim was to identify broader, communally accepted appreciation of the meanings “underlying... the semantic content of the data” (Braun and Clarke 2006). The approach is considered latent as the words spoken by the Participants carried meaning beyond their face value, implying a wider cultural aspect; for example, Participant 1’s expression “**a bigger thing happening outside** ¹⁷³⁻⁴”, assumes my interpretation of it would not involve any large-scale physical objects in the garden. To explore the deeper connotations of such expressions I applied the understanding that conceptualization is framed by our social and cultural understanding based on pre-linguistic, embodied experience (Glenburg 1997; Lakoff and Johnson 1999) to the codes and themes from the text.

Here the themes were applied to the theoretical context of conceptual primary metaphors³⁸ (Grady 1997). Primary metaphors provide a basis to expression, grouping together analogies, phrases, adjectives, and metaphors where there are connections to be made between the target and source of the metaphor. However, I was not attempting to create metaphors (RA is like a ...) or trying to describe the participant’s experience through a metaphor (such as ‘life on a knife edge’). Although the target meaning, in this case the participant’s experience, is subjective, as a metaphor it becomes associated to a meaning (the source) that is ‘conventionally fixed and agreed on *within a speech community*’ (Kövecses 2010, p.8. My italics). It is this inheritance of meaning from the emotive, abstract concept to concrete and universal experience that is distilled into a definitive category of a primary metaphor.

³⁸ The primary metaphors discussed here will follow convention and are rendered in small capitals.

For example, when describing her work/life balance, Participant 1 stated that she became **'hooked into the whole pattern of behaviour'** ¹⁶¹⁻¹⁶² of long hours and work orientated socializing. Her use of the verb **'hooked'** alongside the description of the concept of social behaviour as a **'pattern'** suggests an inevitable intertwining into a complex woven structure. This is a widely accepted analogy, and there are strong historical and cultural connections between the conceptualization of human experience and textiles both manufacture and material; the rich tapestry of life, for example whilst mythology often describes life in terms of weaving, such as the Moirae, the three goddesses of fate in ancient Greece who, each in turn, spun, apportioned, and cut the threads of life.

In the analysis, I correlated the participant's words with the primary metaphor PURPOSIVE ACTIVITY IS MAKING AN ARTEFACT, simple examples of which are seen when we describe hatching or forming a plan, for example. The Participant's work role, her career, is the purposive activity within an interlaced net of social, professional and personal goals, actions, and other entanglements.

However, I also interpreted the phrase within the primary metaphor ORGANIZATION IS A PHYSICAL STRUCTURE, correlating an understanding of organization with the understanding of interacting with complex objects, our experiences of piecing together or taking apart objects made up of different parts (Grady 1997, p.40). With our example, the workplace as an organization is associated with a **'pattern'**, by describing herself as **'hooked'** into it, the pattern becomes more than a diagrammatic image but becomes a structure of many parts, a woven fabric.

Although established through social recognition, often across many diverse cultures (Kövecses 2010), primary metaphors are not conclusive, drawing on both emotive interpretation and subject experience to be understood. Therefore, it is possible that one phrase could draw on different roots, as seen here. Application becomes clearer when the elements are seen in context, in the case of this process of interpretation, drawing on the first stage of the analysis where the themes developed provide a framework to the interpreted meaning thus allowing the emotive intent of the original to carry through. The text was also re-read allowing me to consider the structure of the primary metaphors in relation to the sense of the overall conversation.

In this analysis, primary metaphors were taken from an established and verified list compiled by Lakoff, Espenson Goldberg and Schwartz (1991). I used this list with the understanding that although comprehensive, the authors acknowledged it as a work in progress and that over the several decades since its publication, research into primary metaphors has added to it (e.g.: Grady 1997; Kövecses 2010; Semino 2010; Forceville 2006). Many of these contributions can be seen throughout this thesis (for example see p.26).

6.5.4 STAGE 3 a distillation of themes into core meanings

The third step in the thematic analysis of the text aimed to develop a 'master' list of themes, a further distillation of meaning that allowed me to re-contextualize the interpretation into another medium, translating what was said without misrepresenting the original.

The stage of analysis from primary metaphors to schema is an alignment of the cultural/historical context of what was said by the participants to its roots. These roots are the embodied source of the meaning, stemming from our physical interactions with the world. As a universally human foundation to understanding and expressing that understanding, image schemas allow the meaning to be reformed in a different language but still maintaining the essential truth of what was said. Lakoff and Dodge stated that for something to qualify as a schema it needs to comply with three basic rules:

- (1) "recurrence across many different experiences;
- (2) a relatively small number of parts or components; and
- (3) an internal structure that supports inferences" (2005, p. 59).

Schemas represent something that cannot be reduced any further³⁹ but allow for interpretation through metaphorical links, to the initial reference.

The image schema used as the basis of the analysis for this stage stems from a list compiled by Johnson (1987, p.126) of what are considered to be the most important image schemas. These are as follows (rendered according to convention in small capitals and bold): **ATTRACTION; BALANCE; BLOCKAGE; CENTRE-PERIPHERY; COLLECTION; CONTACT; CONTAINER; COMPULSION; COUNTERFORCE; CYCLE; ENABLEMENT; FULL-EMPTY; ITERATION; LINK; MASS-COUNT; MATCHING; MERGING; NEAR-FAR; OBJECT; PART-WHOLE; PATH; PROCESS; RESTRAINT REMOVAL; SCALE; SPLITTING; SUPERIMPOSITION; SURFACE; VERTICALITY.**

If we consider the phrase from Participant 1 where she describes the development of a bone joint deterioration as a consequence of RA:

³⁹ In the context of this study I include Mandler and Cánovas' building blocks of perception, spatial primitives (2014), as image schemas although they are considered as pre-schematic by many.

‘when I think back over the years there were probably little symptoms I could have-----you know, you amass all that stuff don’t you, I had dry eyes and I remember getting the clicky hips which was pre-empting what then happened’⁸⁵⁻⁸⁷.

From this we can see how the participant perceives the ailments as entities; she already had possession of the dry eyes, the clicky hips were a new acquisition. The adjectives ‘dry’ and ‘clicky’ suggests that the parts are faulty, and therefore not wanted.

This correlates with the primary metaphor, HARM IS A BURDEN WHICH SLOWS DOWN MOTION (Lakoff, Espenson and Schwartz 1991, p.52), which can be also seen in phrases such as being weighed down by something, a bad cold, red tape, or responsibilities, for example (harm in this sense does not have to imply physical injury, rather something which damages one’s ability to act). The implication of this primary metaphor lies in the fact that reaching the goal of action is harder and slower because of the burden, but still possible as it only slows down motion as opposed to ending it. The ‘dry eyes’ and ‘clicky hips’ are a burden impairing the participant’s freedom of action.

Stage 3 leads us to examine the primary metaphor itself, which we can tie to several of the image schema on Johnson’s list (1987):

- **COLLECTION**: the acquisition of a burden,
- the lack of **ENABLEMENT** as the participant is restricted by the burden,
- **COUNTERFORCE**: one thing pushes against another (the participant’s desire to move against the ‘clickyness’ of the hips), and
- **PATH**: there is a direction of movement (motion).

As standalone entities, image schema provide a broad canvas of meaning. On its own, the schema **COLLECTION**, for example, stands as a root of understanding for ‘*more than one thing*’, in itself an incredibly broad and abstract concept. However, by superimposing image schema they become dynamic and relate to recognizable action (Oakley 2012). In relationship to the three image schemas, **PATH**, **COUNTERFORCE** and **ENABLEMENT**, the schema **COLLECTION** registers an empathetic response to carrying something extra which has a negative impact on one’s ability to get somewhere: **COLLECTION** takes on this negative aspect because it relates to **COUNTERFORCE** and becomes undesirable to the goal of **ENABLEMENT** and **PATH**. In this way image schema become relatable as ‘properties of action’ (ibid. p.4).

The stages 2 and 3 of analysis of each theme are shown diagrammatically in a template showing the path from primary metaphor to image schema. Context for the use of the primary metaphors is given in the form of quotes from the transcription with line reference. An explanation for the use of schemas and their superimpositions is given with each diagram (see Figure 65).

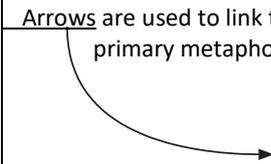
STAGE OF ANALYSIS	
CODES and MAIN THEMES	<p>In this bar the main themes outlined through the first stage of the thematic analysis are listed. For the sake of clarity each code with its corresponding themes is given its own page.</p>  <p><i>Figure 66: example of positive/negative connotation slide bar motif.</i></p>
THEORETICAL APPLICATION (placement into a wider social context).	<p>Here the themes are applied to a theoretical context, primary metaphors taken from an established and verified list compiled by Lakoff, Espenson, Goldberg and Schwartz (1991). Where the primary metaphors are not taken from this source the reference is supplied in situ.</p> <p>According to convention primary metaphors are rendered in SMALL CAPITALS, whilst image schemas are in LARGE CAPITALS AND BOLD.</p> <p>Context for the use of the primary metaphors is given in the form of quotes from the transcript with line reference.</p> <p>PRIMARY METAPHOR</p>  <p>A representative slide-bar below each theme and primary metaphor shows the emotional context derived at through the first stage of the analysis; red represents a negative context and green a positive.</p> <p>Arrows are used to link the path of analysis and show the relationships between the themes, primary metaphors and image schema.</p> 
MASTER LIST (DISTILLATION To IMAGE SCHEMA)	<p>In this bar the primary metaphors are further distilled into image schema. It is this refinement that allows the metaphors to develop multi-modally.</p> <p>The schemas are taken from a list compiled by Johnson (1987, p.126). Any transition between the schema is shown with arrows.</p>

Figure 65: template used to show the path of analysis from primary metaphor to image schema with explanatory text.

Within the diagrams I applied a basic slide bar motif denoting positive and negative to each primary metaphor, with red standing for negative and green for positive. Although simplistic, this visual aid helps maintain the empathetic context of what was originally said by the participants and when seen in context to other statements starts to give a clear signifier of the intimated mood.

For example, the primary metaphor HARM IS LACKING A NEEDED POSSESSION incorporates numerous phrases referenced in Participant 1's account, '**the hips went**'^{2nd stge:183} or '**my shoulder goes**'¹⁸² for example. These have undeniably negative connotations and result in a red slide bar.

However, the primary metaphor PROGRESS IS FORWARD incorporates more complex emotive

HARM IS LACKING A NEEDED POSSESSION



Figure 67: primary metaphor with negative connotation

states: '**I've got a life again so I went off**'⁹⁵ (getting her life back is progress allowing her to move forward) is positive. '**I'm in a space where I've come back**'¹²⁹ (progress is regaining a sense of self and peace of mind seen as a place that was left but now returned to) is also positive but the phrase '**the speed with which that came on for me**'²³⁰ which also fits within the primary metaphor (the progression of the disease is moving forward) is negative. Therefore, the slide bar motif would reflect this as 1/3 red and 2/3 green.

PROGRESS IS FORWARD MOTION



Figure 68: primary metaphor with mixed connotations

This process allowed the primary metaphors to be checked against the text as a whole, that they made sense in context, ensuring validity. By reflecting on the emotional context in this manner, I not only reinforced the Participant's understanding in what was said as the analysis inevitably refined and abstracted their words, but I also provided a hierarchy and structure for the visualization process so that the connotations of something being positive or negative translated accordingly into three dimensions.

6.6 THE VISUALIZATION PROCESS

The second phase of the analysis involved the application of creative design thinking. This involves revisiting the text and re-evaluating the analysis through drawing, to establish the sketches as visual conventions between abstract symbolic text and embodied expression of making.

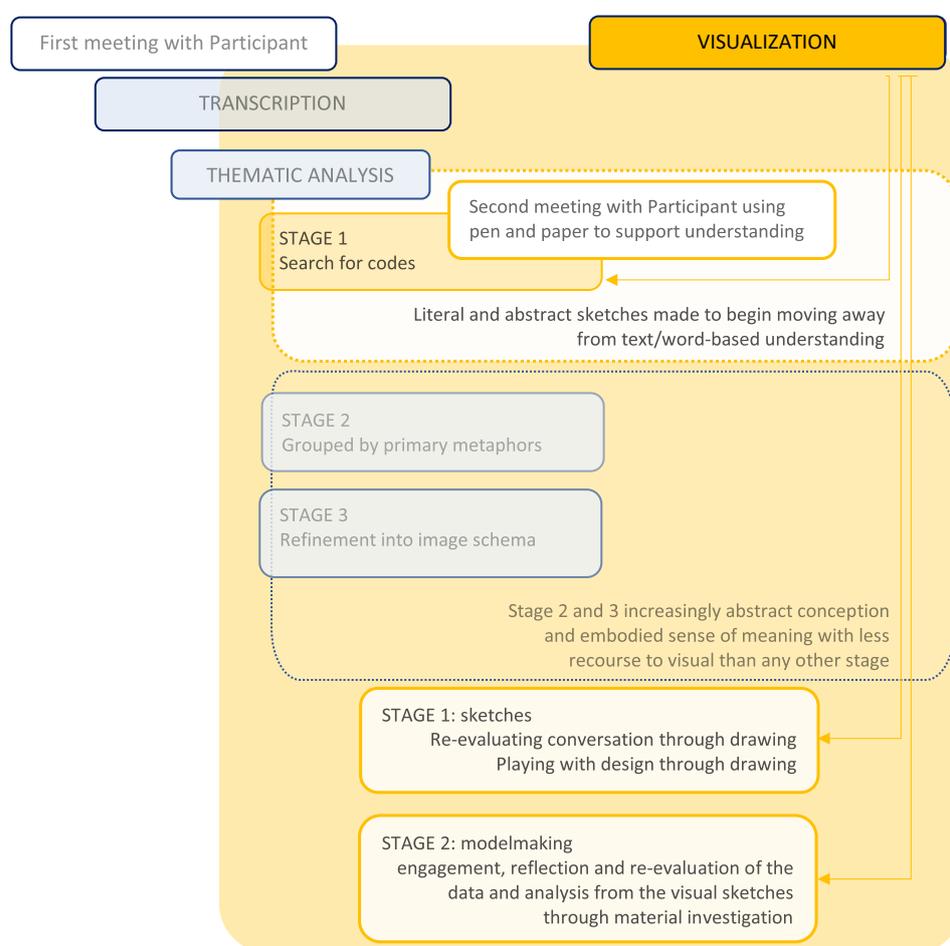


Figure 69: road map highlighting in yellow the integral and pervasive role of visuals throughout the analysis

Figure 69 shows how the process of analytical thinking involving drawing as a mode of thinking and expression is evident throughout, from the rough doodles in the first meetings, the visual diagramming of the primary metaphors, through to the design development sketches for the models. Drawing is so ingrained into my way of being as a means to communicate and understand, using pencil and paper as tools to think with, that it is important to note that although the road map lays out a clear path in a series of sequential stages, these are so displayed to allow me to explain the individual parts involved that drive the analysis as a whole. It is in fact much more compounded and interwoven than this. The following section outlines the different ways in which sketching has been used in the analysis, as a means to understand the text and as a way of design and visual

reflection in the design of the models. I also explain the increasing abstraction in the analysis as part of the development of a visual language.

6.6.1 Analysis of the text through drawing

Ferguson in 'Engineering and the mind's eye' (1992), describes three kinds of sketch as part of the design process, thinking sketches, talking sketches, and prescriptive sketches:

- the prescriptive sketch is the drawing used to explain something already understood by the drawer (an illustration in a note book to remind one of what they saw),
- the talking sketch supports the words said in meaning making during a conversation with another (for example, explanations of complex spatial descriptions such as a map drawn to show someone how to get to your house),
- whilst the thinking sketch refers to the subjective, extended cognitive process involving pen/pencil and paper (Shapiro, 2014) where ideas are played out in the mind's eye, continued on the paper and subjectively re-evaluated through this circular relationship.

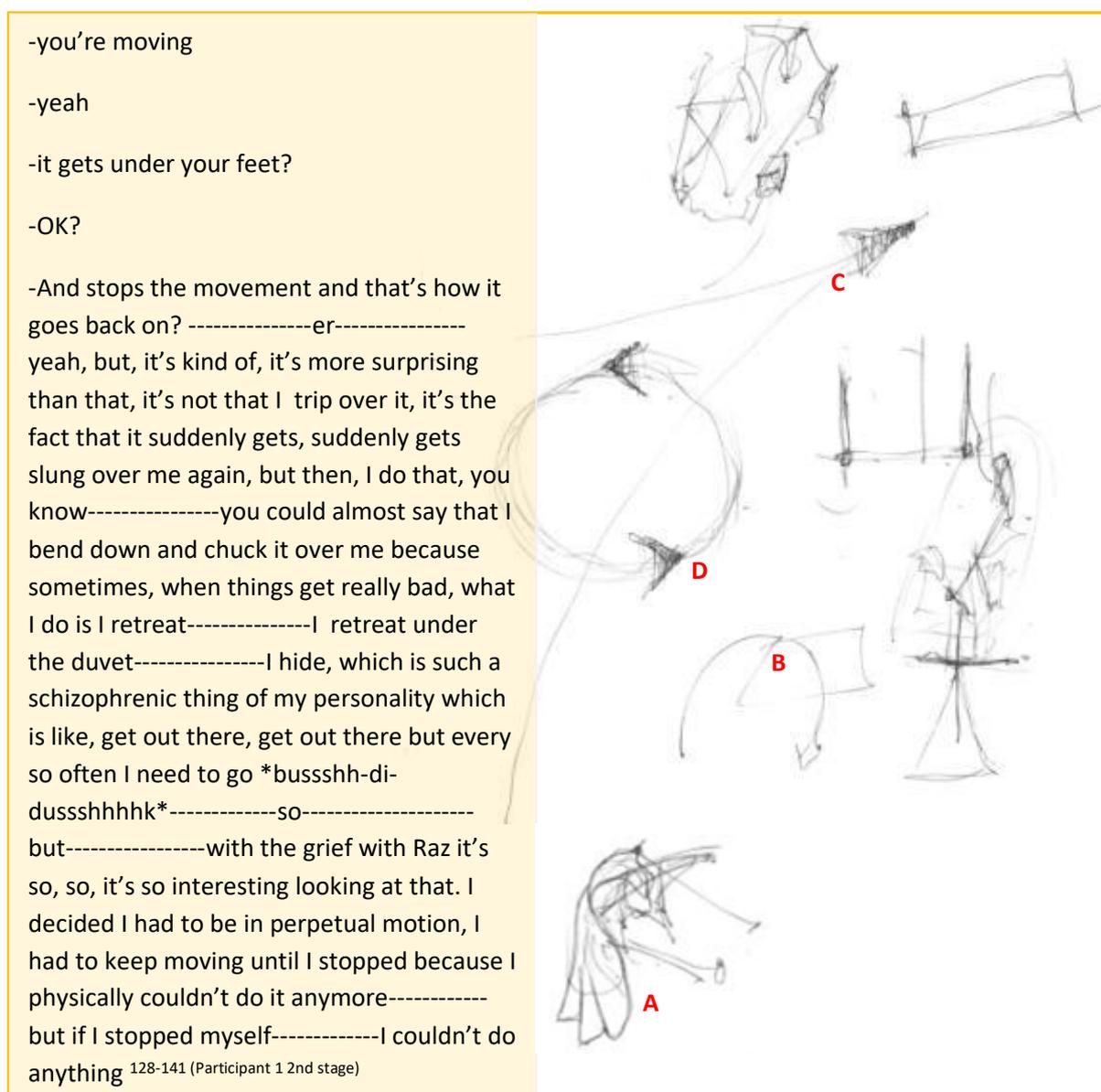


Figure 70: example of 'talking sketch' with Participant 1 with corresponding transcribed conversation.

Figure 70 above shows an example with Participant 1 of sketching used to help understanding as an integral part of the conversation. The sketches are shown next to the corresponding transcription. Here the Participant was trying to create an analogy of how the RA could suddenly envelop her, physically and emotionally, using the concept of a black shroud. This analogy was readily understood as an established visual metaphor, however, the Participant wished to emphasize the complication of the auto-immunity, the contradiction that this was something she felt was inflicted on her but something she imposed on herself, something that she was always aware of but constantly caught her by surprise. To clarify our mutual understanding, we used the sketches as a visual clarification. Initially this was literal (A), a figurative representation of the shroud metaphor, then developing diagrammatically (B). Sketches like these, act in the same manner as physical gesturing, emphasizing

action ('slung over'¹³⁴), and animating the narrative ('I had to keep moving'¹³⁰ as seen in **C**). This is most clearly seen in the Participant's own sketch (**D**), which was almost unconsciously doodled when discussing 'perpetual motion'¹⁴⁰.

Talking sketches are contextual and have a temporal quality. By definition, they are linked to the conversation and in reflection can deepen or lose meaning just as words can because the perlocutionary stage of discourse, the contextual, emotive stimulus and effect of what was said or drawn, continues past the moment of communication (Ricoeur 1973).

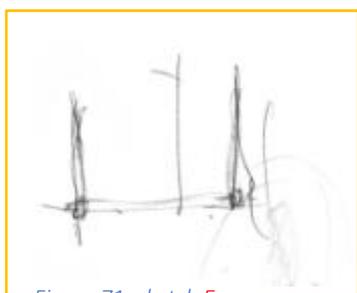


Figure 71: sketch E

For example, in examining two sketches in Figure 71 (**E**) and Figure 73(**F**), taken from the same extract of the conversation with Participant 1 in Figure 70, although once part of the conversation, sketch **E** has lost any contextual relevance. It was drawn in a moment, presumably to reinforce the understanding between the Participant and myself, but that purpose has passed.

Sketch (**F**) on the other hand although part of the same dialogue has more independence in meaning. More effort was spent in it communicating and so it is more developed as a drawing, elements develop becoming recognizable and, as an object it has a sense of narrative, it becomes more figurative, with a base, middle and head, but it is also contextualized as one can see traces of simple movement lines acting out the black shroud being thrown over.

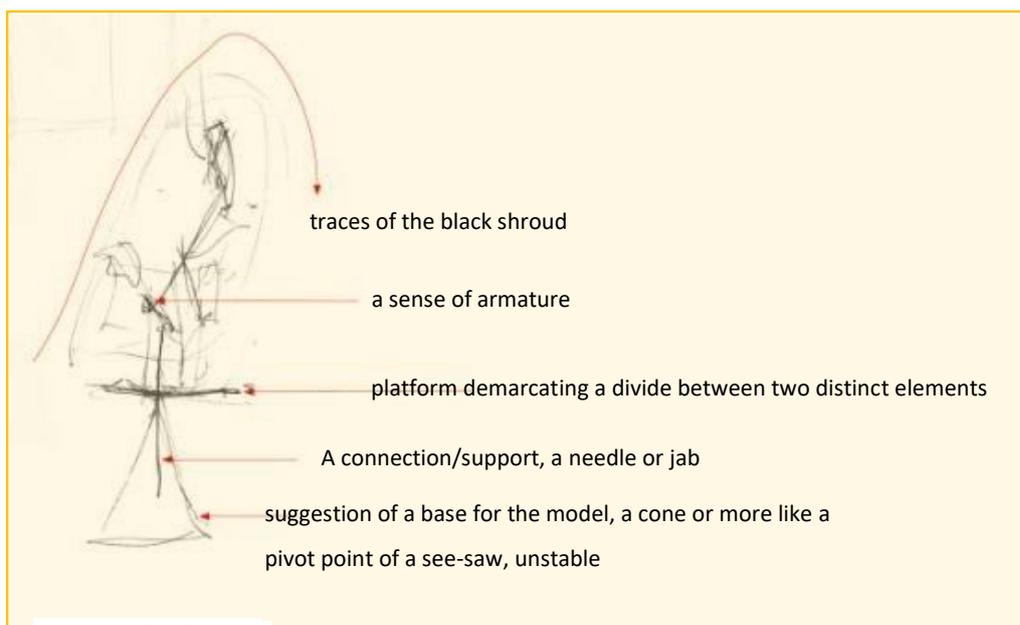


Figure 73: sketch F

However, this concept of communicating and resolving immediate thoughts with drawing, which I had taken for granted as a necessary language in my profession, raised a level of self-consciousness in the participants that detracted from the conversation. Only one of the participants was willing to commit their thoughts to paper (see Figure 72), and this with a great deal of self-criticism and unhappiness with the outcome of their drawing abilities, the second participant involved in this stage refused to pick up the pen.

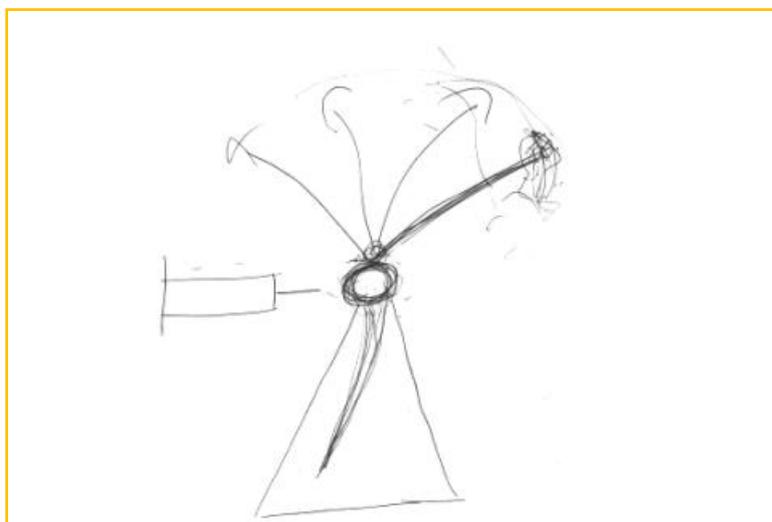


Figure 72: Participant 1's only sketch of her concept for a model. The sketch proved to be pivotal in the development of the model. One can see the hip replacement form in the cone like base, with the concept of being stabbed/injected represented by the needle. The energy of the upper part represented by line is also clear to see.

With both participant's an agreement was reached that the intention of this stage was to reflect on the analysis and to start to find metaphorical links to the themes with my understanding that

abstract, conceptual metaphor has an embodied basis (Lakoff and Johnson 1999). They would leave any drawing to me.

6.6.2 Playing with the design through drawing

Despite this set back, going through this process enabled me to pursue the design of the models within the constraints of a visual and material palette determined in consultation with the participants, ensuring that their voice was not lost in the creative process.

This step involves a process of design which I define as 'play' as explained by Gadamer (2004). Outlined in greater detail in APPENDIX 4, Gadamer explained that to play one needs to submit, to lose oneself in an act of de-subjectification (ibid.). This act of 'letting it go' is a willingness to yield to the context of the data and in doing so, allowing one's preconceptions to be questioned, my assumptions about any models I thought to make at the outset of the project but instead engage with the possibilities offered by the context, wherever they may lead.

After the second meeting with the participants, I began to deepen my understanding of the themes developed in the first stage by using sketches to explore my interpretation visually, 'focusing and guiding my nonverbal thinking' (Ferguson 1992, p.97).

Sketches are messy. They are made with an immediacy and creative ambiguity comparable to a hummed melody that only after consideration and practice becomes a song.

The sketch, however vague or generic, is integral to creative research analysis. However, a drawing or sketch, in and of itself, lacks the immediacy of comprehension of the written word or the perceived rigour of current research practice. For this reason, in the initial stages the drawings were somewhat prescriptive (see Figure 75) often directly referencing the text.



Figure 75: prescriptive drawing of whirling Dervisher seeking empathetic response to the notion of losing oneself in dancing/movement and the exhaustion that follows.

Visual languages develop through use as one seeks the right mark to clarify and express that thought you cannot speak or the line simplifies and abstracts as comprehension comes easier. This is also seen in the analysis, in the way that the drawings begin to reference themselves through line and texture, they became more dominant and abstracted, evolving from their source in the text and becoming definitive of their own meaning (see Figure 74).



Figure 74: 'you build with it/you live within it'²⁹⁹ (Participant 1) sketch showing development from a figurative understanding to abstract concept.

As the sketches developed I relied less and less on the caption to aid comprehension. The intention for the final models was for them to 'speak' for themselves, as they have always been considered the conclusive statement of the research, the interpretation of the lived experience of the participants in my understanding; any captions or descriptive statements used in conjunction with the models being seen as literary crutches (see Figure 76).

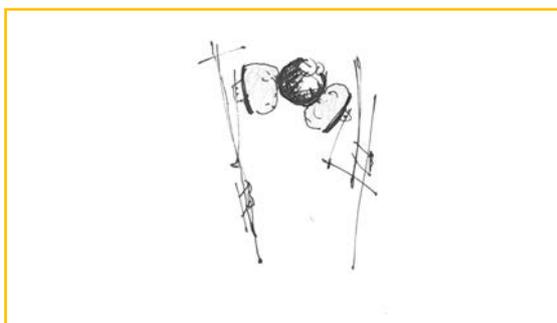


Figure 76: the meaning of the sketch has its logic tied to the context of the analysis.

This path from figurative to conceptual, concrete to abstract is shown in Figure 77. The diagram highlights how both the text and visualizations rely less and less on concrete, referenceable concepts as the analysis develops. The diagram also shows how the more abstract sketches rely less on the descriptive text, the thematic groupings of Stage 1 or the metaphoric associations of Stage 2 and draw more on the schema as a guide to meaning making.

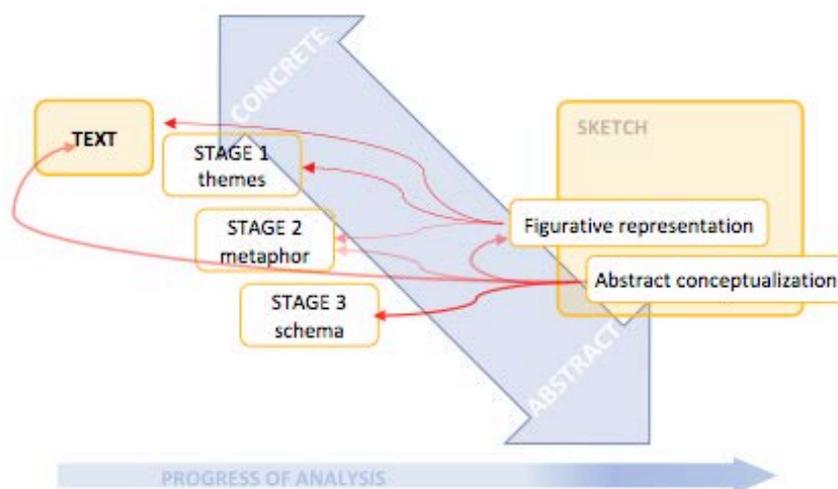


Figure 77: showing the path of analysis from concrete to abstract

Also considered in the design, evolving alongside the sketches as they develop, are schematics. These are diagrams that act as visual, theoretical structures. These schematics lack physicality and are not intended to show materiality, but they provide an important, basic narrative. Derived from a summary of the thematic analysis at the close of stage 3, the iconic superimposition of the themes (see p.128), and consolidated through the analysis of the sketches, they offer a skeletal map for any model that stems from them, particularly in considering the model form as an overall. The schematics are shown for the three models in Figure 80, Figure 79, and Figure 78 below.

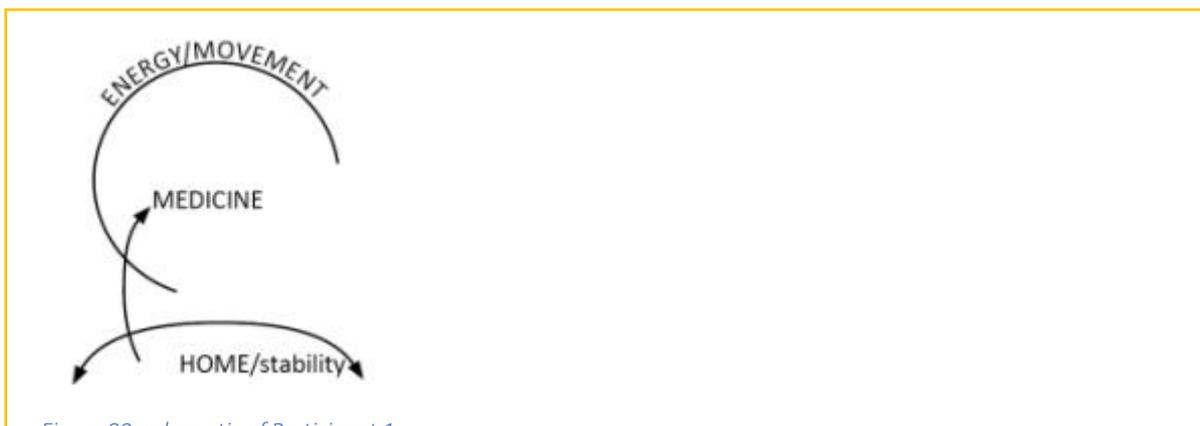


Figure 80: schematic of Participant 1

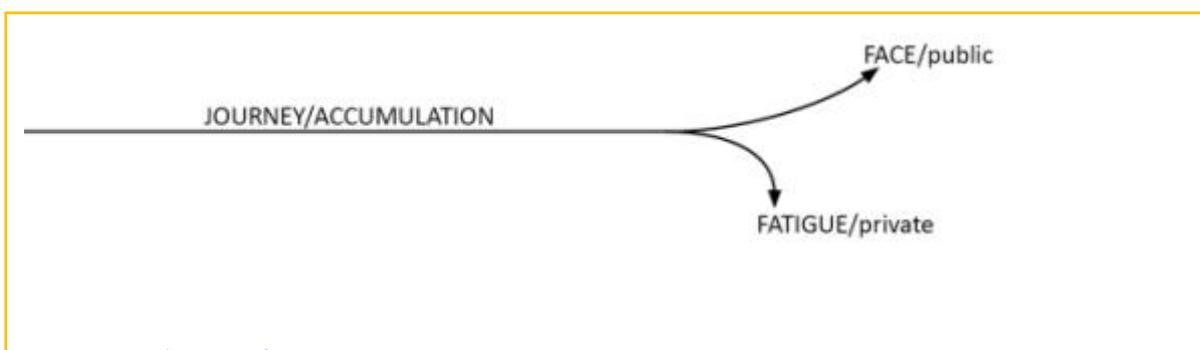


Figure 79: schematic of Participant 2

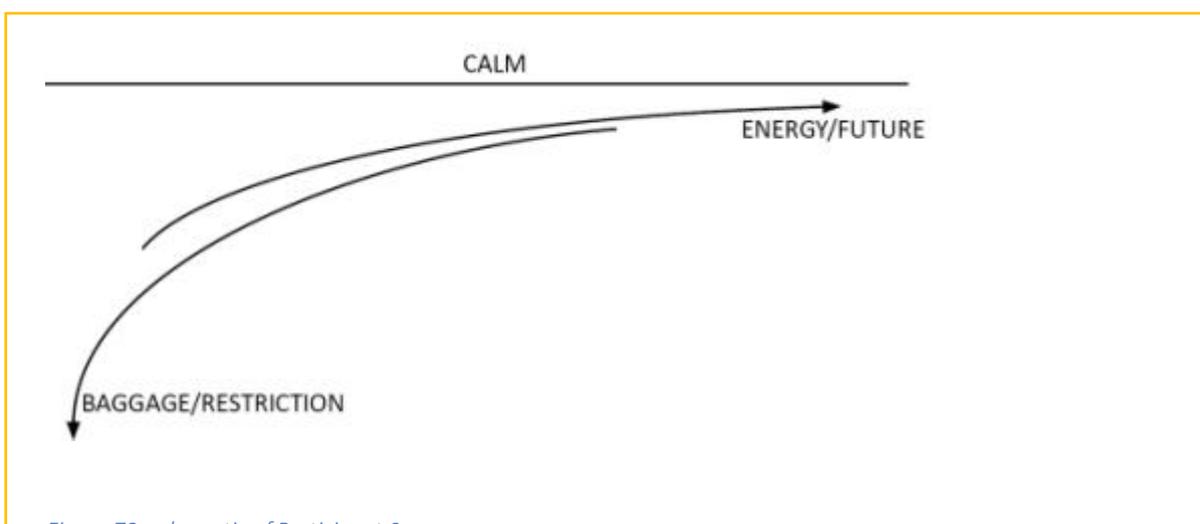


Figure 78: schematic of Participant 3

6.7 THE MODEL MAKING PROCESS

The third stage of the translation, the model making process, was also an engagement, reflection and re-evaluation of the information taken and interpreted analysis of the previous stages from the transcription to the visual sketches.

It is important to note that I did not generate themes, refine them, explain them through process within a final conclusion and then convert these into models. I see such an approach as merely using models as illustrations, an already well-trodden, methodological path. In terming the analysis through the model making process as one of translation, my intention was to speak in a different language whilst maintaining the sense of what was said by finding an equivalence of meaning (Munday 2015).

The models are an active engagement in the research not a static moment captured as a positive example. Although explained here in sequence, the model making process and the second step of the analysis, developing a visual understanding of the interpretation through drawing, ran in conjunction, weaving together, influencing and informing, all the while constantly referencing the text to build a coherent translation.

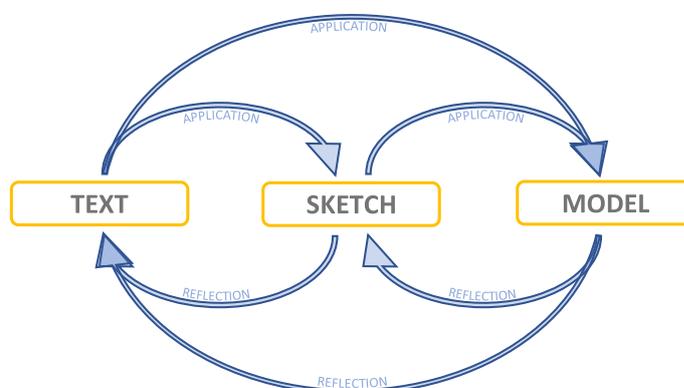


Figure 81: mapping the path of reflection and application in the analysis

Despite the fact there was no participant involvement in the making process, the feedback of the second meeting was reflected upon alongside the themes from the thematic analysis to ensure that the meaning of the text was upheld. In translating the understanding of the text into material and form I have argued that the meaning could not be conveyed as said (see p.81). Translation is an act of transposing meaning through interpretation. The meaning of the models stems from the cultural and emotive connotations they evoke through the choice of materials, colour and the way in which these were formed, brought together and related to their environment.

The models are not schematic representations, where each 3D shape stands for a visual representation of a specific aspect of the experience of RA in a way that can be identified symbolically by a spectator. Rather they create affective forms that show forces, struggles, reactions and movement as a translation. The models are abstract 3D bodies that aim to elicit affect or a physical response in a spectator. I do not expect these to be understood by all spectators in a universal way, but they can convey embodiment and become dialogical devices, points of departure for a deeper understanding.

6.7.1 FROM SKETCH TO MODEL

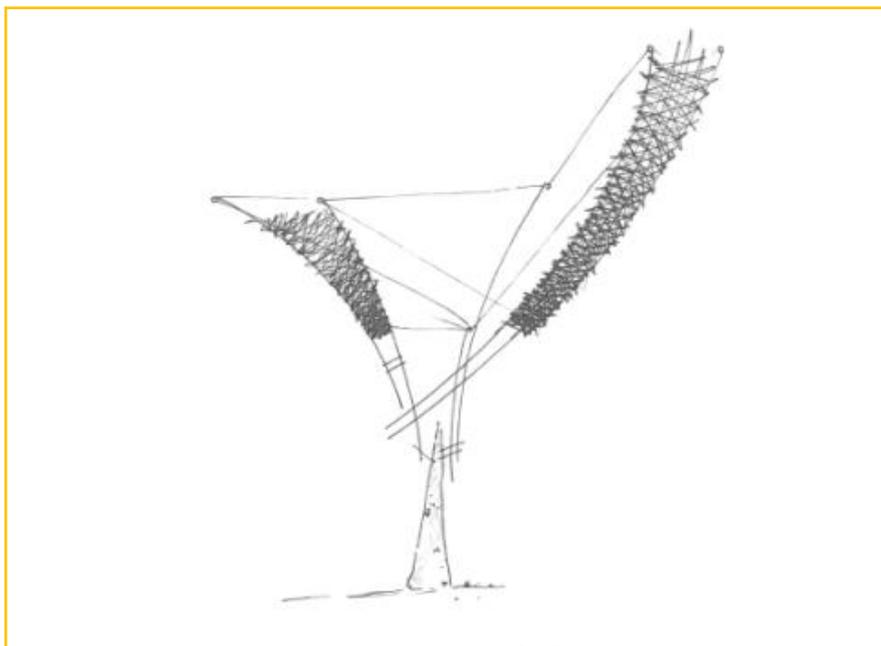


Figure 82: conceptual sketch of rejected proposal for final model Participant 1. The drawing shows no measurements or scale and is only understood from one perspective, meaning that constructing a model from this alone would be difficult.

Sketching in itself is a different language to making, despite their long collaborative affiliation. The sketches of this research, as described earlier, were a subjective Q and A rather than a guide for others to follow (see p.133). I will explain how the analysis develops from simple diagrammatic drawings to models through a detailed description of one sketch in particular. For another person to make a model from a conceptual sketch like Figure 82 above, a good deal more information would

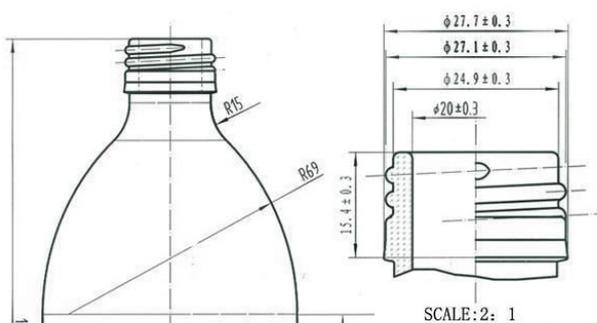


Figure 83: Orthographic detail drawing of glass syrup bottle



Figure 84: design in process at Ford Innovation Centre

Image courtesy of <https://kbtrade.gr/> be required. For example, orthogonal drawings in design practice provide multiple views from different, conventional elevations with measurements, and carry the visual information necessary to build three dimensional objects from two dimensions (see Figure 83). However, such drawings

Image courtesy of

require a clear and accurate appreciation of the final outcome beforehand and they create a critical division between material process and design, there being no need for any physical interaction with the materials you design with. Working with materials within such a rigid set of instructions denies any opportunity for the materials to offer something of themselves to the task; a compliance well suited to manufacture but not creative play.

Another approach, commonly used in movie production involves a process following from the sketch to conceptual drawing, a detailed, 'realistic' and representative illustration is drawn as a concept. This can then be modelled in three dimensions, usually in soft modelling materials such as clay from which accurate measured drawings can be taken and a final detailed model can be made in scale. This approach is also seen in automotive design (see Figure 84), where the haptic engagement, according to Lloyd VandenBrink, modelling manager at Ford, is appreciated as hugely beneficial to creative output alongside drawing in the design process (Gibson 2016).

Attempts to follow these potential routes are frustrated by the fact that in each case there is an appreciation of an end goal, whether that be a product, a science fiction monster, or a car. Throughout the evolution of the analysis, I held no pre-conceptions as to the outcomes, with no idea as to what the physical translation would look like or whether any of the translations would be similar. I used sketches throughout the project as reflections, open ended phrases, highlights, and suppositions. As analysis the sketches literally drew out meanings from the text, what the model making brought was a physicality to these expressions, a weight and tension to the lines and the embodied sensations the materials stimulate. In this process, the 'sketchiness' of the drawings is an advantage, over worked design drawings stifling the potential of variation in line or form. they provide answers in the shape of proposals rather than solutions, starting points from which to work rather than end goals to aim at. Although they appear to lack technical detail or any material demarcation, the sketches provided a platform where the various points of analysis could come together, suggesting visual compositions as drafts for construction. The following pages explain how the sketches translated into physical dimensions and materials.

The approach to construction of the model followed an almost mirrored path to the thematic analysis, where I took the schematic elements, and rebuilt their complexity of meaning, their superimposition reflected in their relationship as an overall structure. However, acting as an equivalence of meaning to an entire conversation, I never considered that the models would be one singular form, but rather an amalgamation of parts, potentially disparate, but with the understanding that the model as a whole, the combination of its parts/materials as a form, was understood to have an importance in conveying meaning.

6.7.2 SIZE AND SCALE

Unlike a descriptive text, models are first seen and appreciated in their entirety and then, only on a closer inspection, would any details of the model begin to add to any meaning. One obvious consequence of this overall ‘first view’ would be its need to act as an iconic superstructure, providing a metaphoric framework for the intended meaning of the model’s ‘sub lexical units’ to build on (see p.100). That is not to say that a first glance would tell you everything you need to know, more the sense similar to the impression and judgements made of someone lead to how one interprets what was said during a conversation with them. The schematic diagrams of the thematic analysis (Figure 78, Figure 79, Figure 80) provided a skeleton, defining the model’s overall ‘first impression’.

Scale is always a primary concern in modelmaking, not only how big is the model to be but what ‘true’ size does the model represent; but here, decisions on the size of the models was based directly on the meeting with the participants, mostly first impressions, but also how their personality came across during the conversation. Physical impressions are accepted as playing an influential part in how we form judgements during conversations (Zebrowitz 1996) and similarly with models, as discussed in chapter 3.1. Therefore, the design of the model would reflect the embodied experience alongside the thematic analysis. For example, my experience of meeting Participant 1, was such that I knew the overall stature of the model would be somewhat gaunt and delicate, matching my first impression, but the participant exuded a confidence that meant that anyone looking at the model could not have a sense of power over it because of its size.

6.7.3 MATERIAL CHOICES

What the models were made from derived from three approaches in the analysis:

- either directly named in the text, ‘**made of lead**’^{327 (Participant 2)}, ‘**black silk**’^{135 (Participant 1)}, or ‘**crumbly chalk**’^{231 (Participant 1)}, for example,
- or inference came from references to objects or activities that culturally suggest or are suggested by that material (such as paper for leaflets^{Participant 2}, or rubber for sport^{Participant 3})
- or if the material provided the correct metaphoric bridge to a theme from the analysis in the light of their syntactic and semantic properties, for example, using resin as a visual substitute for aspirated fluids^{Participant 3}; (resin as a visual substitute for aspirated fluids, we

can say that resin, with a viscous consistency and shiny, translucent surface, has similar syntactic qualities in appearance if not in touch to a 'generic, oozing, bodily fluid).

Both the syntactic and semantic properties of materials have the potential to convey metaphoric meaning but practical considerations regarding for example, the structural compatibilities involved in combining various materials, also needed to be addressed as part of the design and making process. The resins, discussed above, are liquid plastics that set hard with the addition of a catalyst whilst maintaining an appearance of fluidity, which also makes it a practical alternative for the idea of bodily fluids in a model.

The appearance of a model rests heavily on the way it is assembled, no more or less than the wording and grammar of a letter or the stationary with which it is written. If one can see how a model is put together, the nails, nuts and bolts and screws all visible, they disturb any suspension of disbelief and effect how the model is read. It was an important part of the design process for me to either include any fixings into the narrative of the model or to hide them so that they would not detract from the narrative.

Figure 85 shows details of a sketch and how they offer proposals to questions around materials and technical details.

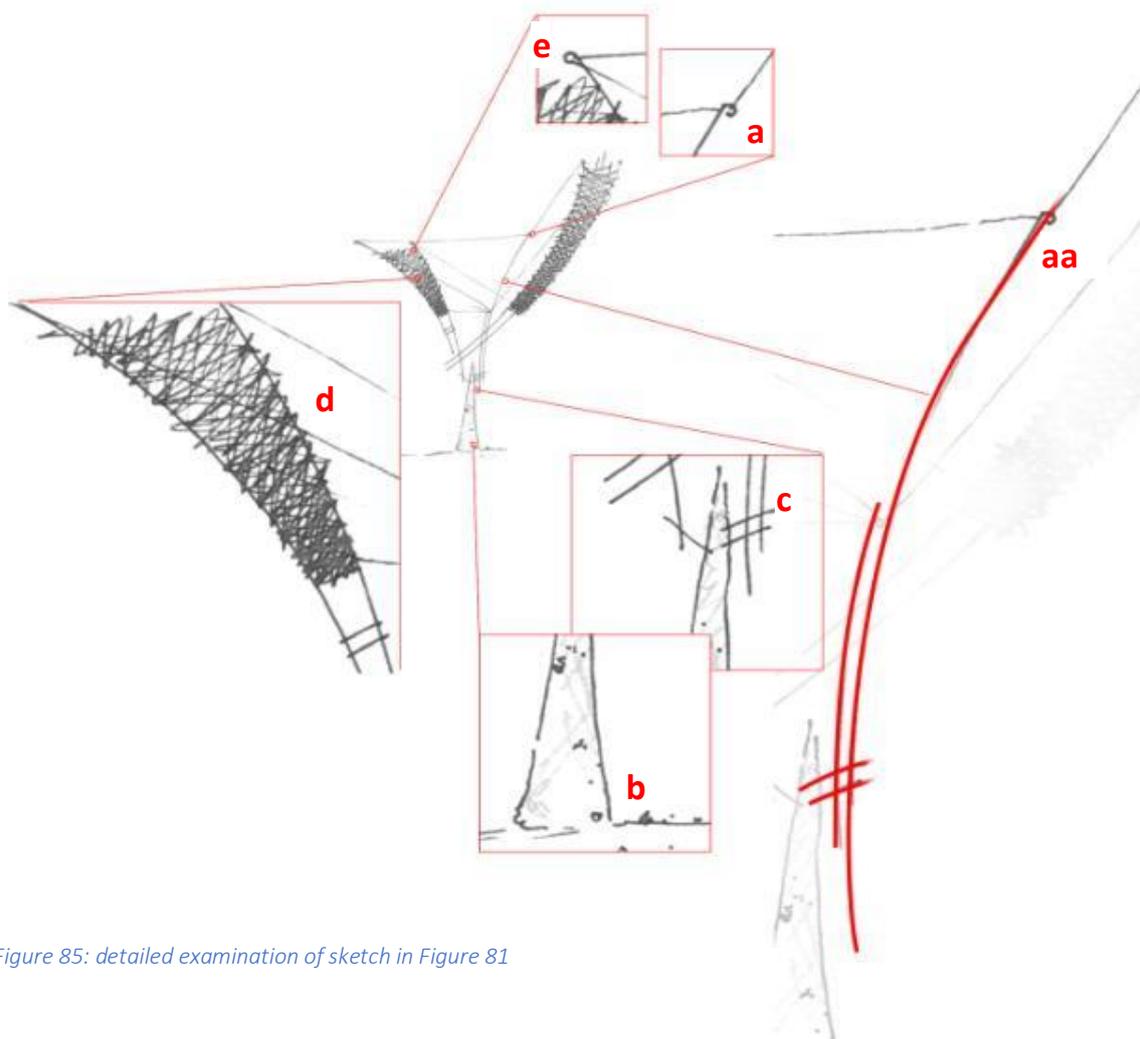


Figure 85: detailed examination of sketch in Figure 81

- a) and aa) shows a small technical detail where two lines meet. One line is in tension (straight and does not curve on the bend) the other (shown in red) has a slight curve and finishes on the junction in a loop. This suggests that the red line is the stronger, being able to hold the other line in tension from its tip. The end loop was used to imply machines that deal with thread (knitting machines or spindle looms). The curve in the line (shown red) goes against the angle of the line in tension and also seems to support other elements too. These lead to material assumptions; that the curved, strong, supporting line is steel wire and the straight line that runs from point to point is fabric, which as opposed to wire is very easy to hold in tension.
- b) shows a material detail, a texture and crumbs on the ground suggesting a natural dry material, which I already had established as chalk. The light cross hatch shading also implies a solidity.

- c) combines the understanding of a) and b), steel wire and chalk and suggests a potential fixing using the line (wire/needle/steel) to poke into the crumbly solid from various angles.
- d) suggests a sail like structure made from a strong, thin frame (with the similar curvature as shown in a). The cross hatching on the 'sail' suggests an open weave or fraying fabric, the gesture of line to open and chaotic to represent a solid. Also, the fact that this hatching crosses over the curved 'frame' lines hints at it wrapping or weaving around rather than hanging between.
- e) suggests that the fabric line (in tension) is the source of the woven fabric around the sail. When considered in the light of a frayed material it also invites the sense of something like a garment unravelling.

These suggestions are iconic signs, drawing their meaning from figurative reference or the material's physical attributes to provide characters and abbreviations that, even in a simple sketch, build a narrative.

It was from this sketch that the concept of the fabric and the steel wire holding each other in tension, instigating them as the support network for the upper structure and developing them as a metaphor for auto-immunity. The sketch also started to imagine a chalk base to the model and how any possible upper structure could attach to it. These elements are drawn together in a way that ties in with the schematic sense of the overall taken from stage 3 of the analysis (discussed on p.140), where there is a sense of freedom of movement and energy at the top, only connected to a seemingly stable platform by a needle thin, delicate link (Figure 86).



Figure 86: schematic overlaid on sketch highlighting the thematic intention

This process of translating through visuals is an iterative one, where new questions often run alongside solutions that always suggest alternatives. But sketches such as the one discussed here invite concrete proposals, which I was able to address through material investigation; for example, looking at the amount of tension silk thread can bring to steel wire, or testing the capacity of

rammed chalk to hold together when squashed into a fine point. By engaging with these practical steps in unison with the immediacy of the sketching, the materials were able to engage in the process, interpreting and furthering the designs. By allowing the materials this opportunity to speak, the desired result may not be what I expected at the outset, but it followed a hermeneutic path of understanding through application.

6.8 REFLECTIONS

Maintaining communication with the participants over the length of this research has proven very complex. My initial ambition to present the models to them became complicated when initially one participant withdrew from the study, one moved to Scotland and the third retired and changed contact details. I would very much have appreciated and undoubtedly benefitted from meeting with them to garner feedback on the models. It is my hope that contact will be resumed and work following this path can be continued, hopefully leading to a collaboration describing how they felt about the research and its outputs.

It was never my intention to involve participants in the analysis/translation and making process. From my role teaching model making, it is clear that asking materials to do the things you want, to express your thoughts, is not an easy task to learn, even for a professional the process can be frustrating. Making can be cathartic and the participants and supervisory team were all interested in it, but in this project making was a process, no different to writing up the analysis. I found that explaining this in the methodology without excluding it required levels of justification I did not expect, resulting in the inclusion of the chapter explaining the value of art practice in research.

Throughout the study one of the most complex issues was to explain the workings of the analysis path from talk to text, text to concept, to sketch, to model. While at times I found this both confusing and constraining, being more used to intuitive action in my work, on reflection this was to prove the most beneficial. Self-reflection on my practice, and finding ways to convey this, allowed me to redefine the thesis. For example, it was in the first stages of reflection that I began to understand the process as translation. Learning this opened new doors into sign language poetry and new perspectives in how to read shapes.

On reflection writing the thesis was truly a hermeneutic act. Each stage, exploring rheumatoid arthritis, understanding my world view and defining a philosophical stance, researching theories and new fields of study, the practicalities of how, with whom and where, all influenced and changed the other; no element was a simple stand-alone task, tick box exercise.

7. FINDINGS

In this chapter I lay out the analysis of each of the three participants.

Each participant analysis follows the same structure: after introducing them, I first provide the thematic analysis of the conversations. This involves a brief overview followed by an explanation of each theme I found within the text, each referenced with quotes and examples from the text itself.

I then show the development of the visuals through sketches, also with quotes and examples from the text itself. The sketches are shown sequentially as a development of understanding the text. I have tried to avoid displaying them as step 1, step 2, step 3, however, as the intention here is not to offer a set of instructions to each model. This process was not a clear evolutionary trajectory in designing but more a conversation with myself, debating ideas through sketches and the way they are displayed here reflects that. I have provided captions that are visually linked to the sketches in a manner kept deliberately conversational rather than explanatory as a way to guide the reader through the process.

Finally, for each Participant, I show photographic images of the completed model initially overlaid in relevant locations with quotes and references from the original text to further the understanding of the paths of translation in the process. As part of this document, I have included a video of each participant model, an obvious substitute to an actual encounter, which in the current climate would not be acceptable. The intent is to provide as complete a picture in the round as possible though the limitations are unavoidable.

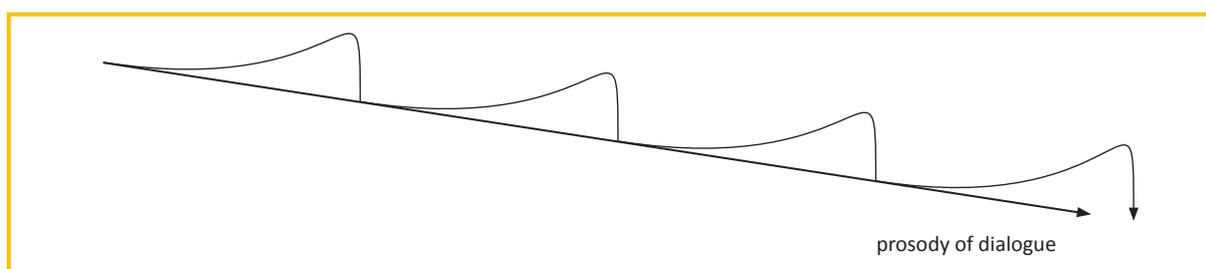
7.1 PARTICIPANT 1

The participant has an aggressive form of RA, for which she has been taking medication for many years. She is an academic, with an established career at the University of Brighton but has previously worked in the health service and the NHS. As a result of this she is fully aware of the implications of her disease and the medical path she has chosen to counter this.

7.1.1 THEMATIC ANALYSIS OF TEXT

7.1.2 OVERVIEW

There is a flowing feeling to the whole discussion; the main thread throughout was the story of the ‘dance’ with the disease, which brought a sense of journey (past to present) with it. **‘I’m not sure if this is what you want to hear but anyway I’m off’**⁴⁶. The prosody of the dialogue was fast paced, the participant talking with the rhythmic sense of someone running downhill trying to fly, nearly lifting off until a **‘BLOODY HELL!’**⁵⁸ and the pace comes to an anti-climactic drop **‘I’ll put you in the list tomorrow’**⁵⁹, then up and up again, until, **‘WOOOOF!’**⁹⁵—dropping to- **‘I’ve got a life again’**⁹⁵, then again, until, **‘RA goes wohoooo! again/hello!! Whallop! *laugh* and then’**¹⁰⁴—dropping to- **‘---*urm*-*sigh*-----and then what happened?’**¹⁰⁴. This rise, peak, **‘whallop’**¹⁰⁴, back down to Earth tempo continues throughout the conversation seemingly mimicking the cycle of the participant’s **‘dance’**³⁸⁵ itself, reflecting both her **‘high energy’**¹⁹³ and its frequent undermining.



The participant is very conscious of being part of a system, **‘There is a bigger thing happening outside what’s happening to you’**¹⁷³⁻¹⁷⁴. This understanding prevents the **‘recluse’**⁸⁹ from emerging and makes the participant useful. Using the verb **‘happening’**¹⁷⁴ suggests that things are going on, potentially something useful; however, **‘happening to you’**¹⁷⁴ gives the sense that the participant is not the agent but the structure.

The **‘bigger thing’**¹⁷³ is SOCIAL/OUTWARD, of being part of something, a collective experience, part of a **‘fellowship’**³⁷⁶ with **‘the girls ... around’**³⁸⁰. This collective could be seen as being part of a PATTERN but the ‘pattern’ is also a necessary that one either gets drawn into (**‘you are kind of hooked into the whole pattern of behaviour’**¹⁶¹⁻¹⁶²) or joins **‘you get into a pattern cos you have to cope’**¹⁷³.

This belonging is **‘the antithesis of RA’**³⁸³, **‘those crumbly, chalky people with webbed hands’**²³¹⁻²³² who cannot be USEFUL (who obviously cannot **‘dance’**³⁸⁵ anymore). This perception and sense of presentation, of being perceived is an underlying current throughout and the concept of dancing relates to this; one is either, dancing and looking outward (at those who cannot) helping to construct the pattern, or you are **‘this kind of recluse’**⁸⁹, singular and not part of a pattern. This sense of

ISOLATION develops as a theme with a negative context reinforced by the fact that the disease **'is a very personalized disease'** ¹.

Being outside of the pattern (**'deviation'** ⁷⁰, **'deterioration'** ³⁷⁰) is seen as not useful. Deviating from the line breaks the unity, disrupts the pattern (it complicates the dance and causes others to question the usefulness, **'get out of the way and stop causing complication'** ¹⁶⁷).

The concept of being USEFUL is very much tied to the theme of MOVEMENT, of going somewhere, **'it would be far more expensive if you weren't working, if you were at home needing care'** ²⁸⁶⁻⁷. Being 'home', represents being stationary and thus prevents the participant being part of the pattern and leaves them isolated. USEFUL can also be seen in the term **'my career with rheumatoid arthritis'** ³⁶⁻³⁷, it has a sense of direction, even growth to it, however there is a resigned sense that this is something that they have created and something that they will have to live (work) with.

7.1.3 THE THEMES

MOVEMENT

There are descriptors of movement such as **'toddling'** ³⁰, **'slipping'** ³¹, **'sneaking'** ³, **'creeps'** ³², **'aggressive'** ⁸³, **'clicky'** ⁸⁷, **'furs'**, **'hysterical'** ¹³⁵, **'stabbing'** ²⁷⁰, **'dissect'** ³¹⁰, **'whirly'** ³³², **'thumping'** ³³¹, etc., and some describe actions such as blown down or hanging, **'becoming less and less'** ⁷⁷, **'shattered'** ³⁴⁵, **'left a bit, right a bit'** ³⁴⁶, etc. Whilst some descriptors convey movement through onomatopoeia such as **'fizz'**, **'wohoooo!'** ¹⁰³, **'*didididi*'** ¹⁰², **'whallop'** ⁹⁶.

Movement conceptually, is often referred to as a **'dance, it has been a dance'** ³⁷ in terms of the relationship with the disease, although in moving and dancing, the disease is seen as quicker; **'the speed-----with which that came on for me'** ²³⁰. There is a distinct back and forth movement with the disease, sometimes as a dance but other times more one-sided, **'that's the stalk of it'** ³⁸⁹, with stalk here understood as a description of movement, a pace, rather than an act.

'Zumba for me is the metaphor of being well' ³⁷⁸. Zumba, described as **'salsa meets aerobics'** ³⁷³ and **'kind of shaky, rattley around'** ³⁷³ is a metaphor here for MOVEMENT the concept of capability, enactment and being useful with links to social **'fellowship'** ³⁷⁶, being a **'point of contact'** ⁷⁶ where **'shaking our stuff'** ³⁷⁵ relates to joy and health.

Zumba is important as it **'keeps me moving'** ³⁷¹ and allows the participant to **'go for it!'**, however, **'people say 'should you be doing that kind of movement?'** ³⁸⁷.

MOVEMENT is how the participant seeks to control her life **'the movement would shake it [the RA] off'** ^{2nd stge:122}. By keeping moving the participant denies the RA a role in her everyday existence, **'movement is what it's all about, and energy'** ^{2nd stge:234}, she perceives no movement equalling to no usefulness, **'I had to keep moving until I stopped because I physically couldn't do it anymore----- --if I stopped myself-----I couldn't do anything'** ^{2nd stge:140-141}. However, this is not necessarily all bad, for example when the desire for the **'perpetual motion'** ^{2nd stge:140} to come to an end, **'let's stop'** ^{2nd stge:262} reflects the Participant's fatigue.

The theme of movement incorporates two further themes connected through the physical connotations of movement as action discussed below. The first, SLOWED DOWN contextualises movement with RA and the second, JOURNEY, considers movement as an event, the consequence of movement being arrival

Sub theme 1: SLOWED DOWN

If movement represents both the personality of the participant and a metaphor for living/being useful then, obviously the disease is the opposite, **'it slows me down'** ¹⁴⁰, **'I was moving even though my movements were becoming less and less'** ⁷⁶⁻⁷⁷.

Being SLOWED DOWN is the worst symptom with the biggest impact, 'it's the fatigue that stops me' ¹⁴⁰; 'all this kind of stuff that makes you feel old, walking on a Zimmer frame, and then crutches- *eughh*' ³⁵⁴⁻³⁵⁵, 'last year when I couldn't move... it was just-----awful' ¹⁶⁸⁻¹⁶⁹. In fact anything that hinders movement is emphasized as negative, particularly in terms of reducing the time available to do things. There is an emphasis that being on the journey means being alive: 'What do I do?-----and then I'm thinking, yeah, but actually, I could probably pay---by the time I sold my house, had a roof over my head, rented accommodation and had to keep going' ²⁴¹⁻²⁴³, with the concern 'how many years could I keep going?' ²⁴³

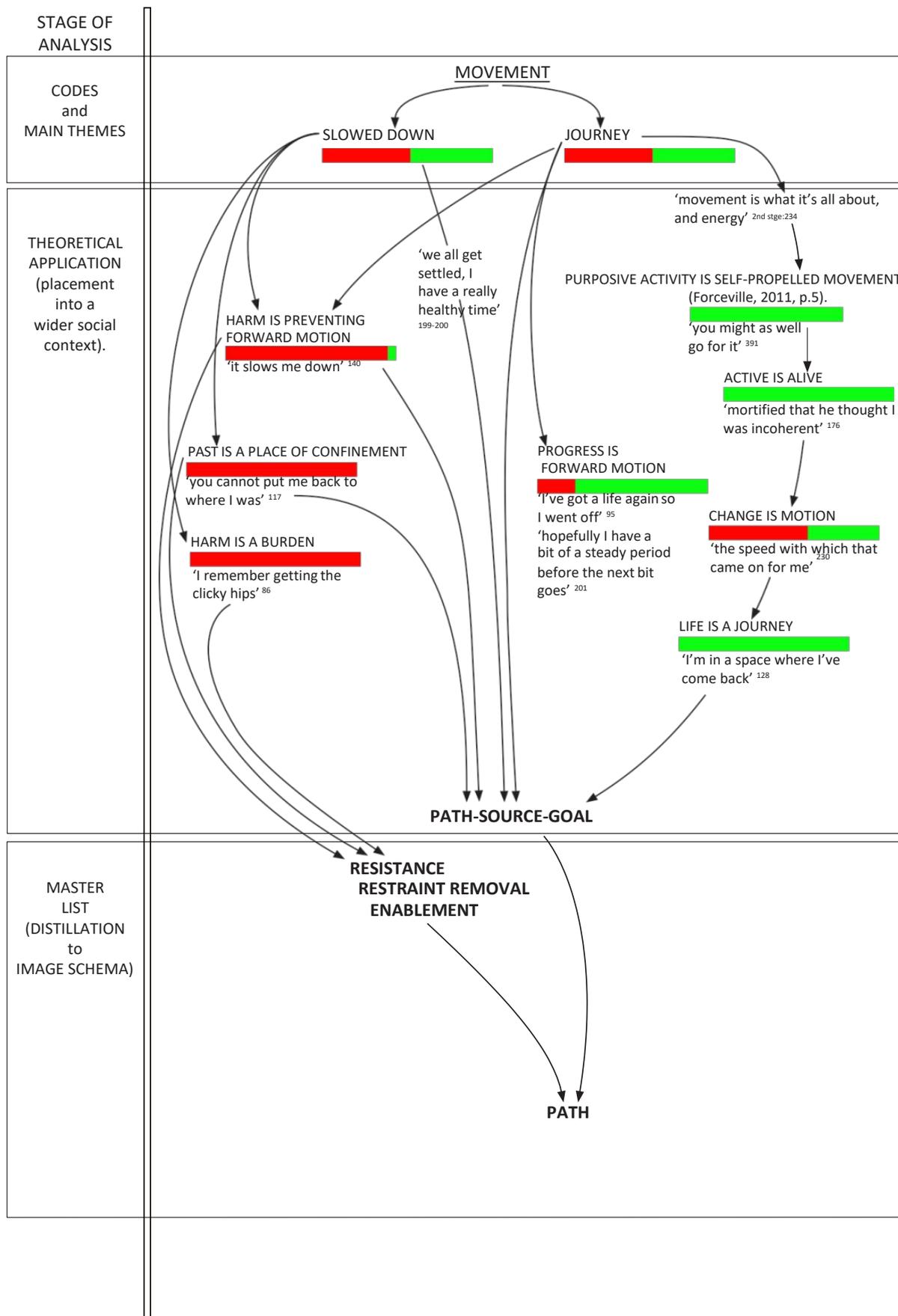
Sub theme 2: JOURNEY

'I'm in a space where I've come back' ¹²⁸ is a positive, forward looking statement giving both a sense of place, a position in the pattern where they fit (**'point of contact'** ⁷⁶) and highlights the concept of JOURNEY. This JOURNEY comes as both going somewhere positive (**'I just need to get out into the sunshine'** ¹⁹⁻²⁰, **'I've got a life again so I went off'** ⁹⁵, **'you might as well go for it'** ³⁹¹) and going somewhere negative **'an admission of where you've gone'** ³⁵⁶, with going backwards having the

most negative contexts (**'the point I do not want to go back to'** ²⁶⁶, **'you cannot put me back to where I was'** ¹¹⁷).

If the journey is stopped it is a result of a **'breakdown'** ²⁹⁸ either physically, with the body breaking, or conceptually, **'goodnight Vienna'** ¹³¹⁻¹³². Having broken down, **'if you were at home needing care'** ²⁸⁶⁻²⁸⁷ and not on journey going somewhere, is seen as very negative. However, going round and round, even though she isn't necessarily going anywhere, is positive, even fun, with the sense of movement such as the experience she described in Sainsbury's ²⁹⁷⁻³⁰² (see APPENDIX p.337)

We are not given any sense of destination, where **'we all get settled, I have a really healthy time'** ¹⁹⁹⁻²⁰⁰, although **'Switzerland'** ²⁴⁹ is mentioned, it seems to hold an almost fabled, land of milk and honey quality. Potentially the point the journey is not the destination but just the joy of moving. However, when I questioned the concept of Switzerland as a 'real' destination, a possible solution or just an ideal, the participant claimed both: **'I may joke about it but Switzerland is the option'** ^{2nd stge:31} yet, more importantly it is just being there, **'there's always Switzerland'** ^{2nd stge:45} brings a stability. The **'ultimate control'** ^{2nd stge:29} as a concept brings stability and acts to calm both the drive of the participant's personality, the need **'to go and do everything'** ^{2nd stge:50} and the progression of the disease itself, the **'up and down, and up and down'** ¹²⁴.



The combined sense of both positive and negative connotations from these subthemes reflects the complex relationship between the Participant and the disease. Overwhelmingly the idea of movement as a representation of being alive is key for the Participant and being active is understood as very positive. Contradicting this is the Participant's awareness and occasional desire that to counteract the progress of the disease and maintain her own energy, she herself needs to slow down, although this desire may be an effect of the fatigue caused by the disease.

However, the disease is also on a journey and is capable of independent movement which is understandably negative, most notably reflected in the primary metaphors CHANGE IS MOTION, correlating with phrase like '**the speed with which that came on for me**'²³⁰ and PROGRESS IS FORWARD MOTION through the idea of the development of the disease as advancing ('**looking at the ultrasound/image thinking that is really advanced rheumatoid arthritis**'⁴⁷⁻⁴⁸).

The disease's impact on the idea of movement is as a restraint '**it slows me down**'¹⁴¹ and a burden, which is reflected in the schema **RESISTANCE**. For the Participant the understanding that '**movement would shake it [the RA] off**'^{2nd stge:122} correlates to the schema **RESTRAINT REMOVAL**. By superimposing these schemas with **ENABLEMENT** and **PATH-SOURCE-GOAL** the desired action can be seen as movement towards or for health. **ENABLEMENT** represents a sense of freedom to act whilst **PATH-SOURCE-GOAL** evokes the mental appreciation of **A→B**, **A** being the source →being the path and **B** the goal.

When the Participant states that she '**had to keep moving ...if I stopped ...I couldn't do anything**'^{2nd stge:140-141} it shows that the idea that movement, the very concept of going rather than seeking to be somewhere is her aim, therefore the principle of **PATH-SOURCE-GOAL**, the idea of aiming towards an objective along a trajectory, in this context can be refined to the schema **PATH** (in other words, the path is both the source and goal).

SYNOPSIS

movement for one is restricted by the competition for energy desired for the movement of another.

SCAFFOLD

I have subdivided the theme of SCAFFOLD into three connected elements: BALANCE, ACCUMULATION and SUPPORT. Although I see them as connected by their association to physical structures, I discuss them here individually.

BALANCE

The concept of BALANCE runs as an undercurrent to the theme of SCAFFOLD. When the participant feels well **'We are on an even keel'** ¹⁴⁶, however, the participant cannot help but to risk that balance by moving, dancing, hanging from things or **'stomping around in heels'** ²⁰³ in both an act of defiance against the disease and a joy in moving (life). Losing her balance causes pain though this is not seen as unexpected; there is always the awareness that the stability will go, **'a steady period before the next bit goes, but the next bit will go'** ²⁰⁰⁻²⁰¹. It is when and how is where the uncertainty lies. Despite the risks taken, the Participant does put effort into maintaining that balance and reduce any uncertainties-**'I've got to weigh up'** ³⁵⁸, **'it's weighing up the balance'** ¹⁴, **'the balance between people'** ³⁷⁰, **'doing more passive stuff or ... doing more active stuff'** ³⁸⁸⁻³⁸⁹.

ACCUMULATION

There is also uncertainty in the participant questioning herself and being questioned by others **'these are the options'** ²⁵³⁻²⁵⁴, **'should you be up there?'** ³⁴³, **'should you be doing Zumba?'** ³⁷¹, providing social, personal and professional responsibilities as further complications in maintaining the balance. This sense of accumulation, **'you amass all that stuff'** ⁸⁶, increasingly complicates the balancing act that the Participant is trying to perform, **'I remember getting the clicky hips'** ⁸⁶, **'she keeps giving me all this stuff'** ³³⁸, **'my GP phoned-----this is the new list of things'** ¹³⁷, **'there's a whole list of stuff you get'** ¹²⁴.

With the feeling of balance comes the idea of being 'put on' something: 'so that's the point when they can say we have to take you off this meths (Methotrexate) and we're going to put you on this new anti TNF which is very expensive-so they put me on this new anti TNF and it was like wayhay! Life back/felt like WOOOOF! I've got a life again so I went off did/started being energized, started exercising-----whallop!/hips went' ⁹²⁻⁹⁶. This seems like a ride, a mechanical rodeo; but not in the standard sense, more a reversed rodeo (the rider wants to be up shaking and rattling around, as in Zumba, but the horse keeps failing). Potentially the participant is both the structure and the rider but the structure here is knackered (literally and metaphorically). The rodeo ride concept ties in with

the sense of an awareness of presentation, not just of being on show but also of looking in general. The ride, the Participant, sits in the centre as an exhibit to be engaged with or to watch.

SUPPORT

As an aid to balance comes a sense of support but in this context, it does not suggest a support one could lean on, in fact that type of support comes across as negative, **'all this kind of stuff that makes you feel old, walking on a Zimmer frame, and then crutches- *eughgh*-----'** ³⁵⁴⁻³⁵⁵. Heels are seen as the antithesis of crutches, giving height, creating a sense of self, although bad, **'what am I doing? I'm stomping around in heels, my surgeon would have my guts for garters, let alone my rheumatologist would think'** ²⁰²⁻²⁰⁴) they play a role, they are useful. The metaphorical link of heels to hip replacements is similar in this way, **'I do talk about my hips because I think they are a work of beauty, those titanium hips, they are like Jimmy Choo heels-their fab! -----nothing to do with me, they're just in there'** ³⁵¹⁻³⁵²—they act more like external support than something hidden, they are **'temporary'** ³⁵⁰ like good shoes, almost not part of the journey but a means to it, whilst other 'aids' inhibit the chosen sense of self/play **'the handles for the RA are like an admission of where you've gone'** ³⁵⁶. The crutches are also seen as temporary but despite being there to help they seem to convey the wrong impression, not an aid to engagement but, like the handles on the secateurs, a symbolic restriction of expression.

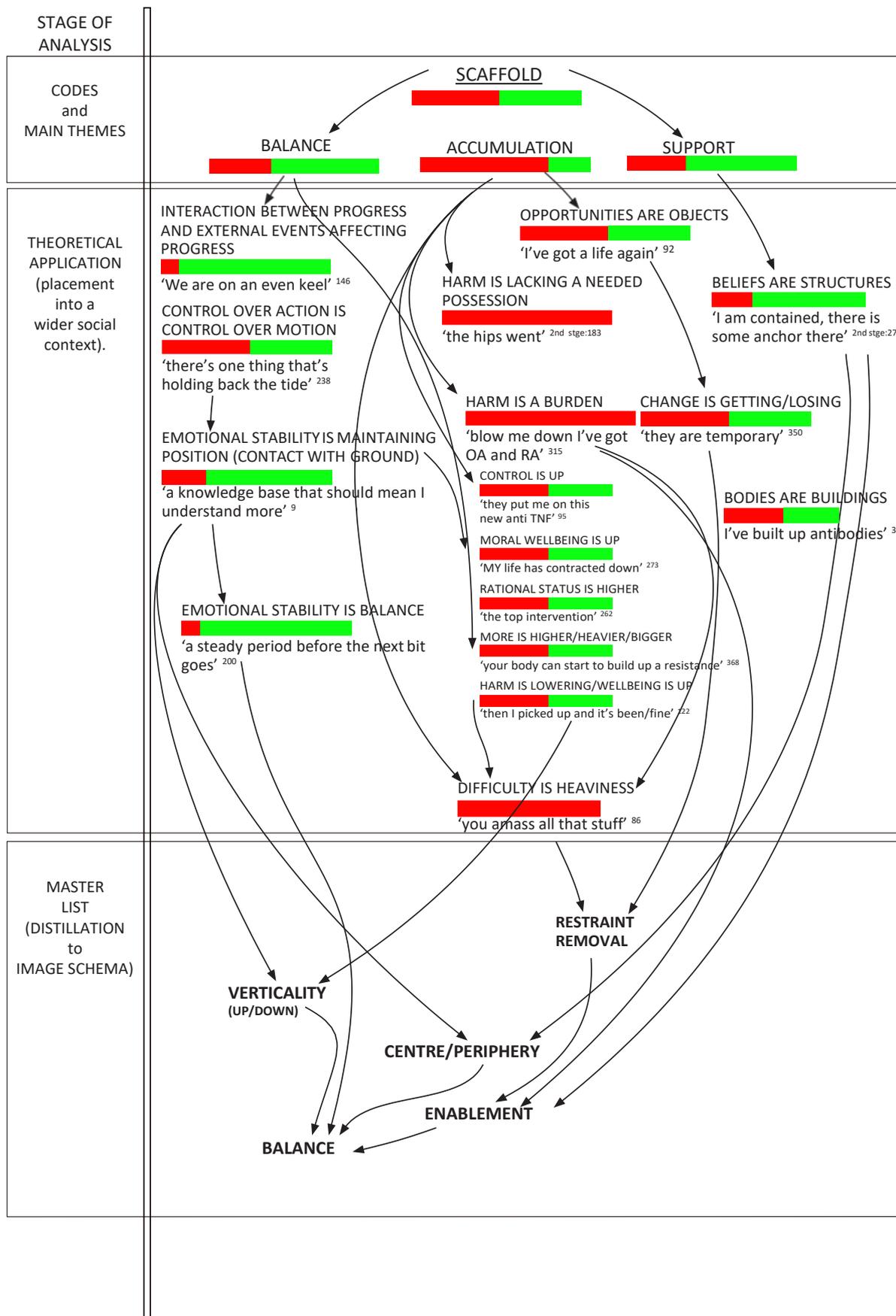
The ground seems to stem from understanding **'a knowledge base that should mean I understand more'** ⁹. But this is not a foundation, more a platform standing above the **'crumbly, chalk'** ²³¹.

Physical references to shape and form for SUPPORT as an entity can be seen through the discussion of hips, high heels, crutches, Zimmer frames, titanium, wheelchair, upright, etc. Fatigue links not only to the physical sense of exhaustion but also to material deterioration, **'the thing that frightens me absolutely more than anything is the fatigue'** ¹³⁹. The reference to **'crumbly chalk'** ²³¹ brings the same material links implying weak foundations, a potential platform, whilst references to points of contact, metal (titanium) replacements³⁵² to joints and temporary supports (crutches) suggest physical connections.

There is sense of being up on high, being able to see the pattern (with the analogy from climbing up the greasy pole ¹⁷⁸) and influence it (by being useful), **'on the top wack dose'** ⁸⁸, **'the top intervention'** ²⁶². This height seems very positive, the antithesis of the **'wheelchair'** ²³⁰ **'hanging from the window sills and they all going 'should you be up there?'** ³⁴³—**'extreme'** ³⁴² (like extreme sport).

Even the statement about needing to rest/hide, '**up you go, you need to disappear cos you've just gone**'⁴⁰³ suggests an ability to escape in order to find peace.

The scaffold provides an illusion of support rather than a trusted structure, 'there's one thing that's holding back the tide although it's not holding it back too much at the moment'²³⁸⁻²³⁹. The support is vulnerable 'I pushed people away from it'²⁷⁶, 'whallop!/hips went'⁹⁶. The disease affects it, undermining its ability to stay up, 'blow me down I've got OA and RA'³¹⁵. The reason for the term scaffold rather than frame, support, etc. comes from this feeling of vulnerability; a cladding framework, a covering that both helps when constructing a building and hides the building work rather than something that provides anything permanent to rely on.



The theme of SCAFFOLD is split into three subthemes BALANCE, ACCUMULATION and SUPPORT.

The subtheme of BALANCE positively suggests the desired goal of the Participant, her acceptance of the disease with the ability to maintain her lifestyle, even if this is not always achievable.

The subtheme of SUPPORT allows this balance to continue, although at times, the visibility of the support highlights the presence of the disease.

However, the sense of ACCUMULATION is more negative. The idea that the disease can upset this balance, toppling the Participant, is seen through the primary metaphors HARM IS A BURDEN and DIFFICULTY IS HEAVINESS or by undermining the Participant, HARM IS LACKING A NEEDED POSSESSION. The schemas **RESTRAINT REMOVAL** and **ENABLEMENT** indicate this understanding of desired action being curtailed by external sources, linking to the schema **BALANCE** reflects the Participant's goal.

The relationship of the primary metaphors CONTROL/MORAL WELLBEING IS UP, RATIONAL STATUS IS HIGHER and MORE IS HIGHER/BIGGER/HEAVIER to the way the Participant describes her life, moods, medication or disease spread, are considered neutral (neither positive nor negative) in the analysis due to the intimate relationship between the Participant and the disease. Being higher can reflect the Participant's ability to do the things she wants to ('**stomping around in heels**'²⁰³) but also the precariousness of that situation, '**should you be up there?**'³⁴³, it can represent the increase in medication '**the top wack dose**'⁸⁸ or the Participant's mood, '**then I picked up and it's been fine**'¹²². All of these primary metaphors correlate to the image schema **VERTICALITY**, the embodied appreciation of up and down.

By superimposing the schema **VERTICALITY** (the accumulation or growth of things, the idea of being grounded, intellectually with '**a knowledge base**'⁹) or physically hanging on to '**a greasy pole**'¹⁷⁸) with **CENTRE/PERIPHERY** and **ENABLEMENT**, (the idea of a support maintaining a steady evenness), the schema **BALANCE** is seen as the goal, providing the overall context to this theme.

SYNOPSIS

maintaining a balance with complicated load is the goal.

CONTAINER

The true support and strength seem to come more from the container. The container is something that potentially can be seen as a thing inside the body. The **'RA's inside'** ²⁶⁷ or represented as a border between public/private, **'I would not let people in to see it'** ²⁷⁵.

The CONTAINER is obviously three dimensional, as to exist, even mentally, it requires boundaries, an inside and outside. However, here it is a conceptual entity and what it looks like in terms of scale, form, texture, etc., is not directly referenced, but being **'a bit bumpy'** ⁶⁹⁻⁷⁰, **'webbed'** ²³² or **'shallow and vacuous'** ¹⁴². There is a feeling that the participant is responsible for building or maintaining the container although aware that despite all efforts **'life'** ⁷³ (container) **'has contracted down'** ²⁷³. The container is potentially thin; the participant refers to herself as **'shallow and vacuous'** ¹⁴² (although this was said in jest) and the reference to the **'fat finger'** ³³⁷ or **'big fat handles'** ³⁴⁸ as an obstacle suggests that shallow has a more positive form in the eyes of the Participant.

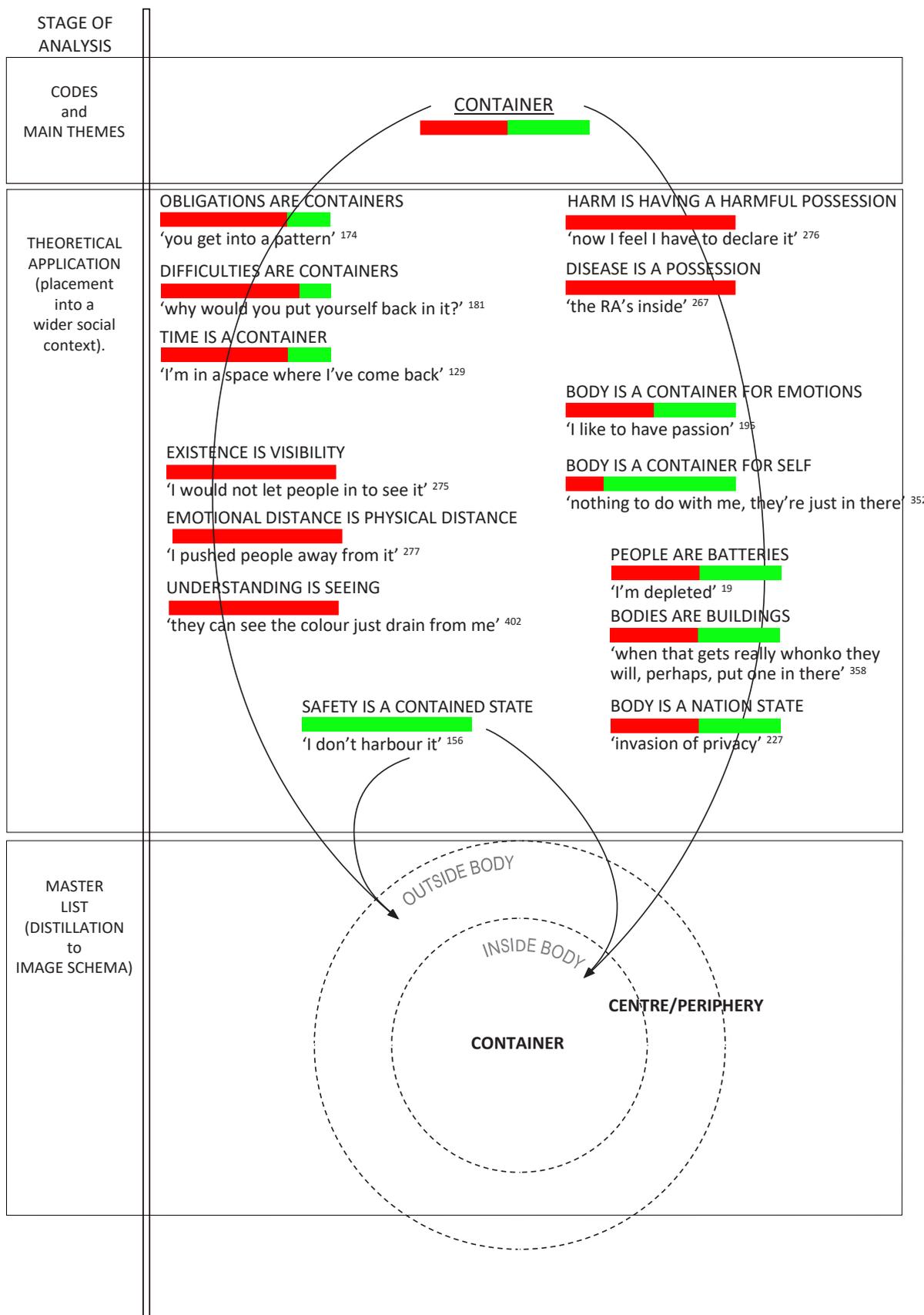
Sometimes the container has to be opened; by exposing its contents, the container, the Participant, becomes defined by what she carries, the RA. For this reason, opening up about the RA **'does feel like a disclosure'** ²²⁶. Potentially, disclosure could be understood as an unveiling but here it has more the sense of the opening of a container at customs, **'now I feel I have to declare it in friendships, close friendships'** ²⁷⁶⁻²⁷⁷. It becomes a declaration, not something you can smuggle through, so it is better to own up, **'you need to say to people you've got it'** ²²⁸.

People's awareness, their noticing the symptoms, is not an **'invasion of privacy'** ²²⁷ however. The contents can be seen, or cannot be hidden anyway, **'people say they can see the colour just drain from me'** ⁴⁰¹⁻⁴⁰². (Here, the analogy is doubled, both the energy/emotion as a liquid leaving the container (**'I'm depleted'** ¹⁹), and the concept that colour brings vibrancy and life, **'Brazilian'** ³⁸⁵, **'Mardi Gras'** ³⁸⁵, whilst the absence of colour suggests the opposite).

If we see the Participant as the container, we can see there is an attempt at control over what physically goes in, **'I go to put it in my mouth and it's like-----I can't do that'** ²⁹³ and also, conceptually (as in information), **'limit what I allow myself'** ¹⁰. However, despite the fact that she does not want too much to go into the container, often she has no control over it, **'nothing to do with me, they're just in there'** (352), **'I don't know what I'm putting inside me'** ²⁷², **'when that gets really whonko they will, perhaps, put one in there'** ³⁵⁷.

Sometimes the container can be seen as holding the participant, **'there might be a combination where I have a window where we all get settled'** ¹⁹⁹; this window provides a view out of the

container/containment, suggesting an ability to interact/look out onto the world but from a protected position where the container protects, **'not allowing that through'**⁵³, **'I would not let people in to see it'**²⁷⁵. This connotation of protecting is seen in the participant's use of the term harbour: **'you're harbouring from way back yonder'**¹⁶⁰, what the container holds is protected from the world although this was suggested from the negative aspect of nurturing negativity, causing rot on the inside. This awareness of the potential to cause harm to the inside is reflected in the participant's **'I don't harbour it'**¹⁵⁶ regarding anger and frustration (although they do let it **'fizz'**¹⁵⁷).



The connotations of the theme of CONTAINER are neither definitively positive nor negative. As a boundary, defining an inside and outside, it brings protection but also confinement and exposure.

In this analysis the primary metaphors are grouped into six concepts;

1. the idea of ownership: HARM IS HAVING A HARMFUL POSSESSION, DISEASE IS A POSSESSION. This is overwhelmingly negative in context; the disease is not a desired possession.
2. the idea of the body as a container: BODY AS CONTAINER FOR EMOTIONS, BODY AS A CONTAINER FOR SELF. Despite the understanding that the body contains the disease, because the participant is confident in herself, this concept is more positive than negative.
3. the idea of the body as a thing: PEOPLE ARE BATTERIES, BODIES ARE BUILDINGS, BODY IS A NATION STATE. This concept is neither positive nor negative; the participant, potentially due to her training, is able to view her body objectively.
4. the idea of the body being contained: OBLIGATIONS ARE CONTAINERS, DIFFICULTIES ARE CONTAINERS, TIME IS A CONTAINER. This concept leans more to the negative. Elements such as time, work, or Society, emphasize the development of the disease, and potentially because of this, are often seen as restrictions to the Participant's persona.
5. the influence that containment has on visibility: EXISTENCE IS VISIBILITY, EMOTIONAL DISTANCE IS PHYSICAL DISTANCE, UNDERSTANDING IS SEEING. The idea of being seen is negative because it opens up the Participant (as container) to other's judgement and rather than being seen as she wishes to be perceived, the disease dictates to others who she is. The visibility of the disease acts as evidence to its progress
6. the value of containment: SAFETY IS A CONTAINED STATE. The sense of support from outside (friends, Healthcare), the feeling that the Participant can both draw on an internal strength and, also, withdraw into herself make this a positive concept.

These are further broken down to the concept of containment inside the body, 1-3, and the idea of the body being contained, 4-6. Point 6 implies both in and outside with the participant feeling contained, **'I am contained, there is some anchor there'** ^{2nd stge:278} and containing, **'that stuff...you're harbouring from way back yonder'** ¹⁶⁰.

SYNOPSIS

a container within a container

MONSTER

The concept of MONSTER is a known metaphor for pain/disease (Semino, 2010). The disease does not sit with the perception of self, an alien that has come from elsewhere, for example the foreign/exotic **'banana spider'**³⁸. As an attacker it is seen as underhand, unfair, **'threatening'**¹³, **'it creeps up'**³² or **'it kind of sneaks up on you in various ways and its tendrils...extend in very different ways'**³⁻⁴. This leaves the participant **'constantly caught out'**⁴.

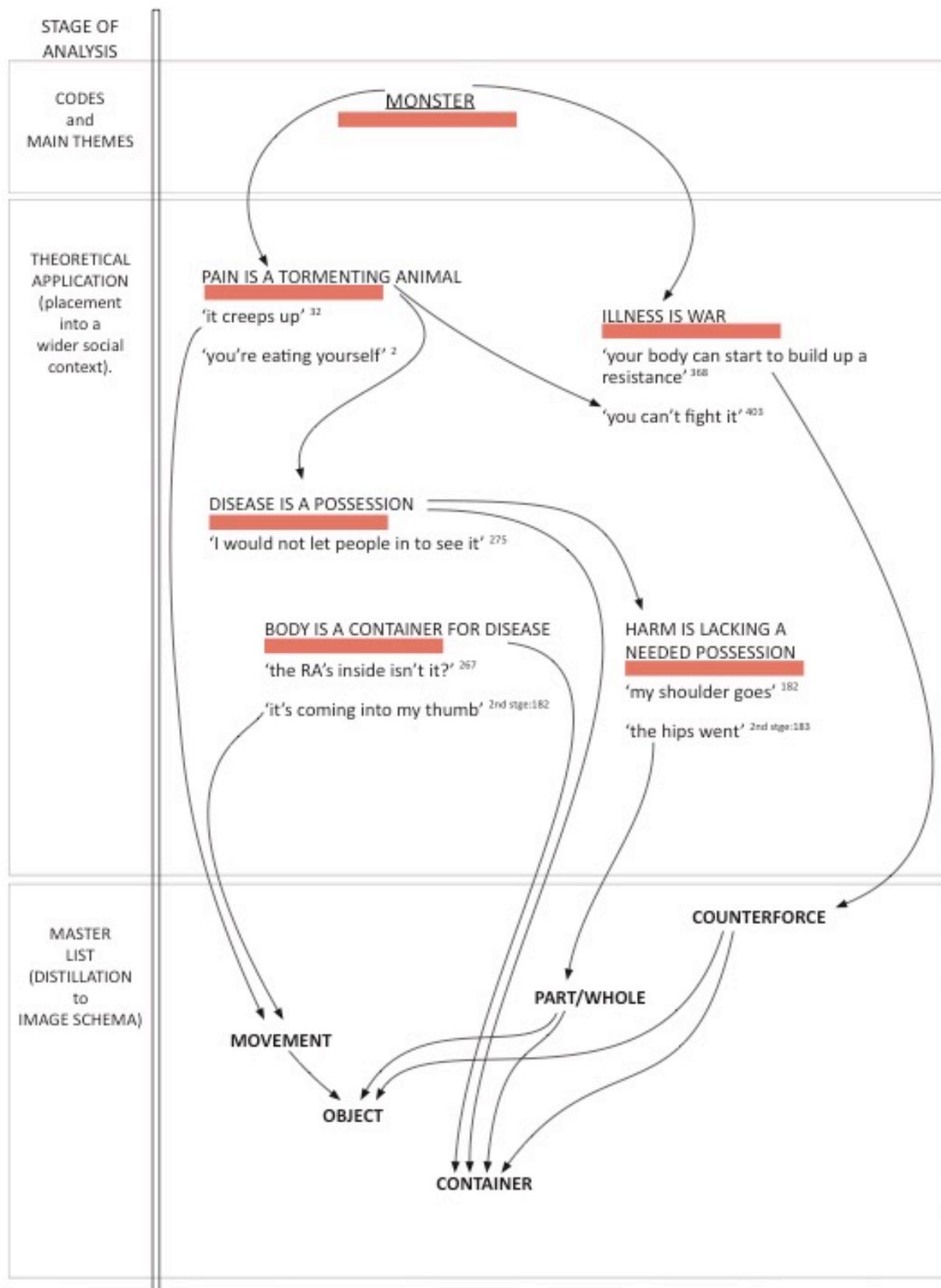
Alongside the concept that the body has been invaded (**'the RA's inside isn't it?'**²⁶⁷) and attacked, **'it furs my brain'**¹⁴⁰, **'it knocked me for six'**²⁶⁴, **'it whalloped me'**²⁶³, **'it comes as...a blow'**²⁰, **'VERDUNCK!'**³⁴² is the understanding that the participant is the monster too, **'you're eating yourself'**², and being **'voluntarily'**²⁶⁸ aggressive to herself, **'jabbed and then I was out'**³⁸², **'SOD IT! JAB!!'**¹²⁰, **'stabbing myself with that drug'**²⁷⁰.

On top of this, **'external'**²⁶⁴ supports also attack: **'they've got all this repertoire of stuff they can chuck at you'**²⁸⁴⁻²⁸⁵, **'secateurs kill me'**³⁴¹, undermining her defence, **'your cancer surveillance has been switched off'**¹⁵², and making you feel weaker **'all this kind of stuff that makes you feel old'**³⁵⁴. Even her own body undermines her efforts, **'your body can start to build up a resistance'**³⁶⁸ (to the medicine). RA can be understood as **'eating yourself'**^{2nd stge:79-80}, **'I bend down and chuck it [the black silk] over me'**^{2nd stge:135} or simply **'I do that'**^{2nd stge:134}.

The sense is often of a doppelganger, the RA as an entity (although never defined) and the participant separate but the same. The Participant's sense of herself as **'a control freak'**¹³³ explains her surprise in the relationship^{2nd stge:133} when the RA dominates. The RA moves like a monster too, **'this big shadow that comes over you'**^{2nd stge:267}, **'it's coming into my thumb'**^{2nd stge:182} and, when it moves, the RA takes the participant with it, **'my shoulder goes'**¹⁸², **'the hips went'**^{2nd stge:183}.

However, ultimately, the understanding of RA as auto-immune dominates; that the participant is responsible for what is happening in that, spiritually, this is an act of self-harming and punishment⁸⁷. In the light of this, one can see that when the participant states that **'I am contained, there is some anchor there'**^{2nd stge:278} she is describing an outside influence exerting control not only over the RA's movements but also her own.

With this seems to come an acceptance that the Participant is on the back foot **'it's a defensive medicine rather than an aggressor-----to the disease'**²⁷⁻²⁸, **'there are certain things you have to give in to'**³⁴⁹ even, sometimes beaten, **'you can't fight it'**⁴⁰³, **'it'll get you/it'll get you anyway'**³⁹¹ and forcing submission, **'did it teach me!! How much I needed it'**³⁶².



The overwhelming sense is negative, undesirable. The principle behind the idea of MONSTER is that of an other; the RA is scary, dangerous and distinct from the Participant. For this reason, the schema **COUNTERFORCE** is used to demonstrate the friction and underlying sense of conflict (ILLNESS IS WAR primary metaphor). As a separate entity the RA is shown in the **OBJECT** schema. The **MOVEMENT** schema suggests an independence from the Participant, that she has no control over its actions. However, the primary metaphors DISEASE IS A POSSESSION and BODY IS A CONTAINER FOR DISEASE show that although independent in action the disease is **'a very personalized disease'**¹ contained within (**CONTAINER** schema). There is a distinct duality to this theme between the self and the disease, both have personality, individual actions and goals (the fact that the disease **'creeps up'**³² and the idea that it will win in the end, **'it'll get you/it'll get you anyway'**³⁹¹). But this is complicated relationship; there is, in one sense, an ownership of the disease both emotionally and physically because it is contained within, and yet there is the underlying understanding that the Participant herself is the disease, that it is part of the whole (**PART/WHOLE** schema); **'its auto immune so the one thing you have to sit on and absolutely reflect upon is that you're eating yourself'**¹⁻².

SYNOPSIS

An object contained within another, intrinsic but undermining.

7.1.4 VISUALIZATION ANALYSIS PARTICIPANT 1

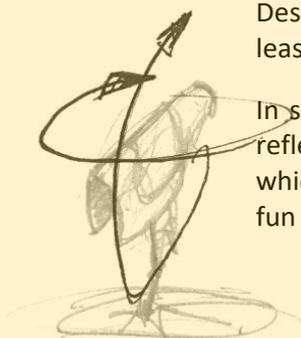
This is the 'irony of RA' (78), RA is both progression and fatigue, growing and destroying and it is important that the model reflects these contradictions as part of one thing; casting a 'shadow' (267) over itself, throwing a black silk over itself to cover the vibrancy it is trying to emit (119, 134). The participant moves, potentially to get away from the stillness of those 'crumbly, chalky people' (303) but in doing so comes closer.



'I have seen the moment of my greatness flicker,
And I have seen the eternal footman take my coat and snicker,
And in short, I was afraid'

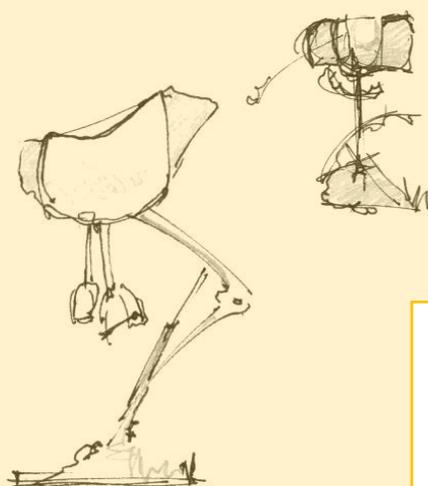
(T.S.Eliot, The lovesong of J. Alfred Prufrock, 1920)

'it has T.S.Eliot written all over it for me' 305

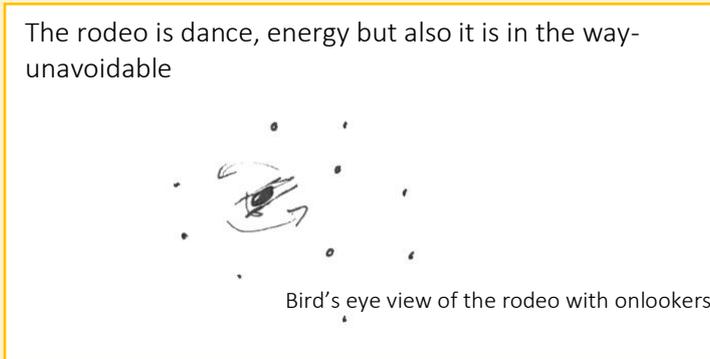


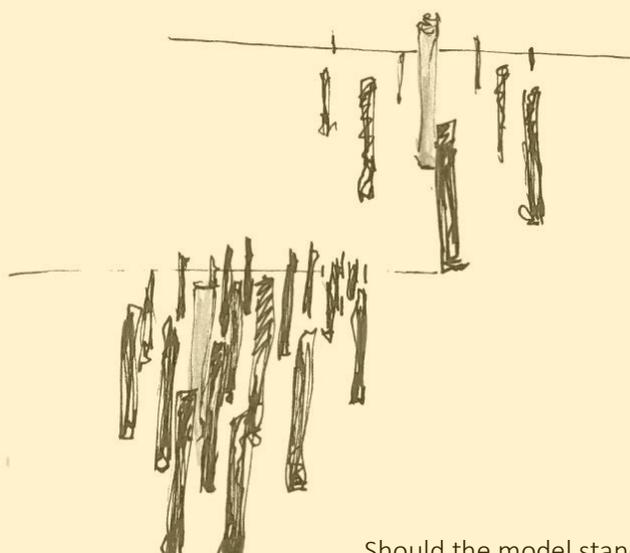
Despite all of this, on the whole, there is a strong sense of optimism or at least some opposition to pessimism, "get over it!" 275.

In spite of the "black silk" 114 and unstable base 319 the model needs to reflect the vibrancy 161, it needs to convey some sense of the "firework" 159 which was the original intention with the concept of the rodeo, a sense of fun tied to movement and unpredictability.



In the rodeo concept, the participant is on display, they are part of something.

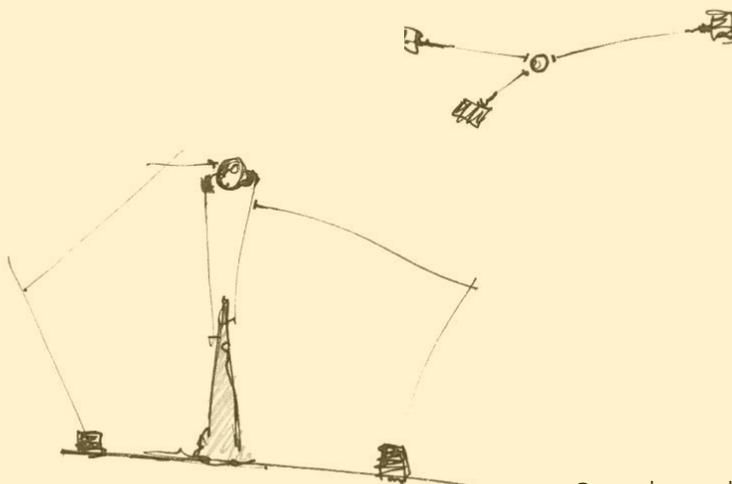




Should the model stand alone or be part of a larger system, would it be crowded in or standing out?



If it stands out is the model exposed/isolated?



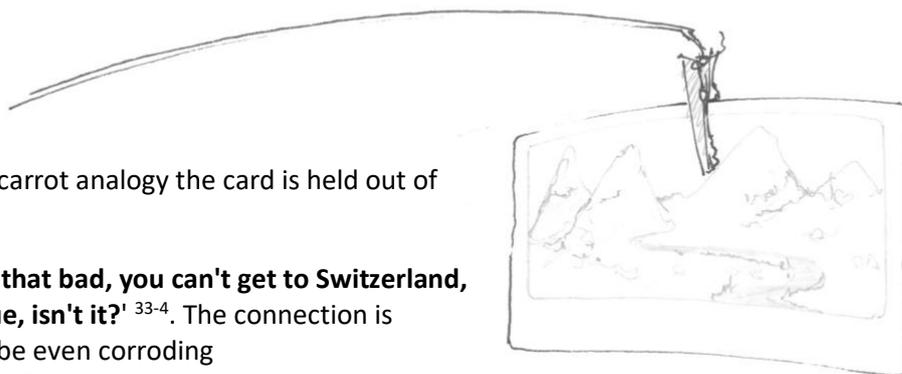
Or perhaps, does some support come from these other elements?



'not in control' ³⁹ -not in the driving seat so not going where they want to. However, the concept of Switzerland as a **fail safe'** ⁴¹ acts as a stop to this, **'ultimate control'** ²⁹, rather than putting on the breaks this is more like an emergency stop.

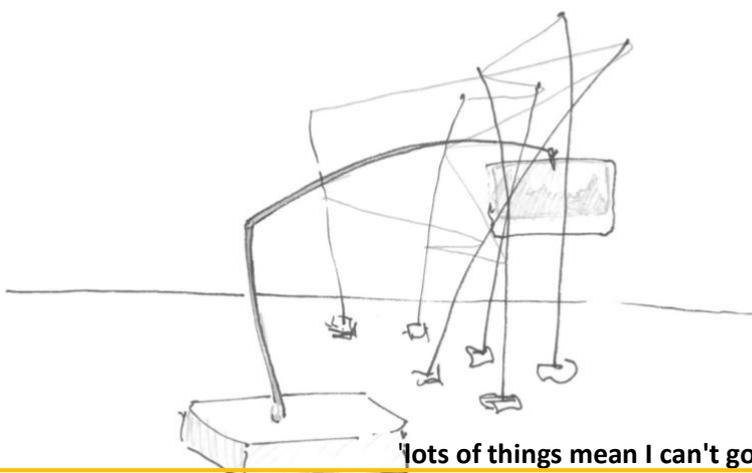
Switzerland is hard to represent as a concept. It is a very direct reference. As both a metaphor for escaping the reality of the current situation (⁴⁶) and a very real possibility (³¹) it is a complete visualization.

However, as direct as it is, and possibly too idiosyncratic it could work in a model. The idea of a postcard held up to view, like a target/ambition (similar to a donkey and a carrot on a stick), but also referencing the idea of holiday-'wish you were here' - and rest (**'let's stop'**¹²⁶²).



Like the donkey and carrot analogy the card is held out of reach.

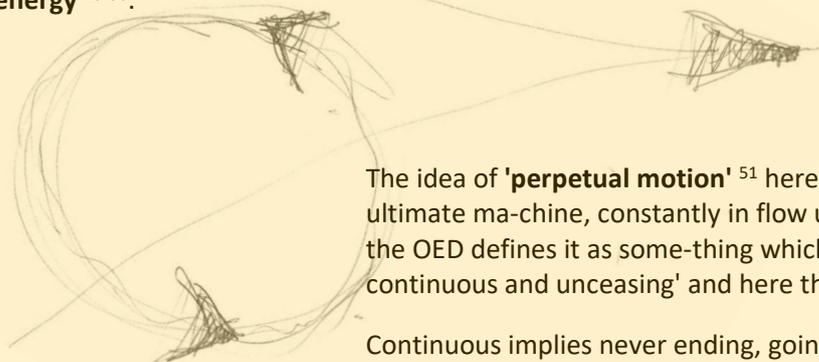
'when you get them that bad, you can't get to Switzerland, that's the whole issue, isn't it?' ³³⁻⁴. The connection is delicate/fragile, maybe even corroding (attacked/undermined?)



'lots of things mean I can't go' ⁴³⁻⁴ The image/postcard concept is visually obscured, hard to get to or the connection could be complex.

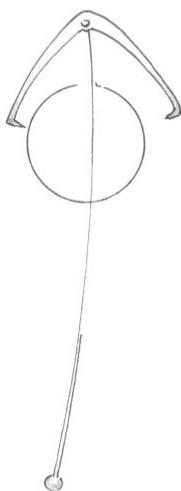
Switzerland may not be possible for whatever reason but the destination doesn't seem as vital as the journey. Knowing it's there brings security (45-6) but the feeling of movement is vital, it brings vitality and distraction, **'don't stop, don't stop, don't stop'**⁵⁵.

The participant holds the desire for **'perpetual motion'**⁵¹ (Participant sketch 1) the ability to keep going and constantly be useful, denies the RA the control over her life that succumbing to the fatigue gives it. The RA **'restricts'**⁴⁸ the energy needed to be in motion and for the participant **'it's all about the energy'**⁴⁹⁻⁵⁰.



The idea of **'perpetual motion'**⁵¹ here is potentially ironic as the ultimate machine, constantly in flow under its own steam, but the OED defines it as something which 'appears to be continuous and unceasing' and here the key is in appearance.

Continuous implies never ending, going around and round like a wheel or roundabout but when considered alongside the desire to be useful the implication is of a machine.



Potentially as close to a perceptual motion device as one could get is the idea of the escapement of a watch mechanism. This also ties in with the themes of movement and balance. But its metaphorical link to time is obviously very strong and time as a concept is notable in its absence. Although the participant states that the RA will **'get you in the end'** the concept of journey is more temporal than any sense of measured moments in time.

However, the sense of balance and journey connects to this movement (it also suggests the tightrope walker bringing connotations of unease and danger).

'It's much more of a pivot/a balance'³¹²

The seemingly aggressive look of the watch escapement with its sharp points constantly moving back and forth whilst balancing on a pivot point which it is undermining starts to play with the idea of the constant motion, the balance theme and the idea of auto immune.

However, the unceasing nature of this goes against the idea of movement as life-giving and enjoyment. The idea of unceasing brings to mind unrelenting and exhausting and it is here that I see the first contradiction in the Participant; energy=identity; there is the '**capacity to go, do everything!**'⁵⁰ but there is a strong desire to stop⁽²⁶²⁾.

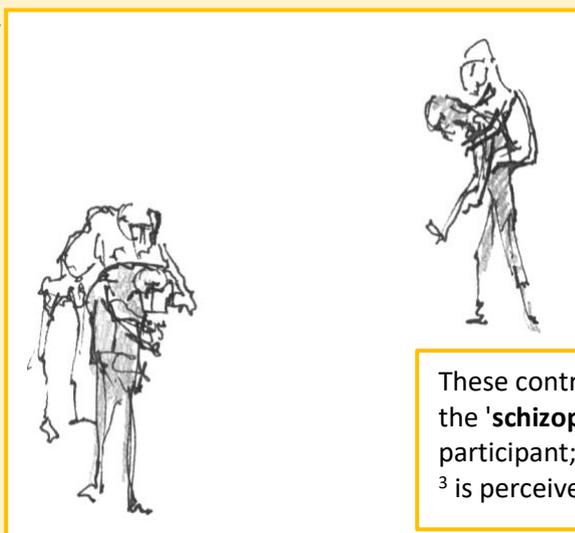


This contradiction runs through the whole dialogue, wanting to keep going but also to stop; the participant defines herself as energy, that it is '**so much about my identity**'⁵⁰, '**movement is the antithesis of RA**'²⁶ but the RA is constantly moving too, '**it jumps out**'²⁷⁴, it '**comes over you**'²⁶⁷. The '**black silk: the shadow**'²⁶⁷ keeps getting thrown over the participant but she also claims that '**I do that**'¹³⁴.

There is a gratitude in the help she gets '**I was really lucky**'²⁷⁸, '**the drugs are here for me**'²⁸⁵, they '**anchor**' her²⁷⁹ giving protection, containing and holding her '**I am contained**'²⁷⁸, '**I was really held**'²⁷⁵⁻⁷ but there is a fear of the side effects of the medicine, making her feel '**awful**'²⁵⁶, the worry that they '**keep discovering stuff**'²⁶¹

By being anchored and held the participant is, again not in control. The participant is the energy with RA controlling on the one side and the 'help' in control on the other. With no personal means of controlling her direction, the travelling has become the goal, perpetual motion has become the ideal state

However, there are 'frictions' which counter the perpetual motion, realities which prevent the ideal, the hips being a prime example, but also the participant herself '**the first person to punish me is me**'⁸⁰⁻¹.



These contradictions are explained as the '**schizophrenic**'¹³⁷ aspect of the participant; the act of '**eating herself**'⁷⁹⁻³ is perceived as a self-inflicted one.

This can be seen when the RA is seen as an entity, a '**stalker**'²⁷³ but it is a stalker that she carries with her. It casts a shadow but this shadow, like in Peter pan, has a life of its own surprising her⁽¹³³⁾ but allowing a self-indulgence too⁽²⁷⁸⁾.

The RA is not represented by any one thing, a 'metaphor', it is both in and of itself '**it sneaks up**'⁴⁰ and it is the participant '**I do that**'¹³⁴.

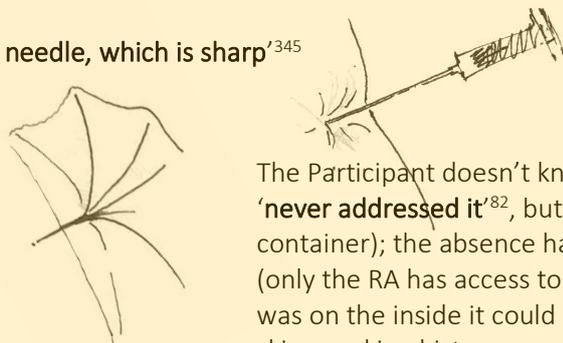
This concept of self-inflicting harm ties with the discussion about the spiritual healer’s comments (79-91), that the root of the disease is intimately connected to the participant’s past (an ‘imprint of my past’⁸⁰)



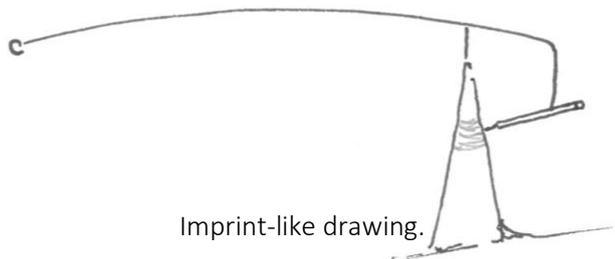
The weight of past events has left a mark (stain?). The idea of an imprint is always related to absence, as something caused by something that can only be seen when that thing has gone. One thinks of footprints, but also the marks left on carpets when the furniture has been removed

There is a strange permanency to imprints-when the snow melts the compacted print of a wellington boot are the last thing to go.

‘the drugs are a needle, which is sharp’³⁴⁵



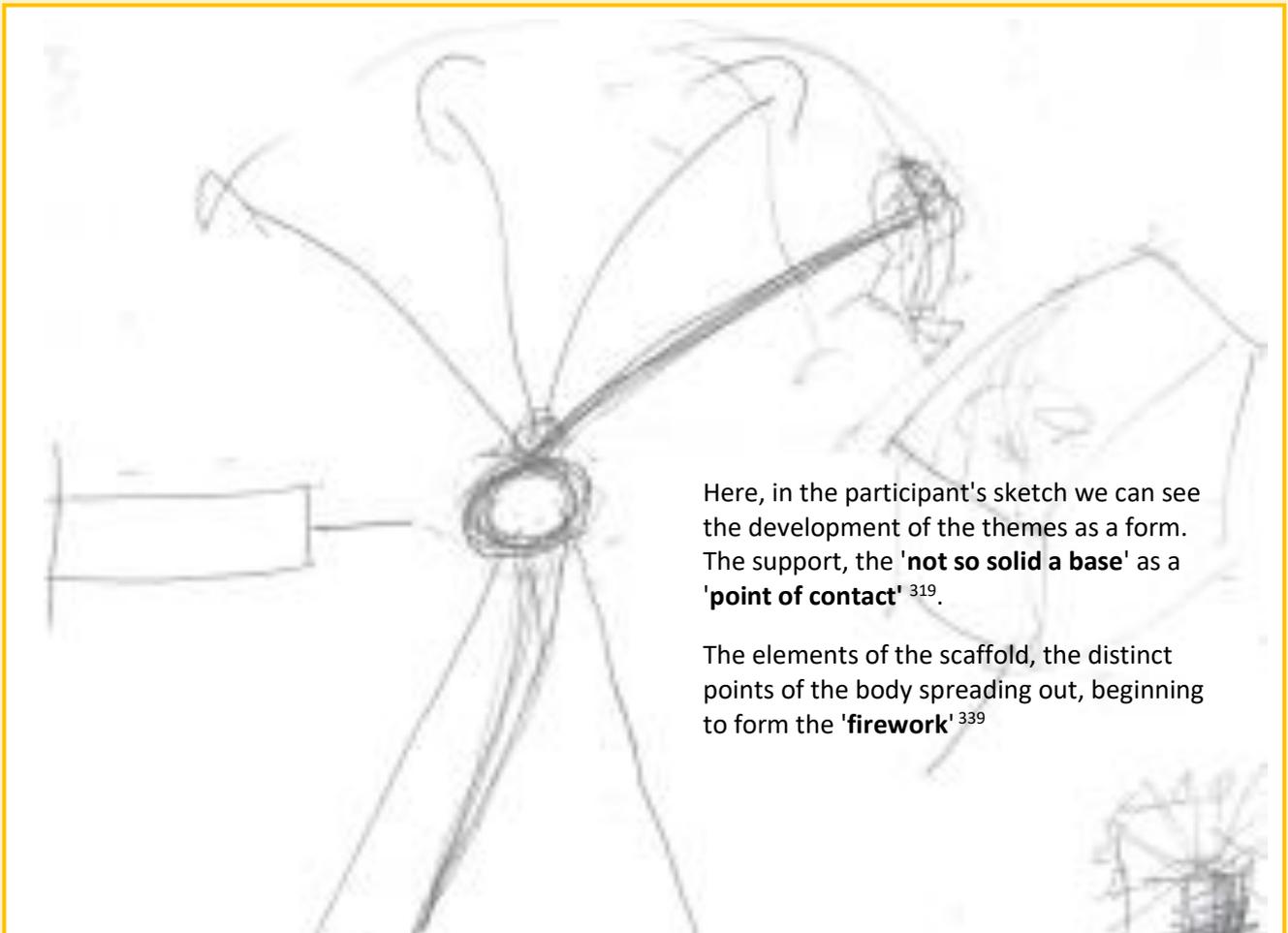
The Participant doesn’t know the cause of the imprint, she ‘never addressed it’⁸², but it has affected her core (the container); the absence has left a hollow, the RA filling a gap (only the RA has access to her core²⁰⁵). Potentially, if the imprint was on the inside it could have pushed outwards like Flusser’s skin, marking history on us like a map with two faces.



Imprint-like drawing.

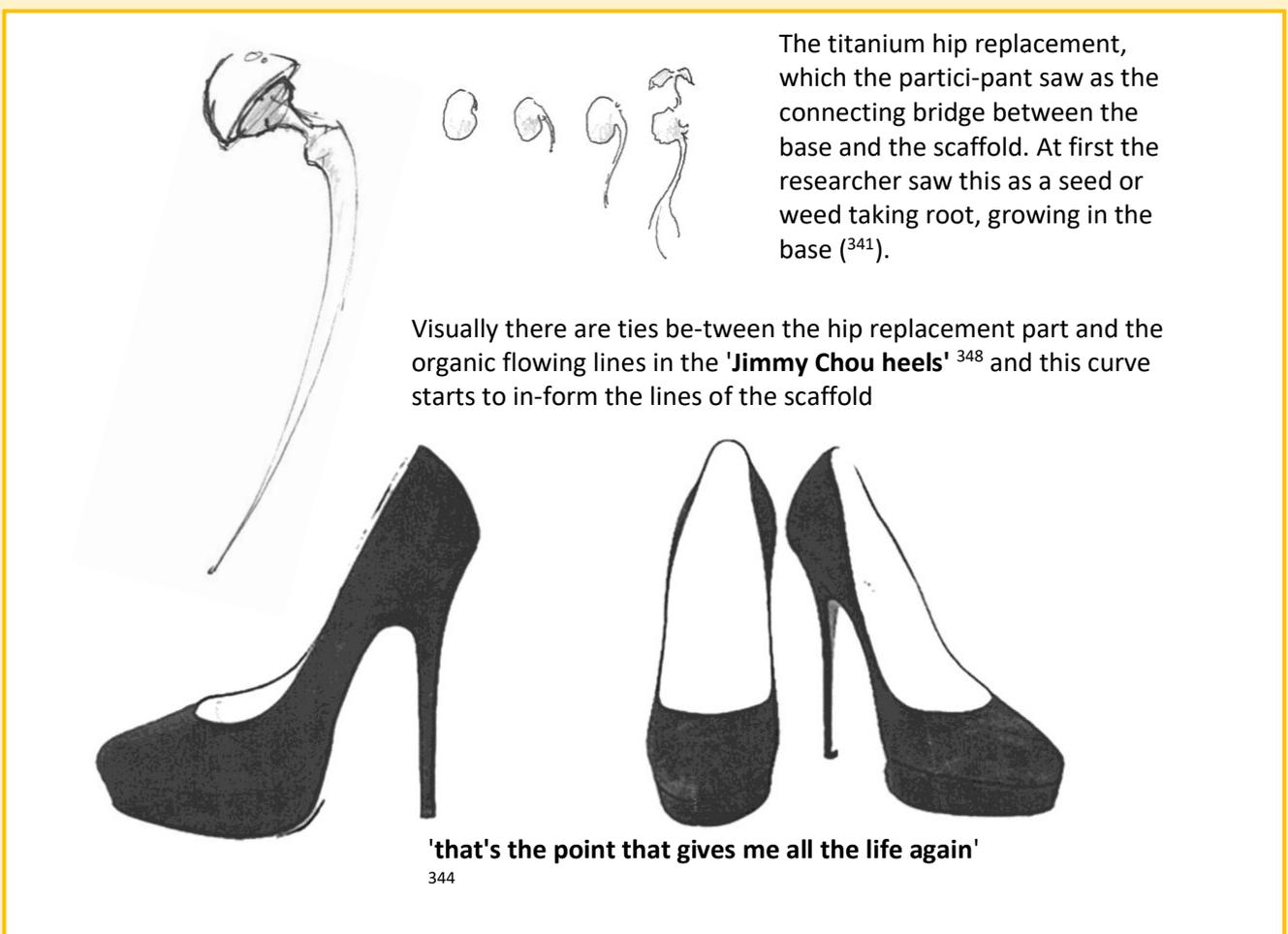
The covering over of something underneath, potentially colouring it in like a censor or a scribe scratching away at the surface like iconoclasm.

The model as a palimpsest with layers of information added or collaged over like a billboard or eroded away and exposed...



Here, in the participant's sketch we can see the development of the themes as a form. The support, the **'not so solid a base'** as a **'point of contact'** ³¹⁹.

The elements of the scaffold, the distinct points of the body spreading out, beginning to form the **'firework'** ³³⁹

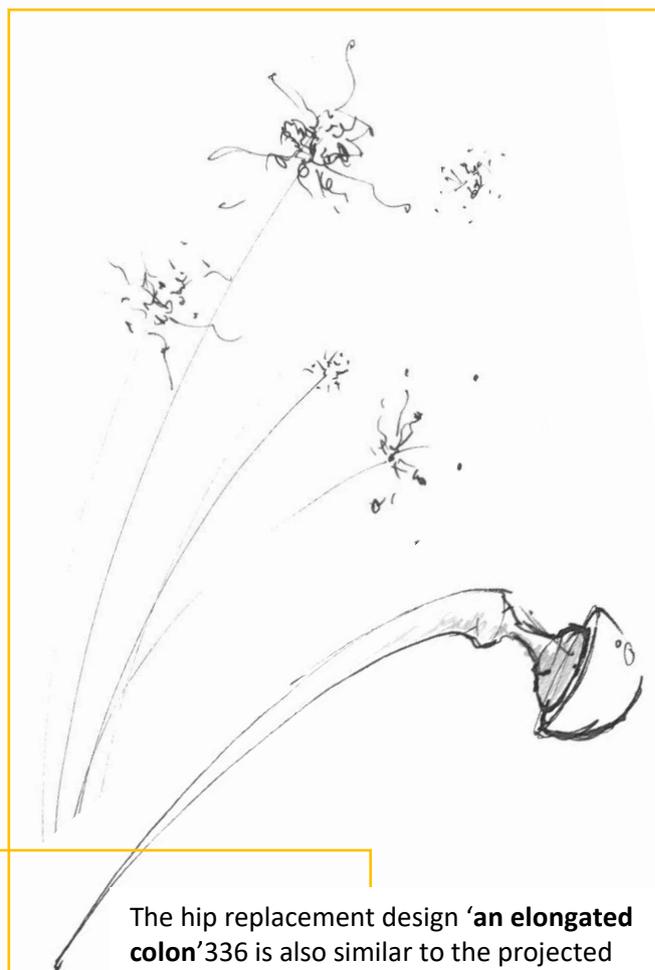
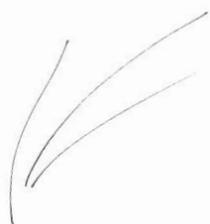
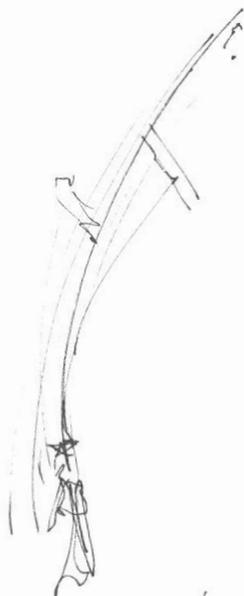


The titanium hip replacement, which the participant saw as the connecting bridge between the base and the scaffold. At first the researcher saw this as a seed or weed taking root, growing in the base ⁽³⁴¹⁾.

Visually there are ties between the hip replacement part and the organic flowing lines in the **'Jimmy Chou heels'** ³⁴⁸ and this curve starts to in-form the lines of the scaffold

'that's the point that gives me all the life again'

³⁴⁴



The hip replacement design '**an elongated colon**'336 is also similar to the projected trajectory lines of the firework giving a sense of flow and more dynamic animation to the form.

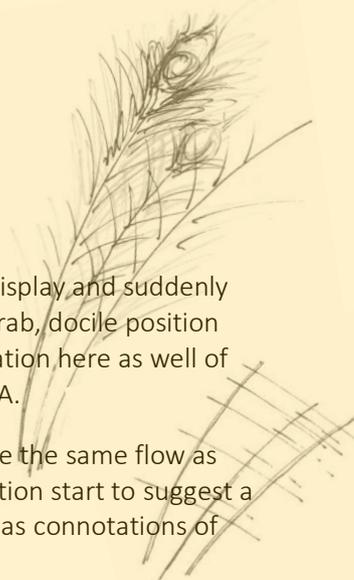
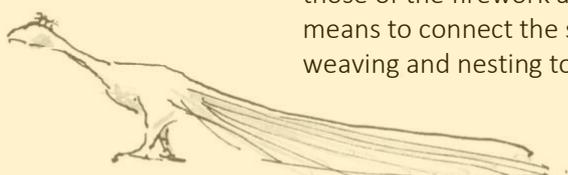


These lines begin to describe the scaffold of the model

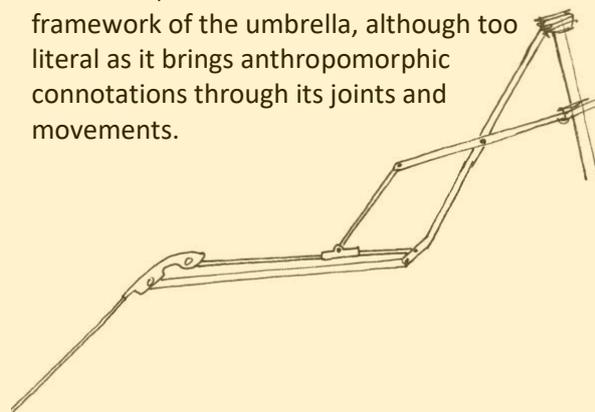
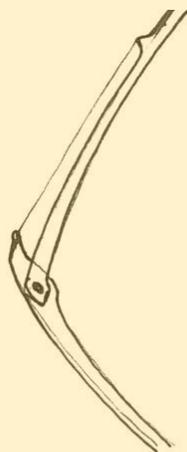


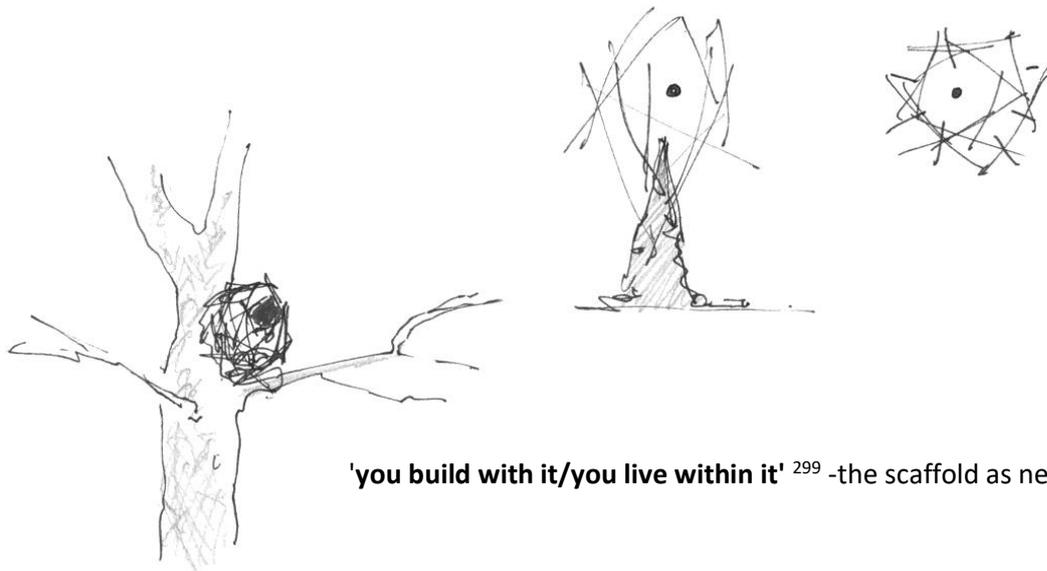
In the way the peacock opens up in display and suddenly collapses the structure into a more drab, docile position brings to mind the theme of presentation here as well of the quick, surprising covering up of RA.

Also, the feathers of the peacock have the same flow as those of the firework and in combination start to suggest a means to connect the scaffold. This has connotations of weaving and nesting too.



The suddenness (¹³⁴) of the draping of the black silk or the coming of the **'big shadow'** ²⁶⁷ suggests the umbrella in its relationship with fabric, structure and shadows. The framework of the umbrella, although too literal as it brings anthropomorphic connotations through its joints and movements.

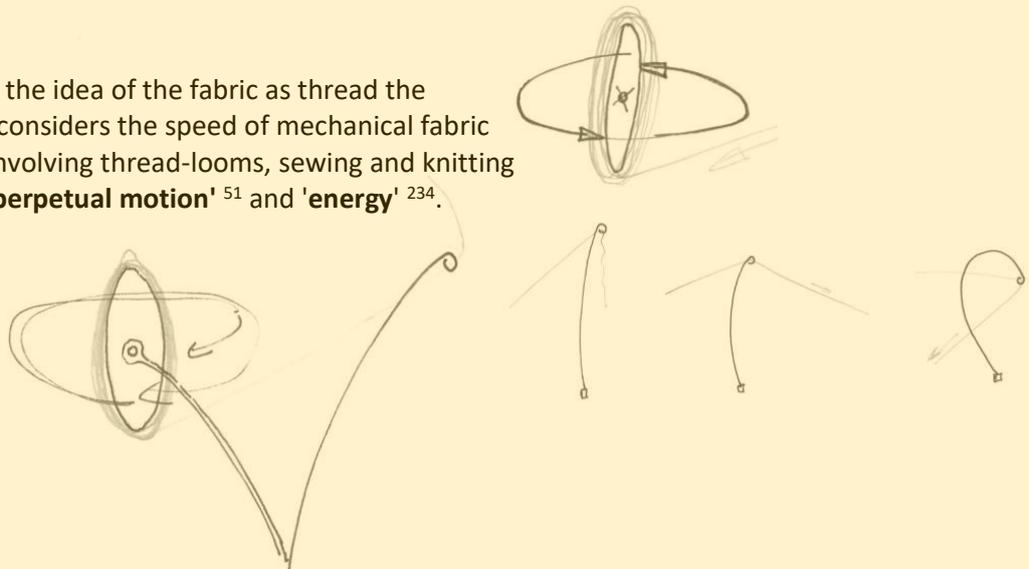




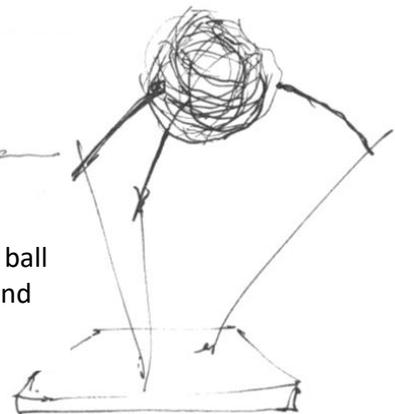
'you build with it/you live within it'²⁹⁹ -the scaffold as nest.

Taking that idea further, I see connections between the sticks that go together in nest construction and the wires considered for the lines of the firework shape, potentially using them to form a tight, protective bristle around the core of the model or potentially it is the core of the model. The scaffold, following the lines of the hip replacement and the firework supporting the 'nest'.

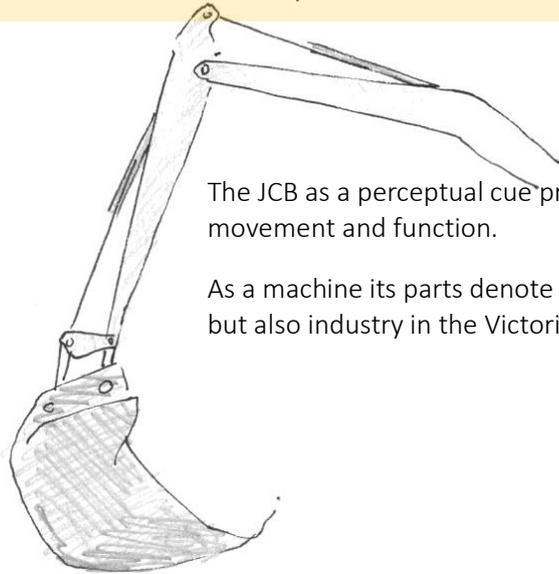
Continuing the idea of the fabric as thread the researcher considers the speed of mechanical fabric processes involving thread-looms, sewing and knitting machines-'**perpetual motion**'⁵¹ and '**energy**'²³⁴.



The nest starts to resemble a tightly woven ball (of fabric), linking to the '**nice material**'¹⁵⁰ and the '**black silk**'¹⁴⁴ of the participant.

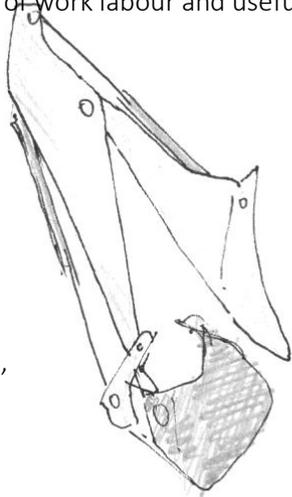


Other forms and direct visual metaphors that came to mind:

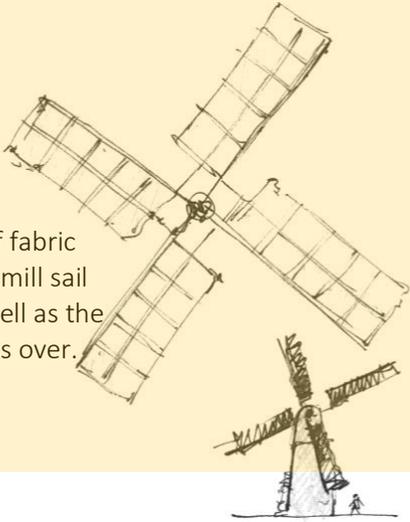


The JCB as a perceptual cue provides a sense of structure, but also movement and function.

As a machine its parts denote industry, not just as a process in society but also industry in the Victorian sense of work labour and usefulness



The JCB, similar in its mechanics to the umbrella, first came as an idea watching one whilst listening to the inter-view recording. Closed up it visually links to deviation of the hand in RA It brings a feeling of tightness, being contracted but it contrasts this with a sense of potential energy, obviously intended for a purpose.



The windmill with the combination of fabric and perpetual motion. Also, the windmill sail has a woven but fragile feel to it as well as the whooping of shadows as the sails pass over.

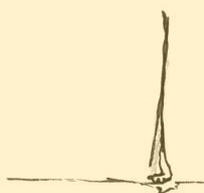
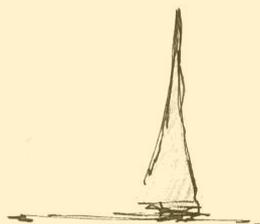


'it would drape over the shape of it but it would emit the vibrancy' ¹¹⁹ suggested the black and white photography and light shielding cape forming the shape of the photographer as the instrument.



The 'whirling dervish-energy, display and the flow and then fall of the fabric as the movement comes to an end

**'you keep wanting to put it on a platform
and it's a point of balance!' ³⁴²⁻³**

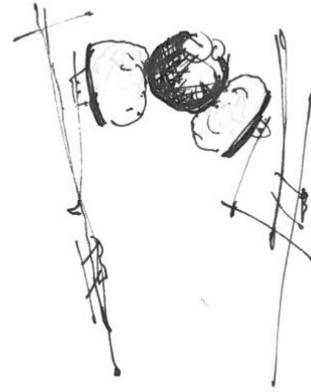


**'I think it's much more unsteady, but that's the
point that gives me all the life again, isn't it?
The crumbly bit' ³⁴³⁻⁴**



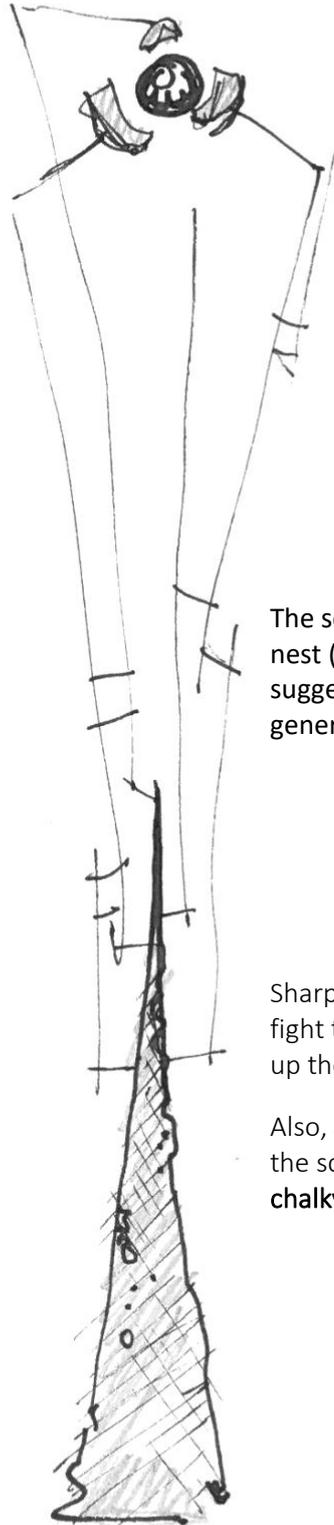
The core, focal point of the model, the RA or the participant?

'-there's this core you inside
which is only available to ...the RA' ²⁰⁵



The 'core' is protected by 'nice material' ¹⁵⁰. Potentially this soft cushion is protecting the presentation of self, 'I dress the container' ¹⁵²

Arced lines of scaffold give sense of movement and the dynamic of the firework, shooting up to the 'core',

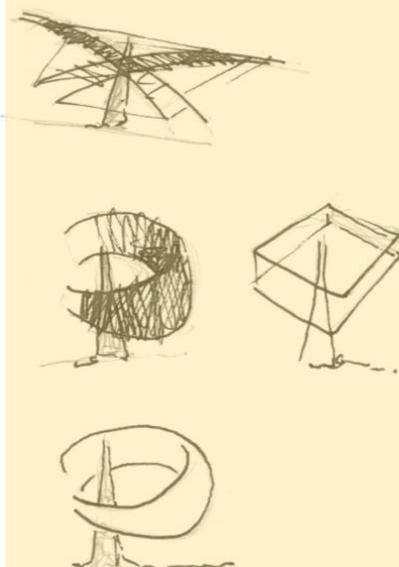
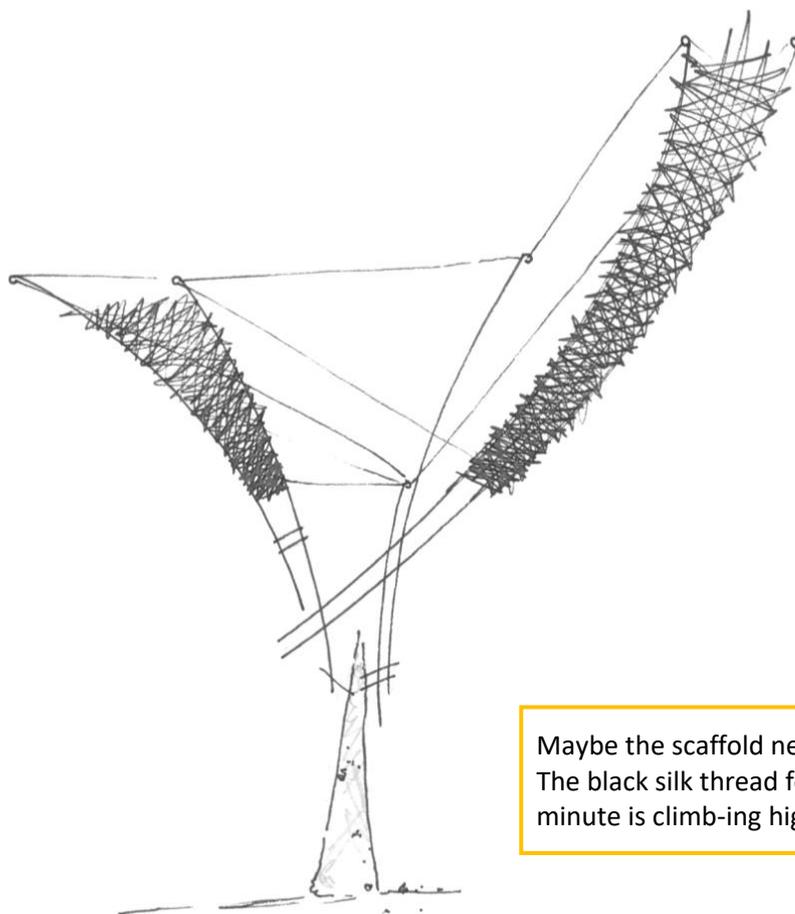


The scaffold holds a core? Built up and lived in like a nest (²⁹⁹) with similar sense of random construction suggesting instability but also creating a form, generating a sense of pattern

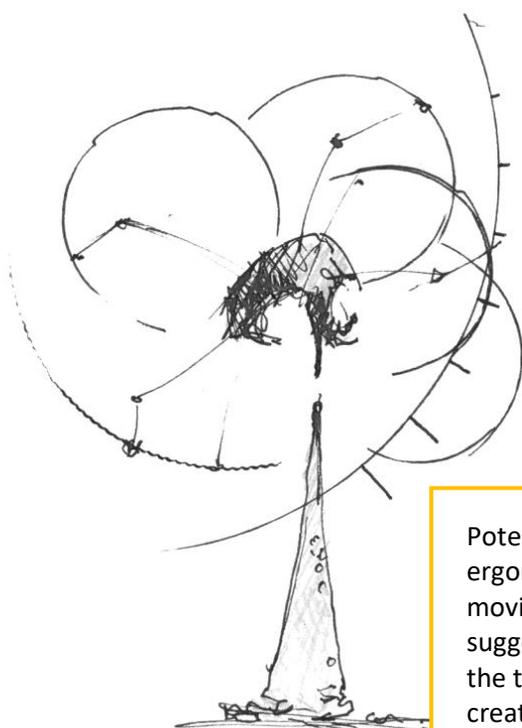
Sharp and hard points ('the drugs are a needle' ³⁴⁵), they fight the movement, erode the supporting base but hold up the structure (like a crutch).

Also, as 'points of contact' ³¹⁹ they keep the Participant, the scaffold and the 'core' away from the 'crumbly, chalky' ³⁰³ base

The pointy, chalk base is the grounding, the reality or fear of some kind of reality. Maybe this crumbling could be on top of the Switzerland postcard? 'There are lots of things that mean I can't go to Switzerland' ⁴³



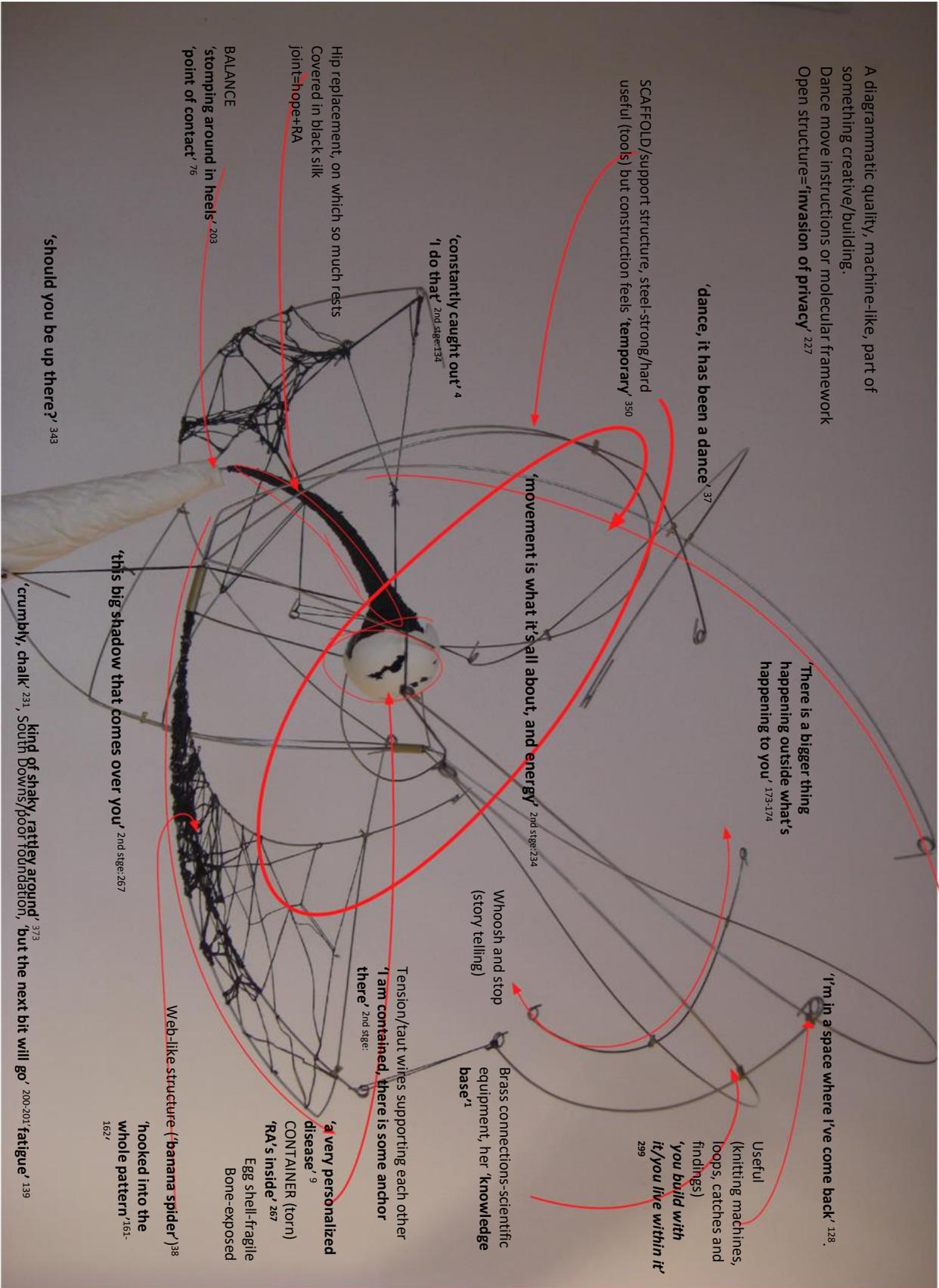
Maybe the scaffold needs to be the 'core' of the model. The black silk thread forming the container which, one minute is climb-ing high and the next it covers itself.



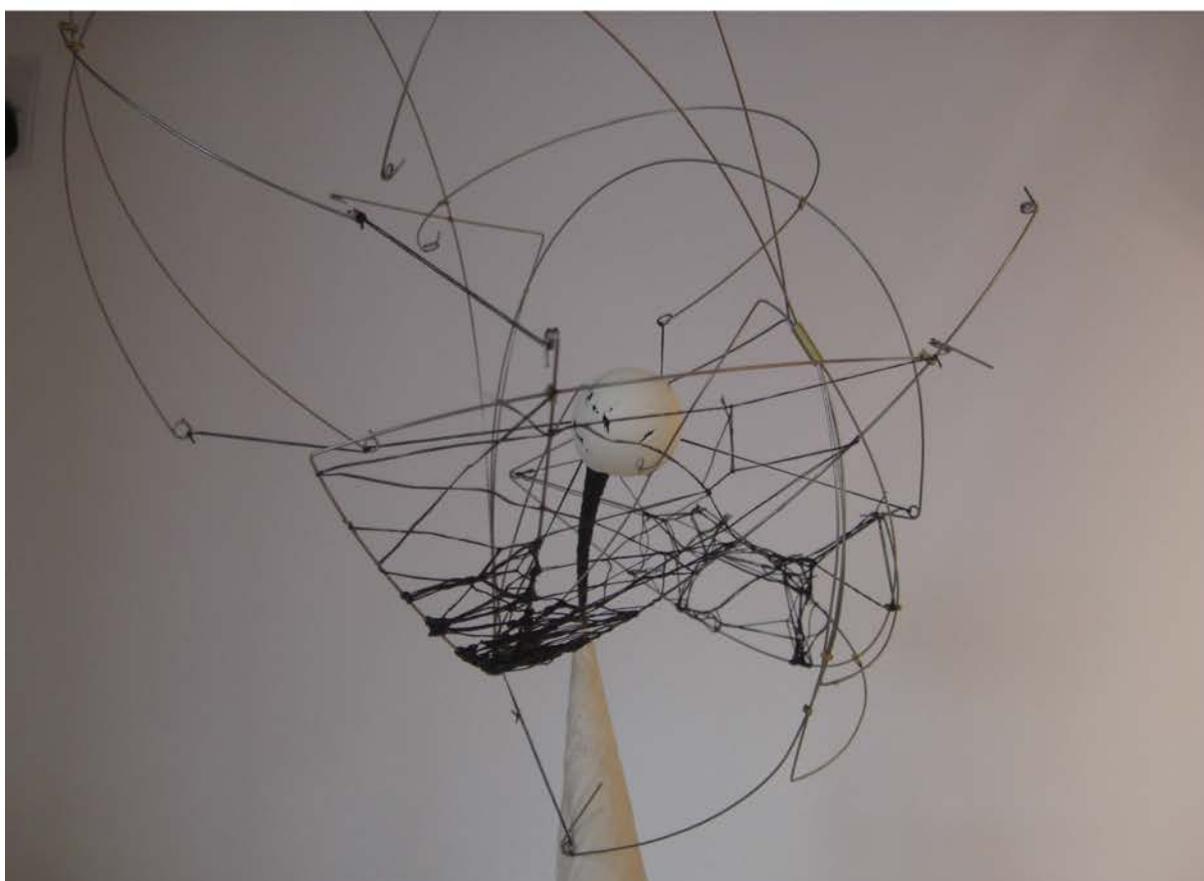
Potentially the scaffold could be determined by ergonomics, the flow and spatial capacity of the moving hand (usefulness). Or this could start to suggest the pattern. The pat-tern shown as the path the thread follows in building the scaffold and creating the shadow at the same time.



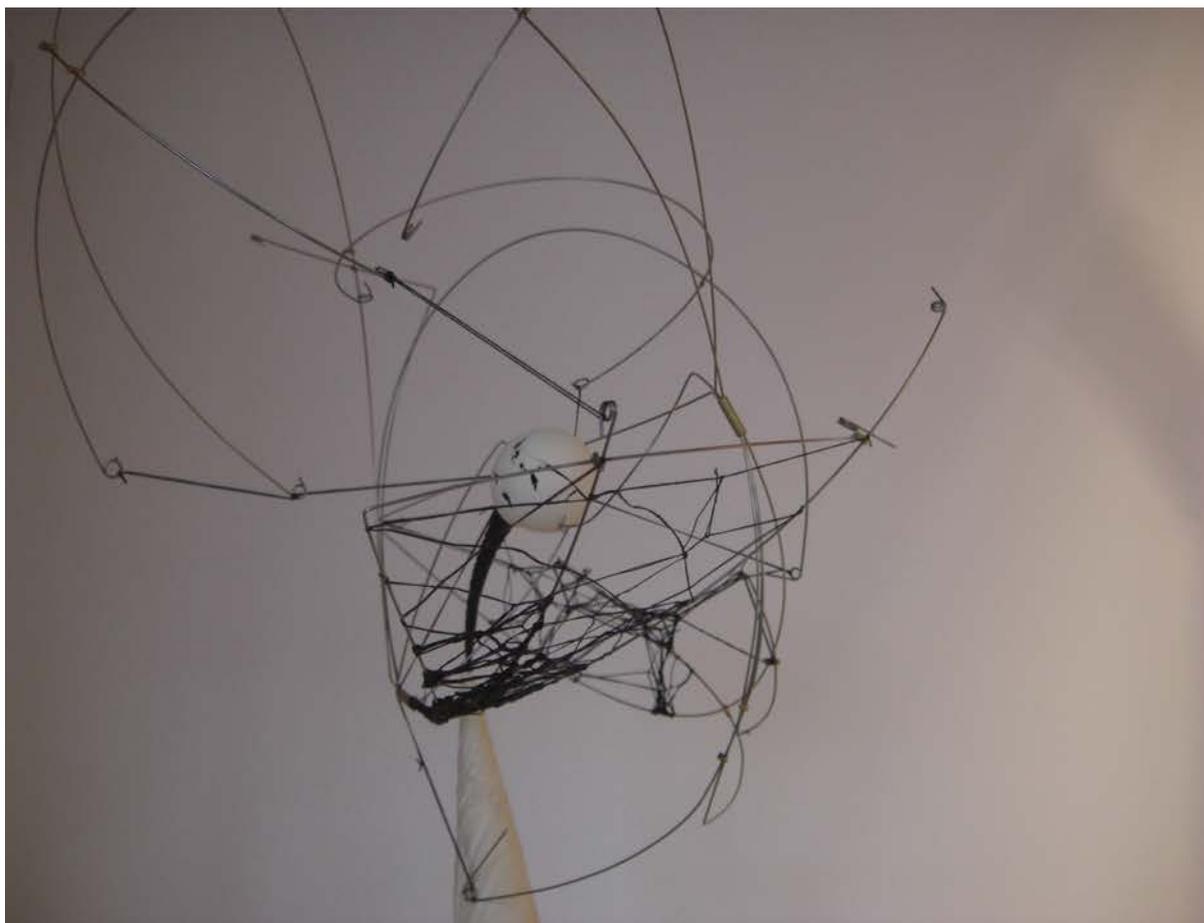
7.1.5 CROSS REFERENCING ANALYSIS TO MODEL: PARTICIPANT 1



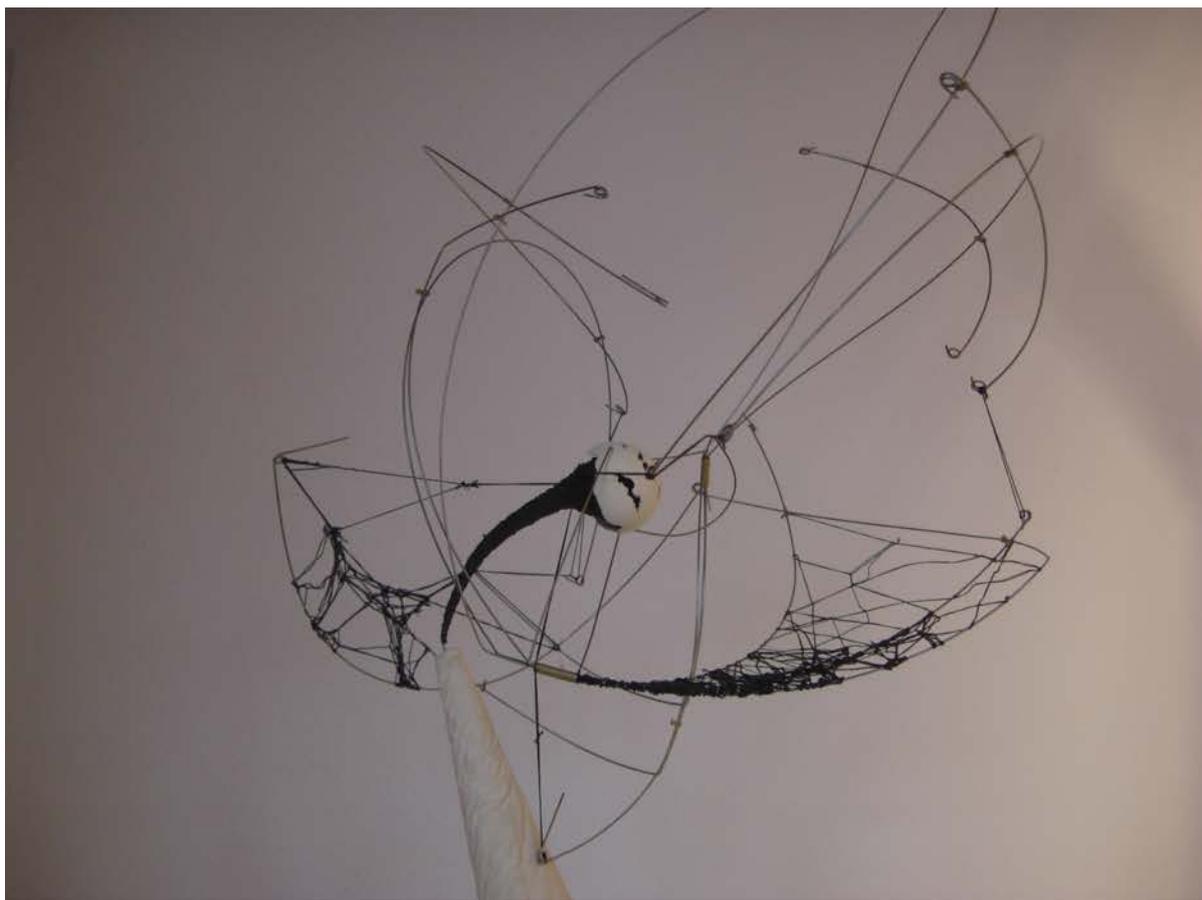
7.1.6



7.1.7



7.1.8



7.1.9

7.2 PARTICIPANT 2

Participant 2 is a professional employee at the University, a single mother⁴⁰ with a ten-year-old son. She is in her late 40's and was diagnosed with RA three years previously.

7.2.1 THEMATIC ANALYSIS OF TEXT

OVERVIEW

My analysis sees six main themes running through the conversation, WAR, SEEN/UNSEEN, JOURNEY, CLUTTER, STRUCTURE and SON.

The theme of WAR ties to the overarching sense of conflict described above and is highlighted throughout the conversation with the metaphoric choices of vocabulary made by the participant.

On the whole Participant 2 came across as defensive. I became if not an ally then at least a confidant in her engagement with the world, her relationships with work, neighbourhood, and medical care. In asking whether or not she could swear the context became more defined for her, what she could be or not.

This concept of her self-identity came across as a conflict; either the perception that she is different to what she believes Society expects her to be, '**Cheer up, we all feel like that**'⁴⁵⁴⁻⁴⁵⁵ or the fact that

⁴⁰ Although not developed as a theme in this analysis, the Participant's experience strongly tallies with the analysis of Feddersen, Kristiansen, Andersen, et al. (2019) regarding the juggling of identities of mother and employee with RA, "women attribute the highest priority to their professional identity, spending the majority of their time and energy in an effort to appear as "good stable workers". The disease is seen as a hindrance in this regard, and the illness identity is almost completely rejected. In motherhood, the women prioritize close interaction with their children, and deprioritize external activities. Extended outbreaks of the disease and issues regarding the children force the women to deprioritize working life" (abstract).

she isn't, at the moment, what she considers herself to be, **'I'm gonna have to change my life, I'm gonna have to stop doing the things I do'** ⁸⁷⁻⁸⁸.

She battles with the way she needs to live her life and work, a conflict with the institution, her role as employee and the public face and her role as mother all handicapped by her illness private to her. She sees little compromise from the outside, work/public, which seems partly her own fault -she responds to the conflict with camouflage, cloaking devices that, rightly or wrongly, denies those outside a means to respond to her handicap, **'you've put your face on... because ... you have to cope'**⁸. Here, the term handicap relates rather to the term applied to horseracing than that of a physical disability. The RA is considered in terms of the effects, the fatigue or the side effects of the medication, that prevent her from performing at her true potential. RA is a handicap and the idea that the race or journey she is on is unfairly balanced against her as she is weighed down by the RA, an almost physical baggage, similarly to the weights added to a jockey.

This idea of excess shows through her more internal conflicts. Clutter, baggage, excess, mess and rubbish obscure the cleanliness and clarity she sees as necessary to her goal; whether that relates to the public face, a perception of the perfect, organized mother, her private desire for peace that comes through mindfulness, or her battle against herself and her disease.

My understanding of the theme SEEN/UNSEEN is that this is the participant herself. The faces she presents to the public and what she keeps for herself behind the closed door are both her, one does not conceal the other. All the other themes mentioned are tied to that of SEEN/UNSEEN. It is a response to conflict (WAR), her JOURNEY is framed around being either in or out, going out undeniably takes courage and although the participant is not afraid to face this conflict but it is undertaken, as much as possible, on her terms and what she allows to be SEEN.

SEEN/UNSEEN

Right at the beginning of the conversation the Participant draws a similarity between RA and the depression she has suffered from for some time, stating that **'they're quite unseen'** ⁵. This statement laid open a theme that runs through the text.

The Participant felt observed, under surveillance, and in response to this what came across was a presentation, a public face to protect her true self **'you've put your face on'** ⁸ **'you put on that face'** ¹⁵³. This 'face' provided a means to hide her true self from misplaced or false sympathy that made her angry, **'oh dear, we all have bad days' or you know 'I feel like that sometimes'** and **'we're all**

tired aren't we' ¹⁰³⁻¹⁰⁴. But the face, the mask, also allows things to be placed beyond her own view, even though visible cues were available, **'you could see/they looked like arthritis fingers'** ⁸²; by placing these at **'the back of [her] mind'** ⁸² she was **'in a bit of denial'** ⁸⁴.

Understanding of her situation arises through seeing, **'you could see'** ⁸³ that things were not right. Her son knows she isn't feeling well **'when he sees'** ¹²¹, other friendship groups don't have the same empathy **'I don't think any of them give it a second thought -----because they don't see it'** ¹⁴⁴.

Being SEEN provides her with both allies and some self-justification. People she works with know her and how she feels when they see, **'they understand the most is because they see me the**

most...when they see me coming in and they see this, they see me limping or whatever' ¹⁴⁰⁻¹⁴²

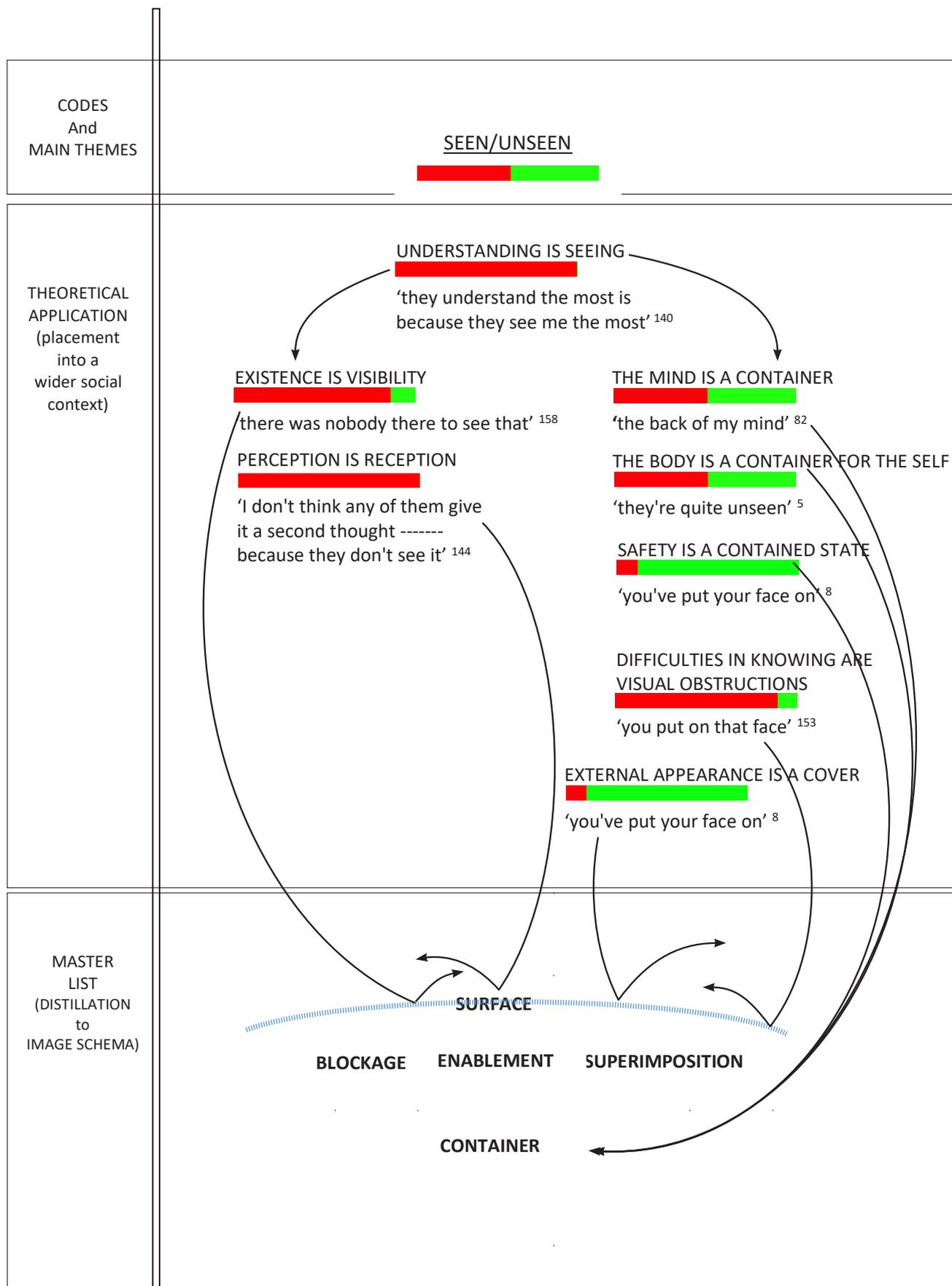
Physical, visible evidence provides the participant with some justification in society's eyes for how she feels inside. However, she places herself beyond society's view when the RA is at its worst, medication days, for example. In stating that **'people didn't see me on Saturday'** ¹⁵⁶ or **'there was nobody there to see that'** ¹⁵⁸ the Participant is both protecting herself, not having the energy to deal with that public gaze or misunderstanding, and providing herself with a self-confidence, only she knows how bad it can be and she deals with it alone.

'I don't want you to see my house like that' ¹⁶⁰⁻¹; where the house, or the state it is in is representative of how she feels; the house becomes a projection of her that she cannot mask from society without an effort that her fatigue denies her; through her home, and its perceived unkempt state, she becomes exposed.

Another element of visibility is through the medical gaze, the **'consultant who I see'** ¹⁹⁵, **'I've seen once and then since then I've seen her registrar'** ¹⁹⁶. However, here the emphasis is on *her seeing* them, rather than being *seen by* them, which suggests that the Participant questions whether the medical professionals understand how she truly feels; she cannot hide the physical symptoms, **'you could see...big swollen knuckles'** ⁸³⁻⁸⁴ and she is aware that they are looking, **'let us know that you've been drinking because it will show'** ²⁶⁴ but **'the consultants aren't really interested in [her] day-to-day'** ¹⁹⁷, how the pain and fatigue change her life.

The idea of seeing as knowledge as a metaphor is also reflected in the Participants inner thoughts, where focusing is a more attentive, directed form of seeing, for example, **'not to focus on the fact that everything hurts'** ³⁴⁵; in not actively looking for it, the Participant can deal better, if not avoid, the realities she faces. With a similar approach, meditation is described as **'kind of focused'** ⁴¹¹⁻⁴¹² and she explains that **'nothing has changed except your mind, your perception'** ³⁵⁷⁻⁸. Mindfulness has had a positive effect on the Participant's outlook, **'it is good, it does help!'** ³⁵³; enabling her to

not be afraid of what she faces but to accept it, **'paying attention to what is now as opposed to worrying about what is going to happen'** ³⁴⁸. She still sees these things, focusing on them but not to allow them to dominate rather to control their importance, **'you don't jump into them, you just observe them'** ³⁸¹.



The theme of SEEN/UNSEEN quickly correlates to the primary metaphor of UNDERSTANDING IS SEEING (linguistical appreciated with phrases such as 'I see...' as a confirmation of acknowledgement). It highlights the physical reliance on the visual but the way the metaphors divide show the increasing complexity of the concept.

On the one side you have the external validation that being visible brings shown in the metaphors EXISTENCE IS VISIBILITY and PERCEPTION IS RECEPTION. These are outward facing concepts affecting how the Participant responds to the world linking directly to the schema **SURFACE**, which by intimately linking to the schemas **BLOCKAGE** and **SUPERIMPOSITION** imply a shield or protective barrier promoting **ENABLEMENT**, a sense of protection from the world's gaze.

The other avenue is more internal, highlighting the private thoughts of the Participant. Whilst the primary metaphors EXTERNAL APPEARANCE IS A COVER and DIFFICULTIES IN KNOWING ARE VISUAL OBSTRUCTIONS link directly to the schema **SURFACE** they are actions, instigated by the Participant in response to the world. The other metaphors reflect the idea of what lies behind the protective **SURFACE**, the contained, more fragile state of mind, which the Participant holds in reserve.

The overarching sense of the theme is negative, the protective mask/shield is necessary, enabling the Participant to continue to function in the way she chooses but the fact it is required at all because Society does not understand without seeing is both exhausting and depressing.

SYNOPSIS

A shield to protect a private entity

CLUTTER AND TIDYING UP

A theme linked to the participant's perception of self is the theme of CLUTTER. 'A tidy desk is a tidy mind' they say and for the participant the analogy of housework and Society's perceived expectations of the clean and tidy home is linked to a clarity of mind and purpose, her ability to engage with the world and the conflicts that brings or, in reflection, a representation of the enormity of that task. CLUTTER is more than just stuff not tidied up around the house, information, medication, and the RA itself, are all understood as CLUTTER. CLUTTER represents things the participant needs to deal with, responsibilities (cleaning is a mother's role⁴¹).

She sees her RA as **'another thing'**¹⁰⁻¹¹ to deal with and carry alongside the depression she also bears. She begins the conversation describing this as a **'history of depression'**² conveying a sense of an archive of things, an unhappy accretion that she carries with her. Days accumulate in the same way, **'with rheumatoid arthritis the day after, the day after that you are absolutely done'**¹¹⁰⁻¹¹¹, **'I do two weeks straight and two days off, two weeks straight and two days off'**¹⁸⁰

This sense, that the accumulation of things is negative, reflects in her description of the advice offered from Occupational Health, **'loads of leaflets, so many leaflets that in the end I said I don't want any more leaflets, I don't need any more'**²³³⁻⁴

It can also be seen in the reduplication of blah at the end of descriptions, such as her work life **'I work on a computer, blah blah blah'**³⁵⁻³⁶ or advice about medication, **'it's really awful blah blah blah'**⁴³ where the intention is to convey a sense of the repetitive buildup of uninteresting information. The participant also reduplicates syllables such as **'da da da da'**^{177, 198, 216, 242, 435} during descriptions of conversations or listing events, which has connotations of repetitive information but also uninteresting baby talk, an unnecessary noise.

The participant is told to think of her energy levels and how she should engage with activities in terms of **'bags of energy'**¹⁰⁷, however in this context this merely suggests yet more to carry and she admits that she is not good at it, stating that she is **'absolutely rubbish at it'**¹⁰⁸

41 see Cox, 'Dishing the Dirt' in Cox, Pisani, Smith, et al. (2011) for more reading on the cultural link between the responsibility for dirt and its effects on the standing of women in society.

When the participant is describing the fact that RA is going to change her life, she uses the same adjective, stating that it is **'really, really rubbish'**⁹⁰. In using the adjective of rubbish, the participant is highlighting the concept of things she wants and those she does not in terms of waste, unwanted, untidy and not useful (and by duplicating the emphasizing adverb 'really' she is increasing the load, RA isn't just rubbish but brings an accumulation of rubbish).

The analogy of rubbish being bad and the participant's responsibility to tidy up carries through into the analogies she uses to describe dealing with priorities **'I have to function so I binned that one'**²²⁹ or the value of information **'I just had to bin all that cos I was so confused'**²⁴³⁻²⁴⁴.

In explaining the result of taking medication she states that **'it knocked the crap out of me'**⁵¹, the Methotrexate literally emptied her of the rubbish inside. When she **'feels crap'**¹⁷⁵ she sees it as her responsibility to **'suck it up'**¹⁷⁵ like a human vacuum cleaner.

This sense of accumulation and fatigue it brings can be seen in the prosody of the conversation. One such example is the participant's description of being forced to rest as a consequence of her medication:

'I spent all day on the sofa because my son sees his dad on every other weekend, all day on the sofa having taken my new big dose of Methotrexate -----and I was really, really ill but there was nobody there to see that-----I couldn't eat anything, I couldn't do anything, I was tired, the house looked like crap, one woman phoned and actually she did she said do you want me to come round?

and I just thought

no

I can't

I've got nothing to give you'¹⁵⁶⁻¹⁶⁰

Even though she is explaining that she was not doing anything, the explanations and descriptions mount up, with little space to pause, resulting in the exhausted, final refrain that rather than referencing how she felt instead questions her usefulness. Usefulness is important to the participant bringing with it a sense of self-worth and place in Society, an attitude that she reflects in the objects around her, such as the **'horrible brace that you can wear but can't do anything with'**²³⁴⁻⁵; for the participant even relaxing needs attention, **'you need to do something to not engage'**⁴⁰³.

She emphasizes her being **'all day on the sofa'**¹⁵⁶, which serves no value, it isn't going anywhere, **'I couldn't do anything'**¹⁵⁹, in fact she is cluttering up her own house. The fact that **'the house looked like crap'**¹⁵⁹ as one of the consequences of her fatigue and the medication is something that denies access to others, it stands as a visible manifestation of her disease and what lies behind the face she wears for others (^{8, 153}).

The participant is aware of these internal conflicts and their impact on her life, mainly through her understanding of depression. The engagement with mindfulness, of finding oneself amidst the countless pressures and constraints of everyday life, suggests a search for self, or, in this case, the hope of finding a space, some clarity, like a clearing in a forest, for the self to be on its own terms.

She refers to this as **'headspace'**^{183, 388} and mindfulness meditation as the means of **'finding that space in your head'**³⁸⁵⁻⁶. Although a self-confessed novice, the participant lays great store by mindfulness. Her explanation of it and the reasons for it draw analogies to tidying up. She explains that **'you've got so much in your head'**⁴⁰¹, in fact you **'have a head full'**⁴²³, similarly to the accumulation of rubbish or the untidy house. Meditation's role is to help **'you clear that out'**⁴⁰² and to **'try to clear my mind'**⁴²⁶.

The concept of space, somewhere with nothing in it, provides the participant with an environment where she can do nothing as there is nothing (no chores) to do and in this respect a tidy house, or a clear mind, represent a success. She describes a **'space'**²³⁷ at the RA clinic where she was able to be herself, **'I just sat there and I just cried'**²³⁷, a space where there was nothing else to do but cry.

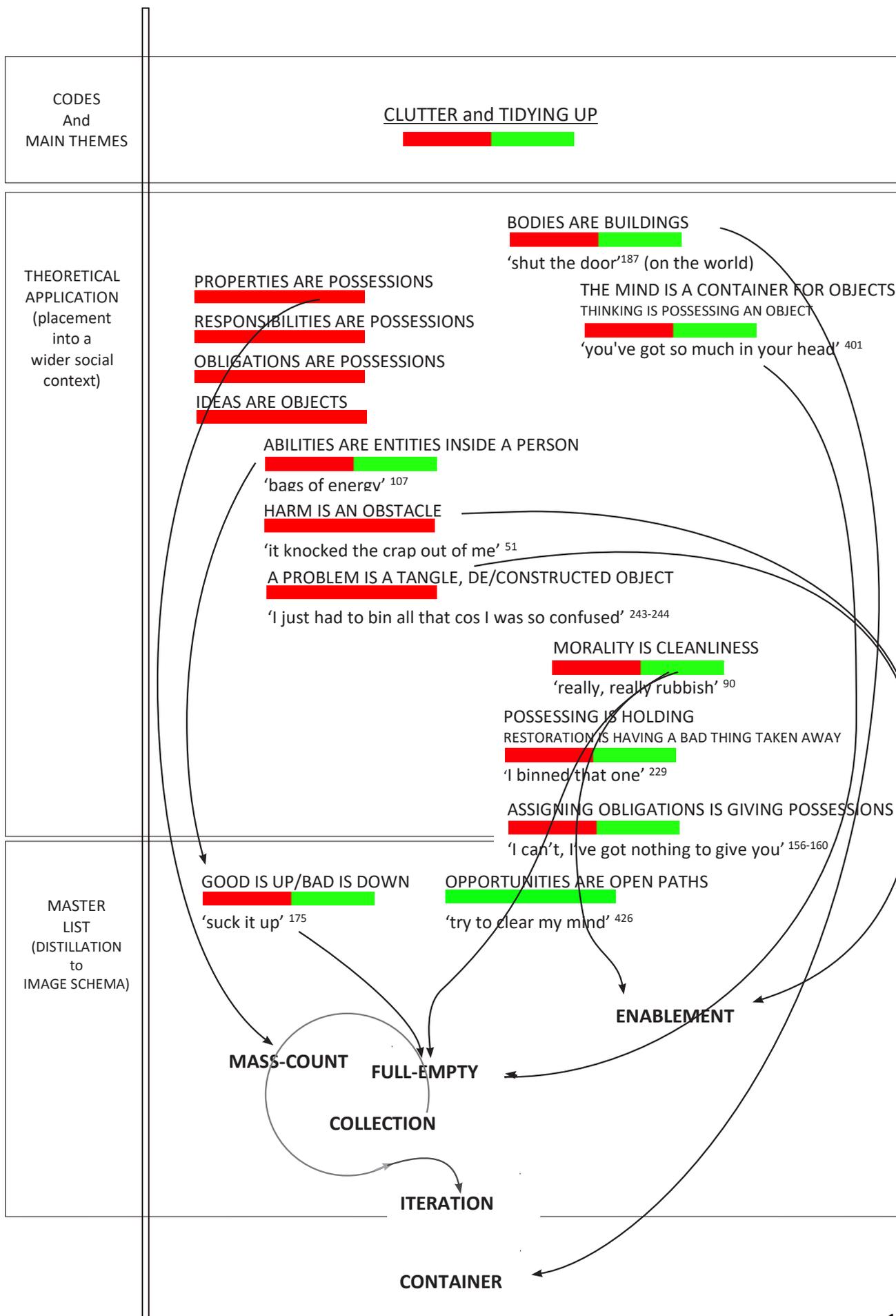
However, in another sense this has negative connotations, the participant's lack of affinity with the medical team, whose personalities being vacant left her with literally nothing to *work* with, **'there's just nothing there'**²⁰³ **'just nothing -----nothing there'**²⁰⁵. Also, when feeling at a low point she states that **'I've got nothing to give you'**¹⁶⁰. This 'nothing' results in a lack of purpose; there are no things to see or to become involved that could be evaluated or appropriated.

The solution to the conflict between clutter and tidying, nothingness and purpose is to be found in a deeper understanding of mindfulness and better meditation to provide a headspace where **'all of those thoughts are going to be there, but you are just going to let them'**⁴¹⁶⁻⁴¹⁷, although the participant appreciates that she is **'not quite there'**³⁹⁸⁻³⁹⁹.

The mother's role is her primary one, **'I've got a ten-year-old and a job'**⁹⁰ both a position of great pride and a burden. Although rarely discussed directly in the conversation, the overriding sense is that the son is the centre. She is passionate of her role as mother, **'I'm a single parent'**²⁵⁻²⁶, **'I'm a**

single parent'¹¹⁴, "I know what it's like to be a single parent"¹⁴⁷⁻¹⁴⁸, 'I'm a single parent'³¹¹, 'I'm a parent ...I'm a single parent'³¹³. Whereas 'Most of them are families, they are family units'¹⁴⁶ she sees mother+son as a unit of one.

In contrast to her own 'history of depression'¹ her son is the future. She sees her role as 'trying to help him manage'⁴²², to 'help him in the future,'⁴²². In contrast to her illness and the fatigue it brings he is energetic and 'physical'⁹², in contrast to her just wanting to 'shut the door'¹⁸⁷ on the world, he wants to be out, 'you're tired but I want to go out'¹³³⁻¹³⁴.



The theme CLUTTER and TIDYING UP play out under the Participant's sense of responsibility strongly tied to her appreciation of herself as a container, a space that for her links strongly to the home (BODIES ARE BUILDINGS). This space needs to hold all the things she thinks, feels and has to do. All of these feelings, symptoms of the disease, parental responsibilities, work obligations, etc. can be conceptualized as physical entities, space occupying weights that she has to carry, shown in the primary metaphors PROPERTIES/RESPONSIBILITIES/OBLIGATIONS ARE POSSESSIONS and the metaphor IDEAS ARE OBJECTS.

The accumulation of these entities seen in the schemas **MASS-COUNT**, **FULL-EMPTY**, and **COLLECTION** again draw comparison to the home. Mentally trying to organise and 'clean up' link to the idea of MORALITY IS CLEANLINESS and the schema **ENABLEMENT** brings satisfaction with removing obstacles, untangling problems or disposing of bad things. The end goal being an empty space, a clear path to the future (OPPORTUNITIES ARE OPEN PATHS).

The schema **ITERATION** tied to **CONTAINER** suggesting repetitive accumulation within an enclosed space is stressful, whilst the schema **ENABLEMENT** could imply freedom but this could be found either through release from the confinement of the **CONTAINER** or being able to organise and control the contents.

SYNOPSIS

Objects have negative connotations, the goal is empty space

JOURNEY

Although there is an acceptance for the participant that RA is **'just what is, it's just there'**⁴³³, there is a definite sense of journey to her experience, which she describes as **'quite a steep learning curve'**¹⁴. The participant describes the medical path for RA treatment, stating at one juncture that she is **'not at that point'**²¹⁰ which suggests a concept of a series of markers along her journey with RA, as does the fact that she feels other people (in this case medical professionals) **'aren't in the same place as me'**¹⁰⁵ and other people's understanding/empathy also falls behind, **'it doesn't go really beyond that'**¹⁹² or **'it's kind of ok but it only goes so far'**²¹¹.

Medication can separate the route she and her RA take, **'It was like it all went'**⁹⁵, and journeying without the RA means that she can **'go and do loads and loads of things'**¹⁰⁸. As an aid to the journey, the participant talks of cigarettes as **'the one thing that keeps me going'**²⁵⁶.

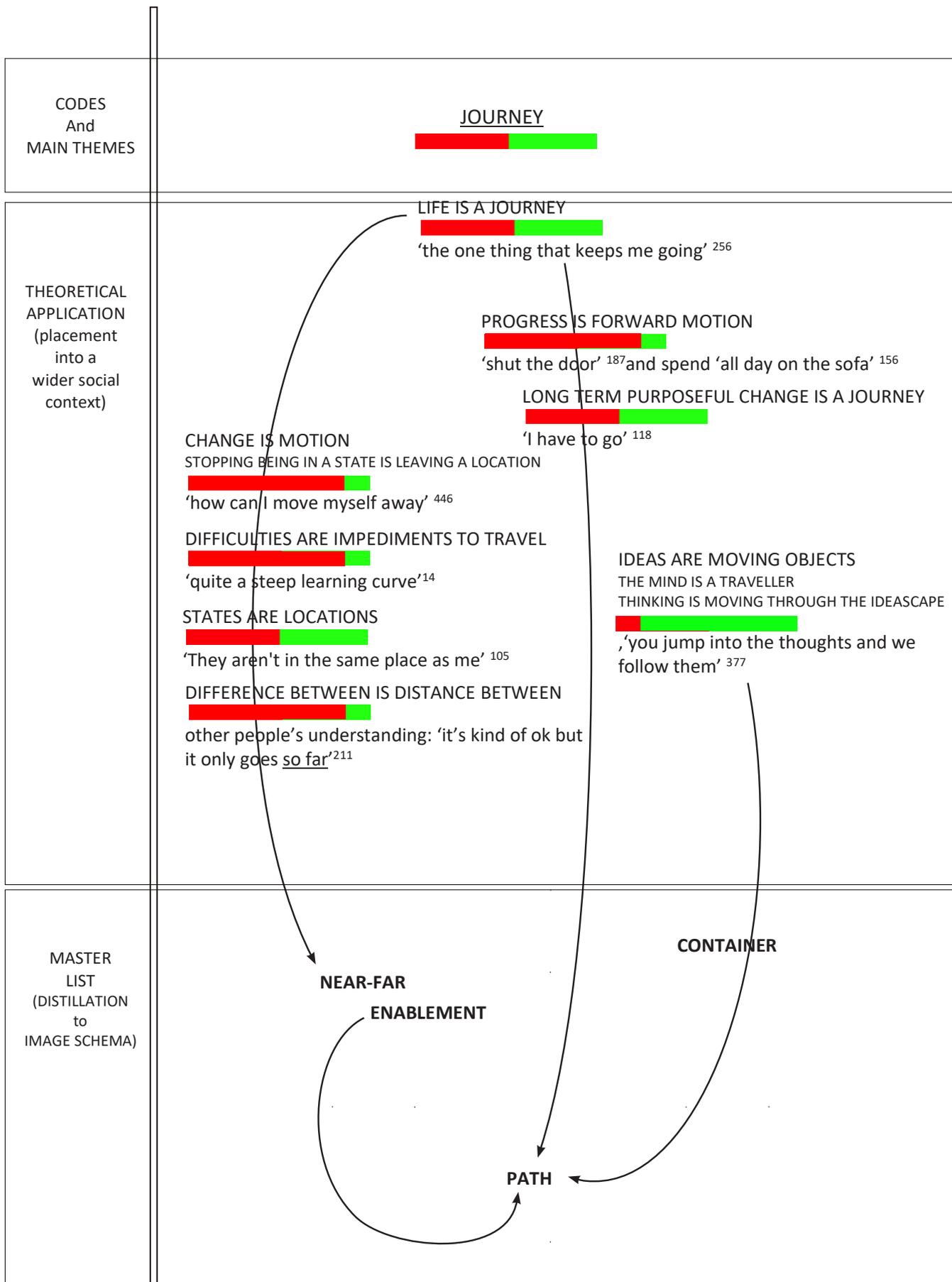
The fatigue caused by the RA denies her of the energetic self she could be, **'if I'd had the energy I would have gone for them, really gone for them'**²⁸⁴⁻⁵. Although the meaning here is attack, the use of the phrasal verb 'go for' links to the sense of purpose that the theme of JOURNEY has here, just as being useful, tidying or functioning brings value to the participant's life, going is positive. The participant's description of the RA clinic's registrar as **'clipped'**²⁰⁴, like the wings of a bird with clipped wings who cannot fly, suggests a limitation, being on a journey has value and is part of being human.

Yet the idea of *going* brings difficulties for the participant with the intensity of the fatigue the RA causes, **'I'm gonna have to -----stop doing the things I do'**⁸⁸, **'things that have changed for me is, er, going for a walk for example'**²⁶⁸. Simply going out is hard, both mentally and literally what the participant really wants to do is **'to shut the door'**¹⁸⁷ and spend **'all day on the sofa'**¹⁵⁶. However, she admits that **'you have to go out'**¹⁵³ **'I have to go'**¹¹⁸. Not going isn't an option **'because it is a positive thing, I have to, for myself'**¹⁵⁵, especially with her son, **'you're tired but I want to go out' --- 'come on mom'**¹³³⁻⁴. The mental and physical effort of going out can be understood as more than a physical act but definite psychological shift, **'you've come out'**⁸.

However, although I do not necessarily see this as a journey to somewhere, there is one example providing a sense of getting somewhere, **'at the school gate, here I am'**¹⁵¹. This place, with all the connotations of successful, happy mothers of Hove is, perhaps, the destination, although I suspect that this is not the case. The Participant isn't happy where she is, **'how can I get myself out of that'**

⁴³³, **'how can I move myself away'** ⁴⁴⁶, and the route she claims as the direction away from her current situation is through mindfulness meditation.

She explains the meditative process through physical terminology, moving, clearing, following, **'you jump into the thoughts and we follow them'** ³⁷⁷⁻⁸ although she admits, as yet, her abilities are **'not quite there'** ³⁹⁸⁻³⁹⁹. However, through Mindfulness she has come to realise that she does not **'have to keep jumping into them/I don't have to hang on to them'** ⁴⁴⁸⁻⁴⁴⁹ potentially, for the Participant, the journey ends in a realization that she does not need to keep striving, moving forwards, but actually **'it's about that thing of just sitting quietly'** ³⁸⁵⁻⁶



LIFE IS A JOURNEY for the Participant. Although she has no obvious end goal (apart from raising her son), the actual act of journeying provides her with enough motivation.

The Participant continues onwards and seeks change from the situation she is in. Her relationship to others, and to the disease itself, is expressed through the distance between them. There is no-one who is 'close' to the Participant's state of mind, they are all far away or in different places. This is represented in the schema **NEAR-FAR** and the appreciation of this provides the motivation, the **ENABLEMENT** schema, to travel along the **PATH**, the sense of which is to presumably find something better although this is not directly addressed at any point.

Although **PROGRESS IS FORWARD MOTION** the Participant often finds the exhaustion of the disease leaving her unable to or unwilling to travel. In these situations, the Participant internalizes, 'shutting the door on the world' and enforcing a distance.

Another element to the concept of JOURNEY is the internalized mental construct of mindfulness, where the Participant sees ideas, thoughts, responsibilities and troubles as objects moving through space, which she can follow or allow to drift away as she meditates. This principle ties to the idea of the mind as a **CONTAINER** where you can enter as a traveller (seen in the primary metaphor **THINKING IS MOVING THROUGH THE IDEASCAPE**), but the spatial sense of direction again link to the schema **PATH**.

SYNOPSIS

Going onwards/forwards/upwards, and leaving things behind is the goal.

WAR

Despite her illness and the fatigue it brings, the Participant sees herself as engaged in a struggle against the world that is not of her making, **'I don't have a choice'**¹¹⁴. Like a soldier in a boot camp she has **'just got to suck it up'**¹⁷⁶ and to make herself understood she has to **'shout really quite loudly'**¹¹.

The participant is fighting on two fronts, primarily **'it is your body that's fighting all the time'**²⁹⁹⁻³⁰⁰ and metaphoric phrases such as **'it knocked the crap out of me'**⁵¹, **'when the fatigue hit'**³¹⁵ **'banging headache'**²²⁴ point to the damage of this internal conflict with RA and reflect the physical effort involved in the day-to-day dealing with her RA. But the participant also battles with the outside world, seeing herself as having to fight to maintain her sense of self and independence but aware of her weakness she knows she needs to choose²⁸⁴ and **'pick'**²⁸⁶ her **'battles'**.

She uses words such as **'engaging'**³⁸⁰, or **'observe'**³⁸¹ **'organise'**^{170/171}, **'paying attention'**³⁴⁸ to describe how she encounters her day to day. When the Participant discusses her situation and how she learns about it, she uses the idea of knowledge, as information, with a sense of its value in supporting her struggle, **'I want to be informed'**⁴⁶ **'I actually volunteered the information'**²⁴⁸

Her relationship with work is stressful as this too is a conflict, one where work, as an entity, responds to her situation with **'absence records'**²⁷⁷, a **'formal written warning'**²⁸² (also²²⁸), she is **'flagged'**²⁸¹, and put on a **'monitoring exercise'**²²⁷ all of which have martial, bureaucratic tones. She is unable, however, to retaliate as she would like, **'if I'd had the energy I would have gone for them, really gone for them'**²⁸⁴⁻⁵.

She describes her routine with her son like a tour of duty, the repetition reinforcing the ordered obligation, **'I do two weeks straight and two days off, two weeks straight and two days off'**¹⁸⁰⁻¹⁸¹

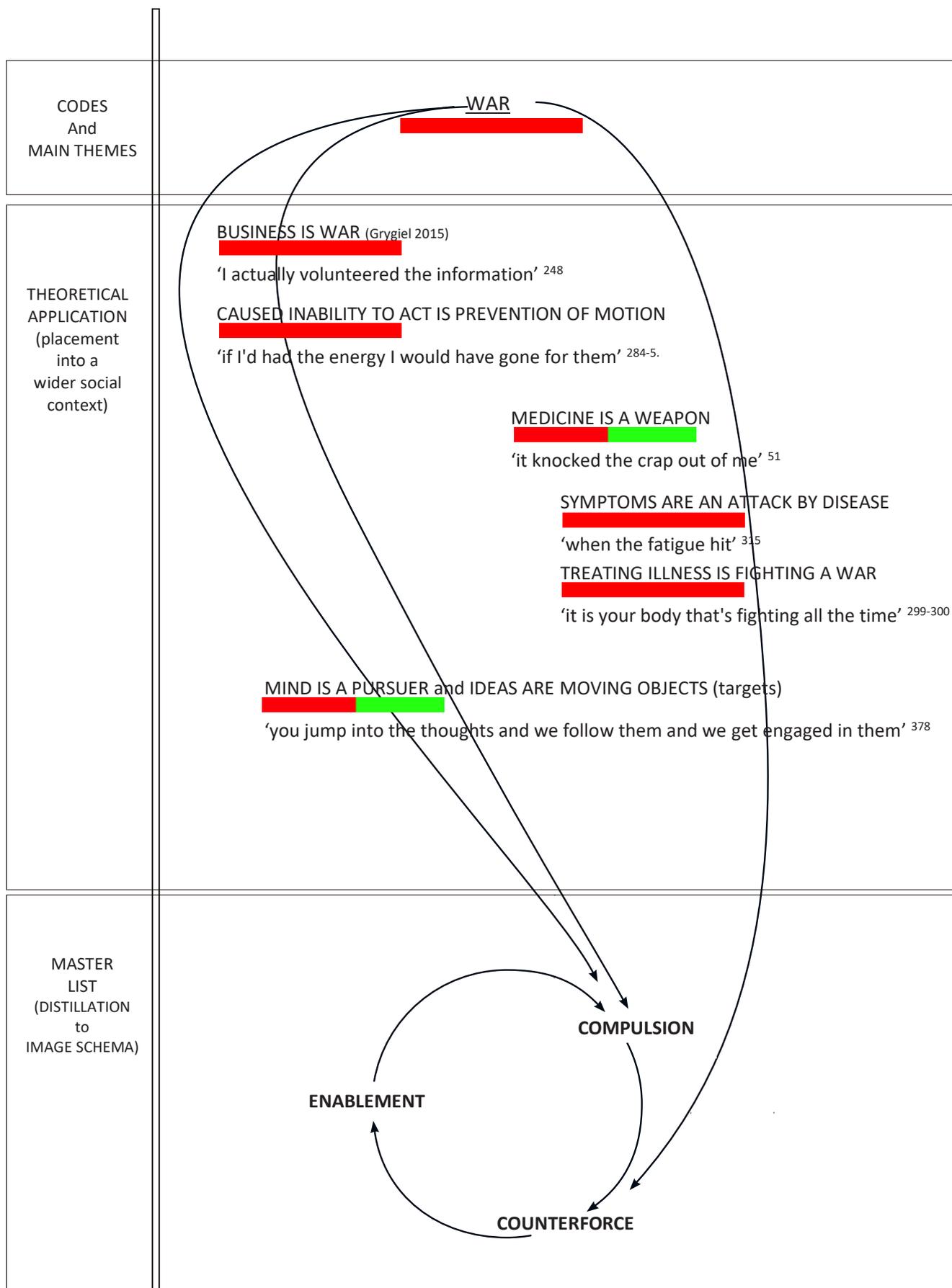
The militaristic choice of vocabulary even picks up when the participant describes meditation, **'it's exercise for your mind, it is about training your mind'**³⁷⁵, **'it's about practice/it's about disciplining yourself'**³⁹². This vocabulary and mentality continue into her description of mindfulness:

'you jump into the thoughts

and we follow them

and we get engaged in them

and so the blue sky gets completely obliterated'³⁷⁸



Although the theme and concept of WAR is an aggressive one, the overarching sense here is defensive, the Participant backed into a corner, fighting against attrition either by the ignorance of others, the responsibilities of Motherhood, work or Society or the disease itself.

All of the primary metaphors link to conflict or competition. The idea of disease as an external enemy invading the body is prevalent, whilst the sense that the Participant is constantly having to fight to maintain her external situation in the world (BUSINESS IS WAR) and internally, her sense of self (MIND IS A PURSUER) potentially reflects the fatigue that the disease inflicts.

This idea is seen in the circular relationship of the three schemas **COMPULSION**, where the Participant feels she has to fight, **COUNTERFORCE**, showing the resistance she feels or faces, and **ENABLEMENT**, reflecting the goal of the conflict which forces her to continue, **COMPULSION**...

SYNOPSIS

An endless resistance to counter endless fatigue

STRUCTURE

In the theme of STRUCTURE, the participant describes herself using direct material metaphors, using physical attributes to establish meaning; **'my body is sort of made of lead'**³²⁷. The weight of lead as a means to describe how tired she feels in her body, physically moving, carrying something so heavy creating an empathetic, relatable experience; the comment that **'you feel like your head is made of wood'**³¹⁷ mirrors this. These metaphors link the idea of weight to her fatigue, the **'main symptom'**⁹⁶, as another thing she has to carry. The fatigue, **'exhaustion'**³²², fills her, it is **'in your whole body'**³²², a physical ballast rather than a sensation. In stating that **'I'm trying to support myself'**³³⁶ one can sense the physical connotations of this weight.

This feeling is sometimes also described as outside rather than in, as if she is immersed in fatigue, which she explains is **'very hard to try and lift yourself out of'**⁴⁴⁴⁻⁴⁴⁵. In contrast to this when the participant is in a better frame of mind she describes herself as **'fairly buoyant'**¹⁵⁵. She is no longer immersed but floating. The drugs she is supplied, whether the effects are described positively or not (**'amazing!'**⁹⁴ through to **'really sick'**²²⁴) act as supports or floats, she gets on them, they carry her, **'I was put onto this drug'**⁴⁰, **'we'll up the Methotrexate'**²²⁹⁻²³⁰, **'we'll try you on a different drug'**²³⁰. However, the potential of these supports as physical, visible things **'a horrible brace'**²³⁴ suggests a restriction rather than a support or **'aid'**²¹⁰, **'that you can wear but can't do anything with'**²³⁴⁻²³⁵. When things are working well for her, there is equilibrium, **'joints have gone down... chronic fatigue lifted... on balance... it is working for me'**⁶¹⁻⁶³

The machine, whether as an analogy to herself, **'I have to function'**²²⁹, or society at large, is a complex entity made up of a myriad, unexplainable, but relevant parts that have purpose. Machines move forward, do not stop, they are unemotional and inhuman. These attributes are reflected in how she sees the medical professionals responsible for her care, **'they seem to be pretty on it and pretty efficient but it is a bit like a machine'**²¹⁴⁻²¹⁵ She describes an average meeting similarly to a computer printout:

'here is your disease activity score, ok

it's a bit high

let's try you on another drug

see how that goes

da

da

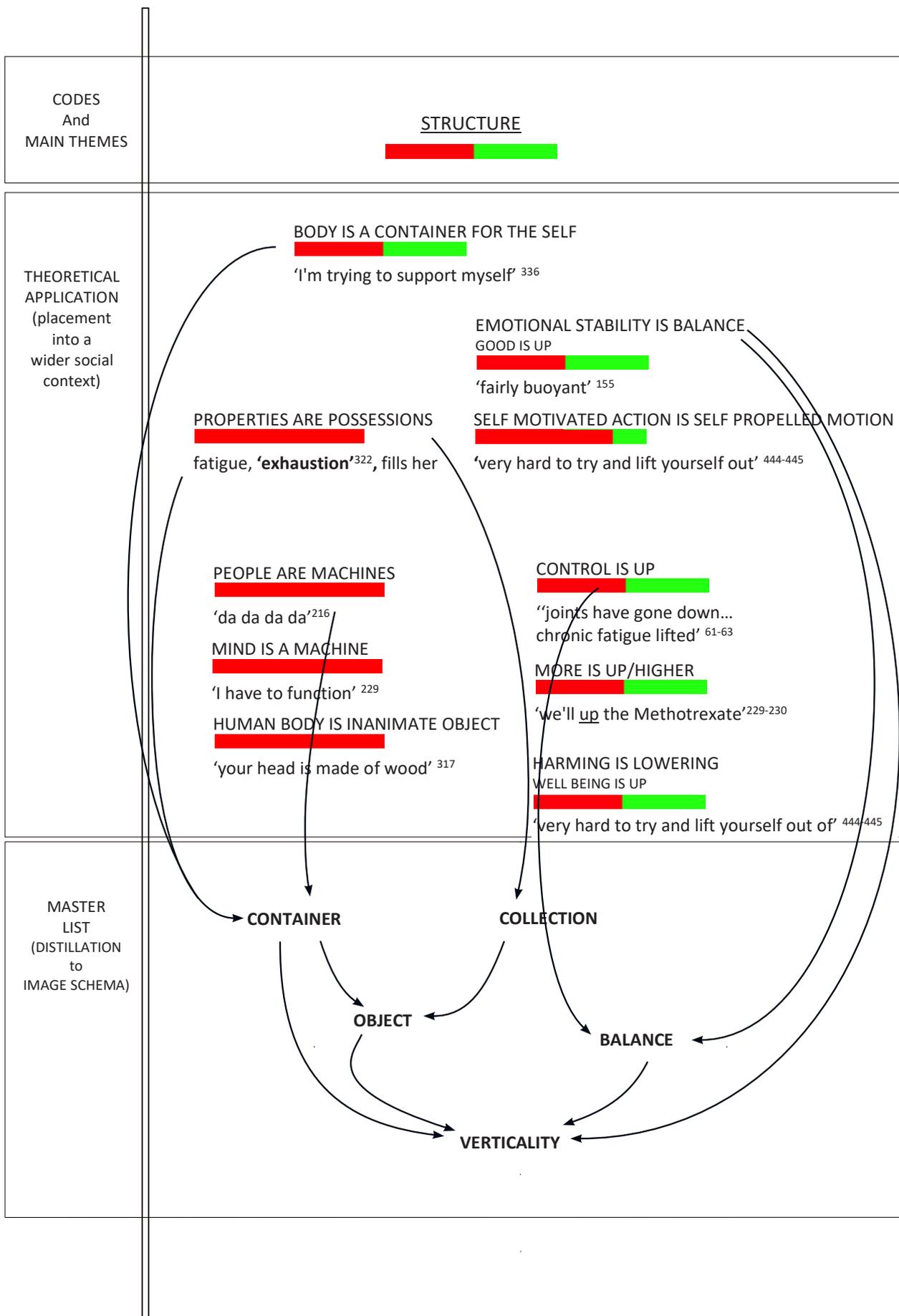
da

da²¹⁵⁻²¹⁶

The **'da da da da'**²¹⁶ noise she makes at the end of the sentence emphasizes the machine-like qualities she feels she faces, repetitive, mechanical and not emotionally responsive.

She seemingly accepts this, **'it's kind of ok but it only goes so far'**²¹¹, separating the principles of treatment, science from care; **'its medical, it's not kind'**¹⁹⁸. However, the fact that she feels emotionally that **'there's just nothing there'**²⁰³ in her interactions with her medical team leaves her distanced from the type of support she feels she needs. The relationship is **'quite hard'**¹⁹⁹, a descriptor that lends itself to haptic engagements with machinery, people become lifeless in their materiality, **'she's as dry as anything'**²⁰². She responds to the nurse who has **'a bit more humanity'**²⁰⁰ as **'he laughs some times'**²⁰⁷ because as she states **'actually what you really need is somebody around'**²¹¹⁻²¹².

The ability to stop, to reflect, to be mindful, is the opposite of this mechanistic drive. The idea of resetting (**'reset'**^{403/426}) allows the participant, in principle, to catch up, not actually stopping but re-starting, whilst still being part of the machinery and purposefulness of Society. The term reset is tied to a cultural appreciation when using digital technology that when things go wrong or become too complicated to resolve, we can take them back to the beginning, untie the Gordian knot by rewinding history rather than cutting it by simply pressing a button.



The theme of **STRUCTURE** represents the most physical of the themes, relating to schemas such as **OBJECT, BALANCE, CONTAINER** and **VERTICALITY**. The principle of the Participant's **BODY AS A CONTAINER FOR SELF** defines the other primary metaphors in the analysis.

Her body contains her mind, which is there to help her function, it also contains the disease and the symptoms that result from it. The construction of this body is far from ideal as it is directly affected by its contents, leadened and dense, her head 'made from wood' leaves her unbalanced.

Maintaining this uprightness is key to success (**GOOD IS UP**), in fact the idea of up is positive throughout, in a sense, 'keeping on top' of things. This feat of **VERTICALITY** isn't easy though, the Participant needs to maintain a **BALANCE** between **COLLECTIONS** of positive elements such as wellbeing, control over the disease or increased medication to help fight the symptoms, against negative elements such as fatigue, literally weighing her down, and the constant accumulation of information, whether helpful or not.

Information underlies the theme. The idea of too much (too many leaflets) or the feeling that medical support is informative but at the cost of being literally clinical, logical and cold. However, to be able to support herself the Participant constantly seeks information. To deal with this influx, the Participant conceptualises her **MIND AS A MACHINE** but the material construction of wood or lead, dense, heavy and very much analogue materials belie the possibility of being able to compute the information or to relate to those around her (**PEOPLE ARE MACHINES**).

SYNOPSIS

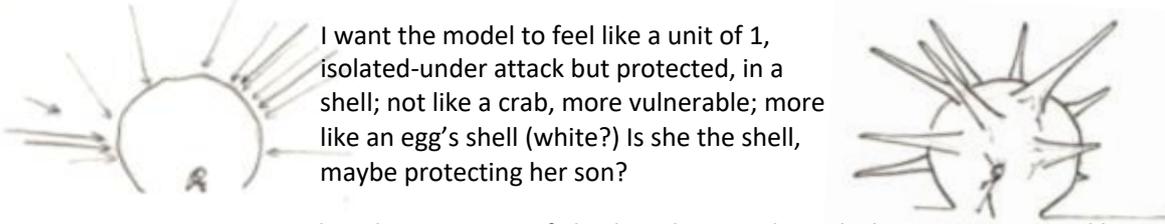
The higher the better, but balance is tricky.

NOTA BENE

At this stage the participant was no longer able to take part in the research. She had read the analysis to this stage and commented that she was happy with my perspective. Although there would be no opportunity for a second meeting to discuss the above analysis, the participant was pleased for me to continue the study and make any models in the context of what she had seen.

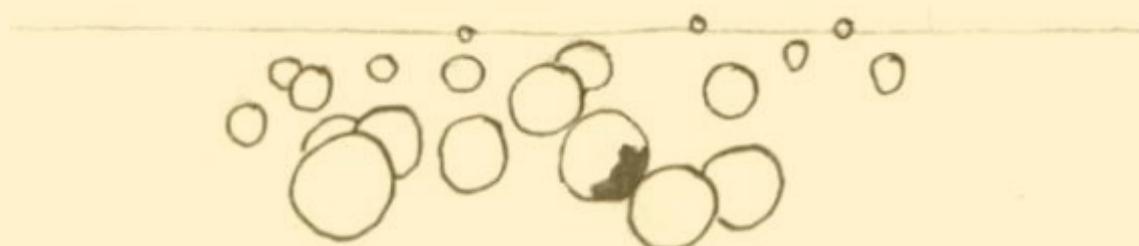
I was aware of the potential of a participant living with a chronic condition needing to drop out of the research process at any point and as part of the consent process it was agreed that if this were to happen the information collected to that point would be available for use to avoid the study being jeopardised and keep the research analysis feasible. It was also explained to each participant that should they drop out of the process they would, if they so desired, be kept informed of the process and outcomes of the study.

7.2.3 VISUALIZATION ANALYSIS PARTICIPANT 2



I want the model to feel like a unit of 1, isolated-under attack but protected, in a shell; not like a crab, more vulnerable; more like an egg's shell (white?) Is she the shell, maybe protecting her son?

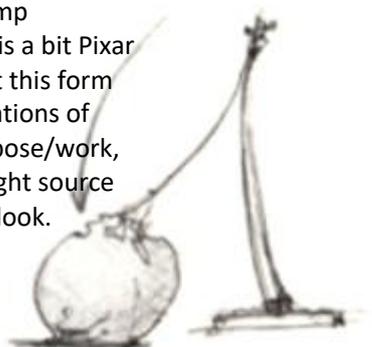
but she is got more fight than that, maybe spiky but not aggressive like a cactus, more like a hedgehog where the spikes are defensive. Maybe pushed out from the inside 'you're tired but I want to go out'133



Although a unit, she is aware of the need to be part of something-society. She wears a 'face' to fit in, like camouflage. Her unit becomes one amongst many. How is she different? Broken shell?

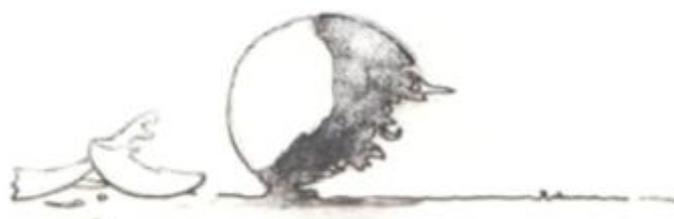
The community distracts from the model as an expression of the individual. My conversation was held as a one-to-one, it was the participant that placed herself in different situations, describing herself. Adding extras, other people, suggests her as more of a social animal but she wants to close the door and sees herself as different, a unit; and this aspect has more value in the model as a description of her.

I see the structure something akin to an angle-poise lamp (although this is a bit Pixar animation) but this form brings connotations of flexibility, purpose/work, a directional light source that seems to look.

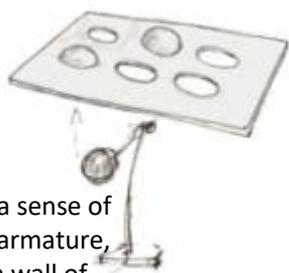


Lead, as a material, definitely works. She describes herself/her fatigue as if she is 'made of lead'. As part of the model, the lead could be used as too heavy for the structure designed to support it, a direct metaphor.

What's underneath the shell? It needs to be something more tarnished, heavy, something like lead, as a contrast to the shell.



The shell could have many layers; discarded like the skins of a snake or more like paint peeled away from an old tin. Paint works well as a material metaphor here, the hiding of something underneath, a protective layer against the elements; thin and weak as a shell, especially when what is underneath has eroded away.



Maybe there is a sense of function to the armature, hidden behind a wall of masks/faces, as if when raised up it forms them...

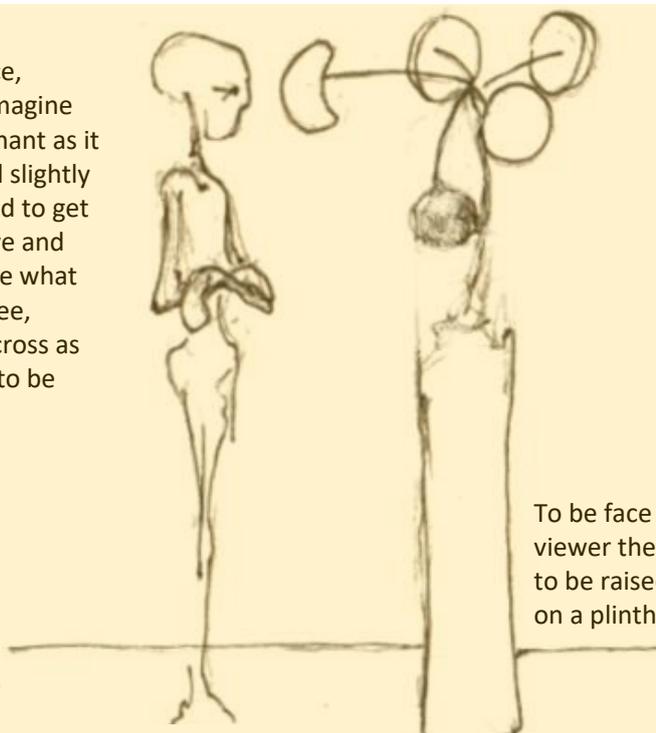


I want the masks/faces to be more integral to the model, coming out of the unit, facing off into different directions and hiding the lead unit inside.

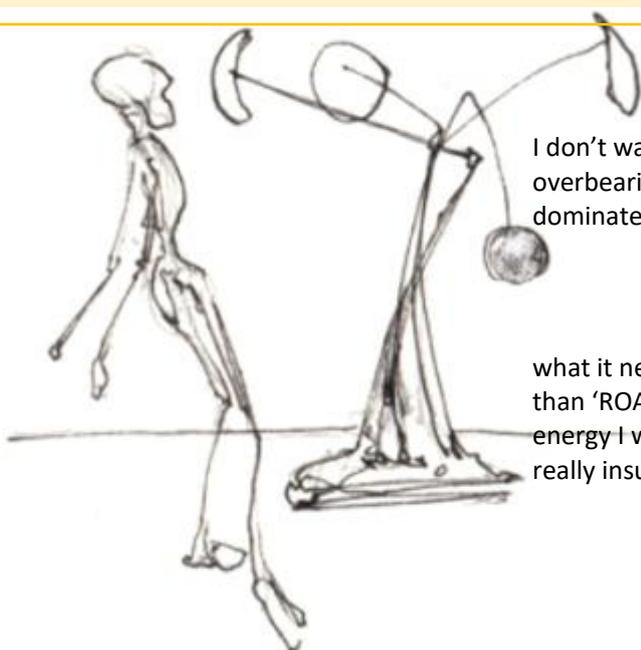
This makes the unit too strong looking; I want it to feel too heavy for itself, fatigued, like it needs to lie on the sofa rather than get up and grow new faces.

INTERACTION!

I want the faces to be in your face, staring directly at the viewer. I imagine the lead unit to be visually dominant as it is a very dark light absorbing and slightly shiny material, but the faces need to get across the idea of being defensive and present in the sense that they are what the model wants the viewer to see, whilst the lead needs to come across as exhausted and having no desire to be seen.

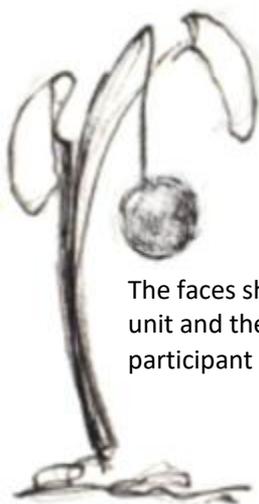


To be face to face with a viewer the model needs to be raised up; maybe on a plinth?

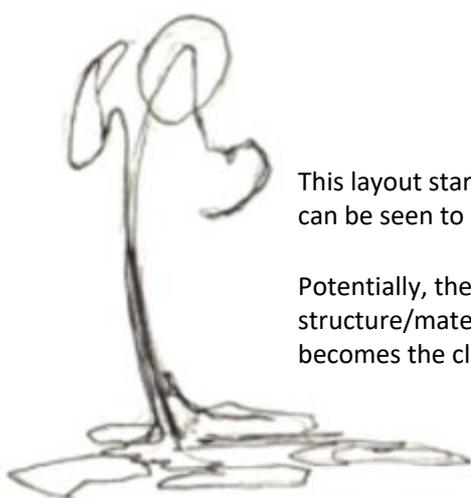


I don't want a massive structure though; the participant isn't overbearing or a loud personality and such a large structure would dominate the view.

what it needs to get across is more 'what are you looking at?' rather than 'ROAR!'; a sense of the defiance with fatigue in 'if I'd had the energy I would have gone for them' 284 mixed with the anger of 'that's really insulting----really insulting' 148

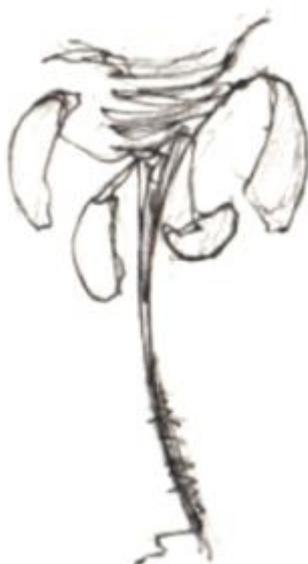


The faces should stem from their own bases as should the lead unit and they should not stem from it. They are as much the participant as the lead unit is.



This layout starts to resemble a flower bouquet where one stem can be seen to be damaged, one flower broken

Potentially, these stems and faces could all be one structure/material, a wire frame that unravels at the base. This becomes the clutter she fights (her stems rising out of it?)



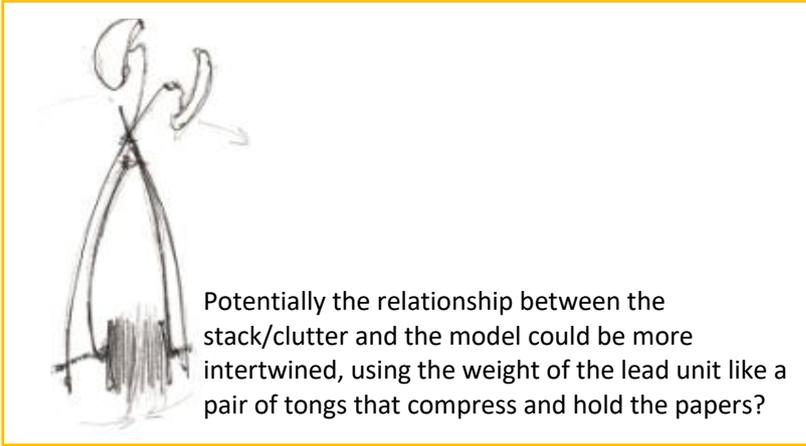
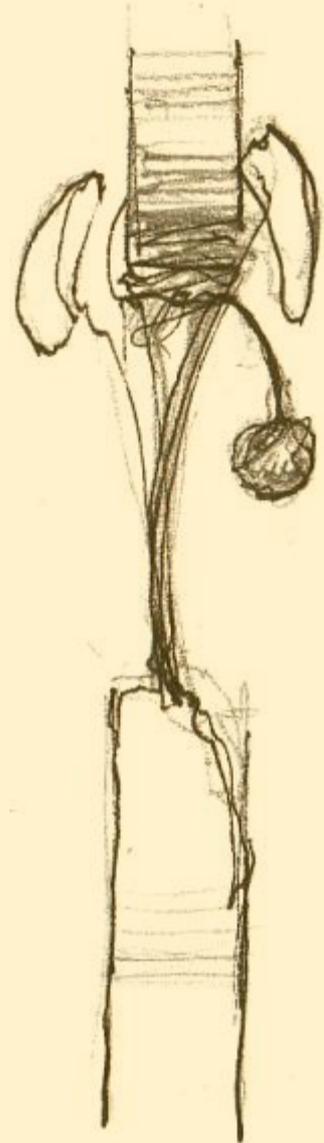
One problem with this is that the concept of clutter is more about the effort of tidying up rather than a mess that she lives in.

Maybe the clutter/stacks of paper/too many leaflets weigh down on the model instead, distorting the stems?

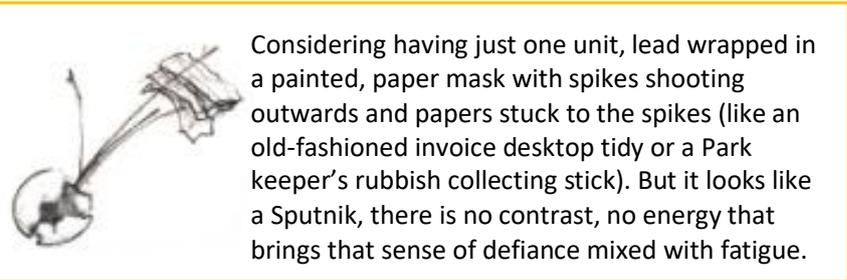
Maybe the model needs to sit within the stacks of paper/excess leaflets, a system that both supports and weighs down upon the model?

Does the stack support seem strong or is it undermined/eroded, eroding?

Not convinced by the concept of eroding as it does not fit the participant's experience of RA, more than any conceptual appreciation of the disease, the RA makes everything an effort.



Potentially the relationship between the stack/clutter and the model could be more intertwined, using the weight of the lead unit like a pair of tongs that compress and hold the papers?



Considering having just one unit, lead wrapped in a painted, paper mask with spikes shooting outwards and papers stuck to the spikes (like an old-fashioned invoice desktop tidy or a Park keeper's rubbish collecting stick). But it looks like a Sputnik, there is no contrast, no energy that brings that sense of defiance mixed with fatigue.

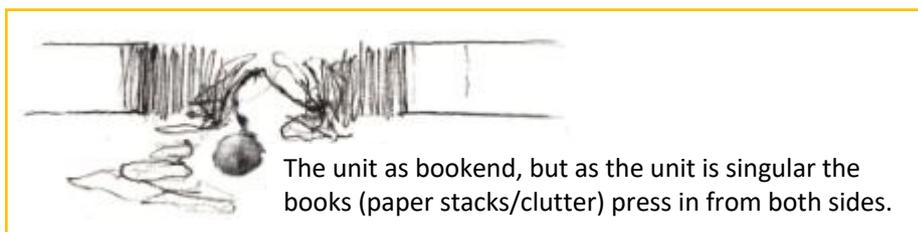
The clutter is becoming more important here. It brings context, becoming the model's environment, representing the participant's desire and attempt to bring order and control (normality?) into her world

The stack, representing order/disorder, acts as a perceptual cue encouraging the viewer to 'tidy up' the papers suggesting that this is the model's role and questioning if it is fit for purpose.

An interesting contrast develops in combining the material elements of lead and paper, the former, heavy, dark, dirty and even dangerous to the touch with paper's inherent sense of potential, the blank canvas, clean, white, transient (economically and physically).



The weight of the lead against the paper suggests concepts like paperweights or bookends.



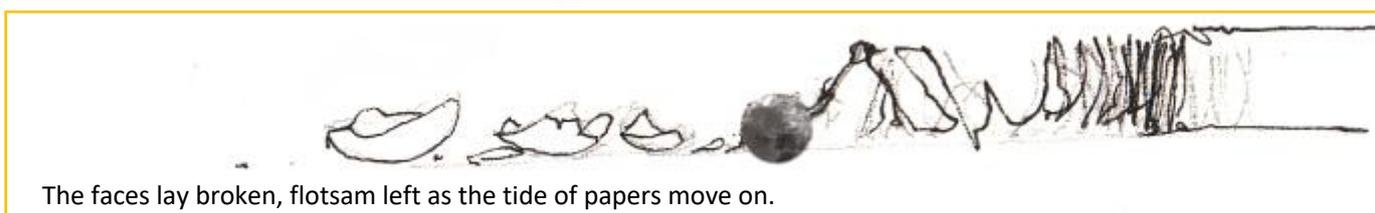
Following the bookend concept, maybe the model is not on a plinth but running sideways (as if on a shelf).

This brings a sense of movement to the model—a direction; creeping forwards.



I'm now seeing the structure of the paper stack as starting strong, a solid column (whether horizontal or vertical) that slowly becomes looser, less controlled as it meets the lead unit. This has similarities to the idea of erosion but links to the participant's uncomfortableness with clutter and a feeling in the viewer that the organisation of the stack is the role of the model.

The stems, with the faces, almost fall out of the stack, like they are running out of the waves on a beach (Canute holding back the sea?).



The horizontal aspect to the model works well, it has a sense of flow, a feeling of purpose but also a lying on the couch quality to it but the order of the narrative is wrong.

The faces need to face the viewer and, in these compositions, they have lost the contrast between energy and fragility that the original paint versions brought.

The lead unit still looks heavy, slumped on the ground but it lacks the sense of implied effort it had when it was hanging from a stem, it brings more a feeling of ball and chain than fatigue. The sense of tension, of 'holding it together', has gone, potentially because there is no longer a sense of balance to the model, no contrast between support and weight? Is the lead unit literally becoming just a paper weight?

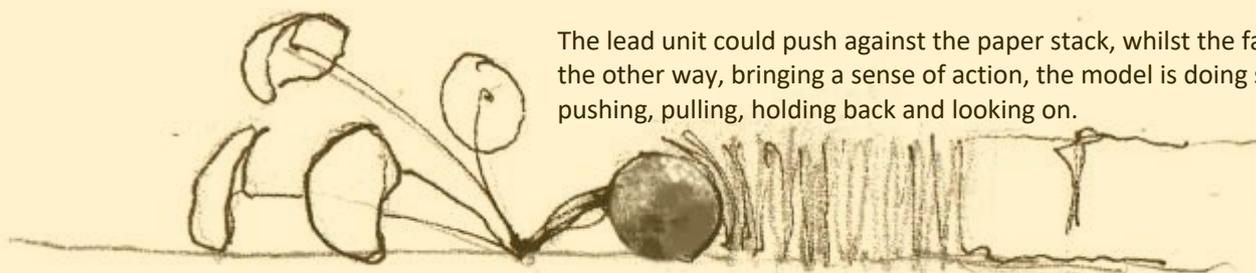


A small elemental unit under the protective wing of the lead unit; mother and child?



The model, both the lead unit and faces, attacking the paper stack?

The lead unit could push against the paper stack, whilst the faces look out the other way, bringing a sense of action, the model is doing something, pushing, pulling, holding back and looking on.

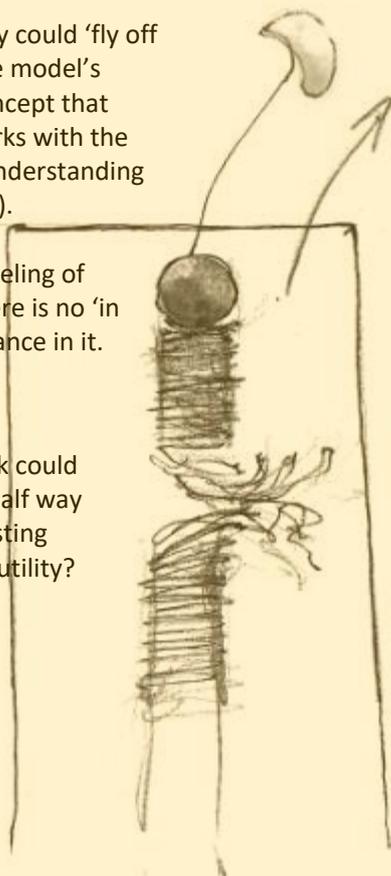


For the faces to work they need energy in their composition and the form of the stems.

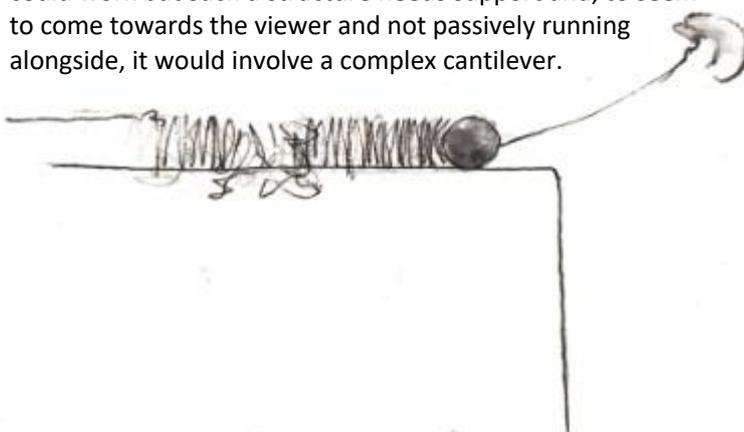
Potentially they could 'fly off the edge of the model's platform (a concept that potentially works with the participant's understanding of mindfulness).

This brings a feeling of release but there is no 'in your face' defiance in it.

The paper stack could be blown out half way through suggesting undermining, futility?



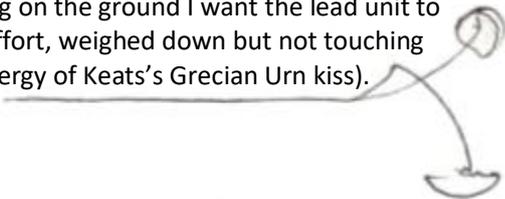
This starts asking questions as to how the model sits. A horizontal composition would need quite a big base, high enough not to be crawling on the ground or below eye level but I don't want it to become overpowering. An actual shelf could work but such a structure needs support and, to seem to come towards the viewer and not passively running alongside, it would involve a complex cantilever.



It also suggests that the face is leaving the lead unit behind like a soul leaving a corpse whereas I want them to feel part of the same, the efforts of one affecting the other; a sense of balance if not physically actually in balance.

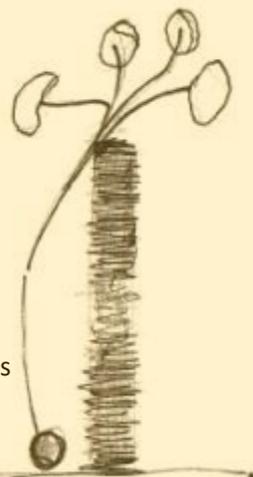


Rather than sitting on the ground I want the lead unit to feel heavy with effort, weighed down but not touching or resting (the energy of Keats's Grecian Urn kiss).



To create this sense of defiance/fatigue/flow on a horizontal plane would involve too much structure and support network, distracting from the model's narrative.

The vertical/plinth structure does not conflict. The idea of a stack of papers/leaflets brings connotations of an office in-tray, bureaucracy and organization, it talks of unnecessary excess ('so many leaflets' 233) and the desire to tidy them up. It also brings structure and height to the model but with a transient and uncertain/unsound quality of precarious balance.



Too energetic, like an ascension or explosion. The lead unit seems to be falling rather than fatigued and the two faces are being torn apart, creating a sense that they are going in different directions, a positive and negative and I don't want the model to have this dichotomy- it is not about 'seeing the light'



Potentially I could use the lead face as a counterweight to the other faces, creating a sense of balance. But this lacks a sense of fatigue, the paper stack becomes an entity in its own right, too much a plinth.

I like the sense of the faces evolving out of the paper stack, forming which makes the stack part of the model, integral rather than a requirement.

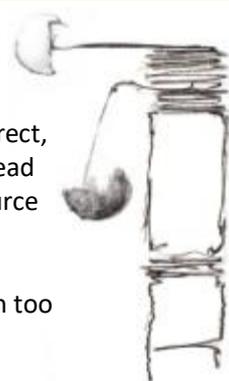


I would rather that they both 'fall' with one face looking up in defiance or with faces growing from the lead unit (like a Spider plant).

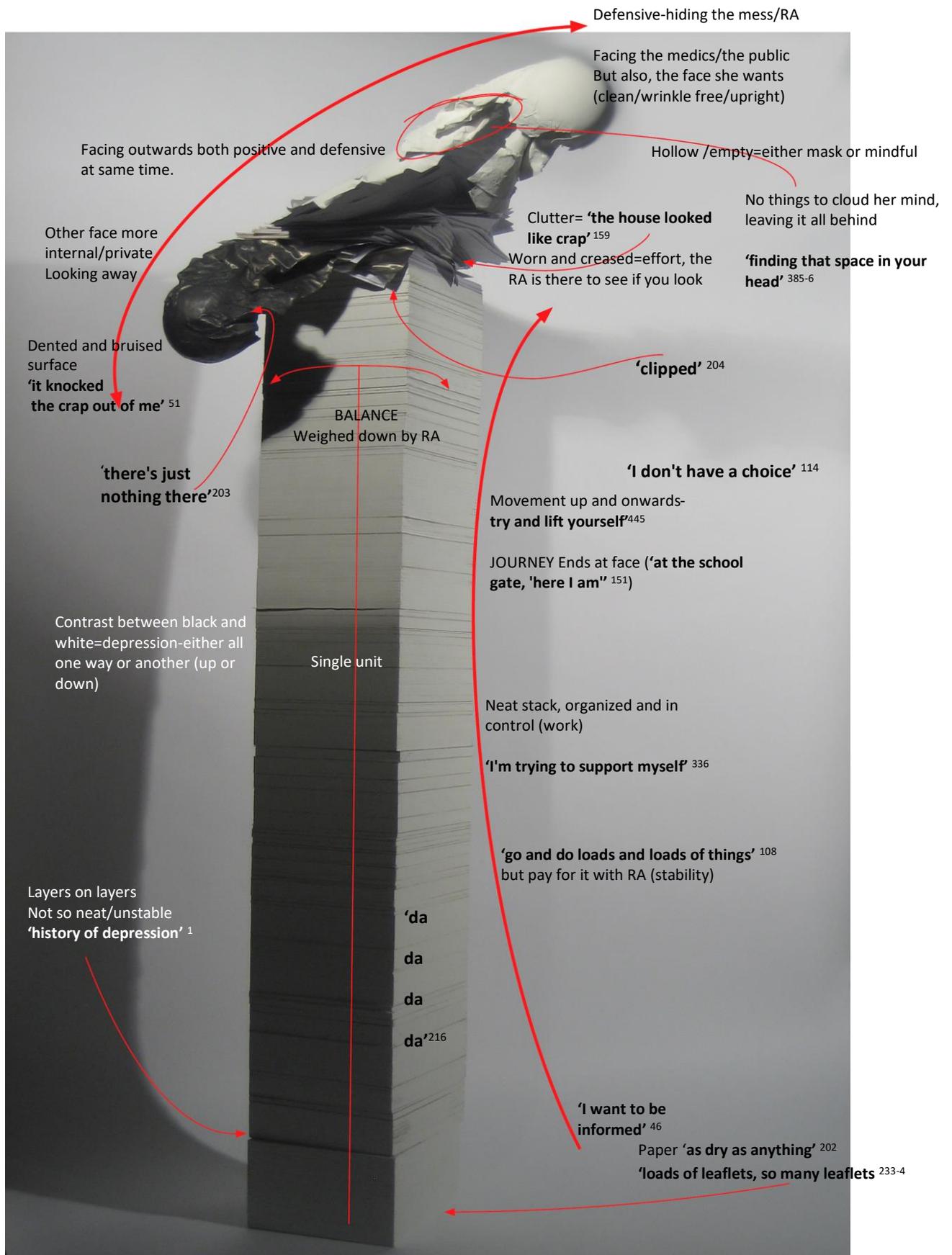
But I don't want the faces to be looked down on. This is too submissive as if it is trying to rise to better heights.

Coming out of the paper stack, direct, almost confrontational with the lead unit stemming from the same source but looking tired.

Not overworked or confusing with too much detail.



7.2.4 CROSS REFERENCING ANALYSIS TO MODEL: PARTICIPANT 2



7.2.5



7.2.6



7.2.7



7.2.8

7.3 PARTICIPANT 3

Participant 3 is an employee of the University of Brighton. She has a family with two children who are both in higher education, and two dogs. She was diagnosed with RA at a young age.

7.3.1 THEMATIC ANALYSIS OF TEXT

7.3.2 OVERVIEW

The overarching themes are as follows TIME, CONTAINMENT/ER, and LEVEL PLAYING FIELD.

CONTAINMENT/ER represents many aspects of the participant; herself the RA, the 'meds', and society (clubs). TIME has both spatial and temporal aspects and brings the participant's relationship to RA into context: simplified as past=positive, future=progression, shown under the subtheme of GOING GOOD, but also time has associations to action, REPETITION. It is something which one can go back to, progression is both positive and negative and certainly isn't inevitable. TIME is malleable.

These themes sit alongside the context of the third theme, LEVEL PLAYING FIELD; a title that should not be taken literally. The level provides the context between positive and negative action, health and wellbeing, communities as well as being the field of play. This level provides a contextual framework for the CONTAINER to be understood. The container sits within/above/below the level, depending on its intent. The level is where 'going' takes place, it is positive, providing a field for activity and/or contemplation.

The idea/concept of sport underlies the analysis of the text, the fact that the participant's description of her life as based around sport, her youth dominated by and her current role geared to promoting it, it isn't surprising that her attitude, references, and metaphoric tendencies draw from a sporting context. In particular, the researcher finds four main themes in the text; the body as a means to an end (ADD+), being part of a team (CLUB), pain as something to be overcome (PAIN IN HIDING), being active is good, doing nothing, bad (GOING GOOD).

It is important to note here that in describing sport as 'play' the researcher isn't belittling the activity. The idea of play, here, isn't the accepted childish or frivolous understanding of the word but more of a creative immersion as understood by Gadamer (1994), with its own system/rules outside the requirements and constraints of normal activity, in some ways similar to Csikszentmihalyi Mihaly's flow (1990). Play is a mental activity as much as physical, which the participant recognises in her drawing attention to '**mindfulness**'⁴⁵¹ as a concept.

A LEVEL PLAYING FIELD

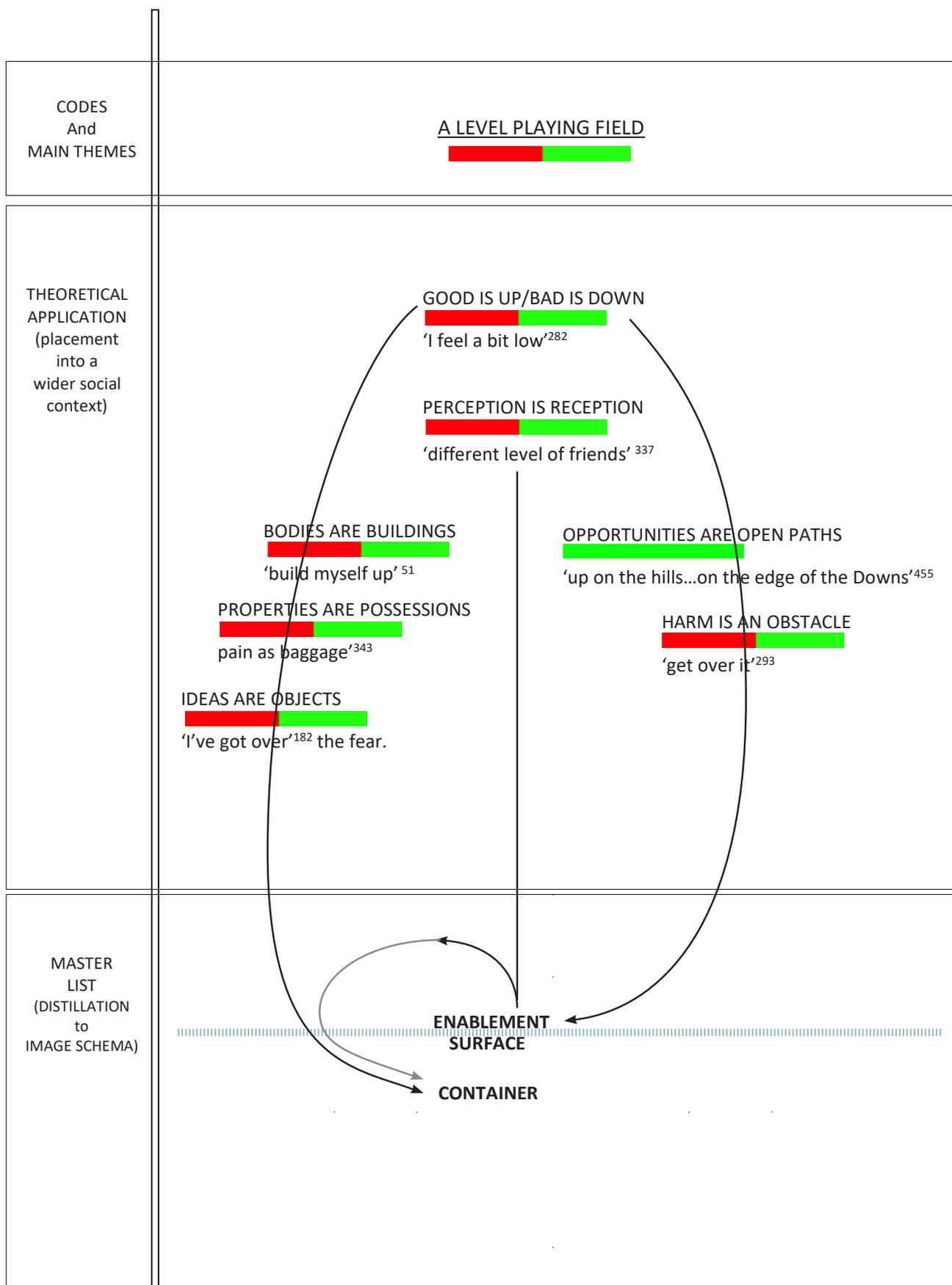
There was a levelness to the whole conversation, and I kept connecting this to sport. The participant comes across as very stable and relaxed, and self-aware regarding her relationship with RA (although this obviously needs to be appreciated in the context of being an outsider/researcher).

The level is the state of balance when she can deal with the RA and can perform. Below this level is bad, **'I feel a bit low'**²⁸² as being pulled down below the level, she also talks of **'dragging'**²³³ her arms as if they weigh her down, the **'heavy drugs'**¹⁹ and pain as **'baggage'**³⁴³, all things pulling down whilst Pilates is seen as **'pulling up your core'**¹⁴² showing idea of going up as positive lifting the core (in this sense an area of the body but metaphorically works too) and she **'builds [herself] up'**⁵¹ to stay on the level. However, the level isn't necessarily flat, the idea of a place **'up on the hills...on the edge of the Downs'**⁴⁵⁵ could be thought of as the location. The level is **'up'**⁴⁵⁵

The participant discusses the **'different level of friends'**³³⁷, a sport connection almost like divisions in football. Here, her friendships are her team, staying on the level, supporting if not always understanding so she is not drawn down by RA.

In the analogy of a level playing field, pain is an obstacle, in describing another's attitude to pain she says that they need to **'get over it'**²⁹³ –and in describing how she felt about the concept of RA being **'forever'** she states that **'I've got over'**¹⁸² the fear.

I think of the 'level' in the same manner as the floor of a building or a surface; below is where the baggage is, where the pain is kept (in some ways not dissimilar to the analogy of the swan with her legs kicking away under the water.



The concept of a **SURFACE**, that the Participant has a place where she can 'lay her cards on the table', provides a mental construct as a means to present what she chooses to the public gaze but also a medium with which to gage her wellbeing, something that she could strive to 'get over'²⁹³ or somewhere to look out on the world⁴⁵⁵

The concept that we believe what we see, PERCEPTION IS RECEPTION allows the Participant to control how others see her and gives her confidence with her day-to-day social encounters. The gaze simply bounces off, only those the Participant wishes to, can see the self as **CONTAINER** underneath the **SURFACE**. For this reason, the schema **SURFACE** is closely linked to **ENABLEMENT**.

The schema **CONTAINER** lies below the **SURFACE**, unseen but in many ways defining the **SURFACE** that is seen. It is important to note, however, that the **SURFACE** is not a mask, a fake representation: it is as much part of the Participant as what lies beneath. The **SURFACE** is also what the Participant strives to be, a place where she feels 'up'⁴⁵⁵ and is best able to take part in life. In many ways this **SURFACE** is the true representation of the Participant, what is contained beneath merely reflects the complications inflicted by the disease.

SYNOPSIS:

A platform that shows the best, hides the rest.

CONTAINER

Subtheme 1: ADD+

As well as the idea of pain as an obstacle, it can also be seen as a handicap, similar to horse racing, the principle of using weights to slow down the horse and rider.

Pain is an excess, an addition, it pulls down and slows her down (**'baggage'**³⁴³) restricting her ability to **'be that person I used to be'**²³⁰, pain and all that associated with RA is **'baggage'**³⁴³ (baggage as reference to the **'issue'**¹⁰⁷ of RA), **'I seem to be collecting pain'**⁹⁶, **'if I get another pain'**⁹⁹, **'more pain'**⁸⁵, **'more just keeps getting added to'**¹⁹ and **'a recent addition to the suite of stuff'**¹¹³. The RA (here in reference to the reactive arthritis first diagnosed) is described as **'hanging around'**¹⁴

Also, the RA itself isn't a part of her, it too is an addition **'it's a pain you live with'**¹³⁴. On being diagnosed with RA it was not hers but was given, (as a **'death sentence'**¹⁵⁴).

In a similar way to the RA, the body can also be seen as divorced, a collection of parts, the means to achieve a goal. She describes going to the doctor as having an **MOT**⁷⁵, the idea of getting used to her elbow 101 and the way of describing an action as **'using a joint that hurts'**¹¹² have connotations of using a tool. The arms have to be dragged through the water (²³³). **'I've still the eye/hand coordination'**²³¹ sounds almost like having an app on a phone.

In describing preparations to meet a consultant, the participant states that **'I build myself up'**⁵¹, she adds to 'I', potentially to make it noticeable, more prepared for the world, making the self the centre but, at the meeting, it is the extras, such as the elbow or the meds³⁶⁻⁷ which are more important.

The idea that she has to carry her body as well as all the extra baggage shows in how hard Yoga is, as it requires **'having to hold your own body weight'**¹⁴⁵. (**'I'm trying to lose weight'**⁴³⁶ in this context carries more meaning if we see the RA and its effects as baggage).

The pain, as extra baggage, is localized but similarly to carrying extra weight, it affects the whole, things are harder (they can still be achieved but differently, maybe not as well¹⁵⁷ or perhaps changed to different things^{165-6, p.11}).

In discussing people and their situations, how they are seen to deal with pain she refers to the fact that maybe the slightest thing could make the difference **'because it's one too many things'**³⁰⁰ (carrying too much like the game Buckaroo). These things are not seen, they are below the surface.

They lie under the level (hidden or ignored?). In her description of her boss who **'set out her pain killers on the table'**²⁹¹, this is pain on show, on display at the level of play and this isn't good. The participant is in no way defined by the RA, and it isn't there for all to see, it is personal and is not to be laid out on the level playing field.

Subtheme 2: INFLATE

The concept of inflate runs as a theme through the text and ties into the theme of container; **'you know if there's a difference in air pressure'**¹⁹⁹⁻²⁰⁰ the swelling that comes with the pain⁹⁷⁺⁹⁹, the aspirating process of the joints⁹

'up and down'³⁹¹ is used as a description of both the physical and mental effects of the progression of the RA

In being **'aspirated'** and then **'injected'**³⁹¹ emptied (**'drained'**³⁹⁴) then filled again (**'swell up'**³⁹⁶), seemingly **'for no reason'**³⁹⁶ the participant describes a process of use for the container, ('dig a hole, fill a hole' concept) but also the movement of breathing. This action, a repetitive in and out mimics the **'in and out of hospitals'**⁴¹⁶ and the fact that she criticizes herself **'I dip in and out of things, that's the trouble'**²⁵³. Also, she is in the system, **'part of all that'**⁴⁰⁶ who's rules have the same repetitive action seen in the motion **'what you can and what you can't'**⁴⁴², a can, cannot, in, out, back and forth motion.

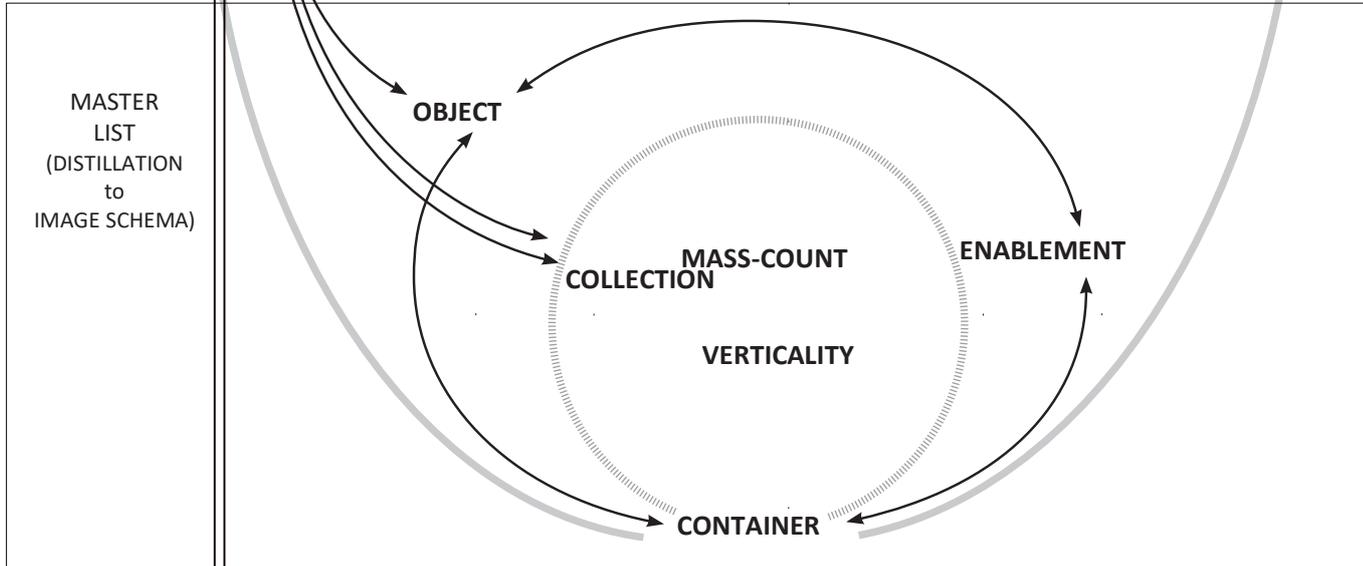
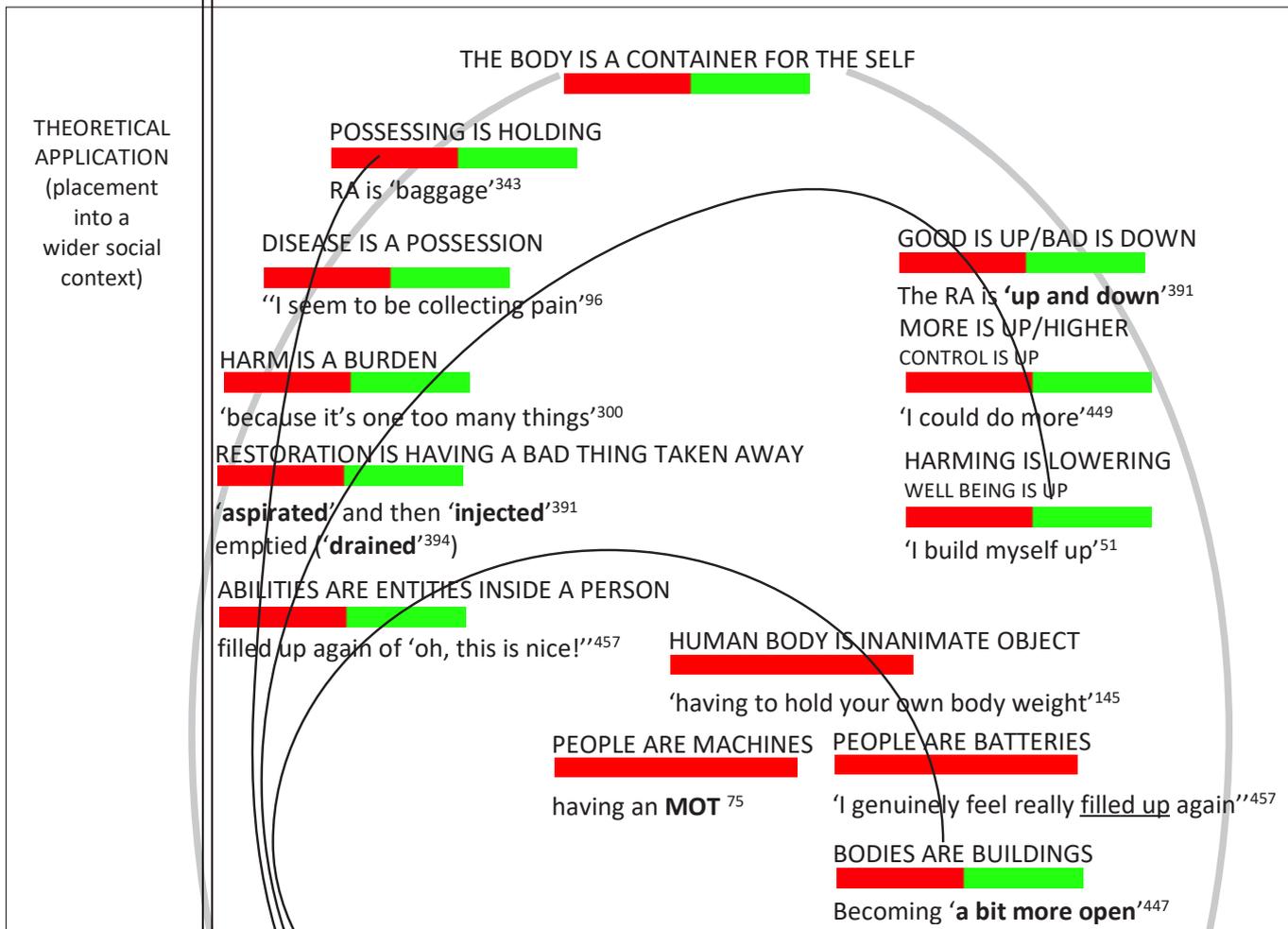
'I don't like the rules and the noise and the receptionist and the other patients, ergh!'⁴⁰⁵ rolling repetition of wording highlights the system and is inconsistent with play-(also seen in repetition of time constant/boring). Positive things are out of this containment, **'you have to get out'**¹⁷⁹ The bad things come out of container in physical ways; **'cut out** (diary, tuna, etc.)⁴²⁹⁻³⁰, **'out popped'**⁴²² suspected allergies. Acupuncture can be seen as an act of poking the container (aspiration by another method?)⁴²⁶ However, although aspiration hurts (³⁹⁷), it worked; acupuncture does not hurt and did not work (⁴²⁶).

Dabbling-⁴²⁷⁺⁴³¹ partially immersing into something (container) has playful connotations. It is used as the non-committal description of the relationship to the system, as opposed to **'embraced'**⁴⁴⁵—what she feels she should do, which has a welcoming context but its roots lie in control and containment, bracing and encompassing things.

Becoming **'a bit more open'**⁴⁴⁷ allowing the container to be exposed to allow others in, potentially letting go of some control? But then would she be **'a fish out of water'**³⁰⁵ again? Even if it hurts, the

sense is that she will **'do it in my own way'**⁴³⁷. This isn't so much about control as choice. She is aware of the **'balancing act'**¹⁷⁵⁺³⁸¹ in her life between being active and not as a way of fighting the RA and being happy. Although between **'doing nothing'**¹⁷⁶ and **'doing something'**¹⁷⁷ being useful/active is always the winner. Useful here is important; taking the logs in, walking the dogs, sponsored walks all involve helping others in the examples given. The worry is that something will happen to remove that choice, **'change the way I can be'**³⁸⁵. There is a possibility in choice **'I could do more'**⁴⁴⁹. This would be her own way, as opposed to the repetitive system as an alternative or the limitations of increased RA (right hand going).

'I genuinely feel really filled up again of 'oh, this is nice!''⁴⁵⁷ shows how the container can be positive, she can choose what to fill it with.



Although **CONTAINER** is split into two sub-themes, both **ADD+** and **INFLATE** are defined by the concept of the Participant collecting and holding on to the symptoms of the disease. This process of accumulation, reflected in the schema **COLLECTION** and **MASS-COUNT** draw on the embodied appreciation that accumulation fills space, whether that is expressed negatively as ‘**baggage**’³⁴³ or of the body as battery, being filled up and ‘**drained**’³⁹⁴.

This appreciation of space filling is reflected in the Participant’s desire to stay upright (**VERTICALITY**) as an expression of self. Being able to conceptualise these various ailments, medicines, responsibilities, etc as objects allows the Participant to evaluate and gain confidence in her health. The Participant’s **BODY AS A CONTAINER** allows her to psychologically carry these loads and importantly it allows her to evaluate how much she can do to stay upright, or cannot because ‘**it’s one too many things**’³⁰⁰.

The schema **MASS-COUNT**, **COLLECTION** and **VERTICALITY** all reflect the interior of the container and its contents, whilst the **CONTAINER** schema itself is linked to **OBJECT**, as it relates to the concept of the **BODY AS CONTAINER FOR SELF**, and **ENABLEMENT** as the principle of the **BODY AS CONTAINER FOR SELF** allows the Participant to show only the outside and protect the inner self from view. However, this analogy is complicated by the flexing of the **CONTAINER**, being built up or deflated. The Participant is aware of her need to ‘**do more**’⁴⁴⁹ to be ‘**more open**’⁴⁴⁷ and she knows that there are limitations and boundaries to a **CONTAINER** and that things could ‘**pop out**’⁴²² or ‘**swell up**’³⁹⁶ entirely beyond her control.

SYNOPSIS:

A container controlled by its contents.

PAIN IN HIDING

The understanding here is that the participant isn't hiding the RA/pain, 'just not showing it; **'if someone asks me...properly asks me, then I'll tell them!'** ³³⁹⁻³⁴²

The pain is a constant but not an interference¹¹¹ although it can be distracting, **'off putting'**¹²⁷ making it hard in certain contexts to concentrate¹²⁸. The participant described the pain as constant, multiple, localised but being more or less **'overt'** ¹¹¹⁺³⁵⁹ depending on the situation. Overt is an interesting choice of descriptor; meant here (potentially) as being more manifest but also definable as more public (noticeable and hidden)?

The pain is hidden in the sense that it is ignored, **'constantly, constantly ignore it'**²⁸⁷

It is obviously not forgettable but is treated as something to **'get used to'** ¹⁰⁰⁺¹⁰³ rather than reacted to. It should not/will not interfere with life (the ability to partake) even if it hurts as she knows it will; **'I know it's going to hurt... but I did it anyway'**³⁶⁶.

The idea of hiding the pain/RA also shows in the fact that the participant does not want it to make her the **'object of attention'**³³¹⁻². When the pain is overt she recedes, becoming **'really quiet'**⁸⁴; quiet as not noticed/noticeable, not an object that attracts attention, crying or any medication on show would do the opposite, only attracting attention to the cause.

But the participant notes that it may be **'worth telling people'**⁸⁶ to improve things (opening up)?

This idea is about her being noticed and not the RA. She showed excitement at the idea of a conversation with a doctor, being noticed (not RA but person) **'about how I was feeling'**⁷⁶, **'an interest-how I was doing'**⁷⁹ (emphasis here on 'I' not on the disease).

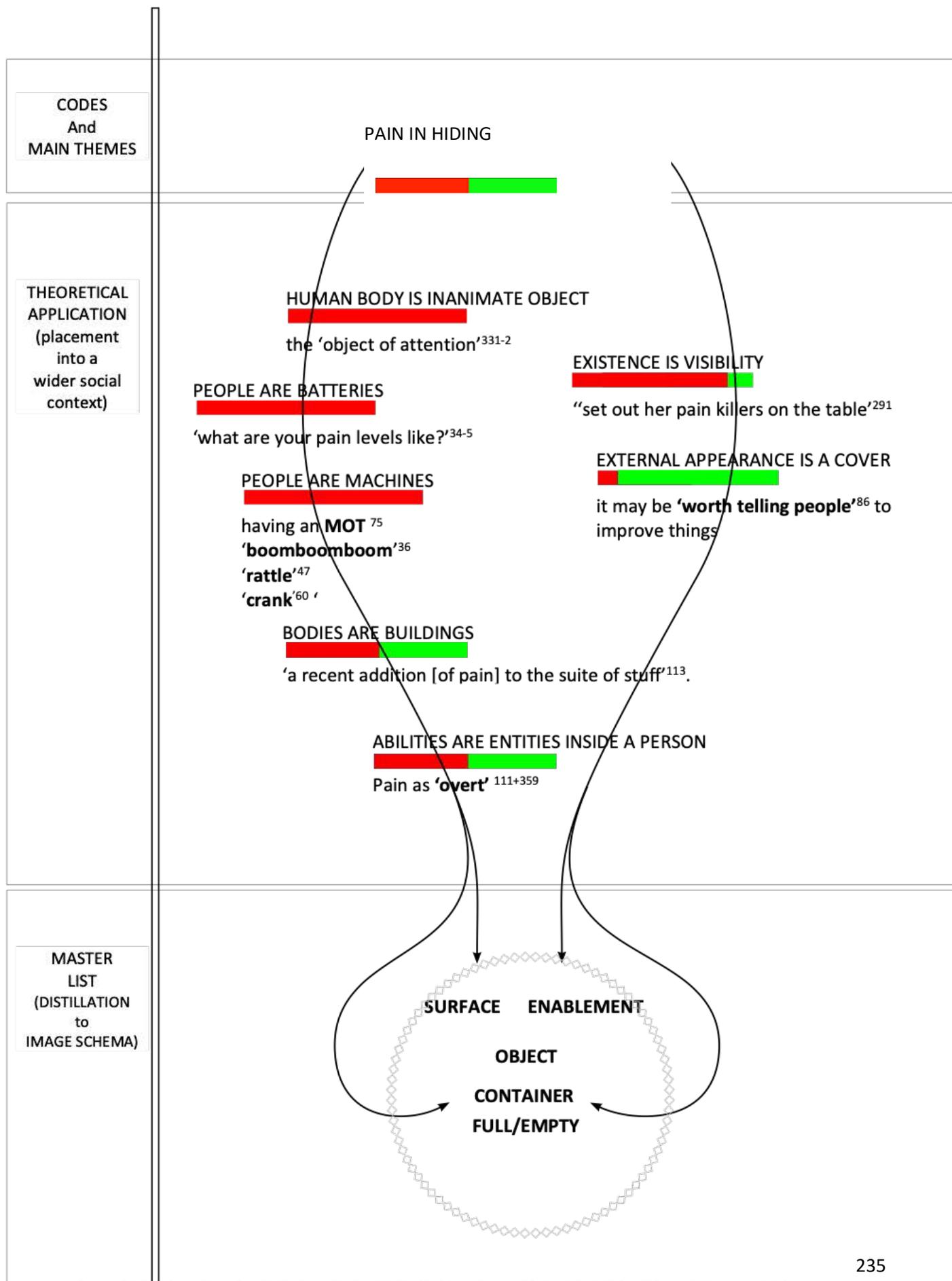
Professionally there is no time to discuss the person: how **'you're feeling/what your pain levels like/how you're coping/if you're tired'**³⁴⁻⁵. There is only time to **'report'** (an impersonal action-almost military) which would then lead to a decision as to **'what to do about it'**⁴³ (again impersonal; the RA is the centre of the conversation and not person, no time for the 'I' just things, baggage).

The consultants=**' don't have time'**³³ in many ways represent the system with adjectives drawing on machines, **'boomboomboom'**³⁶ **'rattle'**⁴⁷ **'crank'**⁶⁰ **'report'**⁴² **'MoT'**⁷⁵

Emotive descriptions of pain such as **'it really hurts today...[in her own words] doesn't really mean anything'**⁹² to the Participant, so she tries to find means to get the system to understand how she

feels, an approach to 'qualify'¹³¹ pain describing her pain as noise, in contrast to the system's reliance on quantification.

The participant describes her diary as having a conversation with herself⁶⁴ however, even here it is only about RA (like a report).



Despite the propensity of the disease to be visible many symptoms particularly pain and fatigue are hidden from the public gaze. In appreciating the body as a vessel, an **'object of attention'**³³¹, something to be maintained, as expressed through the primary metaphor PEOPLE ARE MACHINES, the Participant has power over the disease, that it does not get to define her. However, this control brings disadvantages, not showing and denying EXISTENCE AS VISIBILITY undermines her support and the possibilities for compassion.

The primary metaphors point to a choice for the Participant. This is seen in the schema **SURFACE** and **ENABLEMENT**. The Participant can choose whether the **SURFACE** can be drawn back and the contents of the **CONTAINER** can be seen.

The expression of these internal contents, pain or limbs, for example, as entities or objects allow the Participant to understand and further control the disease and its progression. Denying the symptoms sensuality seems to divorce them from the body and her life. They become 'baggage' on the journey, something carried and tolerated but not conversed with. Another but equally powerful analogy is that the body, with all its parts, can be maintained, potentially repaired but definitely kept running, a much-favoured, old car, that has some problems under the bonnet which can be seen only if the Participant allows.

SYNOPSIS:

Wear and tear are only visible under the surface.

CLUB

'Compassion'³³³ comes from those closest to her, the supporting pillars of the level playing field, her husband, brother, and two best friends (²⁶³⁻²⁸²⁺³³²⁻⁴). Understanding here is less important than acceptance, here she can be the focus of attention, this is her 'club'.

The participant does not want to be her RA, **'I don't want to be singled out'**²⁷⁶ she is part of a team. Being in a club is seen as good, separated out (last to be picked?) is bad, if isolated she is not in the club so not as useful.

Even the RA gave the potential of this, **'I'm in the club'**³⁰³. However, she soon realised that this was not going to work, the people too different, she did not fit. However, there is a chance that someone could be the same as her, with the same condition, and then **'I can be in my little club with them'**³⁵¹. This potential of being in another club (a sport connection) links to when she was how she would like to be (²³⁰), when she was in every club ²²⁰

'I'm actually fine now/it's probably cos I'm older'¹⁶² could also be seen as seeking to be in the right club; her level of activity/ability to partake fits (despite her advanced understanding/appreciation of sport and the fact that it hurts to do it).



The sense of CLUB is a positive one, a collective that provides context for the Participant reflected in the primary metaphor SAFETY IS A CONTAINED STATE. In this sense the CLUB or collective, whether that be a place or a group of people, is a contained thing. It is something the Participant can be inside of.

The ability or desire to be part of this something requires an acceptance from the CLUB of the Participant and for this the Participant needs to be visible. The BODY AS CONTAINER FOR SELF shows how the Participant is aware of having to be *opened* to others to be allowed *in*. This approach does not come without a certain discomfort at disclosure which is reflected in the hint of red in the bar motifs.

Both forms of containment, the Participant and the CLUB are positive and helpful, reflected in how the **CONTAINER** schema is closely linked to **ENABLEMENT**. The **COLLECTION** schema stems from the idea of strength in numbers, being part of a team heading towards a common goal, the CLUB. Although there is some sense of desired isolation from the Participant there is a clear appreciation of not wanting to be '**singled out**'²⁷⁶; **COLLECTION** of like-minded people is important, being separated or distanced is not good (EMOTIONAL DISTANCE IS PHYSICAL DISTANCE), finding yourself an '**object of attention**'³³¹⁻².

SYNOPSIS:

Contained groupings are strong, standing alone is to be exposed

TIME

Here time as a theme is considered not as an abstract concept but a physical element, something which can be eaten away, wasted or saved. The theme subdivides into two. GOING GOOD incorporates the attitude of the Participant contextualised in the time she has available to her and the consequences of that, whilst REPETITION reflects more on the relationship of time to the disease.

Subtheme 1: GOING GOOD

There is a sense of striving, she does not submit, won't sit there crying⁸⁴ and will deliberately push herself against the pain³⁶³, a very 'sporty' trait. When the effect of the RA is stronger/making itself present, she refers to '**down time**'³³⁷ as if playing below the level⁴²; she is still at work (in the game) but less of a team player-she is quieter.

OA is the more commonly recognised (and understandable) form of arthritis in the public eye '**OA is fairly easy cos it's----kind of wear and tear stuff**'³⁰ but also, in this context it is relatable to sport, a result of being active, in a sense it is a positive negative (similar to the concept of 'no pain-no gain).

'**I should go...**'²⁴⁸ exercising (swimming, Pilates, etc.) but the main thing is actually *going*. Going, being active, is very positive and important to the participant, her outlook and profession. No matter the inconvenience or pain, an active lifestyle just makes sense. She has signed up for a sponsored walk²³⁹, combining being active with being useful but, states that '**I just want to be running around/tearing around**'²³² exercising for its own sake-fun.

Talking about her feelings when she is feeling good, reminding herself of the RA, '**hinders**'²⁸⁴ her ability to be on top form. Hinder here has connotations of slowing down/restricting movement or getting in the way of achieving something (in this case, being upbeat and positive). The idea of RA 'hindering' links to the concept of it being an obstacle or handicap (baggage).

42 Traditionally speaking, downtime refers to a period of time that systems (computers) fail to perform their primary function, or, in a sporting context, a period of rest from activity as opposed in this case because of the effects of the RA being stronger/having a greater influence.

In the same vein, the idea of **'heavy drugs'**¹⁹ represents slow/baggage and are again restricting; heavy was used here as the adjective but she could have used serious or major, etc. This links to the theme ADD+, and also to the LEVEL PLAYING FIELD. It is the principle and ability to take part, RA or not, which is the important point.

The word 'coping' appears several times though the text. The idea that the participant is achieving, partaking and working is tied to the sense that she is 'coping' with it, whether that is with the disease or with the activity as a result of the disease, the implication is that it is an effort and only just achieved.

'the desperate stage'⁴³³ (where the understanding of the stage can be seen as both level and time) is in the lack of ability to go. Being **'immobile'**⁴³³ means one cannot play, she would be no longer active but carried along with the dull, repetitive progression.

This stage is when things become **'more urgent'**⁴³⁴. This sense of urgency shows another the underlying metaphor alongside going=good, to time and progression as a spatial quality.

Time going forward (progression) isn't as positive as that going back. She **'might go back a bit'**³⁸⁶ **'could go back... [but she has doubts] don't know really whether I want to'**³⁰⁶⁻⁷

The medication links to the idea of time, most often represented as a future concept, they **'might not be forever, but probably'**³⁷⁶⁻⁷ they are supposed to **'halt the progression'**³⁷⁸⁺²⁰

Subtheme 2: REPETITION

'tired...most of the time'¹⁸⁷⁻⁸ mentioned several times (^{85, 87, 187-8, 450}), is important here, the appreciation of fatigue as a direct and major symptom of RA has massive consequences in this context. Play is positive, lying outside of time, allowing the participant to **'just stand there, for hours'**⁴⁵⁶ or partake (in play/work/helping). Time outside of play is linked to repetition, whilst, slightly contradictory to this, the progression of the RA although constant, like the pain, is shifting and changing all the time (does not play fair?).

Repetition has negative connotations, although not symbolic of RA itself which is shifting and changing **'temporary'**⁴⁰³ in its regressive stages. Repetition is linked to the system, the opposite of play. This sense of repetition shows in the explanation of medication, **'every 4 weeks/every month'**⁶⁹ **'blood test, every month or whatever'**⁴⁰⁴ also RA **'I did it for about 5 months but you have to do it every single day' and I got a bit bored'**¹⁹⁵⁻⁶.

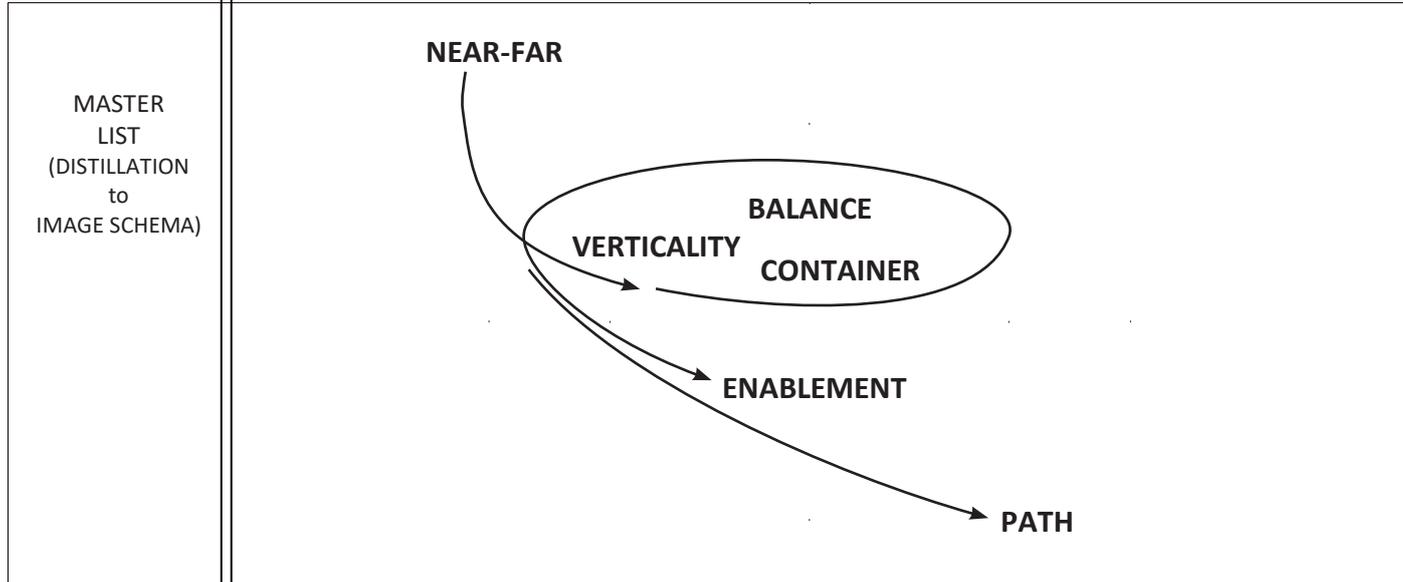
Repetition shows in the use of language in other ways; 'months and months and months'⁴¹⁵, 'cos it's always the same thing'²⁷⁶, 'counting calories'⁴⁴² 'I don't want people to ask me every 5 minutes'²⁷³⁻⁴, 'all the time'⁴⁴⁴⁺⁴⁴⁶. Here, repetition is either linked to the system; 'institutiony'⁴¹⁶ rules fixed to reality that distract from play (boring), or the 'constant'⁴⁴²⁺¹¹⁴ nature of the pain and reminders of that of which she does not 'want to be constantly reminded'⁴⁴³, 'constantly, constantly ignore it'²⁸⁷

But there is also the idea of a '**habit for life**'²⁴⁹ a positive repetition '**and then I'll be alright**'²⁵⁵. This would, however, only happen '**over the course of time**'⁴³⁰ involving '**a good long period of time**' to adjust⁴³²⁻³ '**it takes time to get used to the ongoing**'¹⁰³. This has connotations because of the energy involved, the Participant is '**tired...most of the time**'¹⁸⁷⁻⁸

There is a refusal/denial in response to the system that is linked to memory, '**I keep trying to remember**' '**but I don't really cos I'd be on them forever**'³⁷³⁻⁴. She does not need or want any reminding (²⁷⁵⁺⁴⁴³), remembering is looking backwards not striving forwards.

<p>CODES And MAIN THEMES</p>	<p><u>TIME</u></p>  <p><u>REPETITION</u> <u>GOING GOOD</u></p> 
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<p>THEORETICAL APPLICATION (placement into a wider social context)</p>	<p>HARM IS AN OBSTACLE </p> <p>RA 'hinders'²⁸⁴ her 'get over it'²⁹³</p> <p>DIFFICULTIES ARE IMPEDIMENTS TO TRAVEL </p> <p>Being 'immobile'⁴³³ 'heavy drugs'¹⁹</p> <p>DIFFERENCE BETWEEN IS DISTANCE BETWEEN </p> <p>a 'different level of friends'³³⁷</p> <p>GOOD IS UP/BAD IS DOWN </p> <p>'heavy drugs'¹⁹⁻</p> <p>STATES ARE LOCATIONS </p> <p>'the desperate stage'⁴³³</p>	<p>LIFE IS A JOURNEY </p> <p>'over the course of time'⁴³⁰</p> <p>TIME IS MOTION TIME_MOVING </p> <p>'over the course of time'⁴³⁰</p> <p>OPPORTUNITIES ARE OPEN PATHS </p> <p>'I should go...'²⁴⁸ exercising, etc.</p> <p>CHANGE IS MOTION STOPPING BEING IN A STATE IS LEAVING A LOCATION </p> <p>'how can I move myself away'⁴⁴⁶</p> <p>PROGRESS IS FORWARD MOTION </p> <p>'I just want to be running around'²³²</p> <p>LONG TERM PURPOSEFUL CHANGE IS A JOURNEY </p> <p>'could go back...don't know really whether I want to'³⁰⁶</p> <p>SELF MOTIVATED ACTION IS SELF PROPELLED MOTION </p> <p>'I dip in and out of things'^{253.}</p>
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The varieties of primary metaphor relating to TIME have been separated into two columns, on the left are the more physical states, the obstacles and definable concepts such as distance, levels or weights. On the right the concept of TIME is defined by direction and motion; this can be seen either as the Participant progressing on or looking back over her timeline, or alternatively, time itself could be appreciated as a moving track that carries us on it (Lakoff 1990).

The schema **NEAR-FAR** provides the framework for time to have a conceptual understanding of past=behind and future=ahead, allowing the Participant the opportunity to move forwards, seen in the metaphor PROGRESS IS FORWARD MOTION or LIFE IS A JOURNEY. Moving forward is a positive act so are all primary metaphors relating to this, such as OPPORTUNITIES ARE OPEN PATHS. However, they also represent the lack of forward motion taking place. For example, STOPPING BEING IN A STATE IS LEAVING A LOCATION, the primary metaphor seen in the quote '**how can I move myself away**'⁴⁴⁶ highlights the fact that the Participant is not moving her state is the same so her location t't changed, mainly as a result of RA '**hindering**'²⁸⁴ progress (HARM IS AN OBSTACLE).

Obstacles and difficulties that impede travel or movement cannot be seen as wholly negative; the drugs the Participant needs, however '**heavy**'¹⁹ are necessary.

The end goal of this theme of TIME is the ability to go (somewhere or just forwards). This is seen in the schema **ENABLEMENT** linking to the schema **PATH**. The schema **BALANCE**, **VERTICALITY** and **CONTAINER** are grouped as the states necessary for action (**ENABLEMENT**), literally the Participant holding herself together to stay upright.

SYNOPSIS:

Onwards and upwards is the right way to go!

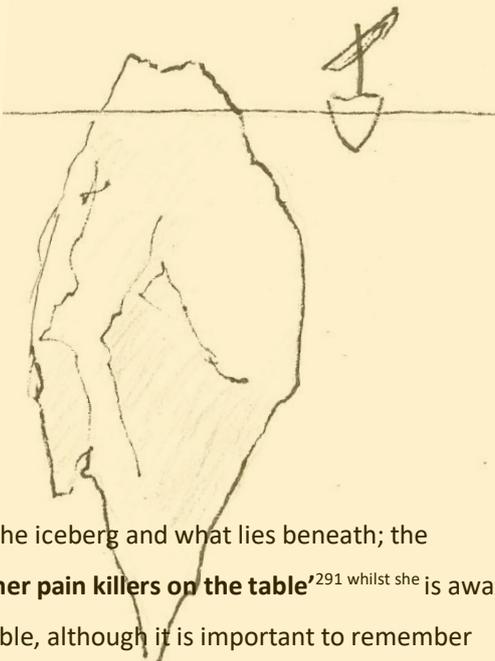
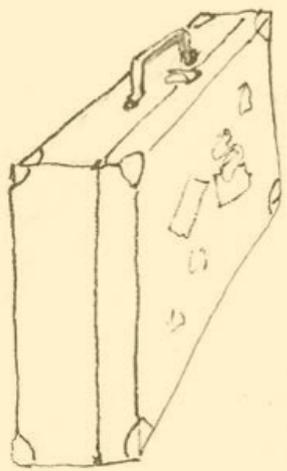
7.3.3 VISUALIZATION ANALYSIS PARTICIPANT 3



really quiet⁸⁴
'boomboomboom'³⁶ **'rattle'**⁴⁷ **'crank'**⁶⁰

The idea of the serene or quiet duck on the water paddling frantically below the surface provides an instantly recognizable metaphor explaining the participant's sense of

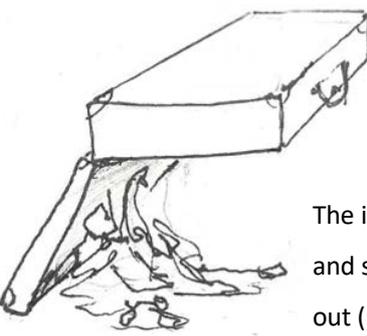
The paddling duck also suggests the metaphor of the iceberg and what lies beneath; the description of the Participant's boss who **'set out her pain killers on the table'**²⁹¹ whilst she is aware that the causes of her pain and fatigue are not visible, although it is important to remember that she isn't hiding them, **'if someone asks me...properly asks me, then I'll tell them!'**³³⁹⁻³⁴²

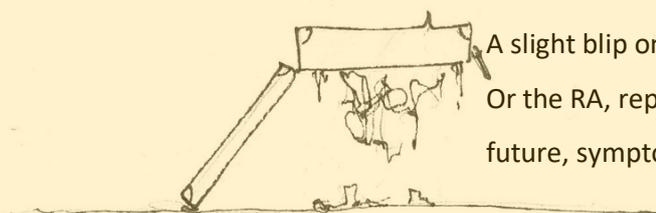
The idea of **'setting things out'**²⁹¹ suggests to me the travelling salesman, carrying their wares in a suitcase. This also works with the metaphor of **'baggage'**³⁴³ as the symptoms of the disease.

The idea of a suitcase, or baggage in general, links to this idea of there being more to see behind the scenes/beneath the surface. Also works with the idea of life as a journey...

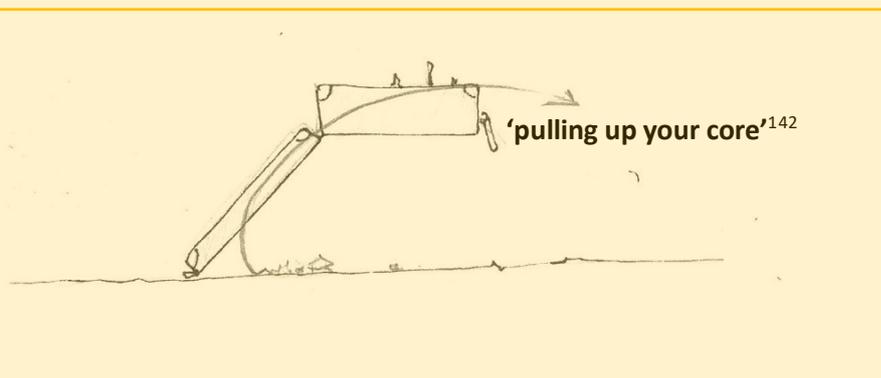
The outside could look well-travelled and a little rough round the edges, **'OA is fairly easy cos it's----kind of wear and tear stuff'**³⁰



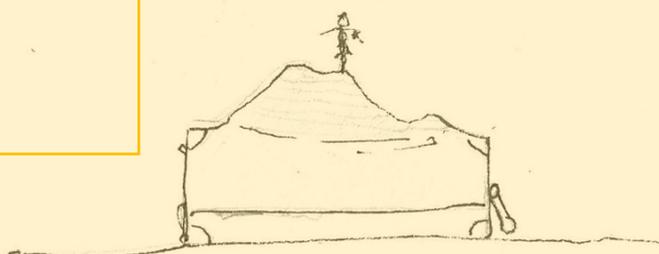
The idea that the suitcase can be the level, what you see all clean and smooth but also be exposed underneath, the contents falling out (restricting the ability to go?)



A slight blip on the 'level'; could be the Participant?
Or the RA, representing what may come in the
future, symptoms of RA that can't be hidden

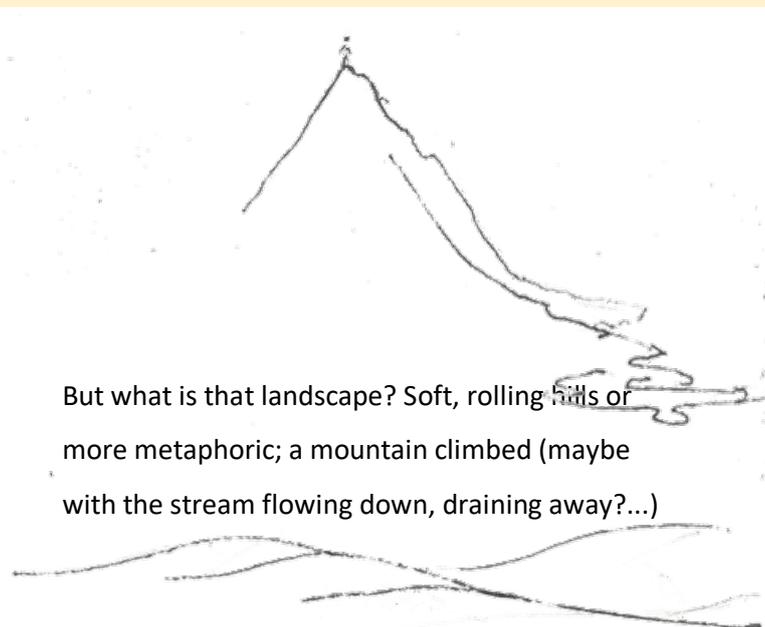


'pulling up your core'¹⁴²

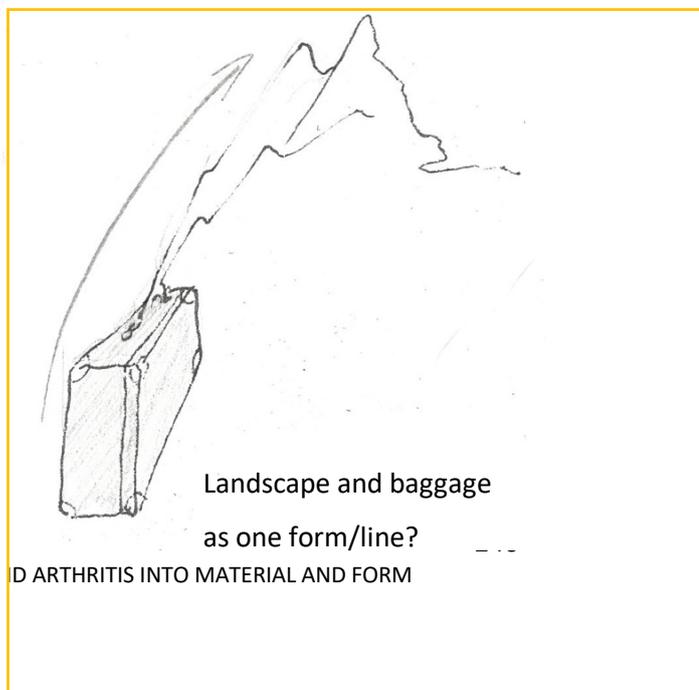


The level could be representative of the
landscape so favoured by the Participant,
**'up on the hills...on the edge of the
Downs'**⁴⁵⁵

Showing the shape as pushing out from
inside the suitcase links to the idea of how
the landscape left the Participant **'filled up
again of 'oh, this is nice!'**⁴⁵⁷

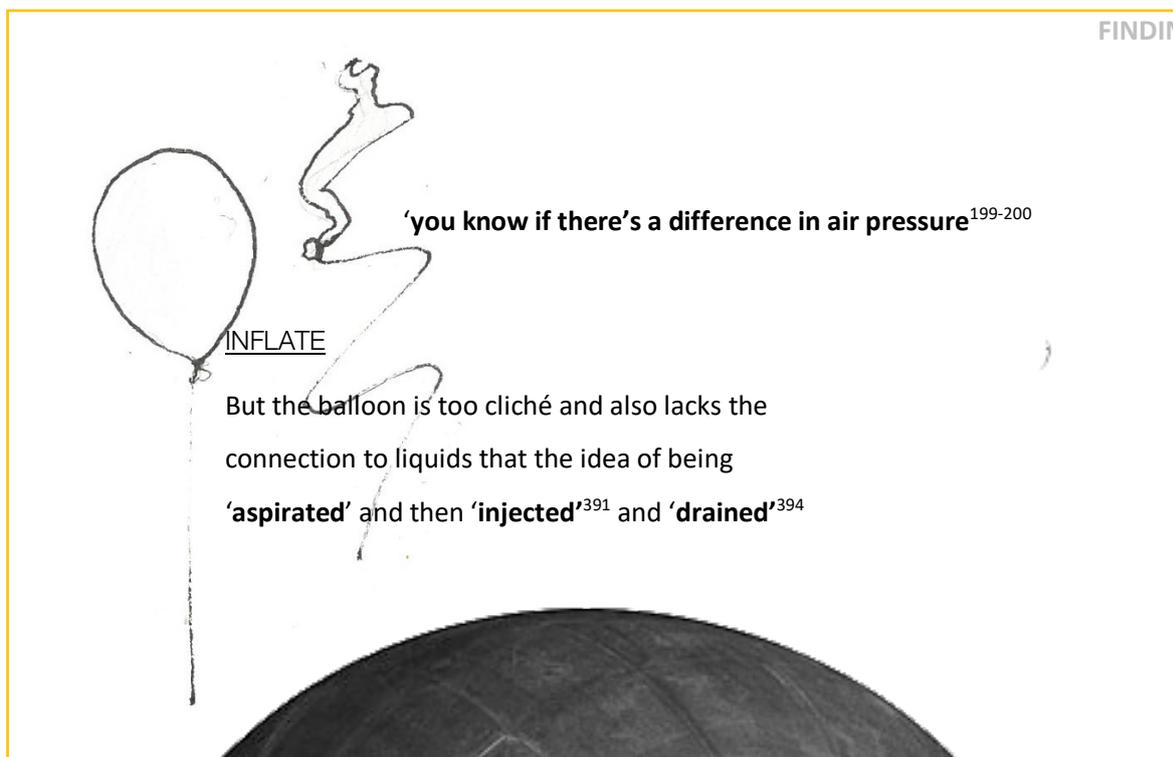


But what is that landscape? Soft, rolling hills or
more metaphoric; a mountain climbed (maybe
with the stream flowing down, draining away?..)

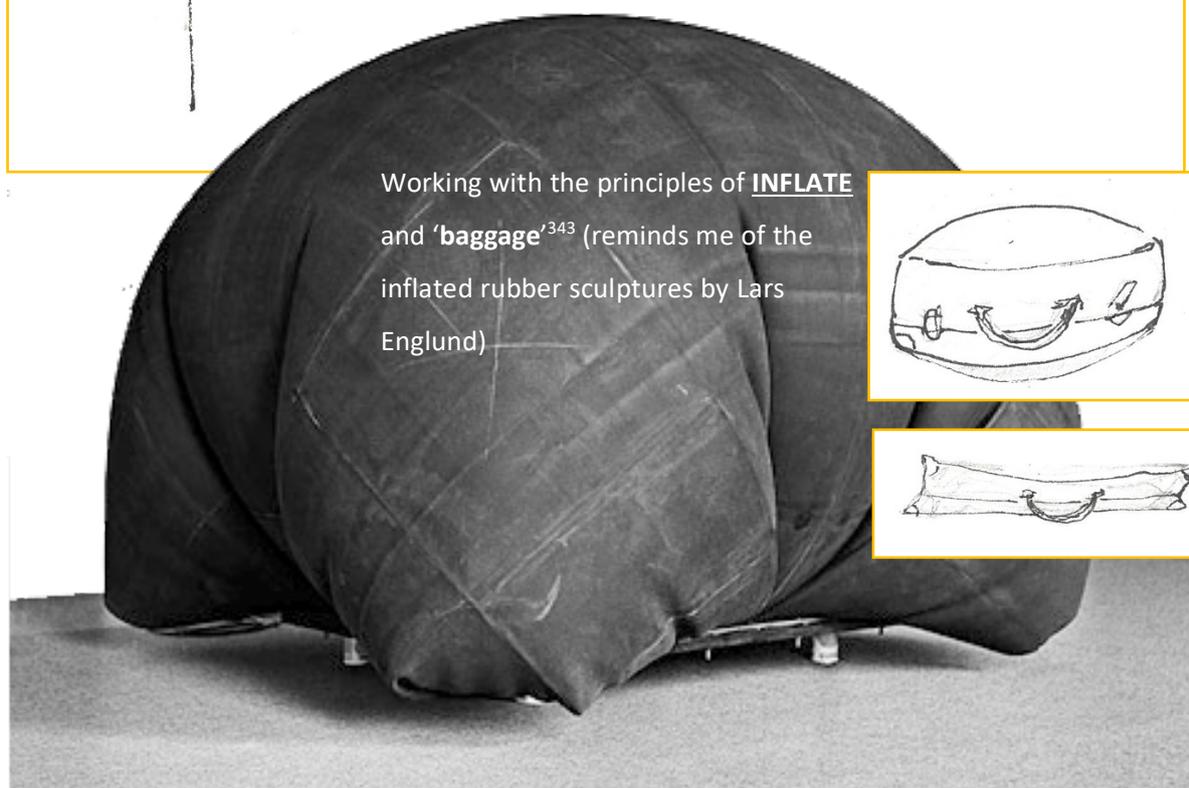


Landscape and baggage
as one form/line?

D ARTHRITIS INTO MATERIAL AND FORM



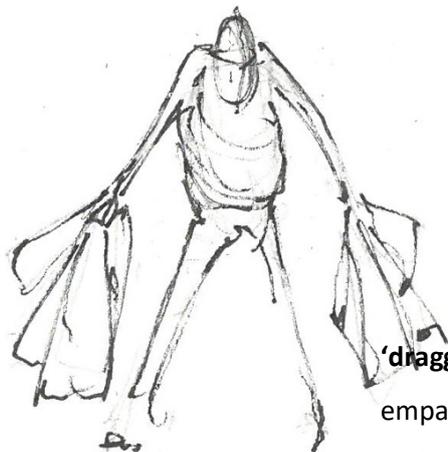
But the balloon is too cliché and also lacks the connection to liquids that the idea of being 'aspirated' and then 'injected'³⁹¹ and 'drained'³⁹⁴



The idea of the inflated form, almost bursting with the pressure, alongside the references to liquids, aspiration, etc. suggests that one important process will be casting using fabric forming (literally pouring concrete into a bag).

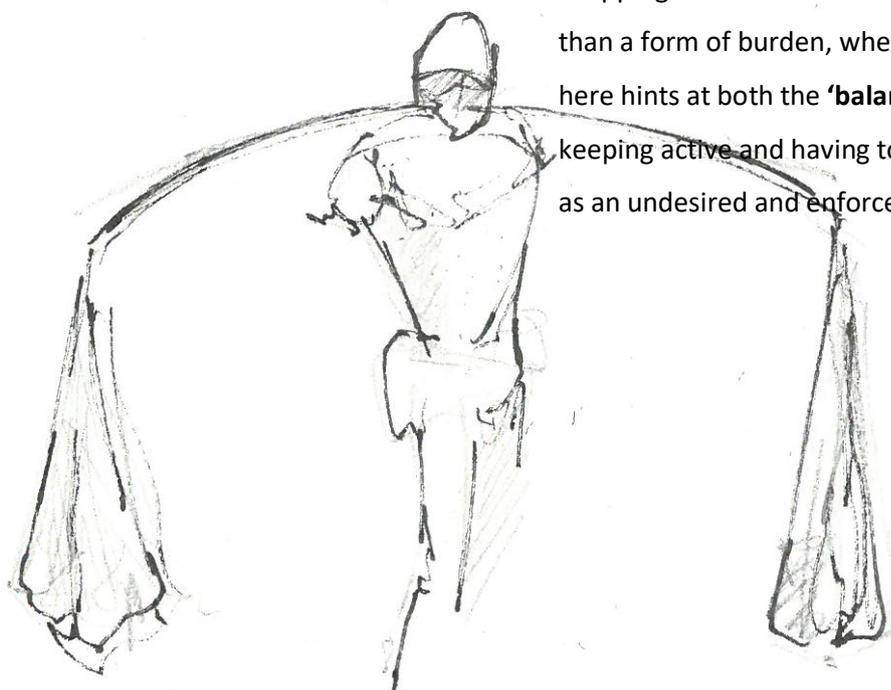
This process brings an energy in the stresses shown through the form and the creases convey a sense of organic, fleshy joints, which links to the earthy realism of the Participant's attitude, the conversation around aspiration of the knees and, also, the idea of skin as a container marked from the outside but also marked from the inside.

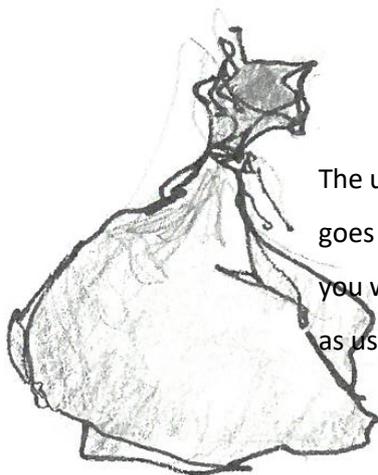
'I just want to be running around/tearing around'²³²



'dragging'²³³ her arms as if they weigh her down, using an empathetic image to literally visualize the 'heavy drugs'¹⁹ and pain as 'baggage'³⁴³

the idea of carrying many bags suggests shopping as a means of accumulating rather than a form of burden, whereas the yoke shown here hints at both the 'balancing act'¹⁷⁵⁺³⁸¹ of keeping active and having to carry the baggage as an undesired and enforced task.

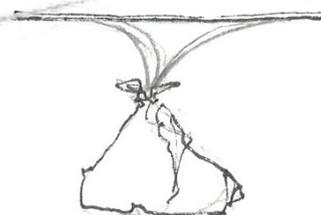




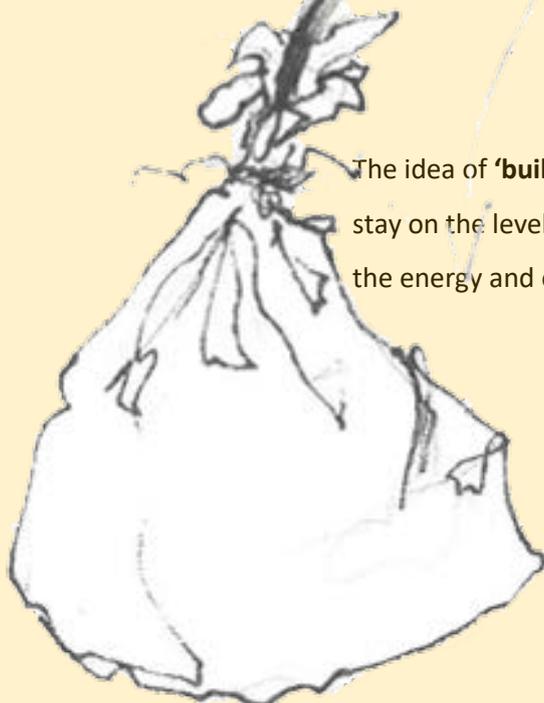
The use of the term **'baggage'**³⁴³ as a descriptor of RA, pain and all that goes with it is fundamentally negative; this is not a collection of luggage you want to take with you on your journey, it needs to be appreciated as useless, rubbish in bags or a sack that holds unprecious cargo.



there is also a sense of being able to see what the bag holds, (like Santa's sack) but if it holds a liquid it has a more visceral/medical/organic sensibility

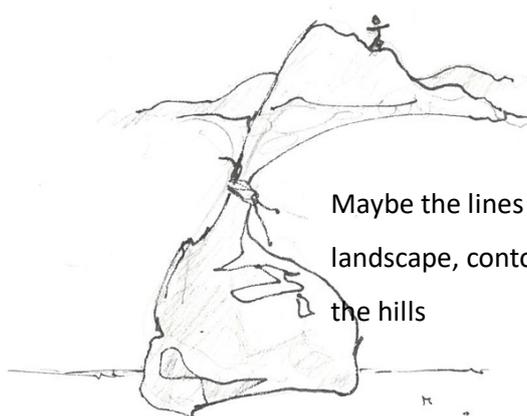


Yet even with the concept of a sack load I still want the level to be present and for it to be intimately tied/connected to the core/baggage

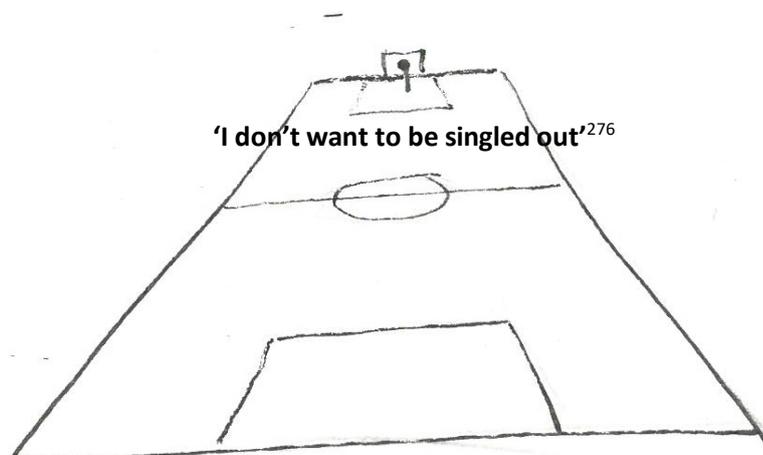


The idea of **'building [herself] up'**⁵¹ to stay on the level, somehow showing the energy and effort of getting **'up'**⁴⁵⁵

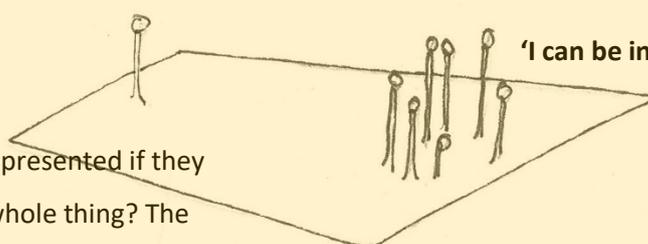
This effort links to the idea of the Participant **'having to hold your own body weight'**¹⁴⁵.



Maybe the lines fill out to form a landscape, contours or silhouette of the hills

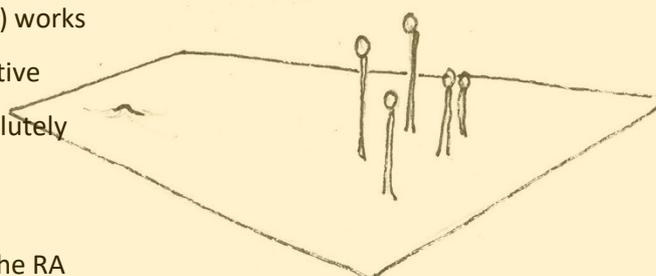


'I don't want to be singled out'²⁷⁶

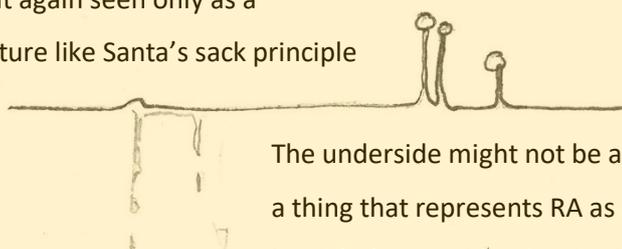


'I can be in my little club with them'³⁵¹.

How is the Participant represented if they are represented as the whole thing? The idea of showing a group of things and one isolated (as shown here, for example) works in a Gestalt manner, creating a narrative and a sense of empathy but it is absolutely literal and graphic.

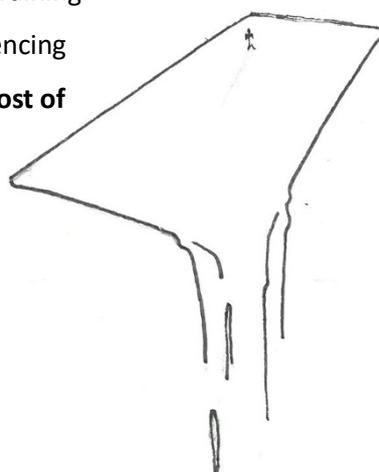


Could they be shown as emerging? The RA being present but not on show. If so it is there maybe as a slight protrusion (a form that is present again seen only as a fragment gesture like Santa's sack principle again).



The underside might not be an actual 'thing', a thing that represents RA as a form. Instead, it might be a residue (aspiration) or an action, such as something dripping...

Working with mixing the concept of levels with liquids; the level draining away, like an egg timer referencing the feeling of being **'tired...most of the time'**¹⁸⁷⁻⁸



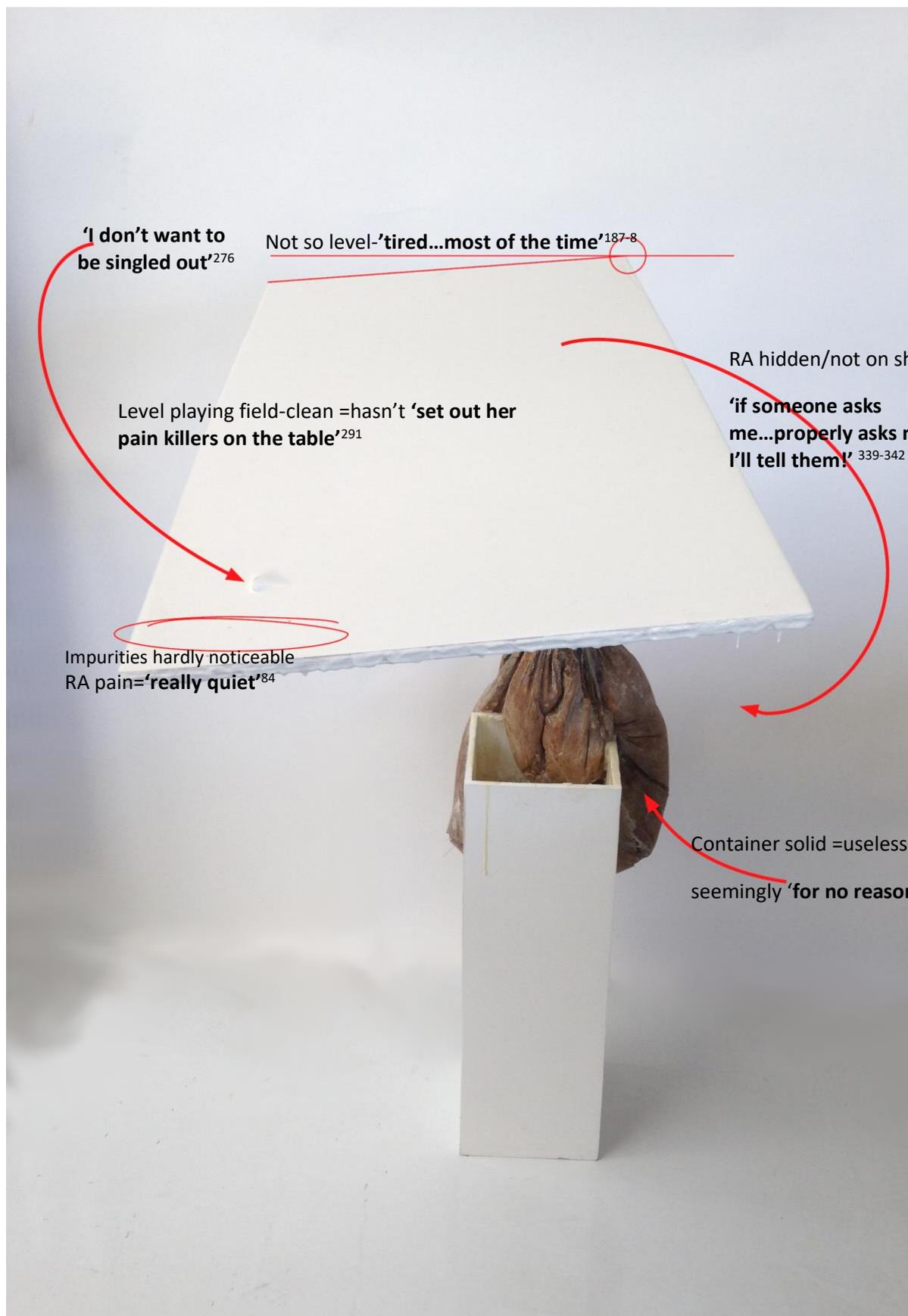
The idea that the level isn't level.

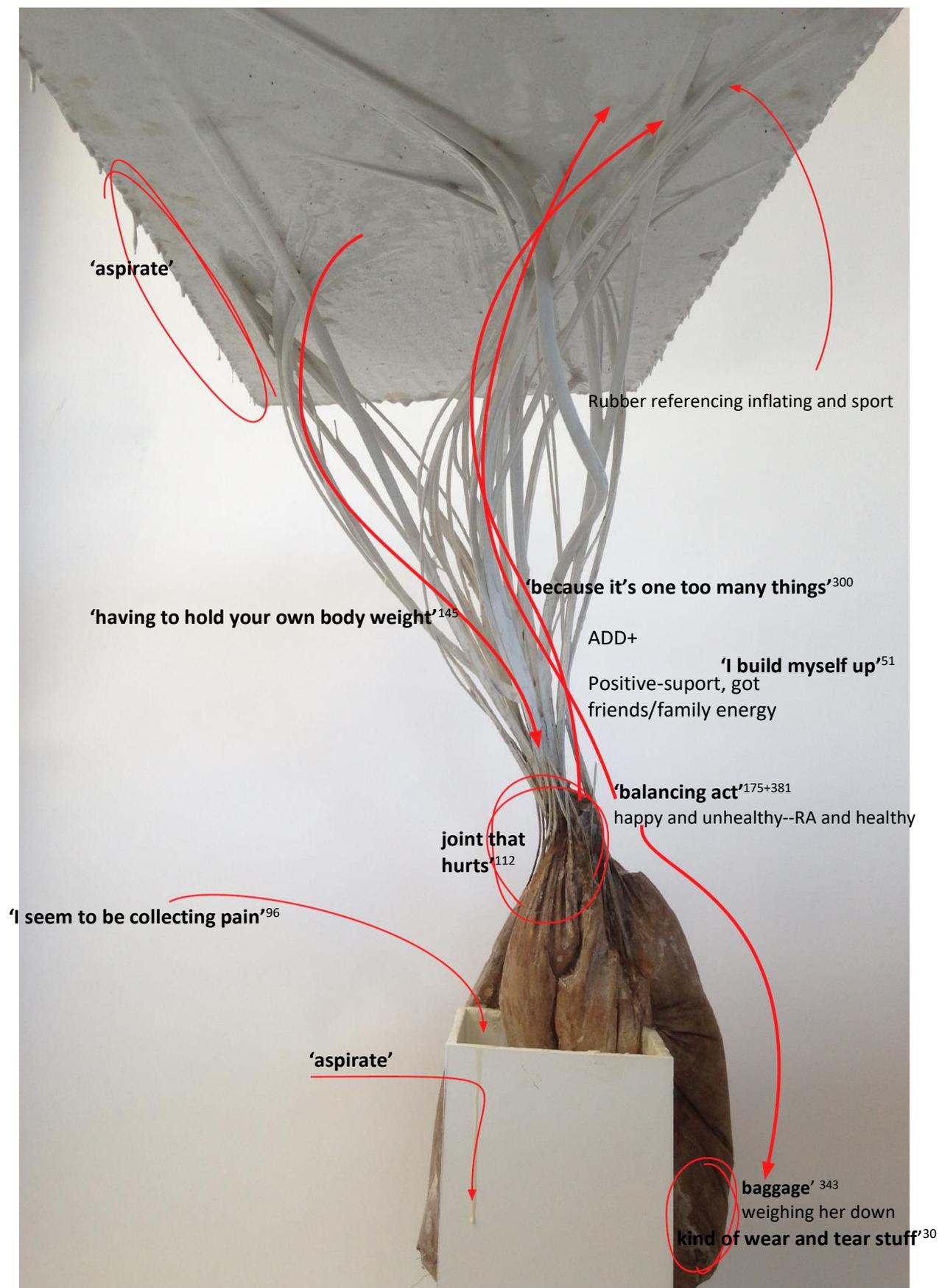
Placing the 'figure' or marker on the level emphasizes the expanse, the idea of **'the ongoing'**¹⁰³, **'always the same thing'**²⁷⁶, the **'constant'**⁴⁴²⁻¹¹⁴ and **'forever'**³⁷³⁻⁴ but also want to show the Participant **'getting over it'**²⁹³ that the level isn't the end; the Participant is forward looking not just seeking to maintain a norm

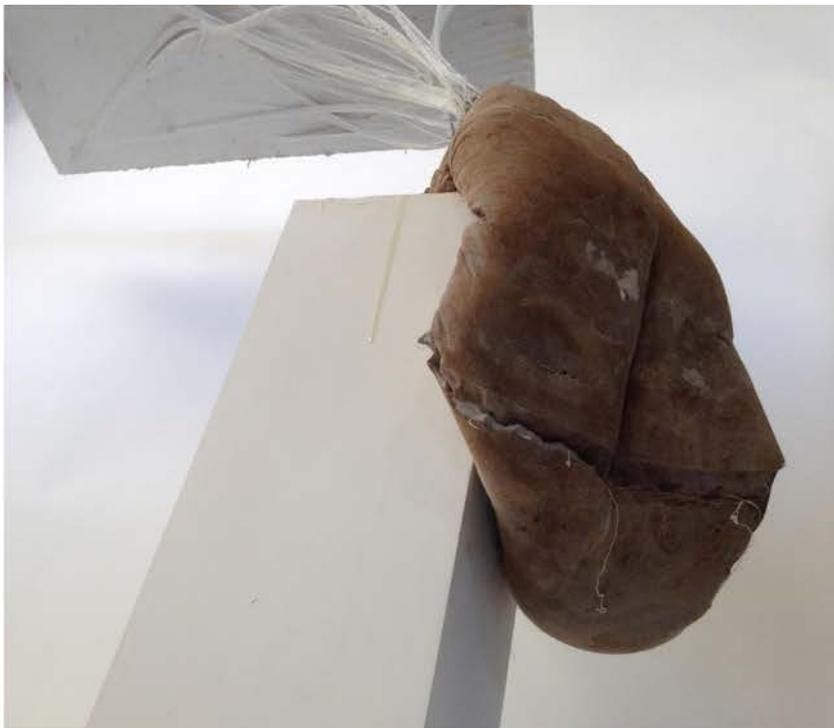


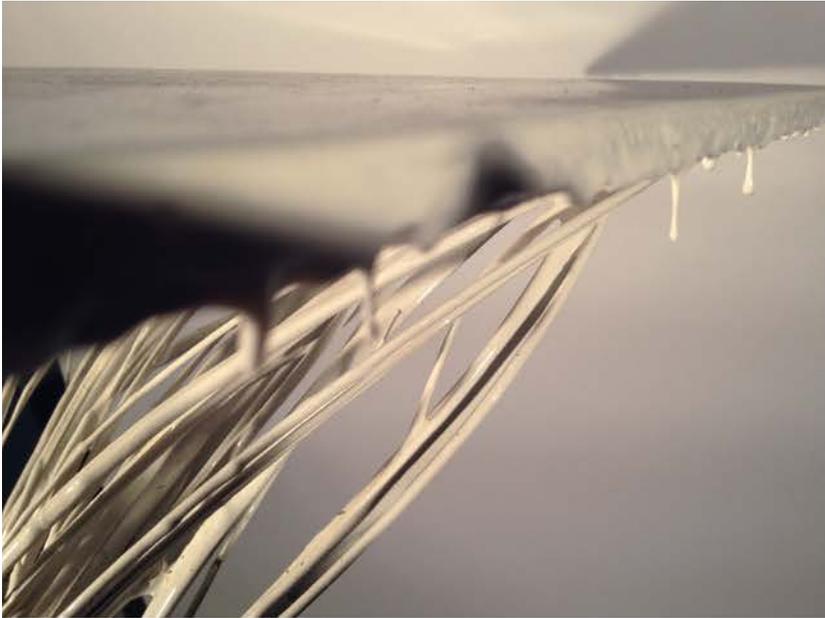
If the level isn't just a level, how can it be used to express an emotional state?

7.3.4 CROSS REFERENCING ANALYSIS TO MODEL: PARTICIPANT 3











8. DISCUSSION

8.1 METAPHOR ANALYSIS OF MODELS

This chapter analyses the models as a collective, showing examples from each of the models in the light of various image schemas and describing the prevalent primary metaphoric links. This is not intended as a way to generalize, although “such metaphors also provide a superstructure for our systems of complex metaphorical thought” (Lakoff and Johnson, 1980, p.256) providing a framework for future action. Rather, through comparison, this discussion highlights how empathy for the models draws on image schema in the same manner as verbal language, following a baseline conceptual understanding central to human thought and common to all as discussed in the chapter COGNITIVE PERSPECTIVES ON EMBODIMENT; that what are considered as monomodal visual metaphors are as rich and complex as the spoken word.

I will explain how the models engage us visually, how they draw the eye, step by step through the model creating a narrative using the concept of HAPPY IS UP. I will contrast this using the primary metaphor UNHAPPY IS DOWN, to describe the path of RA in the model’s narrative. Following the journey of the disease inevitably opens the discussion on how RA is perceived in the models, the concept of RA AS AN ENTITY. The remaining discussion will focus on the primary metaphors and the physicality of the model, the **BALANCE** schema (Johnson, 1987) and VIABILITY IS ERECTNESS (Grady, 1997) explaining the emotive response to the model’s composition, Forceville’s conceptual image schema **LIGHT/DARK** (2013) discussing the use of colour and texture as a narrative tool and Grady’s SOCIAL STATUS IS VERTICAL ELEVATION (1997) will show how the way that we face the models also links to an emotive response. The discussion will conclude describing how the participants themselves are grouped under the **CONTAINER** schema (Johnson, 1987) explaining how they see themselves, their place in society and how they understand their relationship with their disease with the primary metaphor UNDERSTANDING IS SEEING (Grady, 1998)

8.1.1 SOURCE-PATH-GOAL image schema (Johnson, 1987).

There is a spatial logic to this schema (Lakoff and Johnson, 1980), a starting point, a trajectory that moves and an actual, intended (or unknown) destination. Each of these could be physical or conceptual; there can be numerous trajectors, goals or starting points or variations within, however, these elements need to have an internal logic; for example, if going from A to B, then B to C, it is understood that you have gone from A to C (Lakoff and Johnson, 1980).

This schema can be seen in numerous conceptual themes from each participant; MOVEMENT with SLOWED DOWN ^(Participant 1), JOURNEY ^(Participant 1 and 2), ACCUMULATION ^(Participant 1), CLUTTER ^(Participant 2), ADD ^(Participant 3) and TIME with GOING GOOD and REPETITION ^(Participant 3). The primary metaphor LIFE IS A JOURNEY (Lakoff and Johnson 1980, p.44) derives from this schema and can be seen in phrases throughout each text such as **'I'm in a space where I've come back'** ^{128 (Participant 1)}, **'I might go back a bit'** ^{386 (Participant 3)} or **'the one thing that keeps me going'** ^{256 (Participant 2)}, and **'I'm not quite there'** ^{398-399 (Participant 2)}.

Participant 1's understanding of being useful is tied to the SOURCE-PATH-GOAL schema through the primary metaphor PURPOSEFUL ACTIVITY IS SELF-PROPELLED MOVEMENT TOWARDS A DESTINATION (Forceville, 2011, p.5). When Participant 1 discusses that **'movement is what it's all about, and energy'** ^{2nd stage:234}, or Participant 2 that **'you need to do something to not engage'** ⁴⁰³ they suggest goal-oriented actions but without any destination, it is the action, the PATH, alone that provides the purpose. This is reflected in the models through the wire framework in Participant 1 and the organised pile of paper work in Participant 2, although the latter is also closely linked to the primary metaphor PURPOSEFUL ACTIVITY IS MAKING AN ARTEFACT activated verbally in phrases such as **'I build myself up'** ^{51 Participant 3}.

8.1.2 HAPPY IS UP, the visual path that the eye follows along the models

The sense of movement from a source towards a destination can be seen in the physical overall structure of each of the models. In this way the SOURCE-PATH-GOAL schema acts as a superstructure to the metaphoric intention of the models. The composition, form and materials all link to this notion; the upward lift of the visual flow of the models, how the eye 'reads' them, helps

ascertain why the downward pull of the heavy materials metaphorically suggests effort or fatigue and how the different form's relationships suggest support or growth, push or pull.



Figure 87: diagram of visual path through Participant 1 model

In participant 1 the SOURCE can be seen as the cone of chalk on which the model either balances or has grown/rooted from, this continues up the hip-replacement form to the egg shell like core of the model from which the PATH as steel wires fly off in different trajectories. The GOAL is continuation represented in the orbital structure of the wires spinning around the core.



Figure 88: diagram of visual path through Participant 2 model

In Participant 2 the SOURCE is the stack of paper rising up from the ground forming the two faces of the model. The destination, as with Participant 1, is not visually defined, but in this context the direct, almost confrontation stance of the model, includes the viewer directly, making their interaction, that of the model and the viewer, the GOAL.

In Participant 3 the visual path of the model does not start from the plinth; here the SOURCE can be seen as the rusted fabric cast bag that rests on the plinth. From here the PATH follows upwards through the amalgamation of lines that support the platform onto the level playing field.

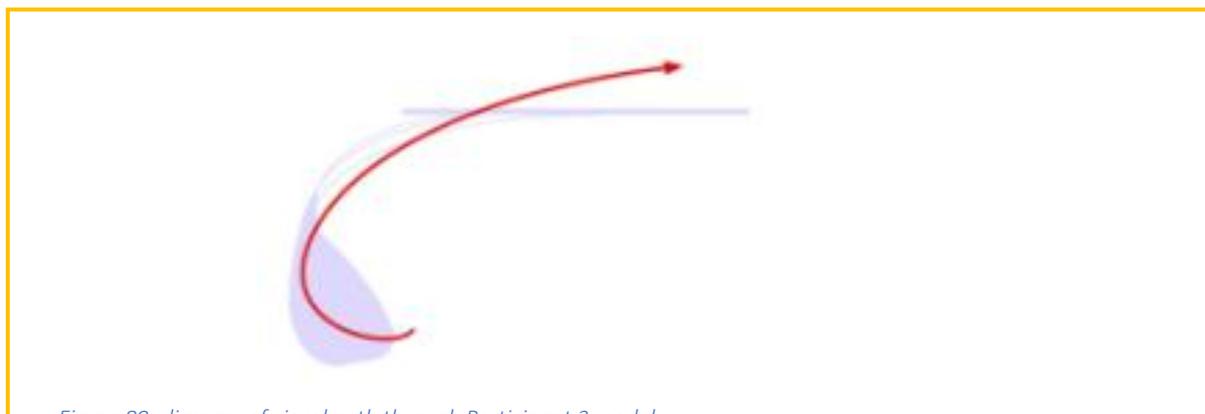


Figure 89: diagram of visual path through Participant 3 model

The use of line as a metaphoric representation of movement in all three models draws on the perceptual cue where the eye of the viewer in following the line continues the form beyond the lines end and so the mind supposes movement, a graphic device most often seen as motion lines highlighting the speed of moving objects in cartoons (Kim and Francis 1998). This is most readily appreciated in the steel wire framework in Participant 1 or the lines rising out of the rusting sack in PARTICIPANT 3, but can also be seen in following the flow of the paper as it forms the paper face in Participant 2.

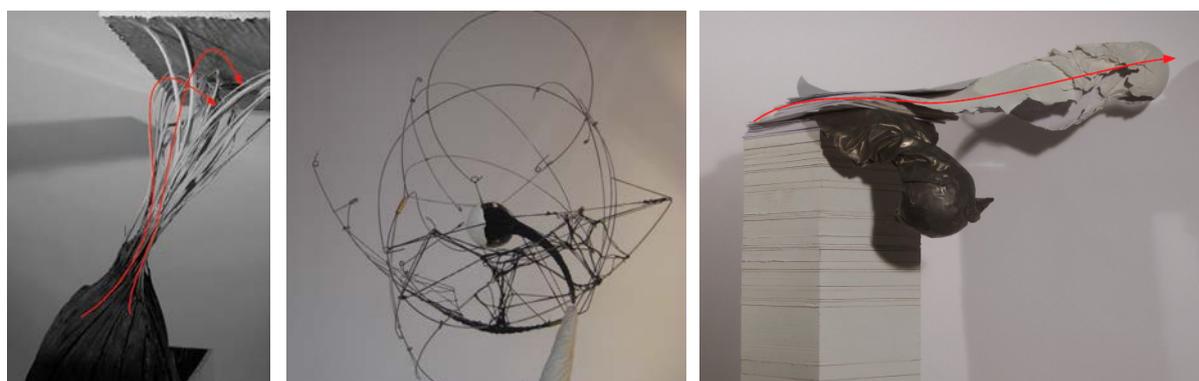


Figure 90: the flow of lines in the models suggesting a continuation of movement

8.1.3 UNHAPPY IS DOWN, the path of the disease through the model

As opposed to the positive visual paths the models express, such as the **'perpetual motion'**^{2nd stge:140} of Participant 1, the defensive defiance of Participant 2, or the strong minded, level headed attitude of Participant 3, the models also reflect the PATH of the disease and its influence on the Participant's

lives. The path of the disease marks a contrast to the overarching narrative discussed above that is reflected in each of the models, but this isn't dichotomic, with the RA attacking the participant, one pitted against the other.

In the media and the public realm, people who have RA are most often portrayed as victims (Bassett et al, 2018) with the 'most common word used to describe the experiences of patients with RA [being] attack' (ibid); terminology also used in NHS⁴³ online information regarding RA. In proposing the RA as 'attacking', where 'the disease tends to be positioned as an enemy or aggressor' (Semino Demje and Demmen 2016, p.634) Semino, et al. developed the primary metaphor BEING ILL IS A VIOLENT CONFRONTATION WITH DISEASE; however, throughout the analysis with the Participants in this research the sense was of relationship, however unpleasant, rather than confrontation, **'it's a pain you live with'**^{134 (Participant 3)} an approach that 'reinforces different ways of conceiving of as well as experiencing the illness' (Semino, Demje and Demmen 2016, p.626) beyond the metaphor of DISEASE IS WAR, a metaphor 'so familiar and commonplace in our medical rhetoric that we easily lose sight of its militaristic origins and significance' (Fuks 2009, p.2). In fact, with all the Participants the violence, the concept of being attacked, stemmed mainly from the effects of the medication rather than the disease itself, for example, Participant 1 **'stabbing [her]self with that drug'**²⁷⁰, the medication **'knocked the crap out of'**⁵¹ Participant 2 and for Participant 3 **'with consultants ...it's just 'boomboomboom'**²⁸⁻³¹.

Drawing on the McGill pain questionnaire (Melzack 1975) seeking verbal pain descriptors used by patients with arthritis, Wagstaff, Smith, and Wood, (1985) correlated 14 words that provided markers for medical professionals to signal RA, shown here in order of prevalence: Throbbing, Hot, Burning, Cramping, Gnawing, Sharp, Scalding, Stabbing, Boring, Pricking, Pressing, Pinching, Shooting, Jumping, Cutting, Smarting. These descriptors activate the primary metaphor PAIN IS A TORMENTING ANIMAL (Semino 2010) which draws similarities to the theme of MONSTER in Participant 1's analysis. This primary metaphor derives from the schema EMOTION IS A PHYSICAL FORCE (Kövecses 2000) as a means to both express the lack of control in the process, that it is happening *to you*, and a description of the physical feeling, whether that is being wounded or hunted. However, none of these words from the descriptor choices were used by the Participants

43 (<https://www.nhs.uk/conditions/rheumatoid-arthritis/>)

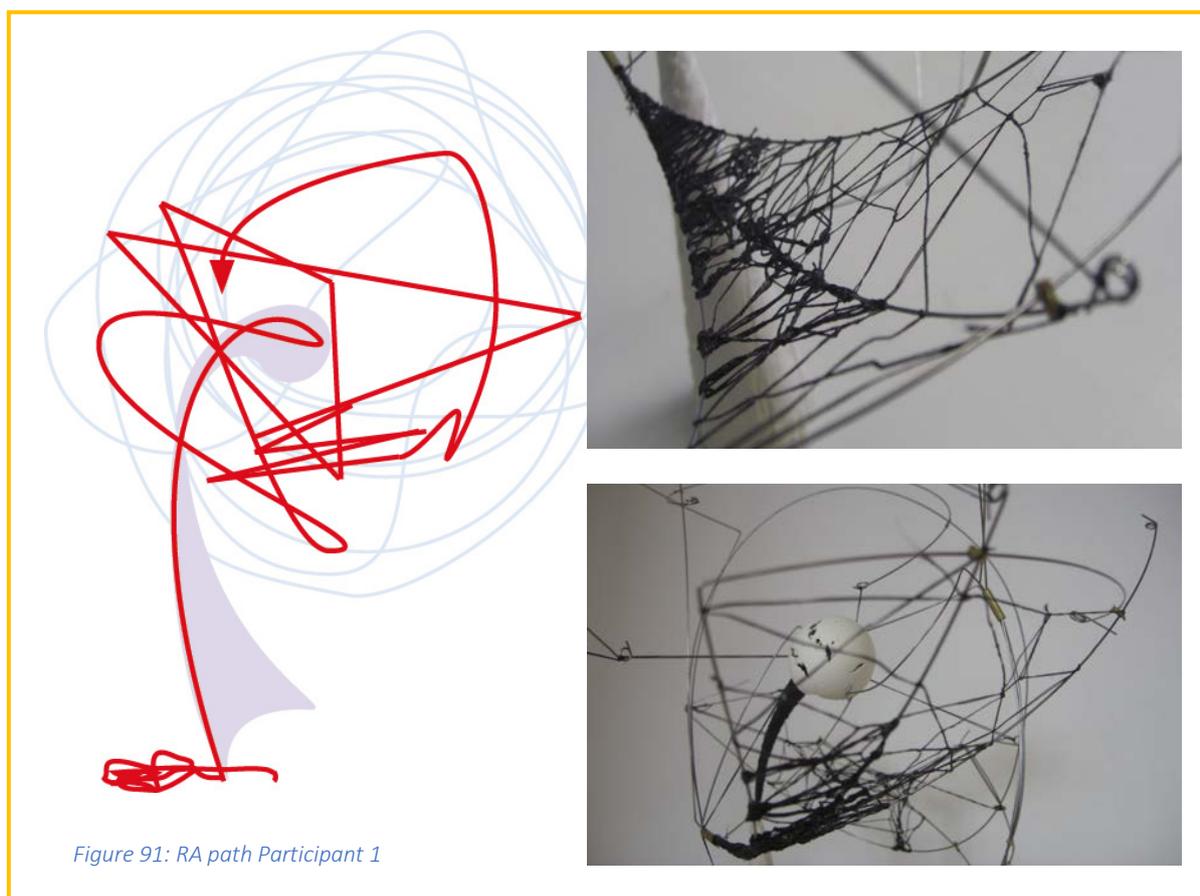
during the conversation to describe their lived experience. I felt that catering to this metaphor would have required too evocative and literal a translation, limiting the potential understanding that could be drawn from it; for example, cut marks would have triggered empathetic responses for the viewer relating to their own experience with animals or knives resulting in a direct comparative on only one level.

Rather than attacking there is a sense of inevitability to the disease, **'just what is, it's just there'**⁴³³ (Participant 2), **'you can't fight it'**⁴⁰³ (Participant 1); which seems to stem from an acceptance of the auto immunity of the RA, **'it is your body that's fighting all the time'**²⁹⁹⁻³⁰⁰ (Participant 2), **'eating yourself'**^{2nd stge:79-80}, **'I do that'**^{2nd stge:134}. Pain, rather than described in terms of action, shooting or pressing, is considered more a hinderance²⁸⁴ (Participant 3). Although the path of RA can be reflected internally, **'it's coming into my thumb'**^{2nd stage (Participant 1)} the RA can be also understood as **'baggage'**³⁴³ (Participant 3) something that can be **'lifted'**⁶¹⁻⁶³(Participant 2) the Participants collect pain⁹⁶ (Participant 3), Participant 1 describes **'getting the clicky hips'**⁸⁶, Participant 2 talks of RA as **'another thing'**¹⁰⁻¹¹.

When considered as other, separate to the Participants, the RA is not completely alien but as something known, **'a pain you live with'**¹³⁴ (Participant 3). The RA does not pounce, rather the pain RA brings **'sneaks'**³ (Participant 1), it is a **'shadow'**^{2nd stge:267} (Participant 1) more than an animal or monster.

There is a definite sense of journey to the Participant's experience with RA, which Participant 2 describes as **'quite a steep learning curve'**¹⁴, whilst Participant 1 talks of her **'career with rheumatoid arthritis'**³⁶⁻³⁷ and Participant 3 talks of **'the progression of'**¹⁶⁻¹⁷ the RA. It is this sense of shared journey, the **'dance'**³⁷ described by Participant 1, that the models reflect in the representation of the RA path in all the models; separate but integral. The path can be seen as a journey from energy to fatigue, expressed as growth, accumulation or decay but always an influence and integral to the model overall.

In Participant 1 the RA path is seen through the woven thread, which rather than any representation of weight as she is a slight, perhaps thin lady and an expression of weight does not suit, is seen more as an accumulation, a growing sense of confinement/restriction.



The thread has its own SOURCE, within the egg shell like core at the heart of the model, its PATH moving through the outer wire frame elements. The thread has no seeming physical destination but if its implied actions were to continue then it would completely entangle the rest of the model as it already smothers the 'hip replacement' form. Another result of this can be seen on the base of the model where the chalk cone is disintegrating leaving the dust obscuring the clinical, transparent surface of the plinth.

With the RA path in Participant 2 there is a contrast between the faces' materials, paper and lead. The lead, although mimicking the paper face in form, does not have the strength to support its own weight and so droops down leading the eye of the viewer with it.

In Participant 3 the path has a downward flow. Not instantly visible, the underside of the level playing field has an oozing quality that drips down the supporting lines towards the large fabric cast sack that, although solid, continues the feeling of a downward pull.

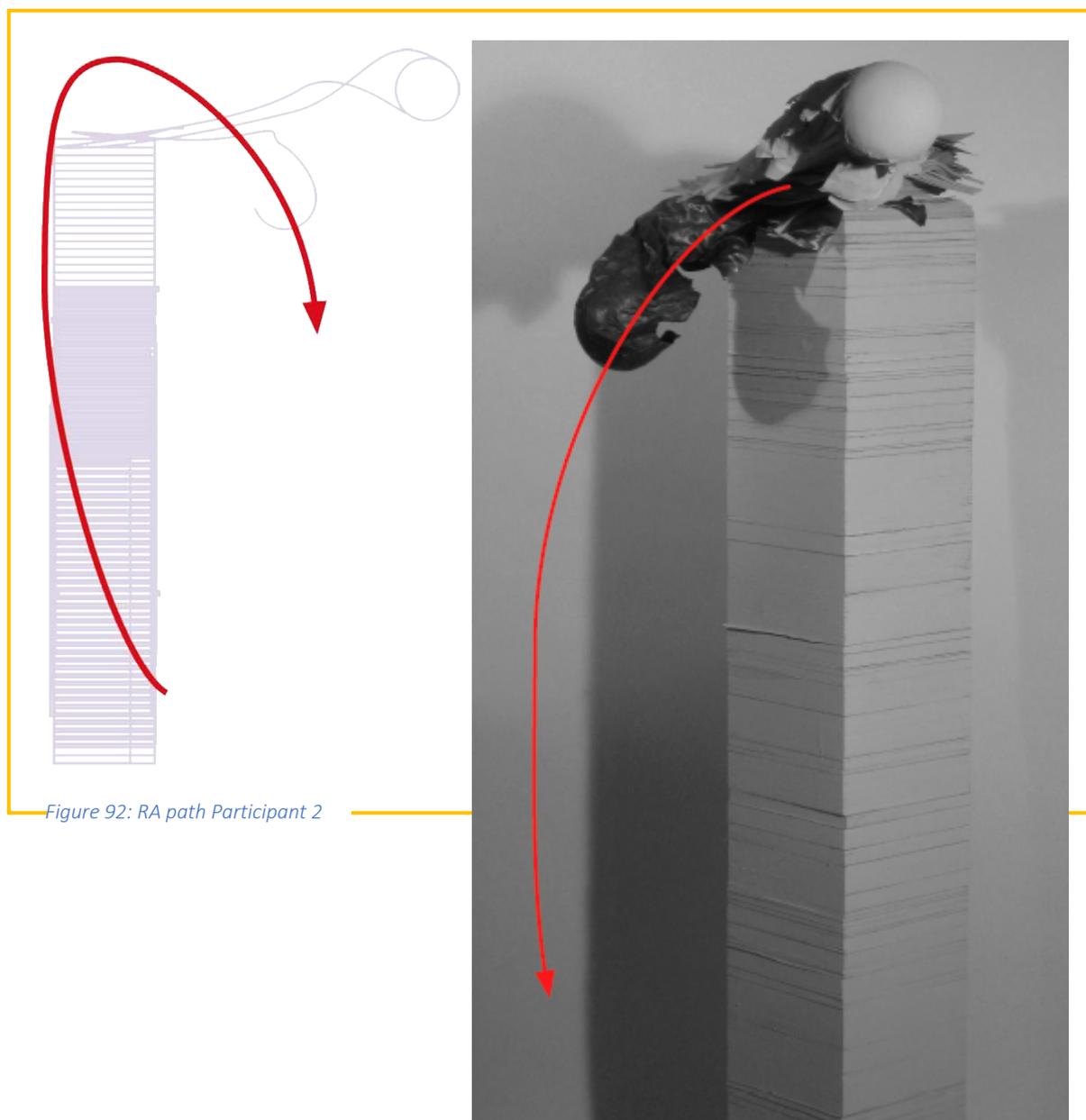


Figure 92: RA path Participant 2

The plinth itself acts as a vessel collecting liquid that seeps from the sack. Only with the small form protruding through the rubber at the far corner of the level playing field is the PATH of the RA led upwards beyond the model towards a GOAL not in view, an unknown future, **‘they might not be forever, but probably’**³⁷⁶⁻⁷ (Participant 3).

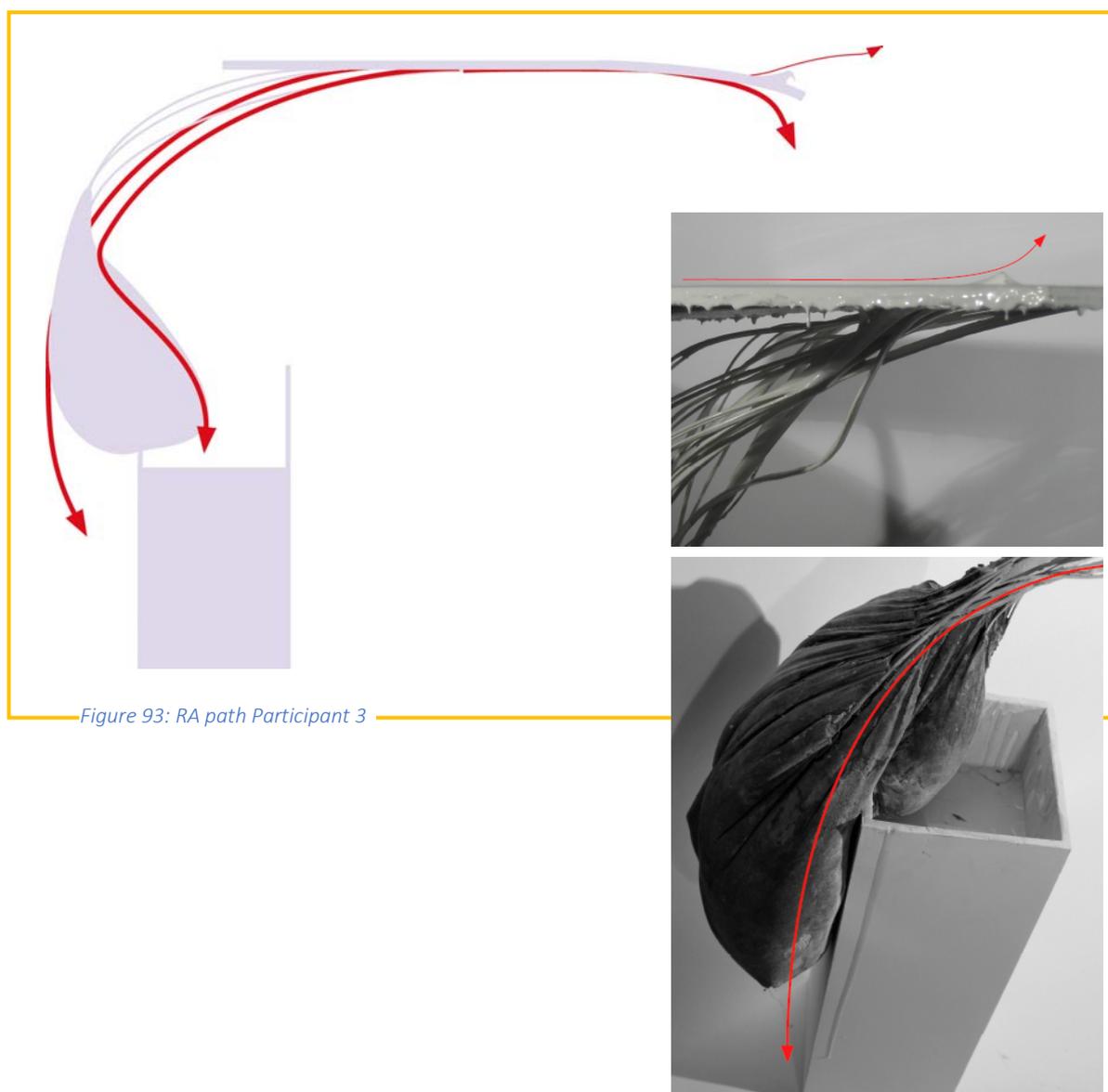


Figure 93: RA path Participant 3

The course of these two paths, the Participant going upwards and the RA downwards is reflected in the primary metaphor HAPPY IS UP/UNHAPPY IS DOWN. Verbally this metaphor is activated in statements such as ‘**and then I picked up and it’s been fine**’^{121 (Participant 1)} or ‘**stop myself from spiralling down**’^{447 (Participant 2)}. This primary metaphor relates to the constant perception of gravitational pull as defined by Arnheim (1954), accepting that objects (or elements within an image) we perceive are subject to the same gravitational forces that we exist with, those on top have potentially overcome this or have been raised up to keep them out of harm’s way, while those going down or on the bottom have fallen and been defeated by it (Ortiz, 2011). The visual sensation of

downwards, the idea of something leaking or falling triggers the same negative response as if we had dropped something or it was leaking.

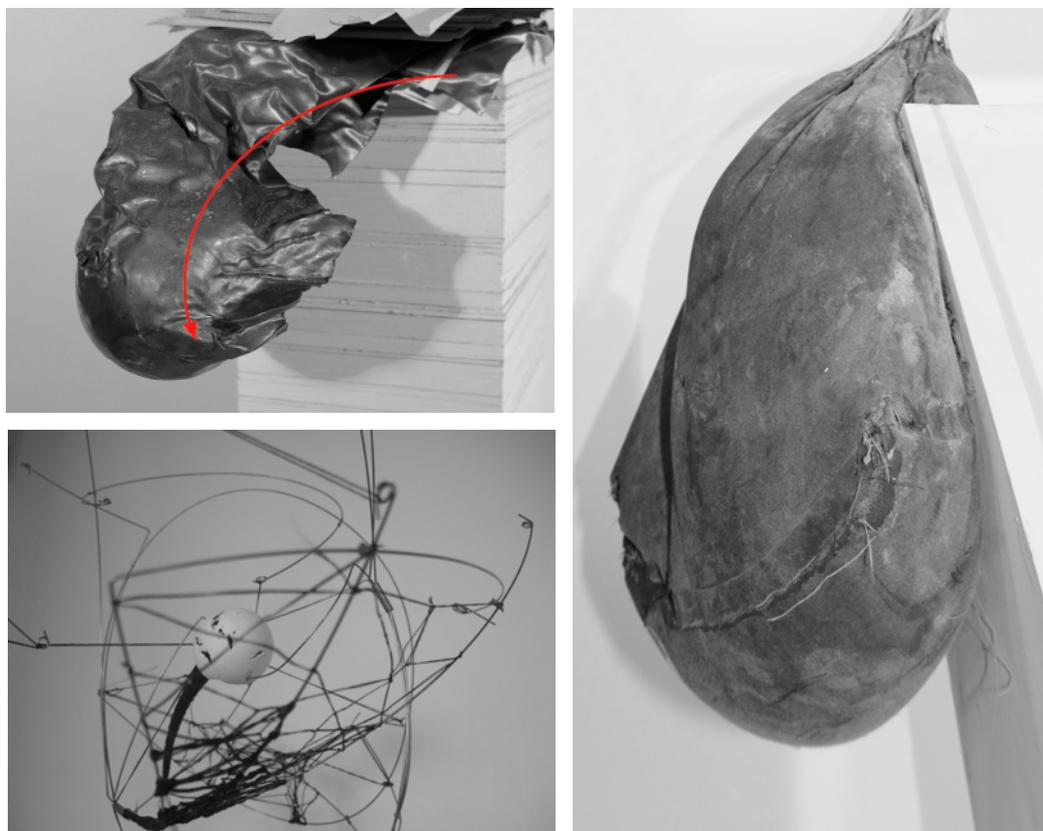


Figure 94: the idea of weight as an expression of effort and fatigue

Strongly related to this is the primary metaphor DIFFICULTY IS HEAVINESS (Grady, 1997) activated in Participant 2's statement, '**the chronic fatigue lifted**'⁶⁰ (Participant 2), or the reference to '**heavy drugs**'¹⁹ (Participant 3). This metaphor was used in the models as a means to convey the effort that the Participant's describe in dealing with fatigue. To describe such an extreme tiredness as chronic fatigue visually I sort an empathetic/sympathetic approach where the visual recognition of weight would trigger an idea of effort or an understanding of something's inability to support itself. With all the models, the idea of *going*, whether that be onwards, forwards, up, etc. is positive; anything denying or undermining movement, pulling them back, or literally weighing them down, has a negative context. Whilst Participant 1 suggests a holding back through the restrictions implied by the thread, in both Participant 2 and 3, effort is expressed by weight, either lead (Participant 2) or cast iron/concrete (Participant 3), both with a sense of being pulled or pulling down.

These inhibitors to movement are representative of the fatigue that shows as a major factor in all the Participant's lives; '**the thing that frightens me absolutely more than anything is the fatigue**'

¹³⁹(Participant 1), Participant 2 describes feeling **'tired on top of feeling chronically tired'** ⁶⁰ stating that the **'exhaustion'**³²² is **'in your whole body'**³²² Participant 3 references that she is **"tired...most of the time"**¹⁸⁷⁻⁸. The importance of fatigue as a symptom of RA, that **'fatigue is an integral part of RA'** (Hewlett, Chalder, Choy et al., 2002, p.1004) can be clearly seen in the Participant's experiences and, although not part of the "core set" of 8 outcomes in disease assessment for RA (Boers, Brooks, Strand, and Tugwell 1998; Hewlett, Chalder, Choy et al., 2002), it is now widely recognized that the individual's understanding of fatigue and its influence on their life experience is integral to appreciating the path of RA (Primdahl, et al., 2019; Nicklin, et al. 2010; Kirwan and Hewlett, 2007; Milton, Hewlett and Kirwan, 2002).

8.1.4 RA AS AN ENTITY, how the disease is visualized in the models.

The divergence of each model although important to me as an expression of meeting different individuals, reflects the varying nature of each participant, three very different people with their own world views and attitudes. What unites them is RA and similarities can be seen in how this is expressed. Although the conversations were focused on each Participant's life with RA, it was a conscious decision to not model RA as a specific 'thing'. The models are an expression of my understanding of each Participant's description of their life experiences and not a description of RA in the body. Rather than any specific or direct descriptions of pain (references were made to knees, elbows, stiffness; **'you amass all that stuff don't you, I had dry eyes and I remember getting the clicky hips'** ⁸⁷(Participant 1), **'aches in my, some of my finger joints'**²¹(Participant 2) **'it's now in this wrist'** ³⁷; (Participant 3) **'knees started to swell'** ⁷ (Participant 3), **'other different joints started to get affected and more just keeps getting added to'** ¹⁵ (Participant 3), **'I can feel it now, it hurts'** ⁹³ (Participant 3)) the overwhelming symptom described was fatigue; **'I think the thing that frightens me absolutely more than anything is the fatigue'** ¹³⁹ (Participant 1). However, even this was expressed indifferent lights by each Participant. With Participant 1 it was reflected in how she fought it through a sheer force of personal energy (**'look at me, I'm in heels, what am I doing? I'm stomping around in heels, my surgeon would have my guts for garters, let alone my rheumatologist would think, but sometimes you just need to put your heels on don't you?'** ²⁰²⁻²⁰⁴ (Participant 1), and whilst Participant 2 claiming to be **'absolutely rubbish at it'** ¹⁰⁸ (Participant 2) allocates a time and place for it, **'my day off work is now...my crap day'** ¹⁷² (Participant 2), Participant 3 carried it with her, her fatigue being just another thing to bring along as she goes, **'mostly it's absolutely fine, but, yeah, really tired'** ⁷⁵ (Participant 3).

All three hide the fatigue from the viewer, their fatigue is personal partly as a true expression of it seems difficult/complex without context, comparable in the eyes of others to feeling tired, which undermines their sense of self and distances them from their communities, as the empathy of others (apart from close personal relationships, **'I have support from my parents who kind of understand'** 67-68 (Participant 2), **'my family, obviously'** 220 (Participant 3)) relies on the public perception of RA, **'all well-meaning'** 2 (Participant 3) but **'you have to shout really quite loudly-----or-----you don't bother----- because it's not worth it'** 11-12 (Participant 2), **'those crumbly, chalky people with webbed hands'** 231-232 (Participant 3).

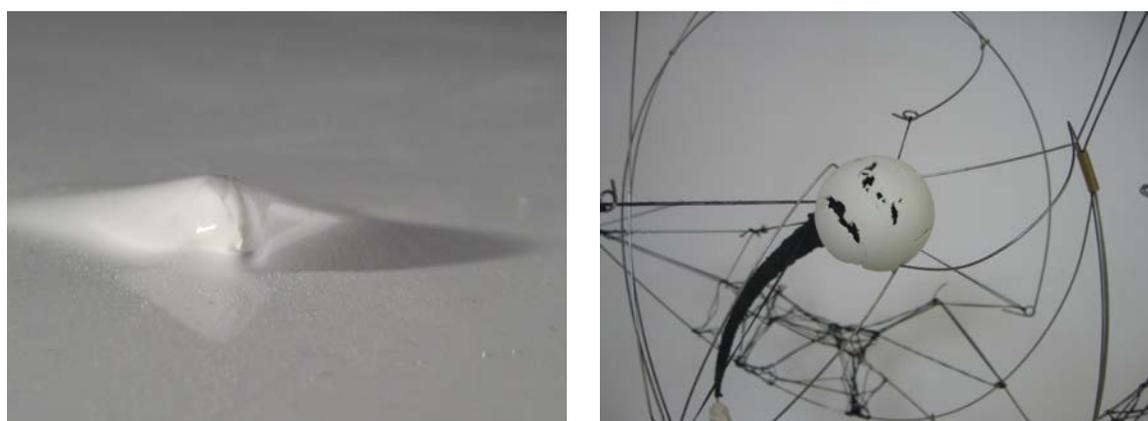


Figure 95: Participant 1 and Participant 3: the RA is expressed as a visible entity, inside but emerging representing its role in the future.

In none of the models were the participants represented by RA, nor was the disease the defining element of the representations. With Participant 1, her professional awareness led to her being more vocal about the disease, discussing RA, a complex series of physical symptoms, cause and effect in a simple manner (**'Anti-Tumour Necrosis Factor, so your cancer surveillance has been switched off'**¹⁵²). The model conveyed both her sense of self confidence and energy (**'I like to have passion----I like to be --you know---go for it!'**¹⁹⁴) alongside her awareness of the fragility of these traits in light of future paths the disease could lead her (**'hopefully I have a bit of a steady period before the next bit goes, but the next bit will go cos... it's a chronic disease'**²⁰⁰⁻²⁰²). RA was represented as a binding, intertwining through the model and inseparable from the form (indeed the binding is integral to the shape). The intention of this was to express the connectedness yet show the sense of difference (her and RA as opposed to her with RA), showing a separate sense from the structure overall, part of the model yet not *of it*.

With Participant 2, her relationship with RA was framed much more around its influence on her life. Aside from **'problems with my toes/my ankles/my knees/blah'**²⁹, fatigue was the dominating

factor, **'the fatigue... still is one of the main things that I suffer'** ⁹⁵⁻⁹⁶, and so RA was not represented in the model, instead the focus was on conveying the effort of being, of having to go out and face the world.

With Participant 3 the RA was always present but never defining; 'I'm in a situation that would exacerbate the pain...I can't concentrate on much else when that's going on-----so I guess in a way it's off-putting'¹⁰⁶⁻¹⁰⁹. I did not want it to appear as though the Participant was under attack, on the defensive, on the contrary she was dealing with it, 'I know it's going to hurt, but I did it anyway'³⁶⁶. The intention in the model was to convey an ever present yet secondary element. By placing it under the model, visualized as excess, the RA is seen as both part of and also something the Participant carries with her, as baggage, a weight, 'because I seem to be collecting pain'⁸³. A sense of RA is also seen on the platform, at the viewer's eye height, referencing its influence on the Participant's future course of action/direction and the fact that she 'had to tell them because sometimes [she gets] a bit of a blue day'⁷².

Also with all the models the references to the experience of RA has an evolving element. This negative connotation is shown as growing or accumulating; more thread binding the model, more paper added to the stack, more inflation increasing the baggage. All of the Participants accepted the fact that **'rheumatoid arthritis is a chronic debilitating lifelong disease'** ^{128 (Participant 2)}, and that **'it's a forever thing'** ^{153-154 (Participant 3)} and these elements in the model were intended to reflect the continuation of the RA beyond the snapshot of this analysis.

8.1.5 BALANCE schema (Johnson, 1987)

BALANCE is exemplified by phrases such as **'on an even keel'** ^{146 (Participant 1)}. To make judgements we draw on the BALANCE schema to **'weigh up'** ^{14 (Participant 1)} our options. When things are in balance they are positive, in the right order, promoting a sense of wellness, **'joints have gone down... chronic fatigue lifted... on balance... it is working for me'** ^{61-63 (Participant 2)}. This appreciation stems from our personal development of a sense of balance, being able to stand and take steps, but also from the

world around us, we see when things are unbalanced, they look unsafe, they may fall and break (Johnson, 1987).



Figure 96: Participant 1 leaning precariously on a pivot point

This sense of unbalance can be seen in Participant 1's model where the upper part of the model, the hip replacement form, the core and the wire frame are precariously pivoting on the tip of the chalk cone creating a sense of unease and fragility. Heightening this sensation, the model also tips off centre suggesting that the model is leaping forward in the rapture of its own **'perpetual motion'** ^{2nd} stge:140 (Participant 1)

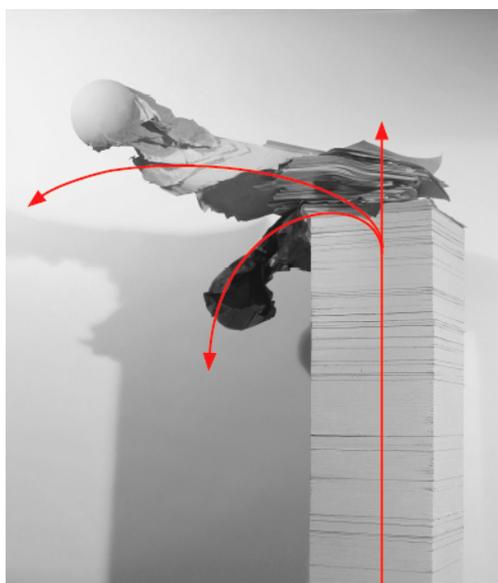


Figure 97: Participant 2 stacked high but everything offset

Compositionally, Participant 2 is also unbalanced with the faces both leaning out from one side of the tall stack of paper. This reflects the **'face'** ^{8 (Participant 2)} that the Participant projects to the world with the understanding of the effort this involves and that she is a single unit unable to uphold this in every situation/direction. The off balanced feel in this model also references the statement that the Participant does not **'have a choice'** ^{114 (Participant 2)} in the actions she takes due to her

responsibilities and illness and as she is unable to weigh up any potential options, so the model follows one path as well.



Figure 98: the sense of balance in Participant 3 is slipping

With Participant 3 the balance is centred around the level playing field, the supporting framework underneath projects it forward as if in presentation, referencing the openness and sense of clarity and fairness the Participant offers; **'if someone asks me...properly asks me, then I'll tell them!'**³³⁹⁻³⁴² (Participant 3). However, the sense of presentation also suggests an offering, 'this is me' because the Participant does not **'want to be singled out'**²⁷⁶ (Participant 3) as different because of her RA.

The fabric cast sack sits on the edge of the plinth, almost falling off, suggesting instability and a future potential failure due to over filling, **'they might just suddenly swell up for no reason'** ³⁹⁵⁻³⁹⁶ (Participant 3). However, the visual weight and size of the sack offsets the large, flat surface of the level playing field compositionally and physically; and the bulbous, organic, unkempt texture of the sack is also counterbalanced visually by the shiny, clean white rubber surface of the level playing field. The Participant comes across as balanced, despite what the RA throws at her alongside the other responsibilities of her life; she seems in control for the present.

8.1.6 VIABILITY IS ERECTNESS (Grady, 1997)

VIABILITY IS ERECTNESS ties to the orientational metaphor-HAPPY IS UP-SAD IS DOWN (Johnson, 1987) and the BALANCE schema discussed above. It is a primary metaphor accounted for 'by the many experiences we have with objects and structures that stand when they are functioning normally, and which fall down when they are no longer in their normal state (e.g., trees, poles, buildings, etc., not to mention human beings)' (Grady, 1997, p.53). For example, the phrase **'blow me down'** ³¹⁵(Participant 1) exemplifies the understanding that up is a positive place.

With Participant 1 the theme SCAFFOLD is used instead of support as by definition, it is a temporary entity that is used to reach one's potential (to support workers and materials during the construction or modification of a building, for example) and then is removed. When discussing support with all the Participants the overriding sense was of SCAFFOLD, external and **'temporary'** ³⁵⁰ (Participant 1), rather than any sense of viability. With references to **'crutches'** ¹⁷⁰ (Participant 1) **'Zimmer frames'** ³⁵⁵ (Participant 1), or **'walking sticks'** ⁴⁵² (Participant 2), for example, this support has negative connotations, a **'horrible brace that you can wear but can't do anything with'** ²³⁴⁻⁵(Participant 2), **'all this kind of stuff that makes you feel old'** ³⁵⁴ (Participant 1).

This metaphor can be seen in all the models; in Participant 1 the off-centring of the model, pivoting on the juncture between the chalk cone and the hip replacement form, suggests that despite the energy expressed in the overall form, it isn't too stable and may topple if pushed. In Participant 2 the stack of paper rises up to the Participant's head height, the neatness of the stack represents a sense of order and control but the papers are not all aligned suggesting a potential instability in the structure.

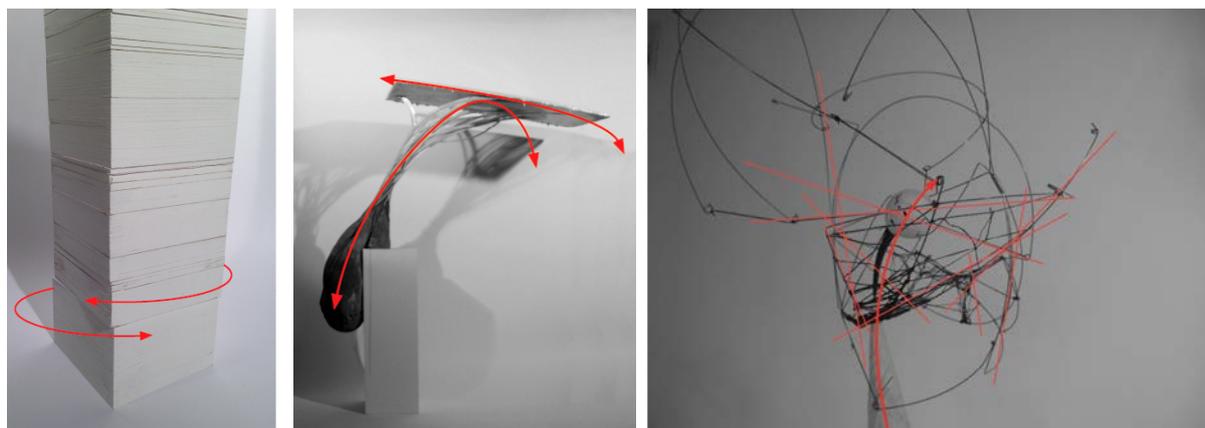


Figure 99: demonstrating the difficulty in staying upright

With Participant 3, the VIABILITY is represented in the levelness of the playing field. This platform should sit horizontally and smooth but the supports do not carry to the edge of the platform and the level drops at the end suggesting a failure in the structure.

8.1.7 SOCIAL STATUS IS VERTICAL ELEVATION (Grady 1997)

8.1.8 the role of the plinths

There was a concern since the conception of the models as to how the models should be displayed to the viewer. In using materials and form to convey the Participants the display stand would always influence the final appreciation. Instead of opting for three unifying platforms, each model on a white plinth, I attempted to build the plinth into each model, not trying to hide them but accepting their role as plinths, with correlating proportions and each defined by the Participant.

The plinths provide, metaphorically and physically, the platform from which the models interact with the viewer. The initial reception of the model, its standing, activates the primary metaphor SOCIAL STATUS IS VERTICAL ELEVATION. This metaphoric concept is seen for example in the social groupings of upper and lower classes. The height of the model dictates how the viewer first perceives the model, are they looking down on it or does it present to them on equal terms, face to face?

Participant 1 the model sits just below eye height. The model itself is relatively small in size and has a sense of fragility with a slight quiver as one moves around it, the Participant on first sight seemed much smaller than her personality came to express. Throughout the conversation, the Participant was extremely confident and therefore although I wanted to show the slightness of frame I did not want the model to appear diminutive.

It sits on a transparent plate of acrylic that separates it from the plinth which is constructed out of spruce plywood, a basic building material that represents a no fuss honesty, which the Participant projected. The separation represents a clinical, clean finish in reference to the Participant's medical background.

With Participant 2 it was important that the model's focus (the paper face) engaged the viewer directly face to face. The motivation behind this draws on the primary metaphor BEING IN CONTROL IS BEING ABOVE, as seen in 'looking down one's nose at someone'. The defiant will of the Participant and the face she puts on to deal with the public/outside world meant that the model needed to engage with any viewer on equal terms.

I wanted this model to be uncomplicated in terms of quantity of materials and forms so that what the Participant wished the viewer to see, her 'face' remained the focus with little distractions, so having the plinth constructed from a continuous, monotony of paper in a stack, representing her relationships with work, tidying up, the medical profession, **(loads of leaflets, so many leaflets that in the end I said I don't want any more leaflets'** ^{232 (Participant 2)}) also allowed the plinth, as a structure, to evolve into the model.

Also, with Participant 3, the plinth becomes another element to the narrative. Although this plinth was constructed more traditionally, squared off, painted white, the model sits on it almost casually.

The plinth is quite low to the ground pre-empting the viewer's focus to remain on the top of the model, the level playing field where the "rules are public, and people play by them, the field is level and the play is fair" (Francis, 2019, p.2). This surface is clean and open to view as the Participant has no desire to put her ailments on display unlike her manager who **'set out her pain killers on the table'**²⁹¹. This platform shields the plinth from view. The plinth is seemingly upside down and has more of the qualities of a bin, drawing on the Participant's references to being **'aspirated'** and, the concept of feeling **'drained'**³⁹⁴; the plinth collects all of this residue, acting as a ballast to the model and as part of the **'the suite of stuff'** ⁹⁶ the participant collects as symptoms of the RA.



Figure 102: Participant 1 plinth and viewer relationship in height

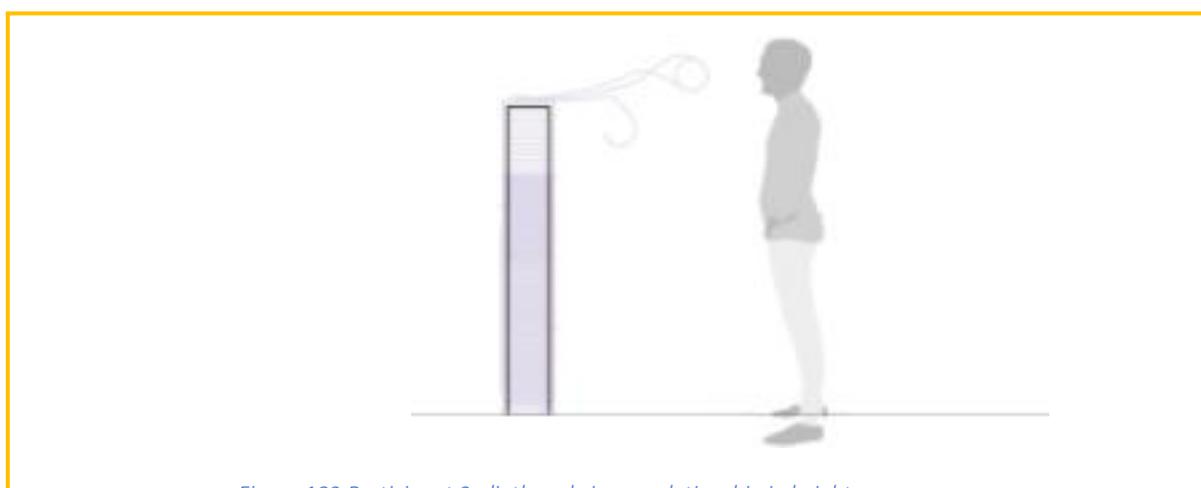


Figure 102: Participant 2 plinth and viewer relationship in height

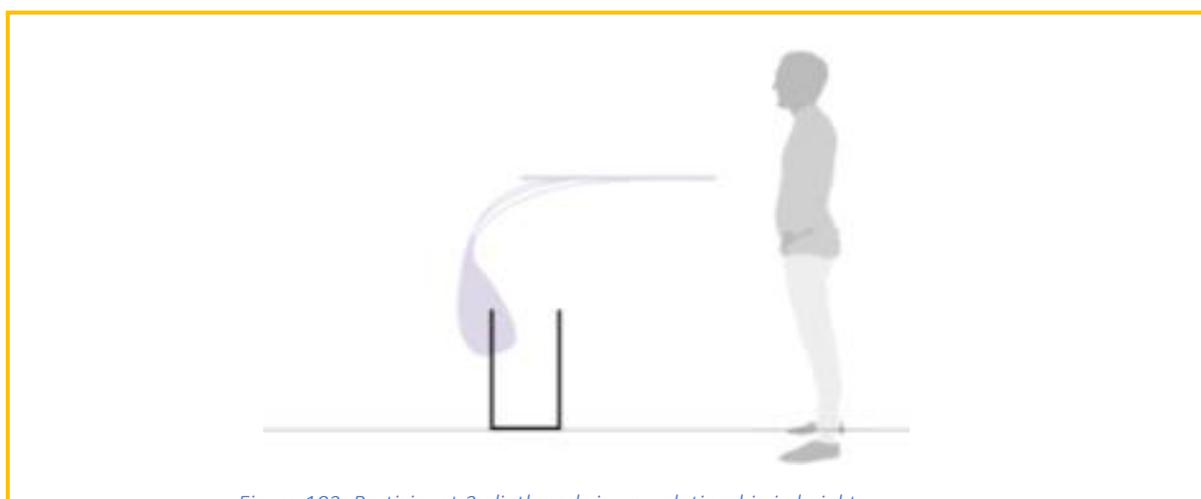


Figure 102: Participant 3 plinth and viewer relationship in height

LIGHT/DARK image schema (Forceville 2013), the use of colour in the models



Figure 103: Participant 3 above and participant 2 highlighting the richness and depth in a material's natural colour

Although the material qualities of each model differ there are similarities in the use of colour. Darker colours express negativity. The colours expressed through the choice of the darker materials convey a deep, imbedded dislike of the unclean (Cox, Pisani, Smith, et al. 2011), a sense of exposure, the

feeling of used. 'The kind of relationship we establish between light and security versus darkness and danger is the origin of GOOD IS BRIGHT/BAD IS DARK, These primary metaphors are related to MORALLY GOOD IS CLEAN/MORALLY BAD IS DIRTY' (Ortiz 2011, p.1571), where, for example, culturally to Western eyes, black is 'bad' (the cowboy in the black hat, the bad witch in the wizard of Oz wears black, the woods where the wolves of the Brothers Grimm stories hide are dark).



Whist this can be seen in the enveloping, black thread in Participant 1, the other models draw more heavily on the cultural connotations of the material's patinas. This can be seen in the earthy, red, rust in the baggage of Participant 3 highlighting a sense of industrial waste and uncared for steel components (a sense of things abandoned at the back of the garden), which conveys both a sense of weight from the mechanistic and metallic and the discarded. The lead in Participant 2 naturally oxidizes to a deep, matt, almost militaristic grey and has connotations of industrial or architectural use (lead pipes or roofing). The lead also suggests uncleanness, as lead is dirty to the touch and poisonous with prolonged contact or ingestion.



With the opposite correlations of cleanliness, expansive, and full of potential, the colour white runs throughout the models, seen in the chalk of Participant 1, the paper of Participant 2, and the rubber of Participant 3. However, in each case the whiteness is tinged with an element of uncertainty, the

instability of the chalk as it crumbles, the overwhelming volume of the paper in the stack and its fragility as it wears and disintegrates in forming the face, and in Participant 3 the gooey underbelly of the rubber platform. White has a susceptibility to stain and this is seen in each model.

8.1.9 CONTAINER schema (Johnson 1987)

The defining point to this schema is that containers bring boundaries, which define an inside and outside. Conceptually any of these elements can be whatever size required, the inside can be bigger



Figure 104: Participant 1, contained within a container within container



Figure 105: Participant 2, overloaded with advice, paper as a container for information

than the outside (Mandler and Cánovas 2014), for example, when Participant 3 **'embraced'**⁴⁴⁵ the medical profession. We can be inside, outside or carry the container. As a boundary the container can be physical, a concrete object such as the body, **'RA's inside'**²⁶⁷ (Participant 1), or conceptual, for example, **'when you step outside of all that horrible-ness you kind of think 'why would you put yourself back in it?'**¹⁷⁹⁻¹⁸⁰ (Participant 1), or both, **'I just need to get out into the sunshine'**¹⁹⁻²⁰ (Participant 1) (Lakoff and Johnson, 1980). Fatigue can be seen as a CONTAINER for participant 2 when she describes the feeling as **'very hard to try and lift yourself out of'**⁴⁴⁴⁻⁴⁴⁵, as could her thoughts we see explains how in meditating **'you don't jump into them, you just observe them'**³⁸¹ (Participant 2). Participant 3 describes herself conceptually as container in becoming **'a bit more open'**⁴⁴⁷ about her illness and physically, being **'aspirated'**⁷ and then **'injected'**³⁹¹ emptied (**'drained'**³⁹⁴) then filled again (**'swell up'**³⁹⁶).

Because of the reference **'I am contained, there is some anchor there'**^{2nd stge:278} the fragile, egg shell like core sits at the centre of Participant 1, which although broken, still offers protection to the ball of fabric within. This core is also contained, lying within the wire frame which orbits it, and this itself is becoming contained by the fabric thread that originally stems from the inner core. This entwining of containers and containment references the auto-immunity of RA (**'you're eating yourself'**²) and

the understanding that the Participant has that in living her life as she wishes she is causing herself harm, **'stomping around in heels'** ²⁰².

The stack of paper in Participant 2 acts as **CONTAINER** referencing information it may hold (fulfilling the role of paper), information that the Participant has no desire for, **'I don't want any more leaflets, I don't need any more'** ²³³⁻⁴ (Participant 2).



Figure 107: Participant 3's history and problems all contained but brought along as baggage



Figure 107: Participant does not show but does not hide how she feels

The sack in Participant 3 is a literal reference to **CONTAINER** and **'baggage'** ³⁴³ whilst the fact that it is solid suggests an uncompromising uselessness.

The plinth in this model also acts as a container for the unknown fluids that drain into it. The proximity and scale of these two elements heighten the sense of accumulation where **'more just keeps getting added to'** ¹⁹ (Participant 3). Less literal, the level playing field also activates the **CONTAINER** schema. The small protrusion at the edge of the model rises out of the rubber like a swimmer emerging from under the water giving a sense of depth to the shiny white surface.

The schema **CONTAINER** can also impose physical attributes such as visual constraints (Lakoff and Johnson, 1980) and it is in this light that the positioning of the level playing field in Participant 3 acts as a barrier to the viewer, hiding the symptoms under rather than setting **'out her pain ... on the**

table^{291 (Participant 3)}. In creating an under the table composition, the model activates the primary metaphor DIFFICULTIES IN KNOWING ARE VISUAL OBSTRUCTIONS, used for example when we describe something ‘camouflaging the truth’ or ‘covering for someone at work’.

This metaphor is a derivative of UNDERSTANDING IS SEEING (Grady 1998) with its experiential basis in gaining knowledge through looking around.



Figure 108: showing behind the mask of Participant 2

This primary metaphor highlights the private-public element to the concept of CONTAINER, what is inside is hidden from view. This is most strongly reflected in the Participant’s attitudes to the symptoms the RA brings, for example Participant 2’s claim that her depression and the RA are **‘quite unseen’**⁵ because they are internal. If they were visible she would **‘get a lot more sympathy’**⁴⁵² what the Participant wants to say is **‘I’m a human being, I feel crap’**⁴⁴⁴ but instead she puts **‘on that face’**¹⁵³. This face protects the Participant because it hides the truth of how she feels even from herself, **‘you’ve put your face on... because ... you have to cope’**^{8 (Participant 2)}. In the model this face is represented by a part formed sphere; part formed as it is representative of a mask, whose role is to hide something behind it. The sphere, as a **CONTAINER** is empty, even if someone were to get inside the Participant, she has **‘nothing to give’**¹⁶⁰.

For Participant 1, opening up about the RA to those around her feels **‘like a disclosure’**^{226 (Participant 1)}, in reference to this, the egg shell core of the model is open allowing the thread to spread. She also explains that public awareness of her RA, as it becomes more visible feels like an **‘invasion of privacy’**^{227 (Participant 1)}, because of this, the model has an open structure allowing the viewer to see all the elements of the RA’s path. These elements to the model activate the primary metaphor

COMMUNICATING IS SHOWING, as does the nothing to hide presentation of the level playing field in Participant 3.

All three Participants have a difficult relationship with the concept COMMUNICATING IS SHOWING. None of the participants have any desire to allow their illness to make them the **'object of attention'**^{331-2 (Participant 3)} but all are aware it may be **'worth telling people'**^{86 (Participant 3)} about it to improve their environment both at home and work. For Participant 1, she is aware that **'you need to say to people you've got it'**^{228 (Participant 1)} because it isn't visible, whereas she explains **'in the bad old days, before those drugs [she] probably would have been in a wheelchair'**^{229-230 (Participant 1)} and therefore very visible. However, she hides her hands, the most visible element of her RA, from view^{207 (Participant 1)}, she is conscious that often in disclosure she alienates herself, people **'take an attitude to [her] about it'**^{226 (Participant 1)}. If COMMUNICATING IS SHOWING there is also a danger in just believing what you see, **'if someone walks into the office with a broken leg, people are gonna go 'oh my God!' someone walks in with depression, people are gonna go 'hi, how ya doin'?', 'Cheer up, we all feel like that'**^{453-455 (Participant 2)}

This chapter has shown how primary metaphors and image schema relate cross-modally by cross referencing analysis of the three models. As discussed at the beginning of this study (see UNDERSTANDING PAIN p.18), the symptoms of RA are not isolatable, anatomically located, solely physical pains. They are experienced holistically, emotionally and psychologically as much as viscerally and they influence all aspects of the participant's personal narrative. Each model was made to convey this experience, translating both an emotive understanding of the situation *and* the appreciation of the physicality in a non-hierarchical language, where they are understood at the same level as part of a holistic 'image' that does not divide along body/mind Cartesian lines. The descriptions in this chapter, with each element under the heading of an image schema or primary metaphor, could be construed as a sculptural vocabulary, i.e. following certain basic aspects that all the models share, namely here, balance, weight, materiality, verticality/horizontality, etc. The visual meanings that the models express, despite their variations in size, form and materials, draw on the same elemental structures as the spoken word yet in combination the subtle availability of meaning each possesses is far greater. It is the iconic superstructure of the model that unifies the metaphoric intent of the model. In this process I have seen this as the visual path the composition of the models leads the viewer, however, models are not linguistically coded and this structure could be interpreted differently. I have attempted to design and make the models so that the core schematic

elements discussed above are pronounced and the composition leads the eye in the way I hoped. In this way, even if seen out of context, beyond the scope of this research and with no link to the idea of the models representing lived experience, the sense of the models, what they say to a viewer will follow a similar path to understanding.

9. CONCLUSION

9.1.1 Reflections on the thesis

As an ontology for research Gadamer's philosophy of hermeneutics, based around his opus *Truth and Method* (2004), has much to offer the creative field, where a great deal of the focus of his thought lay in how truth is to be found in art as much as the reasoning of science.

One of my main focuses within the philosophy was the grounding Gadamer described as necessary for understanding, how we cannot find meaning in isolation from context. Such approaches to thinking are predominantly Western, where answers are found within the subject "characterised by a self-directed 'action' accompanied by a shift in perspective prompted by the observation of something external" (Ansari et al. 2018). The principle of a material or the environment talking back, providing inspiration from 'outside' of the designer/artist is more widely appreciated in Indian and Islamic culture (ibid). In fact, the etymology of the word *inspire*, as 'to breathe life into' has a divine heritage, but what I have offered in this thesis offers a less spiritual approach, I have not advanced the principle that creative acts follow a divine mandate but I have tried to show that they are not the result of some insular *insight*. In discussing Gadamer's ontological stance and placing it as the core to my methodology I have portrayed understanding as a social act and any appreciation of our environment as something that stems from an acceptance of a shared cultural history.

Gadamer's requirement for a historical consciousness, a collective memory that checks our subjectivity and places us in an intersubjective world, where what we say means more than words we use, shows the importance of context in interpretation. In following the path of translating sense for sense rather than word for word (Seleskovitch and Lederer 1995) I was seeking an "equivalence of meaning" (Munday 2009, p.224) based on my experience of the conversations. This appreciation of how we communicate had not previously been applied to the way we experience art or how we could use design to communicate.

Gadamer's concept that we are embodied and enacting in a situation is mirrored in the theories of the cognitive and neuroscientists I have discussed. All the theories discussed in this thesis not only accept that our environment is integral to our cognition but they also draw on the importance of the historical and cultural context that held such value to Gadamer in finding truth. Our ability to engage

in the world is tied to memory (Glenburg 1997), the association and employment of correlated partial embodied experiences as perceptual symbols (Barsalou 1999); how a particular curve in a drawn line places us in a context, seeing in it the emotions of previous knowledge and when applied to our current situation, forming new insights and potential. In this thesis I have applied these contexts as a language attribute of materials and forms in the design of models and used the thesis to outline a methodology for their practical use.

Gadamer's proposal that language is the starting point of all understanding, that we are born into language (2004), can be appreciated through cognitive metaphor theory (Lakoff and Johnson 1999) where the principles of language comprehension are seen to stem from a subconscious embodied awareness we develop from birth, allowing us to make sense of each other and expressing our emotions. I have discussed how materials carry the potential as a medium of this expression and have discussed how models show this, both historically and in practice.

John Ruskin, in *The Seven Lamps of Architecture* (1849, p.74) stated that "To cover brick with plaster, and this plaster with fresco, is perfectly legitimate... But to cover brick with cement, and to divide this cement with joints that it may look like stone, is to tell a falsehood; and is just as contemptible a procedure as the other is noble". Architecture is still pulled by the dictum 'honesty to materials' (Petersen 2012) seeking to build on the intimate relationship we have with the elements of our surroundings. But it is the field of product design and advertising that application through research of the potential of materials in manipulating how we feel has taken strongest hold (Van Rompay and Ludden 2015). We are encouraged to think about certain brands, the usefulness of particular products through the cultural heritage of material language. My hope in undertaking this work was to promote another avenue for research in respect of this language, not manipulative but questioning.

"RA is... a very individual disease with no universal pattern to the symptoms" (NRAS 2013, p.5) and the models made in this project reflect that truth, each different in form offering unique perspectives.

I began this research in looking for a visual definition, a feeling or essence of rheumatoid arthritis. However, once I entered into other people's lives, who generously gave me their time to describe what their experience of life was like living with the disease, I realised that things were not going to be that black and white. Not only was there the uniqueness to each participant, but also the appreciation that I was faced with the complexity of a life, rather than any singular experience

separated like Gendlin's "marbles in a bag" (1992, p.144). Although the analysis was always of the text not the person, the literature on language in this research has shown that context is integral to a meaning's clarity. Ricoeur referenced the perlocutionary stage of transcribing discourse, conveying the influence of emotion and the affective dispositions of those involved in response to what is said *in context*, as the most relevant precisely because it is contextual (Ricoeur 1973; Searle 1980) (for a more in-depth discussion around this see APPENDIX 4). Betty Colonomos emphasized the need to retain the feelings of a message *in context* so that a true interpretation could be made (2015) and hermeneutic philosophy where understanding is not a blind acceptance of information but is always to be found *in context* to our own prejudice, history and culture (Gadamer 2004).

This is also reflected in the methodology applied in the research. By following hermeneutic philosophy over a phenomenological methodology. No attempt was made to generalise the data or seek an essential meaning structure (Dahlberg 2006); instead, the efforts were placed on understanding the individual perspectives offered. The participants were not appreciable as a medical or a symbolic concept and I quickly concluded that no one model would ever have worked. rheumatoid arthritis is lived in a whole life not expressed in relatable parts and just as no one case of rheumatoid arthritis is the same, no life is either.

Suggestions for future research

"What we need is interpretation capable of opening the eyes and ears to the messages transmitted by form rather than distracting them with shapes" (Arnheim 1959, p.9).

The work I have undertaken with the help of the participants in this thesis has been made as means to this end. This thesis has been largely concerned with justifying the ability of models to speak but the ambition has always been for what the models are saying to be heard.

Models are three dimensional objects and as such models need to be experienced. In presentation they are relevant, no longer the dismembered analysis of material and form, metaphor, or iconic reference, they speak as a whole. Arnheim in his paper 'Form and the consumer' claimed that "good form does not show" (1959, p.4); in presentation, the model stands as expression, "the form ...disappears in order to leave only the pure visible embodiment of meaning or character" (ibid. p.4). If all that is seen is the model as an example of models, then the model is flawed. Arnheim explained this in suitably Gadamerian terms:

“In a successful piece ... a pattern of forces transmits its particular distribution of calmness and tenseness, lightness, and heaviness—a complete transubstantiation of form into meaningful expression...As soon, however, as the red circles or the blue bars, the crusts of metal or the carefully daubed areas of nothingness make themselves conspicuous... something is wrong with the ...sculpture” (1959, p.4-5)

I have had the good fortune of being able to have the models on public display at the Social Research Association annual conference 2019 ‘Blurring boundaries and crossing frontiers in social research’, where it was awarded the people’s award for research. Although this was not the first time some of the models had been exhibited, this was the first occasion where the models have been presented without any in-depth, accompanying dialogue such as a research poster. However, the focus on this occasion was on the model as a tool in research rather than raising public awareness of RA. Seeking a public platform to gain data on the model’s impact on individuals outside of a research or academic environment will be the next stage of the project. The initial focus of this will lie with promoting awareness and understanding of RA through collaboration with leading charities in the field, in particular Versus Arthritis UK, where the focus, so long on the models as possibilities, can turn to the message itself.

I have had discussions with different organisations about using the models in a conference setting (International Congress on Systemic Lupus Erythematosus (LUPUS) and the International Congress on Controversies in Rheumatology and Autoimmunity (CORA) and the Pain 360 Congress), proposing that the conferences could host the models in a similar context to the way they would a research poster. However, with current restrictions on social interaction, despite interest there was obvious reticence. The Covid19 pandemic has amplified the value of virtual interaction in knowledge sharing and communication. But it has also reminded us of what can be lost when we do not engage ‘face-to-face’ or when we actually encounter art, sculpture, or models, relating to it, moving around it. Having an immediate encounter with another ‘body’ invites a holistic impression of something complex, feeding our experience and future actions. I am currently focusing on using the models as a means to promote conversation in environments where the complexity of engagement can be discussed and questioned, siting them centre-stage in lecture theatres for students from different disciplines, medical to design, placing them in entrances to conferences as questions to the delegates, alongside anatomical model displays in museums or housing them in surgery waiting rooms encouraging open critique and conversation. These are environments that allow the models

to preserve a context, whilst giving room for criticism. Importantly for the research, they are also environments where the debate can be monitored and documented for future reference.

Contributions to knowledge

I have found my path crossing many others from numerous disciplines and, although some of these are well trodden, I believe that what I have offered here has contributed to knowledge in several ways.

Research such as Moore et al. explore the benefits of patients visualising their chronic pain using medical imagery and (anatomical) models, a mode of communication they believe provides “a more meaningful understanding of their illness and [a way] to manage their condition more effectively” (2019, p.1). However, this is an approach that still localises pain, seeking to further explain the reason, and so to appreciate the symptom, rather than describing the embodied experience to understand the patient.

Alternatively, Deborah Padfield’s fascinating work exploring the visual, figurative representations of described pain (Padfield 2022) approaches pain entirely from the subjective experience and while the work of Padfield et al (2015) suggests an ambiguous response to images as a communicative tool between patient and professionals, her work visualising pain continues to question assumptions about the experience of chronic pain. But in her most recent studies, evaluating the potential benefits of imagery in pain communication (Zakrzewska et al. 2017; Padfield et al. 2015), the work resumes the desire to categorise pain, providing patients with graded ‘pain cards’ they can choose from to describe their condition, a variation on the Wong-Baker scale even if employing more emotive and graphic means to do so.

The models of this thesis build on the understanding shown in the work of Moore et al. and Padfield, but has looked deeper into what, how and why we describe our feelings in the manner we do. I have employed Gadamer’s philosophy of interpretation, a route creatively used in other projects such as Gouzouasis (2013) who established a music research method exploring the multidimensional relationships between tonality and metaphor, or Krantz (2015) who sought creative methods to interpret the experience of students in dance education. In both cases the researchers found themselves confronted with the problem of how to legitimately express the lived experience beyond the spoken word and they too turned to Gadamer. This project continues that narrative, emphasising the importance of dialogue, whilst appreciating the need to develop robust and

creative methodologies to establish a clear creative, visual pathway for analysis, while also avoiding the assumption that arts-based research requires participation with that artistic endeavour, rather than as the expression and conclusion of that analysis.

The depth of engagement with this analysis, grounded in a substantive reality, was important to me, I did not wish to produce a research path that could not be followed. While the resulting models, developed through the many considered sketches shown in the thesis were my interpretation they are not a leap of artistic integrity.

An understanding of how the translation came about means that the path can be traced back. This approach within arts-based research, exploring the breakdown of analysis from an art-based perspective, how literal structures, words, and sentences, can be deconstructed into elemental, embodied meaning, allows translation into any mode of communication. In this research it was models that were applied, physical materials that draw on the deeply rooted cultural cues discussed earlier. But the practical application of embodied cognitive theories such as the foundational principles of metaphor theory within the design methodology and the process of analysis I have outlined here, then translation can be applied to any creative human mode of communication from drawing to dance.

This thesis has contributed to understanding the complexity of the experience of living with RA and I have shown the potential of models to engage an audience at an empathetic level to describing this, offering benefit to those involved.

Visualizing pain is about giving voice to those who need it so that others can understand them. Models have always been used in medicine to “understand the three-dimensional nature of the human form... imperative for effective medical practice” (Smith et al. 2018, p.1) Models of anatomy are now entering a level of reality previously unobtainable using digital scanning and 3D printing technologies (Fredieu et al. 2015).

These new technologies bring material alternatives but what one does with them comes down to how they feel. Walter Benjamin believed the built environment, indeed any physical structure, shapes our habits, how we perceive our world and hence how we are. He appreciated that materials are perceived through use and habit rather than contemplation.

The models in this study explore this deeper relationship we have with our environment rather than seeking for similarities, ‘just like the real thing’; using the accepted medium of models to talk about the patient experience not their condition.

Through a continued discussion with students in my institution, this project has exposed a need to improve the material literacy in design education. With the project's exploration that literacy is not only tied to linguistics, I conceived a student's burgeoning relationship with materials following a similar path to learning to read and write with the ability to compose and comprehend structured sentences directly relating to the ability to apply relevant skills, tools, and processes to a chosen material. An ability to play with a material is key to knowing how it can be applied in practice. Understanding what a word sounds like and how that equates to meaning shared, is to understand how knowing what materials feels like and how they can make others feel. In partnership with academic colleagues, I am looking at ways this can be embedded within the curriculum.

While "our multimodal society means all individuals have a degree of visual literacy from daily interactions with technology platforms" (Morris and Paris 2022, p.107), increased acceptance of digital virtual realities further remove the ability to read materials by constantly prioritising the visual in experiencing the world, a concept stemming from the evolution of gaming where awareness of movement extends your chances of staying alive; our sense of ourselves as part of our environment, proprioception and spatial orientation are completely demoted to visual stimuli. However, this research emphasises the embodied complexity of language and communication and so sees virtual reality technology as a new environment where a metaphorical and multidimensional appreciation of material literacy could be a benefit and will look to further the current debates on modality in the digital realm (Jewitt et al. 2022; Price et al. 2021).

To summarize here on the writing of this thesis:

- I have sought to redefine the role and value of models both as part of the design process but also in the Health Sciences
- I have raised awareness of how rheumatoid arthritis could be communicated through materials and form
- I have increased the potential for hermeneutic studies to include creative practice as a methodology in research
- I have shown that Gadamer's philosophy of interpretation links intuitively with theories of situated cognition
- I have shown a practical application of embodied cognitive theories within a design methodology
- I have furthered the debate on the role of visual metaphors as a means of non-discursive rhetoric

- I have included the concept of the iconic superstructure as a principle in appreciating three dimensional, designed objects and opened up the possibility for further investigation into possible connections between research in sign language and the understanding of form in design.

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11. APPENDICES

I have tried to list the appendices in as temporal an order as possible, relating to the timeframe of the research, although I initially, in **Error! Reference source not found.**, offer the transcripts of the P participant's conversations.

APPENDIX provides the first public face of the research with the open call for expression of interest in a search for participants and the response from lead examiner of the RESEARCH PLAN APPROVAL, a process to regulate the viability and validity of the research before pursuing approval from the University Ethics committees.

APPENDIX provides the Ethics documents submitted for Ethics approval, particularly in the light of my desire for participant engagement. I have included the approval letter as well as feedback from the reviewers with my acknowledgements and responses.

APPENDIX 4 consists of several chapters relating to the establishment of my philosophical position, which I included in earlier stages of the thesis but that have since become surplus to the narrative I have attempted to build. I have included them partly because they provide a potential bridge if the reader finds the links in the text to wide, but mainly they are here as they were positions that were hard fought for in this research and I feel they have earned their right to inclusion.

APPENDIX 5 provides a list of abstracts, publication and events resulting from this work to date.

11.1 APPENDIX 1

11.1.1 PARTICIPANT 1 transcript

1 -and it is a very personalized disease, its auto immune so the one thing you have to sit on and
 2 absolutely reflect upon is that you're eating yourself-----which is kind of interesting but it
 3 kind of sneaks up on you in various ways and its tendrils, using a different metaphor, extend in very
 4 different ways so you are constantly caught out-----by additional diseases that are
 5 associated with the auto immune response.

6 -when you talk about the tripping you up and the catching you out, are you aware of these tendrils,
 7 where they might be? Do you have an idea where you can expect them?

8 -*erm*, yes, because I suppose I'm no more than an interested patient but hopefully with a
 9 knowledge base that should mean I understand more, although it's quite interesting cos I find I often
 10 limit what I allow myself to think about and understand

11 -ok

12 -because knowing full well what the disease can do to you but also knowing full well what the drugs I
 13 take to manage the disease-----can do to me-----which are perhaps more threatening than
 14 the disease itself but its weighing up the balance between what is going on with your body-----
 15 where you would be without taking them vs. where you are because you take them and the risks
 16 associated with taking them, so only last week I was given two additional diagnoses----so-----I
 17 was given---- osteoporosis

18 -right

19 -and pernicious anaemia---I'm depleted with vitamin D which means I just need to get out into the
 20 sunshine but also have to supplement-----so it comes as a kind of a blow-----and then I
 21 kind of reconceptualise it and go 'oh get over yourself' cos actually what's happening is that these
 22 associated diseases all around inflammation-----are to be remedied by vitamin supplements

23 -ok

24 -so I kind of/the osteoporosis I have to take a drug but-----that is really interesting in terms of its
 25 representation and *erm*, you know, the New Mortals exhibition they were talking about this drug
 26 that they've invented/that they've discovered that can make your bones stronger again so, that's
 27 not a vitamin supplement but it's a defensive medicine rather than an aggressor-----to the
 28 disease-----does that.....?

29 -yes/no, go on

30 -but then again the disease/so what I mean about it tripping you up is you, you're toddling along and
 31 then suddenly these things happen and for me-----they do feel like slipping on banana skins, which
 32 is changing the metaphor yet again-----it creeps up behind me its constantly there you/you need to
 33 be aware of it and I suppose with the stalker-----*sigh*----you have to take care, you have to
 34 manage the risk and I suppose-----that might have been how I was feeling when I talked to you
 35 before but-----I don't know how I'm feeling today-----when I think about stalking as a
 36 metaphor, that's not helpful-----*erm*-----and I think that my career with rheumatoid
 37 arthritis-----has been really-----has been really a dance, it has been a dance so -----
 38 suddenly I developed this lump on my hand-----that I used/to joke/was/a banana spider, just
 39 laid eggs and that's what the bump was and I went off and had all these investigations-----I
 40 remember teaching at the medical school and they went 'oh, that's rheumatoid arthritis' and I went
 41 'eoooh, don't be silly' no its not its a -----it's a banana spider laid eggs in my hand-----and I went
 42 to the MRI scanner and the MRI bloke said what he thought it was and somebody else said what
 43 they thought it was, so everywhere I went somebody else said 'it's a ganglion in the wrong place'-
 44 and that was like 'err, ok'-----anyway, in the end I had to go for an ultrasound and I remember
 45 looking at the ultrasound thinking-----'that is a real worry'-----but this left side, right side of
 46 brain not being connected-----I'm not sure if this is what you want to hear but anyway I'm off-----
 47 *erm*-----and looking at the ultrasound/image thinking-----that is really advanced
 48 rheumatoid arthritis recognizing it, recognizing rheumatoid cysts, recog/ and I said to him----what do
 49 you think is going on there? And he went well I'm not here to be able to report to you and I said to
 50 him 'that looks awfully like rheumatoid cysts' and he said 'yes, well you would, you know, you could
 51 say that' and I thought 'ok well, maybe I'm just being/and then you think shut up cos they think
 52 'nurse-neurotic'-----so-----*sigh*-----*urm*-----*tt*----but there was this kind of
 53 thing in my brain which was going no, not allowing that to happen, not, not allowing that through
 54 and then I had to go for a biopsy-----so I met the hand surgeon, this famous hand surgeon
 55 who was not interested in the slightest, said he had to see me cos his wife was working for the

56 rheumatologist and she told him over breakfast-----he had to see me-----and then
 57 I said I think you can see the X-rays and from the ultrasound*um* because they are on the electronic
 58 record and he looked at them and he went/he pushed back his chair and went 'BLOODY HELL!' I'll
 59 put you in the list tomorrow-and it was like *laugh* suddenly I became interesting, he said how long
 60 did it take you to do that and I said it was 3 months---

61 -*um*

62 -this lump has come up in 3 months and that was like even he reacted to it and then I remember him
 63 saying as he went away *laugh*-----I took him chocolates even though his bedside manner was
 64 shocking but I know how to keep, you know. How to contain these blokes and he said well this is
 65 really nice, its really great to meet you cos we'll be seeing a lot of each other over the years and I
 66 was thinking 'oh, thank you *laugh*-----so, he's probably right and this one here is probably
 67 gonna need some attention at some point and actually I'm in the cycle now of a new anti TNF-----
 68 where that normally goes down and this is the first month it hasn't gone down-----cos
 69 normally it would be really quite nice and I'd be showing it off to you but actually it's kind of a bit
 70 bumpy and I am getting webbed I am/I have deviation/so-----*urm*-----
 71 ----so back to stalking-----it's kind of-----creeps up on you and stuff
 72 happens-----and yeah so then they put me on the Methotrexate which made me so ill for 4
 73 years-----I had no life, I worked flat out-----took the drug passed out on a Saturday
 74 night-----regain consciousness came back to work on Monday and worked from Monday-----
 75 -----till Friday evening-----Saturday morning, did some stuff, interestingly I always kept going to
 76 Zumba cos it was kind of like this point of contact and I was moving even though my movements
 77 were becoming less and less-----and then I'd take this dreadful drug which was like having flu and
 78 a hangover at the same time.

79 -As a nurse did you know this was going to be how it would affect you?

80 -no, no because-----I remember saying to the rheumatologist and sitting there, my bestest
 81 friend in the whole wide world came with me and she sat me down and I said to him ok----he said
 82 'well this is what we can do X Y and Z, you see the thing that is bothering me is that in 3 months
 83 you've got a very aggressive form of RA-----and my kind of/I'm a quick care nurse-----if its
 84 aggressive treat it aggressively and I suppose maybe that's the stalker bit, it's aggressive and it
 85 suddenly came on but when I think back over the years there were probably little symptoms I could
 86 have-----you know, you amass all that stuff don't you, I had dry eyes and I remember getting the

87 clicky hips which was pre-empting what then happened-----but so I did the Methotrexate, got iller
 88 and iller because I was on the top wack dose-----and I had 2 other drugs-----and then I
 89 became this kind of recluse because I was just working passing out, never relaxing, never getting rid
 90 of the stress of anything that was going on, just sitting there and feeling ill and mulling it and then
 91 going back on the Monday I must have been as mad as a box of frogs-----and then-----
 92 blessedly, they took my bloods and my liver was starting to conk out-----so that's the point
 93 when they can say we have to take you off this meths and we're going to put you on this new anti
 94 TNF which is very expensive-so they put me on this new anti TNF and it was like wayhay! Life
 95 back/felt like WOOOOF! I've got a life again so I went off did/started being energized, started
 96 exercising-----whallop!/hips went-----

97 -OK

98 -now, whether or not it was because i had more energy from the embroils/so then I had the two
 99 new hips so then I had to come off the enbrel-----for each hip operation, come back, I think the
 100 other hip is going to last 2 years, conks out 2nd hip----have to come off the drug again then I've built
 101 up antibodies to the enbrel so then they have to stop me, then I came back to work after 2 big ops---
 102 ----get the flu that was going around-----absolutely no immunity-----*didididi*-----can't take
 103 my anti TNF so my RA is going/I'm stressed/I'm tired, i'm like RA goes wohoooo! again/hello!!
 104 Whallop! *laugh* and then---*urm*-*sigh*-----and then what happened? -----yeah-----
 105 -----and then I had jury service-----but i got to the point where i was feeling so ill and so breathless
 106 and then I've been to the G.P. and the G.P. said 'oh, by the way---think you've probably got
 107 pericarditis and pleuritis and it was like wh?/wh?/how we going to treat that then? Where's
 108 that/and that's part of RA-----connective tissue inflammation-----and and I'm thinking-----but
 109 i'm not an old person, i'm not frail, I'm not ill but I'm actually breathless and I thought it was to do
 110 with the flu and the chest infection and he said 'oh, what we need to do is put you on a new anti
 111 TNF, 2nd generation anti TNF', sorry/which has got a page like this of complications-----and I
 112 sat there reading it thinking 'oh dear lord do i really want to take that?' I was absolutely terrified cos
 113 its 2nd generation and it's hugely expensive, it's £1000 an injection/you take it once a month-----
 114 --the company phone you up and they talk you through all the complications and they give me
 115 chapter and verse what all the complications can be-----and he said the fatal words 'it may be like
 116 your symptoms you had on Methotrexate' and I went 'WHAT?!' He said 'it could be 2 or 3 times
 117 worse'-----and I said 'you cannot put me back to where I was on Methotrexate even if it's
 118 once a month'. Then I remember talking myself round and talking to my friend and saying can i put

119 up with this, it's once a month---oh, I'm going to get tearful-----*laugh* it's once a month and then,
 120 you know, and then I was getting so ill and then I thought d'you know what---SOD IT! JAB!! *laugh*
 121 -----and then I picked up and it's been/fine, its fine-----so this-----

122 -That takes a lot of guts

123 -Well it's just/it's kind of like, you know, having RA makes you 4 times more likely to get cardiac
 124 disease, X times, 8 times more likely to get lymphoma, there's a whole list of stuff you get, you
 125 know-----if you take 2nd generation anti TNF that is quadrupled risk-----so then you
 126 start thinking-----*pfffff*-----the only thing that puts me off having lymphoma is that I might
 127 have to take Methotrexate *laugh*-----and I'm so phobic about the Methotrexate but even-now
 128 I'm in a space where I've come back and so every time they give me these new diagnoses, these new
 129 drugs and they want to treat the osteoporosis with this drug and the top side effect of the drug is it
 130 gives you bone pain and muscle cramp? I think not! *laugh* given what I've got-----I then/I
 131 thought, you know what-----it's in my spine and if my spine goes-----goodnight
 132 Vienna, so actually just take the tablet get on with it. 15:00 So its a pattern

133 -hmmm

134 -and I'm a hysteric/I have been hysterical -----about it-----my friends
 135 must be in despair with me for it and actually-----on my friend's birthday, my GP phoned-----
 136 'this is the new list of things'-----and I just burst into tears-----before I reconceptualise it/it's
 137 vitamin supplements, get on with it-----so I'm now in a situation where I think
 138 the thing that frightens me absolutely more than anything is the fatigue-----and post
 139 operatively it's the fatigue that stops me being what I can do/it furs my brain/it slows me down-----
 140 -----and I have two social criteria, don't let your hair fall out, keep drinking coffee, let me use my
 141 hair dye-----social-----shallow and vacuous to the last-----but-----what's my
 142 absolutely, absolutely is my bottom line and the thing that turned me around about the pernicious
 143 anaemia was it could be the pernicious anaemia that could be making me go bald and not the
 144 simpony though all the drugs could be making me go bald as well/it does not matter, if I can keep
 145 dying it and I can keep drinking coffee we are on an even keel-----so-----

146 -fatigue, work/life balance?

147 -I was doing 80 hours, I was doing 18 hour days-----

148 -does the routine help the framework?

149 -maybe-----I was subject to verbal assaults and threats, which is an interesting metaphor for
150 what's going on in the joints cos that's what's going on in my joints-----chew/cho/cho/cho/cho and
151 that's/this anti TNF/ Anti-Tumour Necrosis Factor, so your cancer surveillance has been switched off-
152 ----it's a fairly scary thing to switch off in your body

153 -yeah!

154 -yet I know, as someone in the position I'm in, that the external stress-----is not good in
155 terms of me getting wound up and I'm somebody who gets wound up but then I don't harbour it----
156 --I do tend to fizz with it----so-----which is another metaphor for what happens in the joints-----
157 this disintegration-----so I think/my friend said/it's interesting it's all heart chakra stuff, it's all
158 inflammation and all the rest of that stuff comes from the heart chakra it would date back to
159 something that you're harbouring from way back yonder and you're actually positioning yourself in
160 work life to be a metaphor for what's going on inside you or that it's feeding----and you are kind of
161 hooked into the whole pattern of behaviour-----whatever, maybe interesting.....

162 -Maybe focusing on life rather than work?

163 I'd need to be genetically modified for that to happen because at the end of the day I like to serve a
164 useful purpose, that's what probably made me controversial-----in the roles that I had because I
165 wouldn't sit back and go ok-----I wanted to help-----although people often thought of it as
166 me being 'would you get out of the way and stop causing complication'-----so-----
167 we are what we are-----and-----last year when I couldn't move/when my
168 hips were really bad and it was just-----awful and it happened *click (finger)* really suddenly---
169 -----and my pelvis was broken at the same time/it did re-break and I'm wondering around on
170 crutches trying to carry on-----couldn't do it/couldn't sleep/couldn't sit/couldn't stand/taking loads
171 of drugs which were making me incoherent I was trying to drive/shouldn't have been trying to drive,
172 so I'm up and down, you know-----you get into a pattern cos you have to cope cos there is a bigger
173 thing happening outside what's happening to you-----and then suddenly I was told by my boss
174 to stop 'you have to stop now and go off sick'-----I was like you wha/a/bu../ jus...wha...really?---
175 ---mortified, mortified that he thought I was incoherent but I was incoherent-----and then I went
176 off sick and I had my hips mended and I came back and I was like 'whoa!!' but it was really
177 interesting because the hands had been taken off the greasy pole and its taken ----I can't tell you

178 how long, to try to get my hands back to engaging-----because when you step outside of all that
 179 horrible-ness you kind of think ‘why would you put yourself back in it?’

180 -yeah

181 -----so I’ve taken a different role with it so it’s not so much my problem although other stuff
 182 happens and it percolates up again, does not it, cos that’s how we work-----but one thing this
 183 is not going to do to me and that’s why I hate the fatigue is to stop me being-----useful---
 184 -----

185 -fatigue? 80 hour weeks?

186 -I can’t do that anymore-----at the moment I can’t-----you know—I can’t

187 -the fatigue, is it like physical exhaustion or a child-like ‘switching off’?

188 -it is---*urm*-----I first felt the physical exhaustion when I fell off my horse and broke my pelvis
 189 and in the process of healing the fatigue of healing first hit me-----that was when I/before I was
 190 diagnosed with RA and then I noticed that I had this fatigue-----a little bit-----I’ve been pre-
 191 disposed to liking my sleep all my life really---but---when that lump came----the thing I really
 192 noticed about myself was fatigue-----because I think I’m a fairly high energy person, I work with
 193 energy, I like to have passion---I like to be --you know---go for it!-----so when you have that thing
 194 that you can’t---I used to be able to catnap, wake up after half an hour and be able to run, get up
 195 the next morning and do something but this thing you cannot do that-----you don’t ever wake up
 196 feeling refreshed-----and that’s horrible-----so now there is a new
 197 hope with the pernicious anaemia that the B12 will make me feel less fatigued-----it might
 198 not, it might do, but there might be a combination where I have a window where we all get settled, I
 199 have a really healthy time-----and then hopefully I have a bit of a steady period
 200 before the next bit goes, but the next bit will go-----cos it’s not a cure, it’s a chronic
 201 disease---so-----*mmm*-----but look at me, I’m in heels, what am I doing? I’m
 202 stomping around in heels, my surgeon would have my guts for garters, let alone my rheumatologist
 203 would think, but sometimes you just need to put your heels on don’t you? *laugh*-----hah!,
 204 and kick them!!*laugh*

205 -

206 -Anyway-----I've started to do this—I've started to become embarrassed about it in certain
 207 company

208 -Are you conscious of other's looking?

209 -*erm* I remember sitting on a bus talking with my friend about what we were most terrified of
 210 Multiple sclerosis? Kidney disease? RA? Which would we prefer? RA I think, although I couldn't
 211 decide----I remember that conversation soo clearly and do you know what? She died, she got RA,
 212 she died in child birth, she got it in her twenty's-----yeah-----and
 213 then, my flatmate, my bestest friend,-----she had it when she was a teenager and it sort of
 214 went away-----which is interesting that its not come back for her-----and then, I got it-----
 215 --in my old age, not to put too finer point on it-*ur*-----three of us from one flat had RA----I don't
 216 know-----but I live in a very small village and 10%-----10% of us have RA or lupus-kind of makes
 217 you think 'hang on a minute!'

218 -1 in 6 in UK have or know someone who has RA type disease

219 -well, the way I trolley on about it all the time, but the only reason I talk about it/people say 'I know
 220 somebody with RA, it's her, she rabbits on about it all the time'-----but actually I think it's
 221 so obvious in my hand that I kind of think-----'oh heck!,-----that does really feel, like kind of
 222 very obvious'-----and I know when I meet new people—I'm kind of really conscious of it and
 223 people looking at my hand and -----and-----I've met new people and
 224 they take an attitude to you about it-----and it does feel like a disclosure

225 -like an invasion of privacy?

226 -----yes, but I feel that you need to say to people you've got it because it's a chronic
 227 disease and in the bad old days---before those drugs/given the speed-----with which that
 228 came on for me-----I probably would have been in a wheelchair-----maybe not-
 229 -----but when you go to the clinic and see people who are those crumbly, chalky people with
 230 webbed hands and they are like this and it's because it all happened to them before the great meds
 231 came along-----but I know that there are 2000 people from that one clinic that are on the
 232 drug that costs £1000 per month-----and we are all the people who are at the
 233 stage where they are giving it/it's unsustainable-----

234 -yeah

235 -and that's what scares me/that scares me-----that really scares me-----
 236 -----cos you think there's one thing that's holding back the tide although its not holding it back
 237 too much at the moment 30:45 but I'm feeling a bit better-----but-----if they suddenly
 238 said we can't afford it, we stop paying for it-----I could sell my house-----then where
 239 do I live? What do I do?-----and then I'm thinking, yeah, but actually, I could probably pay--
 240 -by the time I sold my house, had a roof over my head, rented accommodation and had to keep
 241 going-----how many years could I keep going? Paying for the drug at that rate?-----
 242 so-----*urm*-----

243 -nice of them to tell you how much it cost!

244 -I asked

245 -Fair enough

246 -I did say to the GP that I must be a bloody nuisance, I must be so expensive, I mean, a one way
 247 ticket to Switzerland would be cheaper and he said 'believe me you're not in the top 5%'-----
 248 -----so there are people who are on different drug procedures, but I do feel, you know, 12000 each
 249 hip, 12000 per year, I nicely round up to 12 anyway

250 -The drugs were your choice, no?

251 -yeah-I remember saying to the rheumatologist when it was first diagnosed, he said 'look, these are
 252 the options...' and I said 'look....what would you recommend, I mean, I know I'm supposed to be
 253 empowered and supposed to be a really intelligent person that should know/that should be
 254 informed about this and know what to do but, actually, I'm terrified, I'm thinking about the bus
 255 conversation, thinking 'bloody hell! This has happened to me and obviously I'm not going to die in
 256 childbirth, cos I'm not going to have a child, but she was so debilitated because she didn't have
 257 access to these drugs I'm/he said 'what treatment would you like?' I was like 'Oh! You tell me mate!'
 258 and I said to him 'please would you tell me what you would recommend if this was your wife in this
 259 situation, on the proviso that you love your wife *laugh* What medication?' and he said 'you need
 260 to go to the top triple-----which is the top intervention that we can do but that's why it
 261 whalloped me, that's why I was so ill but there are colleagues who take much lesser stuff who get on
 262 with Methotrexate, it's fine yet actually it knocked me for six and there were external people who
 263 came in who saw me that ill but largely I just hid under the duvet and just shut the front door but it
 264 was horrible-----and that for me, is the point I do not want to go back to but its the

265 drugs-----not the RA-----but the RA's inside isn't it? But the drugs are the things that you
 266 voluntarily give to yourself

267 -yeah

268 -so when I go back to stabbing myself with that drug when I knew all the complications and actually--
 269 -----we've run some clinical trials but we haven't a clue what will happen in 20 years time----I
 270 don't know what I'm putting inside me but it's just making me feel better for now 34:30 and I just
 271 want to live because I've had episodes where my life has contracted down, this sounds.../people
 272 have much worse times than i had but to a level of misery and social isolation that made me feel
 273 very sorry for myself-----because I would not let people in to see it-----
 274 ---and I pushed people away from it-----so now I feel I have to declare it in friendships, close
 275 friendships-----and some people go 'oh, ok' because they don't get what it is and other people go
 276 'mmm, my Aunty had that' *urm* gone...never see them again, never hear from them again cos
 277 that's like/but I do feel some of that but it could be my personality *laugh*

278 -Declare it? Is it part of you? Do you feel you want to know the full extent?

279 -the full extent is horrendous and they don't really know, cos, what they used to do in the good
 280 ol'/bad ol' days if they didn't understand something was to call it auto-immune-----*laugh*--
 281 *urm*-----which was not good because what they used to do was chuck loads of steroids at you cos
 282 that's what they thought they could do with auto-immune disease, now they've got all this
 283 repertoire of stuff they can chuck at you and its complications, but it is about short term gain and
 284 their view is 'yes, it's expensive but it would be far more expensive if you weren't working, if you
 285 were at home needing care-----which is true, but there are things, for
 286 example, I totally ignore-----there is no evidence of RA in any skeletons they have dug up since
 287 before they started importing manufactured sugar to this country-----there is only evidence of
 288 RA in skeletons since the introduction of sugar, manufactured sugar is the absolute no-no, alongside
 289 nightshades, tomatoes, potatoes, peppers, chillies-----I'm a vegetarian-----so---
 290 -----I remember/I actually can't eat raw tomato, I look and think I crave you/I want you but I go to
 291 put it in my mouth and it's like-----'I can't do that'—which is interesting, but for me a big night
 292 out is a *laugh* a tomato pasta bake, it used to be champagne---now-----it's some tomatoes---in
 293 moderation, you know, when I first got it-----'right, I read everything which you're not supposed
 294 to eat, gluten, you shouldn't do this, you shouldn't eat sugar, you shouldn't have any flour base, you
 295 shouldn't have any of the nightshades, you shouldn't have diary, you shouldn't...I'm a vegetarian, I

296 was left lettuce and avocado-----I remember going/having a bit of a breakdown in
 297 Sainsbury's *laugh* going around thinking there's nothing I can eat!----but thinking actually I'm
 298 going to get really tearful about this as there is actually nothing I can buy, there is nothing I can eat
 299 apart from avocado and lettuce, which, in the end, made me laugh so much that they probably
 300 thought we need to go and fetch somebody for that woman, she's having a bit of a do-dar 40:09-----
 301 -----and then you just got to go let's get this in perspective because if you read the internet
 302 you end up with nothing so-----I then/I just started to reintroduce bits and pieces but the one
 303 thing I haven't given up and that I do-----absolutely abuse-----chocolate-----which is stupid---
 304 ----and the coffee----the rheumatologist said there was no evidence about coffee but the websites
 305 go on and on...no,no,no-----but come on! Hey! A girl's got to live! So-----it is about
 306 thinking and discovering/strawberries, I loved strawberries, can't eat strawberries-----and,
 307 actually, eating plums make me very 'euuugh' and if I eat loads and loads of tomato based stuff I
 308 'euuhghg', so you work it out/I can't look a pepper in the face—I would dissect a meal to remove
 309 pepper

310 -chilli powder?

311 -spicy food? Yeah, you can eat it but you'll know about it

312 -I thought spicy food was good for joints?

313 -well, you know, there are different types of arthritis and blow me down I've got OA and RA, which is
 314 actually slightly genius, I think, but-it's not unusual but-----everything----I'm not unusual-----
 315 my reaction to it is-----is, slightly hysterical, but I do use, I always have done, tried to use comedy---
 316 ---to-----which you may or may not have found

317 -*laugh*

318 -but I do try to use comedy-----to give an account of it

319 -mmm

320 -*urm*---and*um*-----yeah-----I do-----*um*-----I can get very down-----but the
 321 rheumatologist said that's IG6 and that's the inflammatory marker and that's apparently what gives
 322 you fatigue and it makes you feel low but actually absence of B12 and all the other stuff that's going
 323 on can all make you feel a bit like that so most of it's during the day so at least I can say what I need
 324 is the B12

325 -yeah

326 -which is kind of good

327 -In the design of things around you is there anything that bugs you would help? I notice you type
328 well...

329 -Thumping type! They said to me when it got diagnosed 'shall we get you in Dragon?' and it was like
330 'noo!' and then they wanted to get me a whirly thing and I said 'Noooo!' *urm* the one thing I did
331 accept was the little plastic thing that goes around pencils

332 -oh,ok...

333 -and my handwriting is getting worse and worse but when do we ever write these days?-----
334 *um*-----that finger has got fat-----and that's for texting 45:44 that really annoys me, how I
335 manage to have a bit of a fat finger-----opening-----I can't open things-----
336 -----I had to concede, my mother, she keeps giving me all this stuff she/the thing to open stuff

337 -like a ratchet type thing for the lid

338 -yeah, and she wanted to also get me some RA secateurs, which I should cos one of my hobbies is
339 flower arranging, which is a bit sad and tragic but actually secateurs kill me, a session in the garden--
340 --VERDUNCK!-----but, I love my garden, I love flower arranging, I'll always do extreme flower
341 arranging, which is hanging from the window sills and they all going 'should you be up there?' like,
342 last year's flower festival was the day before I went to surgery and I was hanging from the window
343 sills, and the only concession I made to it, one new hip, one absolutely shattered, I was in such a
344 state and I had a mate at the bottom going 'left a bit, right a bit' so I didn't have to keep getting up
345 and down, but I was determined I was going to do it, but that was the secateurs, my mom wanted to
346 get me some stuff for the garden which is particularly for RA'ers with these big fat handles, but it
347 was 'NO!!'----so there are certain things you have to give in to-----*um*-----and it was
348 interesting because when I had the hips, but the hips were temporary and I'm so proud of my hips—
349 and I do talk about my hips because I think they are a work of beauty, those titanium hips, they are
350 like Jimmy Choo heels-their fab!-----nothing to do with me, they're just in there-----
351 but-----they are just---you know---you had to have the raised loo seat, you had to do this,
352 you had to do that, you had to do the other, all this kind of stuff that makes you feel old, walking on
353 a Zimmer frame, and then crutches-*eughh*-----somehow I coped with that because it was

354 temporary, the handles for the RA are like an admission of where you've gone-----I don't
 355 know/I guess they do do knuckle replacements, so at some stage when that gets really whonko they
 356 will, perhaps, put one in there-----but at the moment what that means is I've got to weigh up
 357 coming off the anti TNF for two months-----having surgery/getting
 358 back on it but then wanting me to wait two months so it would be four months off anti TNF, so-----
 359 ---when I came off my anti TNF before-----boy, did it teach me, for the surgery cos you have to
 360 come off cos your immuno's are suppressed-----did it teach me!! How much I needed it-----
 361 and that was worse than anything else that went on...

362 -immunity?

363 -no, yeah

364 -I thought it was a physical drug?

365 -well, the rheumatologist put it as antibodies and the clinical nurse said there is no evidence----but
 366 yes your body can start to build up a resistance-----and if you are on it and you come off it, you
 367 know what you are like on antibiotics don't we-----this is the thing that happens, so yeah-----
 368 every time there is a deterioration-----and the other thing is the balance between people
 369 saying 'should you be doing Zumba?' and I thinking 'yes, cos it keeps me moving'

370 -Zumba?

371 -Zumba is, I love it!-----it is salsa meets aerobics, kind of shaky, rattley around, joyful music of the
 372 festival, just fantastic 49:52 and it's a workout and you know-----women of a certain age in
 373 lycra and some young people crowded into a small room, shaking our stuff on a Saturday morning
 374 and it's the fellowship that goes with it/it's a sisterhood and we're all kind of purple and wheezing
 375 and some people can do it and we are the old birds at the back-----just to get some air and-----
 376 -I just love it!-----but Zumba for me is the metaphor of being well

377 -?

378 -and even when I was on Methotrexate I went to Zumba and the girls were all around me/we did the
 379 Saturday morning thing so everything had to be done before I went to Zumba cos I did Zumba-----
 380 --then had a wash/did shopping/jabbed and then I was out-----so-----it is this kind of/the
 381 antithesis of RA and often, when I'm dancing and I'm dancing and I'm well—I think 'thank you' cos
 382 the/I am being well looked after because I could, potentially, not be doing this-----so, for me, the

383 joy is in the dance and it's such a joyful dance, the salsa, the Brazilian, the Mardi Gras, lively, lovely
384 music and again the reason I love it is 'the music's so loud you can't hear yourself scream, or go 'ow'

385 So it's-----it's moving-----but people say 'should you be doing that kind of movement?' and
386 there is this dual thing of should you be doing more passive stuff or should you be doing more active
387 stuff and that's the stalk of it because you're living, while you're living in the moments when you are
388 well-----and maybe I should moderate—I don't know-----I think-----it'll get
389 you/it'll get you anyway so you might as well go for it-----then buy the ticket to
390 Switzerland----that's my opt out clause

391 -did you used to dance?

392 -I wish! I always wanted/we are sitting on this demographic time bomb, we all want to exercise
393 more but the consequence is we are all going to degenerate very early on-----and the incidence of
394 people having to have hip replacements under 60 is just on the rise--knackering their body-----so,
395 no, I didn't dance-----I always wanted to and I love to dance but I never gave myself permission to
396 have the time to go dancing cos I've always been working and it has stopped everything-----
397 even now-----I live on my own with my dog, who also9 has arthritis and I think if I had
398 family around me would I keep having to push myself to do more?-----or—do I allow myself
399 the luxury of conking out but when we talked earlier about fatigue, people say they can see the
400 colour just drain from me and I have to say to them/I have to go and lie down/or they say 'up you
401 go, you need to disappear cos you've just gone'-----*um*-----you can't fight it-----you
402 just have to make sure that you are somewhere not here because you have got to get home58:05

11.1.2 PARTICIPANT 2 transcript

- 1 -how do you feel?
- 2 -ok, um , the thing I was going to say was that I have, um, I have a history of depression as well
- 3 -right
- 4 -and its interesting because-----it's interesting---to me, having been nearly a year into Rheumatoid
- 5 Arthritis, they're quite unseen-----so-----when you're depressed, unless you're crying-----or-----
- 6 -----very miserable-----people don't think you're depressed
- 7 -mm
- 8 -because you've put your face on, you've come out, you know, because its, you know, you have to
- 9 cope sometimes, you know, and ----it's the same with Rheumatoid Arthritis, a lot of people say to
- 10 me 'oh, you look great' and that, that's been the same with depression as well, so for me, this is like
- 11 another thing where-it's almost like you have to shout really quite loudly-----or-----you don't
- 12 bother----because it's not worth it
- 13 -mmm
- 14 -erm, yeah, so-----it's, it's, it's quite a steep learning curve
- 15 -so, you feel like you have to prove it in a way, like, I need support?
- 16 -when I first was diagnosed, I started to get ill, erm, ill, sort of at the end of 2015
- 17 -right
- 18 -I didn't know what was wrong with me but I started to feel, I started to feel chronically, get ---
- 19 chronic fatigue, I started feeling crap. Can I swear?
- 20 -of course!
- 21 -right, I felt like shit basically-erm-and then I, I started getting sort of, you know, aches in my, some
- 22 of my finger joints
- 23 -right

24 -and in my wrist-----urm-----my Doctor said I was probably, um, RSI, I got a mouse-----
25 but come March, just before March, ----I went to the Doctor because I felt really dreadful. I'm a
26 single parent, so-----um----for me, I was working four days a week,-----coming home,
27 and having to lie down because I was-----totally fucked, I can't describe the tiredness I felt, and in
28 the end I went to the Doctor and I said exactly that, I I feel fucking awful-----um---and then he
29 looked at my joints and/I had problems with my toes/my ankles/my knees/blah/and then I had the
30 blood test and then it was confirmed it was Rheumatoid Arthritis

31 -is this the same Doctor who said initially they thought it was RSI or

32 -no, it wasn't, that was actually a nurse--cos-----in our surgery, if it's not serious, sometimes you can
33 see a senior nurse

34 -yeah

35 -you know/and I kind of understand-that initially----you know---it's like, I work on a computer, blah
36 blah blah, and all the rest of it and/in fact it was in this wrist and that has gone-----bizarrely--but
37 it's now in this wrist----cough-but/so she might have been right/I don't know-----but it was, it was
38 kind of the start of it, if you know what I mean

39 -yeah

40 -urm, and then I had----I was put onto--this drug called Methotrexate

41 -uh hum

42 -which you must know about-----which I was adamant I wasn't going to take-----because I see
43 a chiropractor, and they were very kind of 'no you mustn't take it its really awful blah blah blah'-----
44 ---and I'd read a lot on the internet/which I probably shouldn't have done -----urm

45 -but it's hard not to though right?

46 -yep/it is/but, you know, I want to be informed-----urm-----but basically, 'ha', by the time
47 I'd seen a consultant and she'd explained exactly what would happen if I didn't take the drug-----
48 and what it would do/I came out with a prescription-----because I thought I don't want to be
49 crippled----

- 50 -yeah
- 51 -and that's basically what she said ----would happen-----um-----so, I had six weeks off work----
- 52 -----with the Methotrexate, because it knocked the crap out of me-it
- 53 -yeah
- 54 -its--its a horrible, horrible drug
- 55 -yeah----how did that affect your depression?
- 56 -oh, oh I felt awful/it was a horrible six weeks-----
- 57 -it's a terrible mix, no?
- 58 -yeah, yeah/I mean my depression's managed at the moment-----um---but I was very aware of
- 59 the fact that that was a very ----good trigger-----um, so it was/it was it was a horrible six
- 60 weeks---really-----because I think because I mostly just felt so awful-----because the
- 61 Methotrexate made me tired on top of feeling chronically tired-----um-----and very sick, cos you
- 62 know, it's a chemotherapy drug isn't it, so, yeah, it was, it was miserable-----urm-----but,
- 63 my finger joints have gone down--and-----eventually, the chronic fatigue lifted---a bit, I mean,
- 64 it's not completely gone-----um--so I have to say on balance-it's you know, it is working for me---
- 65 -----not a 100 percent cos they've just upped the dose again for me
- 66 -right
- 67 -because I've still got a lot of swelling here, in my knees, and/you know, it's sort of intermittent and
- 68 that so they want to get it into remission-----urm-----but, you know-----I have support from
- 69 my-----parents [5.00]-----who----kind of understand, I think, my mom understands, yeah, she
- 70 had cancer 20 years ago so she knows what a chemotherapy dose does-----although hers was quite
- 71 different cos it was a bigger dose to--and--interestingly--when I was diagnosed, my dad was actually
- 72 also diagnosed with polymyalgia-----which is also an auto immune disease-----but it affects your
- 73 muscles-----not related--urm-----so basically, he couldn't move his arms-----at all-----and he had
- 74 to take steroids and that so, he kind of understood it from that point of view, like, what it's like to
- 75 be-----you know-----physically unable to do stuff, when, you know, you were able to-----
- 76 before I took the Methotrexate, when my hands were bad I couldn't open a packet of crisps-----I

- 77 couldn't open my cat food pouches, I couldn't, I couldn't squeeze a flannel, I couldn't, I couldn't open
78 a door, I -you know what I mean, it was really-----
- 79 -did you/when you were describing the actions was that before you were diagnosed?
- 80 -mmm ^(AFFIRMATIVE)
- 81 -what did you think was going on?!
- 82 -urrr-----I/I mean there had already been some kind of notion from the Doctor that, you know,
83 this could be, this could be this-um--so it was already in the back of my mind/I knew that there was
84 something not right because my fingers hurt and you could see/they looked like arthritis fingers/big
85 swollen knuckles, you know----um-----so yeah, it was kind of/I suppose I was in a bit of denial-----I
86 don't want this-----at all
- 87 -'ha'
- 88 -this is like, this is really bad, what does this mean-----I'm gonna have to change my life, I'm gonna
89 have to -----stop doing the things I do, yeah, it was hard but you know,--it's amazing how much you
90 adapt in the end-----you know---I can cut through pouches with my teeth, my elbow but, you
91 know, at the end of the day, it's like this is really, really rubbish-----because I've got a ten year old
92 and a job----
- 93 -boy or girl
- 94 -boy, so that was difficult as well, cos, you know, he's very physical and I couldn't play basketball
95 with him anymore, I couldn't I just couldn't, do things with him----I think for me though, once,
96 when----they started me on the Methotrexate they gave me a big shot of steroid-----which was
97 amazing! Fantastic! It was like it all went-----but I still had the fatigue and I think the fatigue
98 has been one of the/and still is one of the main things that I suffer, one of the main symptoms
- 99 -so that just hasn't gone away?
- 100 -----its better
- 101 -is it there all the time or does it

102 -what the Rheumatoid Arthritis generally or t

103 -no the tiredness/not tiredness fatigue its kind of exhaustion really

104 -yeah it's like the difference when you're depressed, it's the difference between having a bad day,
105 and depression and being tired and, you know, so, so again, it's that thing of being like 'oh dear, we
106 all have bad days' or you know 'I feel like that sometimes' and 'we're all tired aren't we' that kind of
107 thing and you think ok I can't have this conversation with you cos you aren't in the same place as
108 me-----urm-----the fatigue, I think, um, is about managing energy levels, that's what I, that's
109 what they try and teach you to do and they/you know/you have to think about your energy in terms
110 of bags of energy and I'm absolutely rubbish at it-----because, if I feel good I'll go and do loads and
111 loads of things, the problem is, with Rheumatoid Arthritis is you pay for that, whereas if you don't
112 have it you can do loads of stuff, get it done and just carry on but whereas with Rheumatoid Arthritis
113 the day after, the day after that you are absolutely done or your joints have come up again
114 something like that, that what I find---and it's something that I haven't managed to do, I'm not good
115 at doing it

116 -yeah, well I understand, you want to do stuff, it's your life

117 -and also, I'm a single parent so I have to /sometimes I don't have a choice it's like, you know, I take
118 my son skateboarding on a Thursday after school so I drive from here to Hove and pick my son
119 up/we go home-----and then we drive back over to the BYC and there have been a couple of
120 times where I've thought-----I'm so tired I could cry, I am, I am sooo tired, I can't do this, and
121 I've suggested to him that maybe we don't go and it's like, 'what? what do you mean? [10.00] and I've
122 thought, I have to go, he's not old enough to understand

123 -does he get that you are not well?

124 -he does get that I'm not well but he gets it when he sees me trying to walk down the stairs-----
125 when he's behind me and I'm trying to get down the stairs in the morning and I suppose he's 10, I
126 mean, how much empathy do you have when you're 10, not an awful lot really, yeah, you know, I
127 mean, sometimes, I don't know if it's a pang of conscience but suddenly he'll say 'are you alright?'
128 and I'll say 'not really no' but the thing is, because he's a worrier -----I don't want to start putting
129 that on him, I talk about it now, I, I, I told him I'm meeting you today, I've told him I'm having more
130 medication, so he knows I have it but he's clever enough, I don't want him going on the internet and

131 looking it up because some of the things say, you know, Rheumatoid Arthritis is a chronic debilitating
 132 lifelong disease -----he's just gonna think 'oh my God, my mom's gonna die' so I don't think he's
 133 worked out how to spell Rheumatoid Arthritis yet so

134 -it took me a while!

135 -'ha', yeah, so I think -----yeah, he understands as much as a 10 year old understands anything and
 136 even if he understands it's like-----it's like, you know, it's about them isn't it -----'you're tired
 137 but I want to go out' ---'come on mom'

138 -so, if you don't mind me asking, how old are you?

139 -48

140 - I thought you were younger, talking about your mom and dad understanding and friendship groups
 141 not understanding 'feeling tired too' etc. but do you have a friendship group that understands?

142 -um, the most, the group that understands the most are my work colleagues who are my friends-----
 143 and I think the reason they understand the most is because they see me the most-----because
 144 they are aware of the amount of time I'm not at work, when I'm late for work, when I've got hospital
 145 appointments, etc., etc. and when they see me coming in and they see this, they see me limping or
 146 whatever, um, as far as my other friendship group goes/no-to be honest with you I don't think any of
 147 them give it a second thought -----because they don't see it-----um-----I live in Hove so you can
 148 imagine that a lot of the people that I'm around -----are middle class families, and I've got some
 149 very good friends but-----Most of them are families, they are family units, so even as a single parent,
 150 they don't get that, so I have the classic 'my husband works away in the week, 'I know what it's like
 151 to be a single parent'---er---no you don't, you have no idea, that's really insulting---really insulting,
 152 but I'm not gonna go there because I've done this for 8 years now and I'm done with people saying
 153 stuff like that so I say 'yeah, I know' so-----yeah, if people don't engage with that then having
 154 Rheumatoid Arthritis/because they see me, at the school gate, 'here I am', you know you wouldn't
 155 know would you

156 -no

157 -but it, part of it is you put on that face, you have to go out, you know, I can't go up to the school
 158 limping, partly because I don't want my son thinking 'crickey!' here comes my mom, what's wrong
 159 with her!?' um----and also because it is a positive thing, I have to, for myself, try to keep myself fairly
 160 buoyant but then people didn't see me on Saturday when I spent all day on the sofa because my son
 161 sees his dad on every other weekend, all day on the sofa having taken my new big dose of
 162 Methotrexate -----and I was really, really ill but there was nobody there to see that-----I
 163 couldn't eat anything, I couldn't do anything, I was tired, the house looked like crap, one woman
 164 phoned, and actually she did she said do you want me to come round? and I just thought no I can't
 165 cos I've got nothing to give you ----and I don't want you to see my house like this because, you know,
 166 she probably would have been absolutely fine and said, you know, 'I'll just help you an that' but urm
 167 --I felt to ill for that and I think if it had just been a case of can you just/would you mind just coming
 168 round and helping me cos I just felt too ill I thought I don't want to speak to anyone -----so no I
 169 don't have a group of people like that/I have a couple of/I know one guy, one of my friends who has
 170 um-----he has a form of arthritis but it comes out as a form of psoriasis, er, one's liver and one's the
 171 skin thing, it's the skin thing anyway,-um-----but I think that's different I think that's a/ I don't
 172 know if that affects him, I don't know but I don't think it does -----in the same way

173 -do you try and organise your dose intake around your son?

174 -no, I don't because I have to organise it around, it's usually one day a week that I feel really bad so I
 175 have to organise it around the one day I'm off work, which is a Monday, so I take the dose on a
 176 Saturday-----and for some reason it seems to be late Sunday/Monday that it hits me so my day off
 177 work is now my -----you know, my crap day-----because I can't be at work like that-
 178 um--it the moment I'm trying to cut down my hours so I just do three days, so I get one day a week
 179 that I feel ok and I can actually do something nice or, you know----but I can't afford to do that at the
 180 moment----er-----so that's how I have to arrange it, so if my son's around and I feel crap I've just
 181 got to suck it up, somehow or you know, I mean I can text a friend and say that would you have my
 182 son ta-da-da, I'm not feeling very well-----

183 -but you want him too no?

184 -well I do, don't get me wrong, I do two weeks straight and two days off, two weeks straight and
 185 two days off so trust me there are days when I think 'please'

186 -'ha'

187 -I mean if you want to have him for the day that's great because I do need that sort of headspace
 188 anyway, RA or not, it's quite an intense relationship, Sometimes when his dad comes I am literally
 189 counting the hours down, I'm thinking you can't come quick enough, so if he texts me to say he's
 190 delayed I think that's half an hour too long, cos you know, if it's been a week that's been quite
 191 intense, or I've not been well or my son's been a pain in the arse which he can be its just I want to
 192 shut the door, be alone, I just want it to be me and the cats and that's it and it's like just letting go of
 193 that responsibility and doing what I want to do, so if I don't want to eat or cook food or make
 194 something that I should make ----you know, it's my time, it's when I can go out or get pissed or do
 195 whatever I need to do --so it is nice-um-----but I think that thing of, if I say to certain people I'm
 196 not feeling great because of this-----they'll say 'oh, I'm really sorry'-----but it doesn't go really
 197 beyond that so I don't think there really is a -----an understanding

198 -what about medically? Is there someone there?

199 -well, the way I see that it works, I have a consultant [20.16] who I see, who's like the head of the
 200 Rheumatology department who I've seen once and then since then I've seen her registrar, and then
 201 a nurse-----er-----the consultants aren't really interested in your day-to-day, they are there
 202 as a-----you know-----this is what we are going to give you and ta-da-ta-da-da' its medical, its
 203 not kind, its nothing like that at all erm-----which is quite hard sometimes, --er-----but then----
 204 er the nurse is slightly better, there's a guy I see who seems quite nice/he seems to have a bit more
 205 humanity

206 -'ha'

207 -no, seriously, because the consultant that I see -----has, er--well she's as dry as anything
 208 really, I mean, there's just nothing there, I mean, her registrar that I was seeing until just recently
 209 was just awful, I mean she was really super posh-----clipped, kind of girl who that I really
 210 didn't like, there was just nothing -----nothing there sort of thing erm, I've got a new one now who
 211 seems to be slightly better, she seems to be slightly more concerned if you know what I mean, erm--
 212 ----the nurse has a bit more humanity I mean, he laughs some times which is nice, you know what I
 213 mean

214 -yeah

356

215 - you can talk to him-----erm, but they did refer me to occupational therapy, which was ok but I
 216 think the thing is that, I think that I'm not at that point where I need any ---aids or anything--thank
 217 God-----so they kind of give me tips on doing exercises on your hand and all the usual stuff kind of
 218 thing and its kind of ok but it only goes so far -----because actually what you really need is
 219 somebody around for me anyway, ---that's what you need is somebody----around who'll say 'I've
 220 done the shopping' or you know -----erm-----so-----yeah, I can't complain in terms of how
 221 quickly it happened and they seem to be pretty on it and pretty efficient but it is a bit like a machine-
 222 -----they'll go 'here is your disease activity score, ok its a bit high/let's try you on another drug
 223 see how that goes da da da see how that goes with you even though I'm not taking that I took
 224 another drug for a day and I thought no, it made me feel so awful not taking that -----urm--

225 -which drug was that?

226 -I dunno, hydra, hrydra chlor/hydra clim hydra something whatever, it is just something that they
 227 said usually is something that works best with Methotrexate and a combination of one or two other
 228 drugs, so they gave me this other drug and said right, you know, give yourself three or four weeks,
 229 side effects should lessen but I took it for one day and I felt really awful, it was like being really tired
 230 but really wired, you know, banging headache, really sick and I thought no I'm not doing that for the
 231 next three weeks!

232 -'ha'

233 -because, well, it's the Summer holidays for God sake, I mean I've got to work, I can't do that, I can't
 234 be like this for three weeks-----I've just come back to work, you know, I'm on a monitoring
 235 exercise with work now because I was given a written warning for absence -----i can't do this,
 236 I have to be at work and I have to function so I binned that one and they just said that's fine erm----
 237 we'll up the Methotrexate and if that doesn't work we'll try you on -----a different drug -----
 238 ----you know, the consultant's main aim is to get the disease into remission -----once they've
 239 done that, you know, if you've got problems with your hands, you can't open tins then go and see
 240 the occupational therapist and the occupational therapist gives you loads of leaflets, so many
 241 leaflets that in the end I said I don't want any more leaflets, I don't need any more reading
 242 material/and a horrible brace that you can wear but can't do anything with -----erm, and do these
 243 exercises and -----'sigh', try not to smoke I suppose, try not to smoke, try not to, try not to
 244 drink too much (REALLY QUIET) and -----But! but, but it is a space where the first time I

245 went I just cried I just sat there and I just cried because I just felt so awful that day anyway and I was
 246 really tired and the whole thing was just 'pah'-----I just don't know what I'm really doing at the
 247 moment -----and there's a lot of stuff on the internet about alternative therapies, about
 248 which diet works -----and it goes from vegan-to paleo, you know, 'you must be vegan! blah blah,
 249 vegetarian, no you gotta be veg, no normal diet to paleo and everything in between, this is what will
 250 cure it this is what ta-da-da-das and even within each of those groups there is contradictions-----
 251 don't eat hazelnuts/do eat hazelnuts, and in the end, I just had to bin all that cos I was so confused
 252 the medical-----professionals view on it is a healthy diet-----that's it, they won't get into any
 253 dietary, it's like just eat a healthy diet, so, yeah ok-----

254 -yeah

255 -I was told last week when I had my meeting with this woman, and she did tell me the first time
 256 actually, you have to stop smoking-----up until then I actually volunteered the information cos
 257 the first time I went to see the consultant a year ago I thought yeah I'm gonna have to give up
 258 smoking, I know that's gonna come up and she didn't mention it and I thought, er, ok I'm not gonna
 259 mention it but the next time I said I smoke and she said well you know you should give up but one
 260 thing at a time, so I thought great, carry on, but this consultant was like no you have to give up
 261 smoking, which I haven't ----yet-----urm, because it could make it worse, could make it worse?
 262 it's thought to be a factor in causing Rheumatoid Arthritis, it's one of the things, but then smoking
 263 causes millions of other things can't it-----so, yeah, so it can delay the effectiveness of I
 264 don't know, whatever-----I should give up smoking anyway but you know it's the one thing that
 265 keeps me going sometimes, I mean, I'm not a massive drinker although I am a bit of a binge drinker,
 266 when I go out, I drink and I get twated and that's it but I don't do it very often/they're not too
 267 worried about that, it's just moderate alcohol-----you know, she said a couple of glasses of
 268 wine a week, I don't drink like that, I don't drink at home I go out and I get ---pissed,-----

269 -'ha', save it all up

270 -absolutely! and -----and basically what she did say, which was quite useful was if you do that,
 271 because I do realise that you have a life to lead, just make sure that if you're having a blood test
 272 after that you do let us know that you've been drinking because it will show your liver function as
 273 being high, because you've been drinking and we don't want to think it's the Methotrexate that's
 274 doing that -----we need to know that that's vodka-----actually just before Christmas I'd

275 been out and I cancelled my blood tests because I thought it's a bit pointless really, its gonna show a
 276 rather odd reading, yeah, so-----for me, on a, some of the things that have changed for me is
 277 er going for a walk for example, because I know if I went for a walk, walk down to the seafront, walk
 278 down to the pier, if I do that now, I'd be in pieces by the time I get home probably and the next two
 279 days that'll be it everything would be swollen and sore and stuff-----so-----that's something
 280 I have to think about now, you know, if people say 'do you want to come out for a walk?' its 'how
 281 long are you going for? What does that entail? Because -----I can't, I can't stride through the
 282 countryside anymore, I have to be careful of stuff like that

283 -about the work, the University from what you mentioned earlier doesn't seem to understand your
 284 position?

285 -I have -----I don't have a very good absence record -----primarily to do with my mental health

286 -right

287 -over the years----but also because I was off quite a lot before I was diagnosed with Rheumatoid
 288 Arthritis [30.15] I didn't know why but I was sick quite a lot but that was why I was getting sick and
 289 then I had this long period of absence and basically-----because it was -----i don't know, flagged,
 290 it was raised, it basically triggered a formal written warning

291 -??

292 -yes, I know, but it's about choosing your battles, if I'd had the energy I would have gone for them,
 293 really gone for them, and said this is absolutely out of order -----however, I just thought---
 294 pick my battles here, I need to get myself well urm-----since I've been back I've ticked all the right
 295 boxes ----I've used a lot of my annual leave on days that I've needed to be off -----and I've, I'm now
 296 off of that, -----so-----but I've had to use my annual leave to say 'I'm not coming in today,
 297 I'll take it as annual leave rather than taking it off sick-----which is not fantastic cos I only get 15
 298 days a year cos I'm part time-----what really pisses me off, is I know that there are many, many
 299 members of staff that are off sick but never sign a sick book, it's never recorded -----that really
 300 riles, really, really riles-----urm-----yeah, I have to take it, I have to use annual leave if my
 301 sons off sick as well so it's quite a precious pot for me.[32.46]

302 -can you tell me about any misconceptions of your illness you've encountered?

303 -most people just think 'it's Arthritis' where you can't move your hands, yeah?

304 -yeah

305 -what I didn't realise is there is Osteoarthritis, Rheumatoid Arthritis, and they're very different, and I
 306 think for me, the thing for me is that Rheumatoid Arthritis is, is that it is a systemic disease, so-----
 307 ---even if your joints aren't so bad, it's in your body and, so the way I see it is your body that's
 308 fighting all the time and that is why you feel crap and tired and that is quite significant -----it's not
 309 just-----I can deal with, more with----I've got quite a high pain threshold, I can deal with pain more
 310 than I can deal with fatigue, you know, I am quite bad at being tired but chronic fatigue, for me is
 311 harder to deal with than a sore toe -----you know?

312 -yes, of course, that makes sense, although I think no-one can truly understand fatigue unless they
 313 experience it, I've obviously been tired but is the fatigue you describe always there or does it hit you
 314 on occasions?

315 -urm-----sigh, ---yeah, I think-----it's a tricky one, cos as a parent, I'd say you pretty much say
 316 I'm knackered anyway, you know, first, this all started when I hurt my finger, this was last Summer, I
 317 hurt my finger, I got massively swollen, couldn't move it da da da, and I saw this woman who was a
 318 hand/wrist specialist and stuff, and she started asking questions which weren't relevant at the
 319 time/now they are-----she said to me 'are you more tired than normal?' and I said to her, 'I'm a
 320 single parent, what am judging this against?, Are you a parent?', 'no' she said, so I said 'so you won't
 321 understand when I say of course I'm tired I'm a parent One-I'm a single parent'-----and I just
 322 thought, 'stupid woman, what a question!' but--come Christmastime, I thought-----now I
 323 know what she means, cos that is when the fatigue hit-----and that is quite different, and I've
 324 thought how I would explain it to somebody and it's definitely, it's a physical--you know that kind of
 325 -----head tired you get with a child, you literally, you feel like your head is made of wood, you
 326 know? You feel numb from the neck up, you know, there's nothing in there, you feel so tired, I'm
 327 either sleep deprived or my child is being such a pain in the arse I cannot, they won't go to sleep or
 328 something and you feel 'argghhhh', but it's almost you feel so tired you feel a bit mad, you know?
 329 Shit, I'm so tired I can't----but you will get some reprieve from that by sleeping, at some point, and it
 330 might be years but you kind of think 'oh, I'm not so completely knackered!' and whatever,----but
 331 this, this is like----just an exhaustion, in your whole body----so-----sigh-----yeah-----
 332 -----and I think it kind of is there, when the disease is in control better, and you have managed to

360

333 deal with your bags of energy and you've had a bit more rest/your mom's been down/your mom and
 334 dad's been down and done a bit of cooking-----yes, I can feel it, yes it's a bit less, there, a bit less
 335 but I can't remember the last time I woke up in the morning and didn't get out of bed and feel like
 336 my body is sort of made of lead-----that sort of ----sigh,-- 'right -----'

337 -and you know this before you sleep, you don't go to bed thinking when I wake it will be something I
 338 can deal with?

339 -no, not anymore-----not anymore no, and in fact,-----a couple of weeks ago, I got out
 340 of bed and my-----both of my feet, and my heel, and my toe, and my knee, and everything, it all
 341 really flared up and I stood at the top of the stairs, and it's almost like I almost can't be bothered to
 342 try and get down here, cos it's so painful but also what happens is because you're compensating,
 343 you know what I mean, I can't go down the stairs like that, I have to go down like that, and so I've
 344 pulled my lower back, and my shoulders cos I'm trying to support myself on the banister and so it's
 345 like my whole body is just completely fucked, I just can't be bothered/can't be doing with this
 346 anymore and I just wanted to go back to bed but I can't because I have got to go to school, but
 347 usually, it takes an hour, maybe an hour and a half, and then everything starts to free up but that is a
 348 classic sign, they always ask, 'how long does the morning stiffness last?', and sometimes, when it's
 349 bad, it's all day/it's just there, I feel very stiff and heavy, and other times-----it's just slightly
 350 better

351 -do you notice it going? Do you find yourself feeling 'quite good?'

352 - I do,-----but because I feel more mindful, I'm doing mindful meditation so I'm trying to be a bit
 353 more mindful about -----recognizing the good things and not just the bad things, so, trying not
 354 to think/not to focus on the fact that everything hurts,-----to go, oh actually that's much better,---
 355 -----

356 -what do you mean by mindfulness?

357 -well,---mindfulness is-----in a nutshell, is---about being present,-----so being in this
 358 moment [43.28] and paying attention to what is now as opposed to worrying about what is going to
 359 happen-----and what has happened, and mindfulness meditation is combining those things----so,
 360 meditation is about letting go-----um----and finding that quiet space, but the mindfulness part of it,
 361 is kind of teaching you through that meditation to be present, to be present with your body, to be

361

362 present with your breathing, and the idea is that after you've done that, that you take that with you,
363 so that you-'live in the now, man!'-----but it is good, it does help!

364 -so did you start that because of this or before, because of the depression or--

365 -because of the depression, yeah/and it definitely, definitely helps, yeah/I use an App called
366 'Headspace' and I try to do it every day-----um-----kind of----yeah, because it does, it
367 does make a difference, it just does, it's strange because nothing has changed -----nothing has
368 changed except your mind, your perception and that moment of doing that-----but, I do
369 feel better, so it's like 'ok, I'll keep doing this', but the bizarre thing is, you know, this App is good, it's
370 one of the main reasons for this becoming mainstream, because they are trying to take away the
371 whole Hippy aspect of meditation, and say this is really good and really positive for everyone-----
372 -so it's not just like joss sticks and mung beans, you know-----this is actually a really good thing to
373 treat your mind really well, because it's about your mental health

374 -so how long does it take out of your day to do a meditation?

375 -well, they are talking about 10-20 minutes

376 -oh,

377 -but you'd be surprised how hard it is to do that 10-20 minutes and that's the whole point of it, it's
378 like -----they know that people don't do that because it's -----it's-----you can't even say why
379 people don't, but, um, ---when you start it you do 5 minutes, so you do 5 days of 5 minutes, 10 days
380 of ten minutes and so on and there is lots of different ones you can do for lots of different aspects
381 like relationships, or depression, or I'm doing one at the moment which is about gratitude, so it's just
382 about being -----grateful, present and grateful for what is/for what you have and, you know, it does,
383 it makes quite a difference

384 -it sounds like exercise

385 -that's exactly what it is ----it is, but it's exercise for your mind, it is about training your mind to
386 think, it's not about training your mind to think in a different way, they talk about blue sky and that
387 you imagine your mind as blue sky, and the clouds are all your thoughts and you jump into the
388 thoughts and we follow them and we get engaged in them and so the blue sky gets completely

362

389 obliterated, so when you meditate you allow those clouds to completely go so the blue sky is there
390 but it can't be there unless you can stop engaging with the thoughts, the thoughts are still there, you
391 can have millions and millions of thoughts, we all do, but you don't jump into them, you just observe
392 them and come back to breathing, especially when you start you get distracted and you realise that
393 you are thinking about something, but he'll say 'if you feel like you're distracted, you go oh! and
394 come back to your breath, and breathe in again, it is, -----you have to practice it, I've got a very
395 active mind, so you do realise that you've started to think about dinner tomorrow night or
396 something/whatever, but it is about finding that space in your head-----I recommend it-----
397 ----it's about that thing of just sitting quietly, sometimes I do it sitting in my car, coming back from
398 work, it's -completely silent. So this meditation thing is that chance for you to find some headspace. I
399 don't do it in the morning, I haven't got time and also I'm too tired, I'll just fall asleep so-----If
400 my son is away I can do it then/I'm more inclined to do it in the morning -----but usually I do it
401 when he's gone to bed----um-----and its good, it's really good, and the fact is the more I
402 talk about it the more I think 'yeah, actually' ---um-----but it's about practice/it's about
403 disciplining yourself to do it, and it is bizarre because it's like 10 minutes a day, you can----once you
404 finish the start pack -----everyone you start you can choose whether you do it for 10,15 or 20
405 minutes, but I do the maximum, I do it for 20 minutes, but it is still only 20 minutes -----

406 -mmm, I was expecting much longer

407 -no not at all, you can but not initially, some people build up to that, they swear by it, they get up
408 half an hour earlier and meditate for 40 minutes every morning-----and they feel great, but I'm
409 not quite there but I kind of get it,-----

410 -I imagine this working/helping with the 'bags of energy' thing

411 -you know what it is like when you've got so much in your head that you cannot think straight, so it
412 is a little bit like -----you clear that out, it's still there but you're not engaging with it, and
413 sometimes I think you need to do something to not engage, you know, to -----to sort of,
414 reset, if you like, you know, I mean,-----I watch TV, I don't watch TV in the week, I do it again, I binge
415 -----I'll save up stuff that I really want to see and when my son is away I'll do 2-3 hours of crime
416 drama, which is what I love, Nordic noirs, and I love it cos I'm totally in that and I don't think about
417 anything but it's not quite the same as letting your mind-----relax, almost [51.33]

418 -it's interesting that you have to train your mind to relax

419 -I also smoke, though I tend to use smoking as a procrastination tool, I'll just have another fag sort of
420 thing, oh that's an hour gone and I've just been sat around thinking about stuff but not really doing it
421 productively, and I think the difference with the mindfulness-----the meditation, is-----it's kind of
422 focused-----relaxing, if you know what I mean,---

423 -yeah, absolutely

424 -as opposed to a bit 'fleugh', so you could have your cigarette but you could still be thinking about
425 stuff-----but I suppose it depends how you think, could you could be smoking, thinking I've got
426 to do this da da da, but I suppose the headspace is like, all of those thoughts are going to be there,
427 but you are just going to let them, I always imagine like bubbles, or balloons, just drifting by and I
428 was trying to explain this to my son and I was saying that you could grab hold of them and you can
429 look at them or engage with them or you can just let them go, you don't have to -----cos he says 'I
430 can't stop thinking' and it's like 'you can', well, you can't stop thinking but you can stop yourself
431 engaging with the thoughts that you have/it's quite a hard thing, obviously, for him to understand
432 but -----he has anxiety and I'm trying to help him manage those anxieties in a way that will
433 help him----in the future, -----but I think, in terms of the Rheumatoid Arthritis, yeah,
434 there are some days, if I have a head full of -----'maybe I should start a new diet, maybe I should
435 do this, da da da', I get sucked into the Internet again and then I come out and thinking 'oh my God, I
436 don't know what to do, I'm gonna have a pizza tonight-----and 20 fags' 'ha'-----it's like I need to
437 reset, so I need to do this -----try to clear my mind a little bit and then sometimes in the
438 morning I think 'ok, I've got a better perspective on this,...I'm not going to become a vegan, that's
439 ridiculous but I am going to try--to ---stop---eating sugar'-----or cut down on, you know-----
440 -----

441 -when you do the meditation, do you treat RA as one of the balloons/clouds?

442 -no

443 -so do you see it as part of you or a thing?

444 -I see it as a thing...oh, do I?-----it's just what is, it's just there, now, no it's not, most of my
445 thoughts will be completely to do with 'oh, have I paid the ParentPay, what are we doing this

446 weekend, or I must take out the da da da' and then sometimes it's more general things, it's kind of
 447 negative thoughts/it's more negative/it's about negative thinking/this is shit, I feel shit, why did this
 448 happen to me?-----all that stuff/I'm crap, I could be a better mom, all that negative self talk we
 449 give ourselves, which I have to say, I'm very good at-----it's something I've become more aware
 450 of through this mindfulness, listening to myself-----so, ok, when I'm thinking like that I'm going to
 451 [55.50] be aware that I'm thinking that thought, I'm going to brush it off/I'm going to think something
 452 better-----it's more like that and I think that helps to -----um-----make you more aware, for me,
 453 it's about being more aware of what's going on in my head and how I can almost -----
 454 perpetuate that feeling of-----feeling crap by spending the time thinking I'm feeling crap, it's like,
 455 how can I get myself out of that mental groove----I mean sometimes, you have to be able to say 'I'm
 456 a human being, I feel crap', and it's very hard to try and lift yourself out of that and say-----I/do
 457 you see what I mean, I mean, if you are in pain, or if you are really, really tired but on a day to day
 458 thing, how can I move myself away from that sort of spiral, it's like depression, how can I stop myself
 459 from spiralling down, I mean, I accept I'm depressed, I accept I have these negative thoughts, but I
 460 don't have to keep jumping into them/I don't have to hang on to them and go 'yeah, I am a shit
 461 person, blah blah', why do I always feel depressed, why is it always me/no!, let's find a different way.
 462 I think with the Rheumatoid Arthritis yeah-----yeah-----for me with the Rheumatoid,
 463 there's two things, there's the physical side of it, which is almost, if I walked with a walking stick, I'd -
 464 -----I'd get a lot more sympathy-----you would though wouldn't you? If someone walks into
 465 the office with a broken leg, people are gonna go 'oh my God!' someone walks in with depression,
 466 people are gonna go 'hi, how ya doin'?', 'Cheer up, we all feel like that' sort of thing, yeah-----
 467 -----anyway-----[58.06]

11.1.3 PARTICIPANT 3 transcript

- 1 - - yeah, you get people that sort of go 'ooo, have you tried, er,---such and
2 - such bath salts, or, -*ha*---have you tried glucosamine or something like
3 - that? You know, all well meaning but...
4 - - -yeah
5 - - -yeah, well, yeah...sort of thing, thinks-*ha*---yeah,
6 - - -so, how long have you been diagnosed then?
7 - - -erm, I first started getting symptoms, erm, almost twenty years ago, I
8 - was 30,---literally it felt like it was just my/alternative knees started to
9 - swell so I had them aspirated (I think four times) erm, and at the time,
10 - the consultant said/well he didn't really know, in fact, they still don't really
11 - know what the causes are, it was something called reactive arthritis, so---
12 - -something which was in my environment/diet/an infection/something---
13 - which localized itself----in my knees----but then [1.00]----erm that
14 - was/when you read about reactive arthritis, it doesn't normally hang
15 - around, you know, for years
16 - - -yeah
17 - - so it's probably not/something more systemic if you like-erm—and then
18 - just other different joints started to get affected—and, erm more just
19 - keeps getting added to, if you like, despite being on the, heavy drugs, the
20 - meds,-erm----so, I think the aim is just to stop/halt—the progression
21 - of it all
22 - - -yeah
23 - - -but, they say I've got Rheumatoid Arthritis,-----erm, Osteoarthritis
24 - and I can't even say it-
- 25 - 25 - -*ha*
- 26 - - -wha'sa, I wont to say- Psoriasis --siritic.sritic, sritic
27 - - -yeah

- 28 - - -that! But I'm always like a bit of a-erm--confusing case for the
 29 - consultants because they can never really pin down-----the why----
 30 - osteoarthritis is fairly easy cos its kind of wear and tear stuff
 31 - - -mmm
 32 - - -yeah, so, just-yeah, its, its good that I'd be able to chat to you cos
 33 - mostly with consultants they don't [2.07] have time to go through howyou're
 34 - feeling/what your pain levels like/how you're coping/if you're
 35 - tired/and all the things, you know, the kind of things you were saying----
 36 - its just 'boomboomboom', 'right let's do this with the meds then, and let
 37 - me feel your elbow' or whatever it might be
 38 - - -so they check your movement and?
 39 - - -yeah, um—I've had some shoulder-um, physio and that was obviously
 40 - movement stuff and---getting me more open in movement but, no, the
 41 - consultant, the main consultant at the hospital, will just really have time
 42 - to/you report what's going on and here's a quick look and then decides
 43 - what to do about it-and that's about all you get really, which I don't
 44 - blame him-----
 45 - - -yeah
 46 - - -but, um-----it must be hard for them, you know as well, having to
 47 - rattle through-loads of people *ha ha* all the time
 48 - - -yeah, I guess
 49 - - -um
 50 - - -yeah, I don't know
 51 - - -Its weird because I build myself up-cos they are only every six months
 52 - and I kept an arthritis diary----for a few years now—how I've been-
 53 - treated, I mean medically treated [3.10]
 54 - - -yeah?
 55 - - -when my consultations have been and, also, differences in my ailments—
 56 - over the years—and, um---so I'm building myself up for the next
 57 - appointment, which might be six months and then I get there, I
 58 - forgot what I was going to say, even though I've written down questions

- 59 - and things cos I'm all in a 'ooo, yes, he's only got 10 minutes', two
60 - minutes of that is to crank the computer up, you know, and then, it, and
61 - then, I just go away just thinking 'oh, nothings changed then' *ha ha*—
62 - which is kind of why I keep the diary
63 - - -yeah
64 - - -cos I'm kind of talking to myself
65 - - -yeah, no, that makes sense, I mean, I think after six months you
66 - deserve a little bit more time than 10 minutes?
67 - -yeah, yeah, what was really lovely the other day, it was last week, cos
68 - the medication, you probably know all this, blood tests every 4
69 - weeks/every month---to check your liver [4.02] and kidney function, cos
70 - they affect those, and your immunities, anyway, to cut a long storyshort,
71 - something like one of my liver markers showed up as raised or something,
72 - so the doctor asked me to have, um, a repeat blood test for that, which I
73 - did, and asked to see me—I thought-'hello! I've actually been asked, by a
74 - doctor, to come and see him', I wasn't, like, nervous about what it might
75 - mean or anything and it was literally just a really nice MOT really, about
76 - how I was feeling, and different other things related-osteoporosis, gonna
77 - have a bone scan and---you know, and checking the bloods, which were
78 - fine, it was just a quirk, cos I'd had an infection or something----yeah----
79 - -so that was nice, an actual-yeah, an interest-how I was doing—but, yeah,
80 - mostly, um-talking to people is just not worthwhile, because you can't---
- 81 - 81 ---
- 82 - - -do people at work know about it?
- 83 - - -yeah [5.01] I had to tell them because sometimes I get-a bit of a blue
84 - day—um---not that I'm sitting there crying, but I might be really quiet, I
85 - just think, you know, just, either more pain or, -just really fatigued-and
86 - things so-----my boss said it was just worth telling people how I feel
87 - sometimes, mostly it's absolutely fine-um-----but, yeah, really tired-----
88 - um-----what was I going to say about talking to people?—yeah, I, um---

- 89 - --when the doctor asks me how I'm feeling um I like to think of pain
90 - as noise----which might help?-um----'how local is the pain today?' so it's,
91 - to me, an easy way of kind of telling them, cos you can say, 'oh, yeah, it
92 - really hurts today' but that doesn't really mean anything
93 - - -yeah
94 - - -so, it's kind of like, and also, when you
95 - - -that's genius actually!
96 - - -and so because I seem to be collecting pain [6.00]-----whatever's----
97 - the latest-----swelling or pain normally shouts the loudest so my
98 - elbow is really bad and it consistently hurts, you know, just sitting it
99 - hurts but, if I get another pain somewhere, so like this swollen
100 - here, all of a sudden this is shouting louder than that cos I've got used to
101 - my elbow, if you like
102 - - -yeah
103 - - -so it takes a while to get used to the ongoing feeling—of the new pain
104 - *ha*
105 - - -so
106 - - -so that hasn't got improved, suddenly my hand feels like it's more of an
107 - issue-----
108 - - -if it's a noise, is it like an interference noise, annoying?
109 - - -yeah,mmm-I can feel it now, it hurts
110 - - -yeah
111 - - -but no, not in terms of interfering, just, it's more overt, yeah so,
112 - if I'm walking, or using a joint that hurts, it's more overt if a recent
113 - addition to the suite of stuff, yeah, than it would if, say, my elbow is,
114 - which is constant [7.09] cos it's/that's the worst thing really, I can,
115 - - -does it drown out other noises as well?
116 - - -Erm,-----no---I kind of didn't mean it quite as literally as that---
117 - - -I know, I just-
118 - - -yeah, sometimes
119 - - -I guess I was just asking if

- 120 - - Like a nagging in your ear
- 121 - - -I guess I thought it could drown out other things because you would
- 122 - focus on that noise and not, say, listen to someone talking-----
- 123 - 123 - -yeah-----that would depend, so, say, --urm-----
- 124 --I'm in a
- 125 - situation that would exasperate the pain, so, say, driving a manual car
- 126 - and I'm in a traffic jam, having to change gear and my knees going and
- 127 - all the rest of it I can't concentrate on much else when that's going on-
- 128 - -----so I guess in a way it's offputting-----you know to
- 129 - concentrating, yeah-----
- 130 - - -I hadn't heard of that before
- 131 - - -just one I thought of myself really, just helps me, kind of quantify it
- 132 - or qualify qualify, I suppose [8.45] obviously if you've got root/canal
- 133 - surgery done or child birth, you can't sustain that noise, of course you
- 134 - can't-----or a tattoo that went on for hours and hours
- 135 - or something so it's pain you live with, it's a pain you can cope with,
- 136 - you know, but sometimes it's like it's ringing louder really, it just depends
- 137 - on what the situation is it's really obvious, like I tried pilates last
- 138 - week, but I cou-
- 139 - - -which one is pilates?
- 140 - - Pilates is where you develop your core and your muscles, so Yoga's more-
- 141 - -----erm it's harder movements and it's, you know, it's funny
- 142 - angles of your legs and hands, yeah, yeah, pilates is when you're really
- 143 - pulling up your core, or your tummy or your leg muscles, but it's smaller
- 144 - movements
- 145 - - -right
- 146 - - -and it's less reliant on----erm-----having to hold your own bodyweight,
- 147 - if you like, which I found difficult [10.10] with Yoga, I can't sit in the
- 148 - various positions or go in the various positions they want you to, so it's
- 149 - supposed to be a bit easier for someone like me, but really useful, cos
- 150 - muscle strengthening really, really important-----erm-----and so-----

- 151 - ----erm-I, I get upset when I can't do things I used to get upset
 152 - when I can't do things/I wasn't so bad last week, which was really nice for
 153 - me----so, I, in my, so I did what I could and didn't do what I couldn't but,
 154 - erm, for years I, I've been really, really, really sporty, I'm a really sporty
 155 - person, so when I was first diagnosed it was like someone giving me the
 156 - death sentence, 'I'm never gonna do this again!', it was awful to cope/but
 157 - you can do stuff, of course you can [10.54] you just either do it with/in
 158 - pain or you do it to a lesser amount and you're not as good as you were,
 159 - so that was hard for me cos I was good at sport, I've always been in sport,
 160 - I've always worked in sport---you know, I'm a good sportsperson, or I
 161 - was, so to suddenly not to be such a good sportsperson was hard
 162 - for me to cope with, was actually hard for me but I'm actually fine
 163 - now/it's probably cos I'm older so it just goes with the job description
 164 - *ha* doesn't it? *ha*-anyway, but initially it was very hard cos I was
 165 - active and then I carried on being active, it was just a temporary blip in
 166 - my mindset—of course you can do stuff, you just have to do different 166 stuff
 167 *ha*
- 168 - -so did they say to you that you're not going to be able to do
 169 - this/it's going to make you do that-
- 170 - -no, I don't think they could predict really, they probably still can't, they
 171 - say you should avoid/on the one hand they say you should avoid kind of
 172 - high impact stuff cos it'll make it worse or hurt or whatever, so, pounding
 173 - the streets, running or mega weight resistance stuff, but on the
 174 - other hand to mitigate things like osteoporosis, which
 175 - might be a higher-----erm, chance being on medication, you should do
 176 - some impact stuff-so it's just a, I think a balancing act and what people
 177 - feel comfortable, I mean, I would assume doing nothing is worse than
 178 - doing something and giving things a go, cos we all need to be physically
 179 - active, don't we? Hence the dogs erm, cos you have to
 180 - get out, whether you feel like it or not, wind or shine yeah, so,
 181 - erm, it just depends really what/how I feel/about pilates, how I feel about

- 182 - how I feel about myself; depends on the day really generally these
 183 - days-----I've got over, I think, the-----'it's a foreverthing'---
 184 - sometimes I do think that but you think of all these other people
 185 - in the world and how worse off people are, you just can't, that's just silly
 186 - isn't it? You think of all the hideous things people have
 187 - - -yeah
 188 - - -awful, yeah, it's worse when I'm-----obviously when I'm tired, but,
 189 - erm/which seems to be most of the time *ha*-----erm they did/I
 190 - was part of this [13.15] software study, Rheumatoid Arthritis, no Arthritis
 191 - research, is it? Whatever the main arthritis charity is
 192 - - -Arthritis Research, yeah
 193 - - -yeah, 'Cloudy with a Chance of Pain' so they were trying to
 194 - see if there was definitely evidence of a link between weather and
 195 - feelings/pain levels/sleep levels, all that kind of thing, so it's an app-----
 196 - I did it for about 5 months but you have to do it every single day and I
 197 - got a bit bored with it but I think it's coming to an end that will be
 198 - really interesting to see the results so they're really trying to make a definite link-cos,
 199 - some people say 'oh, there's no link' but you know, if
 200 - you've got RA, there's definitely a link---you know if there's a difference in
 201 - air pressure, you know cos you instantly feel more pain or sunnier climes,
 202 - people feel less pain, don't they?
 203 - - -so that old fashioned idea of going and living in the Mediterranean if it's
 204 - coming on...
 205 - - -I think that would be a good thing!
 206 - - -yeah
 207 - 206 - -*ha*
 208 - 207 - -
 209 - - -yeah, definitely, I'm sure, well I'm not sure, but when I've been in
 210 - sunnier places it's nicer, maybe it's just the whole thing is nicer so your
 211 - coping better, don't know really but it'll still be interesting to see the

- 212 - results of that
- 213 - - -absolutely!
- 214 - - -mmm
- 215 - - -so, what sort of sports did you do?
- 216 - - Erm, well anything and everything at school, then settled into badminton
- 217 - and basketball erm, in my teens, and swimming, things like that and
- 218 - then-----later, well before I stopped doing a lot, a lot of tennis, tennis club,
- 219 - skiing every year, erm, anything really, more badminton-----
- 220 - - So, a perfect combination of high impact and
- 221 - - -yeah, at school I was probably in every sports club I just love sport so
- 222 - much
- 223 - - -is that what you do now?
- 224 - - -yeah, I'm not—I'm sports development, so not a coach, not a tracksuit
- 225 - wearer-----in my job, but strategic sports development for Sussex---
- 226 - Active Sussex, based at the sports centre, County Sports partnership,
- 227 - their funded, there is one in every county, mainly funded by Sports
- 228 - England, so we're mainly about getting people more active more often
- 229 - - -cool
- 230 - - -so, [16.02] I've always been in sports development, since 1989, so it's
- 231 - really hard , I want to be that person I used to be like really goodat stuff. I've still
- 232 the eye/hand coordination-table tennis***I just want to
- 233 - be running around/tearing around on the bike or in the pool, I can
- 234 - still do lengths but-----it really hurts----dragging your arms-----
- 235 - through the water, so,
- 236 - - -and do you pay for it a lot afterwards as well?
- 237 - - Yeah, definitely! I, erm, ---I did a longer walk the other day erm, it
- 238 - was, no-----I did two dog walks and I did a big trek aroundBrighton,
- 239 - I think it was near Christmas time, cos we had family, I was so sore
- 240 - afterwards-----yeah-----I'm doing a sponsored walk in June for
- 241 - Macmillan, the South Downs charity thing with my mate, so I might
- 242 - have to do a bit extra prep for that *ha*, I don't care, I'll just be more

- 243 - sore for a few days
- 244 - - -and when you do that you know it's going to come?
- 245 - - -yeah
- 246 - - -bless you
- 247 - - -swimming definitely, cos that's a deliberate, this feels the worst, it really
- 248 - hurting your knees, it really hurts, so I don't do it that much but I
- 249 - should, I should go swimming every week----thing is, I'm going with my
- 250 - work hat on; it's all about developing a sporting habit for life, that's really
- 251 - all it is, so, in other words, Monday should be swimming, you know,
- 252 - Tuesday should be pilates, Wednesday should be, you know and then
- 253 - you're in 'that's what I do on a Monday, that's what I do on a Tuesday'----
- 254 - --and I dip in and out of things, that's the trouble, I need a set/get my
- 255 - routine going that's just the day, that's what happens on a
- 256 - 255 Tuesday-----and then I'll be alright-----
- 257 - - -I'm rubbish at that, I need to be told
- 258 - - -mmm, you need a buddy as well
- 259 - - -mm
- 260 - - -So you don't go out and do it on your own, you wait to be told/
- 261 - - -Yeah, so talking to people [19.19] who do you talk to about it? If the
- 262 - work is fine but you don't want to talk about it there, who do you talk to
- 263 - about it?
- 264 - -erm,----occasionally well, my family, obviously, not often, not really
- 265 - properly talk, my husband suffers a lot from different ailments as well,
- 266 - arthritis through various things he's had happen to him, so he kind of gets
- 267 - it-----in terms of how you might be feeling, tiredness, that kind of
- 268 - thing, so that's good, but it would just become boring, I mean, it's literally,
- 269 - every time I say/I speak to my Dad, which might be once every couple of
- 270 - weeks "ow's your aches and pains?" [20.06] *ha* ---er 'same as
- 271 - normal, Dad' you know, you don't then go 'well actually Dad, this is
- 272 - how it is, this is what happens...'—he is interested but—if you tell the truth

- 273 - too much about the thing that your upset about/why would you want
 274 - to do that? I don't want the attention I don't want people to ask me
 275 - every 5 minutes-'how's your elbow?', cos it's always going to be the same
 276 - answer, so it's kind of like a reminder that you've got an issue there, I
 277 - don't want to be, singled out as having an issue cos it's always the same
 278 - thing----you know, my brother would ask me 'what's the latest?',-----
 279 - and as he's getting older he's developing some osteoarthritis and I can
 280 - kind of empathise a bit in terms of the pain----erm yeah, but, it's
 281 - probably my husband that would understand the most, or my two best
 282 - friends who are happy for me to witter on about anything *ha*-----
 283 - which is lovely [21.03] but I'd normally talk to people when I feel a bit low,
 284 - a bit blue, I wouldn't naturally trigger a conversation if I was in a really
 285 - positive mood so I wouldn't want to hinder it even though it's probably
 286 - easier to cope to talk about it when I'm in that mood
 287 - - -so do you sort of ignore it?
 288 - - -yeah, constantly, constantly ignore it yeah
 289 - - -is that on purpose?
 290 - - -yeah, I think so, a bit deliberate, I'm not one to seek attention to myself
 291 - really—you know, my boss, yesterday, or the day before yesterday, she
 292 - had a bit of dentistry work, she came in, she set out her pain killers on
 293 - the table/you know, if you've got a sniff you get a Lemsip, you get the
 294 - tissues *ha---I'm not like that -*ha---I'm really not 'get over it, you've
 295 - had a bit of a filling!!'
 296 - 295 - -*ha
 297 - -but, urm, no, you can't compare yourself to others,---everyone is
 298 - different, everyone has different variables and it might not just be the
 299 - arthritis, you know, it could be/you don't know what's going on in their life,
 300 - so, maybe they can't cope with a bit of dentistry work because it's one too
 301 - many things they have to deal with, you just don't know, do you?-----
 302 - [23.47] I've never really spoken to

- 303 - people who suffer, when I first got it, it's a bit like when you get pregnant,
 304 - you think 'oo, I,ve got to go to baby class, talk to people, I'm in the club'-
 305 - erm so, I went to the Lewes branch of Arthritis UK and, but of course, I
 306 - was like a fish out of water cos everyone was like 70 odd and then when I
 307 - was that age, it felt a bit strange but I could go back I supposedon't
 308 - know really whether I want to---
- 309 - 308 - -no?
- 310 - - -no, what's the point? You just hear about people's stories wont you? Not
 311 - interested
- 312 - - -no
- 313 - - -on a personal level, I've got enough friends, I'm interested in how they
 314 - might be feeling if there's anything I can do to help----but I'm not really
 315 - interested in you know, not really, not interested in my own stuff let
 316 - alone anyone else's *ha
- 317 - - so, I was wondering about
- 318 - - -I don't want that
- 319 - - -But, do you experience a lot of misconceptions, about the RA?
- 320 - - -mmm, like I said, [25.27] you happened to mention, dare I mention 'oh,
 321 - I'm in a bit of extra pain today', whatever, and you get' oh, have you tried
 322 - a bit of fish oil?', all well intended nice things, but that's misconception, or
 323 - you get my Dad, tried this, tried that, worked for him, and all that kind of
 324 - thing, nobody, I guess, really knows, other than my brother, my husband,
 325 - my two best mates, really kind of listen, they want to impart their
 326 - information a bit like when you're going to give birth and everyone
 327 - wants to tell you their story—completely irrelevant to you cos it's all
 328 - individual—erm—yeah—so, misplaced, mmm, people just don't know how
 329 - I'm feeling, unless I tell them—in terms of whether they need to adjust
 330 - their-----approach or not, I don't see why they should I don't want to
 331 - be that person cos I said I don't know what's going on in their life, why
 332 - am I so important, really?---I don't want to be that object of

- 333 - attention really---but-I guess, at home secretly, I do, because I'm talking
334 - to people that really matter, that I value their—erm, compassion, I
335 - suppose
336 - - -mm
337 - - -yeah, and also, they're affected more, because they're with me on the
338 - down time, say, more than the people at work, different levels of friends
339 - you know, you have contacts or sort of friends and the really good pals,
340 - so—it's only the really good people I talk to, unless someone asks me! If
341 - someone actually asks me-----
342 - - -yeah
343 - - -I mean, properly asks me, then I'll tell them! Completely, but I wouldn't
344 - want to—baggage-----chuck baggage at people---definitely I mean, my
345 - boss sometimes asks me-she'll go 'how you feeling?' and I'll start to tell
346 - her and she'll, you can see her glazing over or not really understanding---
347 - she does try
348 - - -yeah
349 - - -yeah, she does try,-and why should she understand really?-[27.38]-----
350 - -it's kind of like, I'm waiting for someone really close to me to have the
351 - same thing for, obviously my husbands got different types of pain, and
352 - then I can be in my little club with them
353 - - -so how does the pain work for you? You mentioned your elbow, your
354 - hands, knees, -is it that localized?
355 - - -yeah, it is—it's not like my whole body, my whole body might be tired
356 - but my whole body is not in pain-so if I'm using the clutch a bit too much
357 - then I'll definitely hurt though I've got an automatic now---er or it
358 - could be as much as lifting a cup of coffee, or something from the shelf-or
359 - straightening my hair, so I can feel the different places it's hurting a lotto
360 - do simple actions so it's really more overt, depending on the task you're
361 - doing---so, if I'm just sitting I can feel a bit of pain in my elbow, yeah, it
362 - depends on the moment really
363 - -do you know it's going to come? Like opening the cupboard?

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364 - - -oh yes. I deliberately do it. Yeah.----I brought 4, 4 bags of logs from the
365 - garden centre yesterday and I know my husband would go, or my son
366 - actually, would go 'I'll get them out of the car for you', but I don't want
367 - them to-I know it's going to hurt—but I do I did it anyway because I
368 - want to, I don't want to not do stuff, I can still do it—it just hurts [29.21].
369 - The doctors advised me to take pain killers, but I don't take pain killers,
370 - very rarely take pain killers-

371 - - -why's that?
372 - - -just because I'd be on them for life, so if I can cope generally-then I
373 - don't want to do that---erm---I have got some that now might help
374 - reduce a bit of swelling so I keep trying to remember to take those----
375 - but I don't really cos I'd just be on them forever and I can't think about
376 - that, and they go but they wont be that and well, yeah-I'm almost 50----
377 - -[30.05] I don't want to do that forever I mean the drugs that they put
378 - you on-----er that might not be forever but probably/I've
379 - been on them three times to be honest, this is the third time but
380 - they're supposed to just halt, halt the progression

381 - - -what were they?
382 - - -er, they are the drug called Methotrexate, I've been on Selenium, or
383 - something before as well-----but, yeah-----they're prettycrap-----
384 - --you know, you have to work out whether you'd rather damage,
385 - potentially damage your liver or your kidney or have low immunity-----
386 - --or stop the-----progress/I mean if I got I can't start to
387 - begin thinking if I've got it in my right hand, I'd be really upset, cos I'm
388 - right handed I can just about cope with the left hand, or, more in
389 - my right knee, it's sore but or something that will really will
390 - change the way I can be-----that would be upsetting-----
391 - -----I might go back a bit then, in terms of how I feel about it all, I might
392 - go 'right! I'm having everything you can give me!'-----but-----
393 - yeah, um, probably the right hand would be the worst thing/and right
394 - elbow/seems to have a lot on my left or on my right knee and right foot---

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395 - is sore -and the knee is constant? Cos that was the first thing wasn't it?
396 - - -They've been kind of up and down over the years, so they can get
397 - aspirated and then injected with a steroid
398 - - -aspirated?
399 - - -sorry, yeah, drained, they pull out the fluid through a syringe, erm----
400 - and then you get a steroid injection and then they go through a few
401 - months, or whatever, and then they might just suddenly swell up for no
402 - reason-----so, yeah-----my left one hasn't swollen up for ages---
403 - my right one's-----but I've had enough of all that, aspiration-----
404 - not nice-it hurts!
405 - - -sounds like it!
406 - - -I've had it in my shoulder, and you often get asked if you want
407 - steroid injections-----you know, to help he said he was going
408 - to inject my hand, I said 'nah, you're alright' -*ha*-----ow!-----no-----
409 - 409 so, mmm-----
410 - - -so, you'd rather deal with the 'noise' rather than have that sort of
411 - injection/steroid or
412 - - -it's just temporary, that's the thing. I get fed up with-erm-----
413 - when you go to the doctor's surgery for a blood test, every month or
414 - whatever it might be-----I don't like being part of the system [32.44] I
415 - don't like the rules and the noise and the receptionist and the other
416 - patients, ergh! I hate just being part of all that I don't, I wish I
417 - wasn't--*ha* 418 - -*ha*
418 - - -you have, you know, I come in and think 'what am I doing here?'-----
419 - --erm so the less I can do stuff like that, the better
420 - - -yeah, I understand
421 - - -*ha*, well, some people love it, don't they?
422 - - -yes they do!
423 - - -having a big ol' chit chat across the surgery! I mean, I'm really friendly—
424 - gregarious-well not gregarious, a sociable person but I don't, I just hate

- 425 - being part of this system, my mom was really ill last year and actually
426 - died at the end of October and I spent months and months and months, in
427 - and out of hospitals, old people's homes and I don't want to be part of
428 - this institutiony thing and I can't avoid it that's the thing, so I just try and
429 - minimize it as much as possible-----mm-----
430 - - -do you ever go down the route of hippy alternatives, for want of a better
431 - term?
432 - - -I did, yeah, I mean, in the earlier days I did, erm I had this, I don't
433 - even know what it was called, but this guy swung vials of something over
434 - my chest ha* 436 - -*ha*
435 - - -to see if I had any allergies and so, obviously out popped-----
436 - lactose, wheat, you know, things we're not supposed to have as humans--
437 - -----I don't know, so, that was one thing, another I did
438 - acupuncture I think that was mainly, kind of pain relief at the time, it
439 - didn't really do much
440 - - -did it work?
441 - - -er, it was alright. Acupuncture, it didn't hurt! It doesn't hurt, but no, not
442 - really----*ha* um so yeah, I've dabbled and then I've done, er-
443 - years ago, I've had a food intolerance blood test, sent off my bloods
444 - to see, which I should avoid, to see if that would have any effect, but, if
445 - I'm really honest, I haven't put my heart and soul into something and I
446 - should, I could give that a go, cut out dairy or cut out er, tuna, that
447 - was one, or, yeast and just see, you know, over the course of time, if that
448 - does affect things, I suppose, I've never done that properly I've
449 - dabbled, you know, a couple of weeks or whatever, but a good long period
450 - of time would be needed for your body to adjust I think maybe,
451 - if I get to the desperate stage [35.21]-----when I'm more immobile, for
452 - different reasons, when I'm older maybe things like that will be more
453 - urgent
454 - - -I guess, things like that, diet, becomes an everyday recollection of why
455 - you're doing it?

- 456 - - -I know, exactly-----it's a bit like diet club, you know, I'm trying to lose
457 - weight, but I'll do it in my own way, can't stand diet clubs cos I think they
458 - just perpetuate the need to eat
459 - *ha*
- 460 - - -cos they give you so much you can eat, brilliant! You can eat anything on
461 - this diet, but you're there for three years, giving them your fortune in the
462 - meantime---it's good for the budding and the working with people, but--
463 - -----yeah because you're, say, on a diet, Slimming World, or
464 - whatever, it's constantly on your mind, what you can and what you can't
465 - eat, counting calories and all that, so, yeah, it's exactly the something----
466 - -----I don't want to be constantly reminded-----if I'm eliminating
467 - milk or something, because 'oh, why am I eliminating milk all the time?'
468 - oh, it's a tough one-----I think I'm my own worst enemy really-----
469 - -I don't think I probably embraced it all, even after 20 years, because it's
470 - changing all the time as well-----if I had I would probably do
471 - more to help myself I expect you know, been a bit more open about it-
472 - or, er-----do more self help stuff/I do try and keep active and-----
473 - -all that kind of thing-well, I do walk the dogs, but I could do more-----
474 - -----I can't be bothered half the time, that's the trouble-----
475 - ---I'm tired but then you don't just do exercise for the sake
476 - of exercise, do you? You do it for your mindfulness, that kind of thing-----
- 477 - 479
- 478 - - I know but
479 - - -endomorphins
480 - yeah
481 - - -there's this place, up on the hills, I live on the edge of the Downs-----
482 - and I love it/it's one of my favourite places locally and I can just stand
483 - there, for hours, just looking at the view, it's an amazing view [37.44] ---
484 - -----I genuinely feel really filled up again of 'oh, this is nice' and
485 - it is you know, you can't underestimate all of that and without the dogs I

- 486 - wouldn't be up there-----
- 487 - - -no
- 488 - - -so they are great for that, really good so, anything else?
- 489 - - -er, yes-----sorry, how did you know? You said that your knee
- 490 - went, so, it wasn't just you thinking, I should go and-
- 491 - -no, it was a physical manifestation, my right knee swelled up I didn't
- 492 - actually know what it was then and then, the GP referred me to a
- 493 - consultant, a rheumatologist---yeah so, then, that's when they said
- 494 - 'that's rheumatoid arthritis that is'---'what's that?' that's probably why
- 495 - I went to the Arthritis UK branch in Lewes, I didn't know enough, I don't
- 496 - actually remember, I didn't keep a diary then of all my treatments and
- 497 - feelings and things it's not personal stuff, it's more, kind of factual
- 498 - things,
- 499 - - -so how often do you add to it?
- 500 - - -not often, ailments, facts
- 501 - - -so you would write something like 'shifted those logs'?
- 502 - - -no-no, I should've done, I suppose, cos that's kind of a positive thing, I
- 503 - think, in a way no, it's generally appointments—erm, not just
- 504 - blood tests, scans-not just that but why I normally do it, to be
- 505 - honest, is because I don't remember everything
- 506 - - -yeah, 6 months and I wouldn't
- 507 - - -so I really want to put down what they've told me, how to be, what they
- 508 - think the issue is, so-----you can borrow it, if you want
- 509 - -
- 510 -

11.2 APPENDIX 2

11.2.1 Participant consent forms, invitations, and information

Dear all,

I am looking to work with people suffering from Rheumatoid Arthritis to find ways to express their experience and how they feel through models rather than words or text.

This study forms the basis of a PhD research project and would involve an interview with follow up conversations about how the data from this can be visualized. These conversations will result in a collection of physical models, made by me, with the intention of promoting awareness and understanding of Rheumatoid Arthritis.

Please find attached an information sheet with more details about the project to help you decide if you would like to take part.

If you are interested, please contact me by responding to this email.

Thank you for your time.

Yours sincerely,

Peter Marsh

RESEARCH TITLE:

How models can translate the lived experience of Rheumatoid Arthritis into material and form

Thank you for your interest in this research.

WHY I WOULD LIKE YOU TO BE INVOLVED IN THIS RESEARCH

I'm very interested in what you have to say in regards to how Rheumatoid Arthritis affects you on a day-to-day basis.

I am a model maker, currently employed by the University of Brighton. I want to see if it is possible to use models instead of words to help someone else understand how it feels to have Rheumatoid Arthritis. It would be through an analysis of your description of your experiences, given in an interview, which would enable me to build the models.

WHAT WILL YOU BE ASKED TO DO?

If you choose to participate, I will contact you via email to arrange a time and place to meet, ask if you have any questions regarding your participation, how I would use any information you give to me or what the research hopes to achieve.

I have attached a consent form to this email, which I would ask you to sign saying that you are happy to take part.

Your participation in this research is entirely voluntary and even if you sign the consent form you do not have to undertake any aspect of it and can drop out of the research at any time without needing to give any reasons for doing so.

The interview will be quite informal and, although I will ask a few questions related to the subject, I'm more interested in what you have to say.

I will arrange for the interview to take place in a private location as close to your place of work or as convenient as possible. You don't need to bring anything or prepare anything in advance.

This meeting would be ideally scheduled to last for two hours. Afterwards I will write down the recording of the interview. The written version of our interview will not be like a conversation you see in a book but will include all the pauses for thought, the 'ums' and the 'ers'. If you wish, I will send this to you on completion.

At this point I will arrange another meeting with you to discuss my analysis of this initial discussion. This second meeting will allow us to start making visual connections and decisions on different materials from which I can begin to make the

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models. The intention of the models is not to be a portrait of yourself but a representation of your experience in three dimensions, a physical, 'abstract' model, and so it will not reference you directly in any way.

Once the models are made, you will be invited to see them alongside the other models made from different participants' involvement. This would be a private viewing as it will be valuable for me to hear your point of view. At the completion of the research project, the models are to be exhibited publically.

CAN TAKING PART DO YOU ANY HARM?

All the information I collect during this process will be anonymous; your name and any other form of identification, such as place of work, etc. will be removed to protect your privacy. Your confidentiality will be upheld at all times. All your personal details relating to our contact will be kept separately from the documentation taken at the interview. These details will be stored on a computer hard drive that has a password known only to myself.

The goal of this research is to find an alternative way to describe how it feels to live with Rheumatoid Arthritis in order to make this more understandable to others. This research is not designed to help alleviate your symptoms, and it is important to note that I have no medical training.

I shall be asking you to describe your experiences relating to Rheumatoid Arthritis and, although it is hoped that being able to verbalise your thoughts and discuss them openly may prove to be helpful, should you feel uncomfortable or anxious for any reason I will stop the interview and continue at a later date or, if you wish, you can withdraw from the process entirely.

If you have any questions or concerns about the project and your involvement, then you can contact me as follows:

Peter Marsh

Technical Demonstrator,
University of Brighton,
Room 305, Mithras House,
Lewes Road,
Brighton.
BN2 4AT
Telephone: +44 (0)1273 642350

Email: pjm10@brighton.ac.uk

Thank you for taking the time to read this information.

INFORMED CONSENT FORM

How material models convey the lived experience and impact which Rheumatoid Arthritis has on hand function.

PLEASE READ THE FOLLOWING CAREFULLY AND COMPLETE YOUR RESPONSE AS NECESSARY

The researcher has explained to my satisfaction the purpose of the research and the possible risks involved.
I have read the information sheet and I understand my involvement in the procedure fully.
I am aware that my participation involves two one-to-one meetings with the researcher at an agreed location near to my place of work and that these interviews will be digitally recorded for transcription purposes.
I agree that extracts of transcriptions from the conversations can be used to describe the process in the final documentation of the research and future publications with the understanding that all information will be anonymous.
I agree to take part in this research exploring how material models can convey the lived experience and impact which Rheumatoid Arthritis has on hand function and quality of life.
I understand that my participation is entirely voluntary and that I am free to withdraw at any time without giving any reason.
I agree that should I withdraw from the study, the data collected up to that point may be used by the researcher for the purposes described in the information sheet.

I wish to participate in this research YES/NO Delete as appropriate

Your name (please print):	Researcher name (please print)
Your signature:	Researcher signature:
Date:	Date:

Thank you for your time.

11.2.2 Response from RESEARCH PLAN APPROVAL examiner

Hi Pete

I have read through the work you sent me, and must say that I enjoyed the experience. Overall it appears coherent and theoretically sound. As you say, you are breaking new ground with this approach in research, so it's important for you to be able to explain and justify what you have done in a viva situation. The more practice with this that you can have the better.

I must admit that the second word of your abstract, "hypothesis", set my alarm bells ringing, but you later explained this very clearly (pp 15/16). In fact, I think I shall be using interpretive hypotheses myself in the future!

On page 1, I wondered how your 'perspectival realism' relates to the 'critical realism' of Roy Bhaskar, for example? You may wish to rehearse your explanation of a world 'out there', and how it is perceived and understood subjectively.

I assume the convention in your discipline is to write in the third (passive) person, although this seems rather at odds with your interpretivist methodology?

On page 2 you state that 'our bodies are not a conduit for our consciousness'; does that mean that consciousness is not located, but is expressed through the bodily senses? ... and is it a personal consciousness (i.e. yours and mine)? ... or could it be universal conscious awareness through which perceptions/interpretations construct the illusory story of the self? You don't need to venture into non-duality ... it's just that I'm curious!

I like the representation of the hermeneutic circle on page 3, and wondered if it could be described a little more in relation to your study?

Your handling of Gadamerian thought, and the concepts of prejudice, understanding and language were confident and convincing, but again I wonder if you can illustrate these theoretical constructs with some application to your focus of interest (model making). This would help to guide the readers and keep them 'on track' with where you are leading in later chapters.

I found the differentiation of experience into *erlebnis* and *erfahrung* to be very useful.

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I have to admit that the material on perceptual simulation theory and Barsalou's work was all new to me, so I can't really comment on the accuracy or relevance of these theories. However, with any theoretical concepts (such as 'meshing', 'clamping', and 'suppression' - page 10), some practical applications to your research interest will always be helpful. A definition of semiosis on page 9 will be useful.

In your discussion of 'Play' on page 11/12, I was reminded of the concept of 'flow' (Csikszentmihalyi) and wondered whether this might be worth exploring briefly? If your participants become so absorbed in model making to the extent that they lose the sense of self and time, this in itself can be perceived as beneficial.

On page 12 (Design and making as hermeneutic experience) I was intrigued by the thought of a fusion of horizons with oneself ... fascinating!

Towards the top of page 14, I was not sure what you meant by a 'constructivist trap'?

On page 17, the concept of models as 'text' is interesting ... I suppose music is also 'text'. Musical language is non-subjective and has no 'world'?

On page 18, I was left wondering where you were leading next, and whether you would be guiding the reader back to your research focus. Theoretical flights are fine as long as you come back to the ground safely!

I hope my comments are useful and make some sense ... I am impressed by the originality of your work, but would just gently warn against losing sight of your research intentions and aims. Just imagine taking your readers by the hand and leading them through this intellectual journey, reminding them regularly of the purpose behind these theoretical adventures!

Good luck with your writing, and I hope to see you again soon at one of our SIG sessions.

Best wishes

Graham

11.3 APPENDIX 3

11.3.1 ETHICS SUBMISSION

FREGC REGC-15-067.R1

Health and Social Science, Science and
Engineering Research Ethics and
Governance Committee

**HOW MATERIAL MODELS CONVEY THE LIVED EXPERIENCE
AND IMPACT WHICH RHEUMATOID ARTHRITIS HAS ON
HAND FUNCTION.**

Journal:	<i>Health and Social Science, Science and Engineering Research Ethics and Governance Committee</i>
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Manuscript Type:	Ethics Application
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Keywords:	model making, metaphor, Rheumatoid Arthritis, Phenomenology

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**Health and Social Science, Science and Engineering
Tier 2 Research Ethics and Governance Committee**

Front Sheet

Note: You should allow at least 3 weeks for Tier 2 REGC to review your proposal and be aware that you may be required to revise your proposal and resubmit for further review. Submission from one's mailbox constitutes the signature, and the application is considered with the understanding that all researchers agree to all the information provided and believe that it is accurate to the best of their knowledge. The Tier 2 REGC accepts applications directly from students and it is expected that all students' work will be reviewed by the supervisor before submission. You will make a declaration to this effect on the web page.

Section A

Tier 2 REGC No:

(For official use only)

General Information

Title of project: How material models convey the lived experience and impact which Rheumatoid Arthritis has on hand function.

Is the project a PhD/ProfD/MPhil study MSc study Staff research

(Check as appropriate)

Name of Principal Investigator Peter Marsh

Name of Supervisor or Co-applicant: Kambiz Saber-Sheikh

Please indicate the contact person for all correspondence with FREGC.

School/Division: Health Sciences

Contact details: Email: pjm10@brighton.ac.uk

Telephone: 07986964543

Name of Student(s) (for student project only): Peter Marsh

Names of All Other Researchers: N/A

Does the project require IRAS/LA application?

Yes No

Does the project require the sponsorship of the University of Brighton?

Yes No

How will this project be funded? List all sources of funds (e.g. research grants, commercial sponsorship, school funds etc). No

Has the project been subject to scientific or peer review (e.g. scientific review conducted by research councils or other funding agencies etc)?

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Yes No

If Yes, give details

Do any researchers have any financial interests in this research or its outcomes, or any relevant affiliations?

Yes No

If Yes, give details

If you answer "Yes" to the above question, have you included an appropriate comment on the Participant Information and Consent Form? Yes No

Proposed timescale of study

Start Date: 2 Jan 2013

Completion date: 2 May 2017

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Governance Checklist

You are requested to answer the following questions to ensure that you will conduct the study within the Research Governance Framework of the University of Brighton and to fulfil your responsibility as the principal investigator or the supervisor.

1. I believe that the proposal is scientifically sound and ethical, and I am submitting the work to the Health and Social Science, Science and Engineering Tier 2 Research Ethics and Governance Committee for independent expert scientific and ethical review. I agree that the study does not start without Tier 2 approval and, if applicable, the NHS REC/LA. Yes No
2. I agree that the study will be conducted according to the proposal approved by the Health and Social Science, Science and Engineering Tier 2 Research Ethics and Governance Committee, and that the study will comply with all the legal and ethical requirements. I shall ensure that the study will be carried out to the standards described in the Research Governance Framework of the University of Brighton, and if applicable, the Department of Health and any funding body. Yes No
3. I shall report any major changes in research methods or serious adverse events to the Health and Social Science, Science and Engineering Tier 2 Research Ethics and Governance Committee (and if applicable, NHS REC and any funding bodies) during the conduct of the study. Yes No
4. I have prepared and submitted the appropriate participant information sheet and consent form to the Health and Social Science, Science and Engineering Tier 2 Research Ethics and Governance Committee. I shall ensure that the research team will give priority at all times to the dignity, rights, safety and well-being of participants. Yes No
5. I shall lead and manage the research work and submit annual progress and completion reports to the Health and Social Science, Science and Engineering Tier 2 Research Ethics and Governance Committee. Yes No
6. I shall ensure that the experience and expertise of all researchers are sufficient to discharge their role in the study. In the case of student project, I shall ensure that students have adequate supervision, support and training. Yes No
7. I confirm that procedures and arrangements are in place for the management of financial and all other resources required for the study, including the management of any intellectual property arising. Yes No

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8. I shall ensure that, where relevant and appropriate, service users and consumers are involved in the research process. Yes No
N/A
9. I confirm that there are appropriate procedures for the collection, handling and storage of data. (The university guidelines on data protection are provided in Appendix 1 of this application pack.) Yes No
11. I shall ensure that findings of the research will be open to critical review through the accepted scientific and professional channels and, where appropriate, they will be disseminated promptly and appropriately. Yes No
12. As the principal investigator or the supervisor, I accept a key role in detecting and preventing scientific misconduct. Yes No
13. For applications requiring NHS sponsorship, I confirm that agreement with the relevant Trust has been reached about the provision of compensation in the event of non-negligent harm. I have read the information about the university's indemnity cover (Appendix 3) which is normally sufficient for low-risk research projects. If this is not sufficient, I shall seek advice from the University's Insurance Officers and appropriate arrangement will be made. Yes No
N/A

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Health and Social Science, Science and Engineering
Tier 2 Research Ethics and Governance Committee

Risk Assessment

Please tick the appropriate boxes.

Will the research study involve:

1. Causing participants physical damage, harm or more than minimal pain? Yes No
2. Manual handling of participants, vigorous physical exercise, or physical activity from which there is a likelihood of accidents occurring? Yes No
3. Intrusive physiological or psychological interventions or procedures? These might include: the administration of drugs or other substances; taking samples (eg blood, saliva or urine) from participants; use of probes or other equipment to measure or monitor bodily performance; techniques such as hypnotherapy. Yes No
4. Exposure of participants to hazardous or toxic materials, such as radioactive materials? Yes No
5. Inducing psychological stress, anxiety or humiliation? Yes No
6. Questioning of participants regarding sensitive topics, such as beliefs, painful reflections or traumas, experience of violence or abuse, illness, sexual behaviour, illegal or political behaviour, or their gender or ethnic status? Yes No
7. Vulnerable groups of people, for example children, people with learning disabilities or mental health problems? Yes No
8. Groups where permission of a gatekeeper is normally required for access to its members, for example ethnic groups? Yes No
9. Access to records of personal or confidential information? Yes No
10. Any other risk not identified above Yes No

Please describe:

Sufficient safeguards and monitoring procedures must be put in place in relation to any anticipated risks. If you answer "yes" to any of the above questions, you should describe the safeguards and monitoring procedures in place on a separate sheet of paper and attach it to this application form.

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HOW MATERIAL MODELS CONVEY THE LIVED EXPERIENCE AND IMPACT WHICH RHEUMATOID
ARTHRITIS HAS ON HAND FUNCTION.

PETER MARSH

ETHICS SUBMISSION-REVISED

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STRUCTURED ABSTRACT

(MAX 500 WORDS) RATIONALE FOR RESEARCH, METHODOLOGY, METHODS, SAMPLE (LOCALITY, SAMPLE SIZE, TARGET PARTICIPATION GROUP), TIMESCALE FOR RESEARCH, LIKELY IMPACT.

The focus of this research is to find an intelligible description of phenomenological lived experience using material models as a medium. This research will use the term 'material models' to differentiate purpose built three-dimensional models from digital 3-D or theoretical models.

People find it hard to re-contextualize and transform the abstract notion of sensory perception into descriptions of knowledge representations into language (Paradis, 2013, El Refaie, 2014) which is in part due to the paucity of sensory vocabularies in modern parlance (Viberg, 1984, Vanhove, 2008).

The focus of this research is to question whether the conceptualization of embodied, abstract notions such as pain, which is multi-modal, non-visual and subjective (Semino, 2010), can be communicated visually using material and form as language.

One significant advantage of using material over digital models in this research is that they are a much richer source of information, providing not just three-dimensions (form, scale, texture) to present information but the opportunity to use a host of properties from the sensual world with historical, cultural/semantic and personal memories and connotations (Gibson, 1954, Merleau-Ponty, 2002, Dunn, 2005, Paradis, 2013). Such models are metaphorically provocative (Lakoff, 1990, Lakoff and Johnson, 1999, 2008) and evoke an emotional and tactile connection and a more embodied, multi-modal understanding (Merleau-Ponty, 2002, Seamon, 2010).

This research will use model making, as it is traditionally understood in the fields of architecture and design, to create a visual language that addresses the gap in understanding of Rheumatoid Arthritis (RA) between the sufferer and the public.

The understanding that our perception of the world is embodied, that we are non-dualistic and that our minds and bodies are not distinct from each other (Csordas, 1990, 1994, Merleau-Ponty, 2002), is integral to the researcher's proposal to utilise a person's interaction with material models to convey a phenomenological understanding of RA.

RA is a chronic, inflammatory disease, principally affecting flexible joints though it also affects organs and other parts of the body. RA is, potentially, extremely painful, inducing extraordinary fatigue. If not adequately treated it can lead to substantial loss of functioning, mobility and increased mortality. Treatment and coping strategies rely heavily on understanding and communication (Arthritis research UK, 2015, NRAS, 2015, arthritiscare.org, 2015).

Maycock (Anderson and Bury, 1988) raised concerns with the ignorance around 'the pathology and physiology of these chronic conditions. This gives rise to great anxiety, misconceptions and feelings of stigma in the sufferer which in turn damages self-concept'. These are mirrored in the recent report from the Rheumatoid Patient Foundation (2013), 'Lack of awareness of RA makes it even more isolating. Too often, even doctors doubt how much RA patients endure'

Although RA is a systemic disorder the focus of my interest lies in the hand. With two thirds of sufferers having wrist and hand symptoms of the disease (A.S.S.H . 2013), the hand is the principle

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HOW MODELS CAN TRANSLATE THE LIVED EXPERIENCE OF RHEUMATOID ARTHRITIS INTO MATERIAL AND FORM

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3 image from which most forms of public media draw from in reference to RA. A focus on the hand will
4 allow the researcher the greatest scope for creative expression of form from the body (Pallasmaa,
5 2009) in relation to the disease within the confines of the research time frame.
6

7
8 Hermeneutic phenomenology is qualitative and its role as a methodology within research is to
9 interpret rather than explain (Glendinning, 2006, Finlay, 2008).

10 The methodological nature of this research is two-fold:

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- 13 • To initially establish an understanding of the individual's lived experience of RA in the hand
 - 14 on the using Thematic Analysis (Braun and Clarke, 2006) of one-on-one conversations with
 - 15 up to six participants.
 - 16
 - 17 • Then, following a hermeneutic phenomenological structure (Gadamer, 2004, Lavery, 2008),
 - 18 to interpret understanding using material models as an alternative method of
 - 19 communication.
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23 INTRODUCTION

24 SUMMARY OF CONTEXT (A SUMMARY OF WHAT IS KNOWN ABOUT THE SUBJECT AND WHAT THIS RESEARCH WILL ADD)

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26 Even though the Visual is central to the cultural construction of social life in contemporary Western
27 society (Rose, 2007) the use of purely linguistic approaches still dominate our perceptions of the
28 world in Research. New, more aesthetic approaches are being sort by researchers such as Torres and
29 Galvin (2008) to avoid the use of 'language in summative ways that can over-sterilize or even deaden
30 the aliveness of the shown phenomena'. However, the focus here still lies with linguistic approaches,
31 which S. Root-Bernstein (1985) sees as misguided.
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36 "Neither our experience of nature nor our ability to think about it are limited to, or
37 are even mainly confined to verbal forms. Thoughts may, in fact, be translated into
38 language only for communicating but pictures, music, and other nonverbal forms of
39 thought also communicate and can be manipulated logically" (1985, p62).
40

41
42 Model-based approaches could offer this rich diversity to circumvent philosophical difficulties with a
43 purely linguistic account of the theories and explanations that codify knowledge (Griesemer, 2004).
44

45 There are currently no investigations that the researcher can find into the opportunities that model
46 making brings in this field.
47

48 RATIONALE FOR THE RESEARCH (I.E: WHY THE PRIMARY RESEARCH IS REQUIRED)

49
50 Although RA is alarmingly common, affecting 1 in 100 people of all ages in the UK, (NRAS, 2015), it is
51 a misunderstood disease (Westrich, 2012). A poll commissioned by the charity NRAS (2009)
52 revealed that 62% of people polled believed RA was due to the wear and tear of joints over time.
53 This figure was worst among young people aged 18-24 (75%) exposing a worryingly common
54 misconception about the disease. The King's Fund report (Godwin, Nick et al, 2009) into the
55 'Perceptions of patients and professionals on rheumatoid arthritis care' stated that "one major
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cause of delays for many patients is the low level of awareness of RA among the wider population, i.e: patients may delay themselves seeking help” (p.11).

‘Accurately describing Rheumatoid Arthritis could go a long way at curing the awareness problem ...with RA’. (Young, 2010) and awareness campaigns are a significant focus for the leading charities in the field (NRAS, 2013, Arthritis. Org, 2015).

‘The potential gap between patient’s perceptions and those of professionals is open to both systematic scrutiny and improvement’ (Bury, 1988). Comments such as these highlight the distinct need for contributions to enhance the understanding and awareness of RA “looking beyond the medical and physical elements of the disease” (Godwin, Nick et al, 2009. P.14). “Recognition of the impact it has on other activities of daily living...recognizing the social and psychological impact” (ibid. p. 12) could go a long way to tackling the “feelings of loneliness fear and despair” (ibid. p.22) that people with chronic illnesses endure.

It is the intention of the researcher to produce material models which, through interaction convey sensory experience understood through a hermeneutic phenomenological process and not as an illustration of a subjective point of view.

THE AIMS OF THE RESEARCH OR HYPOTHESIS TO BE TESTED.

AIMS:

- To create an alternative to spoken word or text as a direct means of communicating the experience of Rheumatoid Arthritis to others using model making as a facility.
- To evaluate in what ways a material model can be used to increase awareness of the impact that Rheumatoid Arthritis can have on hand function and quality of life.

OBJECTIVES:

- To use a thematic analysis (Braun and Clarke, 2006) to build an understanding from conversations with participants suffering from RA.
- To use this to generate material models which translate the phenomenon into a visual-haptic understanding.

PARTICIPANTS

WHAT SORT OF PARTICIPANTS (AGE RANGE, ETHNICITY, NUMBER AND GENDER) ARE TO BE RECRUITED? ARE YOU SEEKING UNDER-REPRESENTED GROUPS? IF SO, HOW WILL YOU IDENTIFY THEM AND ENABLE THEIR PARTICIPATION? HOW HAVE YOU INVOLVED USER GROUPS OR CHARITY ORGANIZATIONS TO HELP YOU IDENTIFY AND REACH SUCH GROUPS?

Three to six participants with RA will be sought though an open request via email. This will come via the University’s Uni Info system as a method of recruitment.

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The researcher's main sphere of interest lies in how data can be interpreted through model making and therefore a more generic selection from a wider catchment area is deemed unwarranted.

WILL VULNERABLE GROUPS OF PEOPLE BE INVOLVED? (CONSIDER THE CONCEPT OF 'VULNERABILITY' WITH CARE AND IN ITS BROADEST SENSE AND SHIFTING DYNAMIC WHEN SOMEONE CONSENTS TO TAKE PART IN RESEARCH).

Participants may be vulnerable in regard to access to interview rooms and facilities; however, all participants will be employed by the University of Brighton and able to work under its guidelines.

WHAT ARE THE INCLUSION/EXCLUSION CRITERIAS? (INCLUSIVE OF A RATIONALE FOR THE CHOICES MADE).

In order to gather data it is the researcher's intention to interview people who suffer from RA, in particular, those whose hands are affected by the disease. The research will focus on participants in work from the age of 40 upwards. The rationale for this lies in the "major impact [RA has] on economically active patients" (Godwin, Nick et al, 2009. p.24) and the fact that the "age of onset [of the disease] is generally between 40-60 years" (ibid, p.4).The researcher believes that a mature ability to verbalize and discuss personal issues relating to the disease will bring greater depth to the data collected. Ideally the participants would have longer-term experience of dealing with their disease, therefore being in a better position to both explain their understanding and be comfortable with any discussions. The King's Fund noted that "patients reported that they had a low awareness of RA at the point of first contact but that ... they would become experts in the management of their own condition" (ibid, p.19).

WILL EXCLUSION FROM THE RESEARCH DENY AN INDIVIDUAL FROM THE SERVICES OTHERWISE PROVIDED? IF SO, WHAT PROVISION IS TO BE MADE TO REMEDY THIS SITUATION OUTSIDE THE RESEARCH ACTIVITY?

Exclusion from this research, either by their own action or through process of the research, will not deny any individual from any specialist services or disadvantage them in any way. The research provides no benefits to any participants beyond participation. This research is seeking a means to promote understanding of RA rather than any remedy.

HOW WILL POWER RELATIONSHIPS BE HANDLED?

As the researcher works within the University from which he hopes to recruit from, there is a possibility that he may know some of the potential participants. In a scenario where the researcher knows a potential participant either through his immediate work environment (the department of Architecture in the School of Art, Design and Media) or on a personal basis then the researcher would inform them that he would be unable to accept their involvement on that basis.

All meetings will take place on University of Brighton premises, in a place best suited for the participants within a private setting and where conversations cannot be overheard.

The conversations will be as informal as possible and treated (and described to participants) as conversations with a direction and purpose. It is the researcher's intention to include the participants throughout the research from stages 1 to 4, either by direct contact (arranged meetings and conversations) or through explanation of the process. The participants' involvement and understanding of the process is considered to be a very important part of the success and integrity of the research.

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ARE PARTICIPANTS TO BE PAID OR REIMBURSED FOR THEIR TIME? THIS SHOULD NOT BE DEEMED TO AMOUNT TO AN INAPPROPRIATE INDUCEMENT TO TAKE PART.

Participants will not be paid or reimbursed for their time although any costs incurred by the participants, such as travel or food, in attending the process will be covered. All meetings will take place in daytime hours which are most convenient to the participants. Light refreshments will be offered and available during meetings.

RECRUITMENT STRATEGY

HOW WILL RECRUITS BE IDENTIFIED WITHOUT BREACH OF THE DATA PROTECTION ACT AND TO GUARD AGAINST THE INVASION OF PRIVACY? PLEASE SPECIFY ALL PROCEDURES BY WHICH INDIRECT ACCESS TO PARTICIPANTS WILL BE DEPLOYED.

Participants will be approached via email in an open call using the University of Brighton's internal email system. Any responses will be voluntary and will be seen only by the researcher. Arrangements to meet and any communication from that point will take place only between the participants and the researcher by the method of their choosing (either by telephone or email). Contact details will be kept on the researcher's personal email account with a password known only to the researcher or on his personal mobile phone. Any other data connected to participants will be anonymous and stored separately to the contact details.

HOW HAVE YOU ENGAGED THE GUIDANCE OF USER GROUPS AND APPROPRIATE CONSULTANTS TO SUPPORT THE PROCEDURE YOU OUTLINE.

The researcher has discussed the proposal with a number of University of Brighton employees who comply with the criteria for participant involvement and has tailored the approach in line with their valuable feedback.

The researcher has an experienced supervisory team who have worked collectively on projects involving vulnerable members of the community resulting in art-based data and exhibitions.

HOW WILL PARTICIPANTS BE RECRUITED? PLEASE SUPPLY A COPY OF ANY MEANS OF ADVERTISING, SUCH AS POSTERS, LEAFLETS, EMAILS, WEBPAGES OR LETTERS.

Participants will be recruited by email using the University of Brighton's Staffcentral and Uni-info system. (For email, please see appendix 1, p.i).

MEASURES TAKEN TO ENSURE CONFIDENTIALITY, PRIVACY AND DATA PROTECTION.

All the information collected during this process will be confidential- names and any other form of identification, such as place of work, etc. will be removed to protect privacy. Participants will be informed that their confidentiality will be upheld at all times unless they declare themselves as a risk to either themselves or others in which case the researcher will inform them that he will be required to make the situation known to the relevant authorities. All personal details relating to participant contact will be kept separately from the video and audio documentation taken during the

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3 conversations. These details will be stored on a computer and a portable hard drive which have
4 passwords only known to the researcher.
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6 Any data, discursive or video footage, if it is to be shown publicly or outside of the context of the
7 research (e.g. for purposes of assessment) will only be used with the consent of the participants.
8 Unless consent is given for specific purpose all digital and written data will be held in a safe and
9 secure place for five years before being destroyed.
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11 The use of video recording equipment has the potential to greatly increase the understanding of the
12 data gained during conversations but the researcher is aware of the inhibiting nature of such
13 equipment and therefore will not put any emphasis on this and will take the participants lead after
14 discussion prior to commencing. The video recording will be focused on the hands and, by default,
15 the upper body. The faces of participants will be excluded, as this is not a requirement for the
16 research and will protect the participant's anonymity.
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20 21 22 PARTICIPANT INFORMATION AND CONSENT PROCEDURES 23

24 HOW PARTICIPANT INFORMATION IS TO BE RELAYED (ORALLY AND IN WRITING) OUTLINING THE DETAILS OF THE
25 RESEARCH APPROPRIATE TO THE TARGET AUDIENCE (PARTICIPATION INFORMATION SHEET)
26

27 A call will be put out for participants to engage with research through internal University of Brighton
28 email systems (see appendix 1, p.i).
29

30 Within one week of receiving expressions of interest, the chosen participants will be provided with
31 information (see appendix 2, p.ii) regarding the research via email:
32

- 33 • What the aims and methods of the research are.
- 34 • What the research requires of them and hopes from their involvement.
- 35 • Details regarding the interview process.
- 36 • Details regarding the video process.
37

38 After one week of receiving the participant information sheet the researcher will email the consent
39 form (see appendix 3, p.v). In this email the researcher will also invite the potential participants to
40 ask any questions they may have regarding the proposal. On receipt and confirmation the researcher
41 will contact the participants to set a date for the first meeting.
42
43

44 The conversations will be arranged to last for a maximum of two hours. Timings and dates are to be
45 chosen by participants within a four week time frame after consent is given.
46

47 For participant information sheet please see appendix 2, p.ii.
48

49 PROCEEDURES FOR INFORMED CONSENT INCLUDING A COPY OF THE CONSENT FORM (INDICATING DRAFT NUMBER AND
50 DATE). IF CONSENT IS TO BE OBTAINED FROM ANYONE OTHER THAN THE RESEARCHER-HOW IS THE COMPETENCE OF THE
51 DELEGATED PERSON TO BE ASSESSED.
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54 Only the researcher will be involved with the participants at any stage of the research.
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56 For informed consent form please see appendix 3, p.v.
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HOW WILL YOU ASSESS THAT THE PARTICIPANT HAS FULLY UNDERSTOOD ALL THE INFORMATION IN THE PARTICIPANT INFORMATION SHEET PRIOR TO GAINING THEIR CONSENT?

The researcher will invite questions via email alongside the participation information sheet. In the participation information sheet the researcher will state that he is available for a telephone conversation to discuss the project and make sure the participants understand what is being asked of them before they sign any consent.

STATE ANY LIMITS TO CONFIDENTIALITY AND ACTIONS THAT WILL BE TAKEN SHOULD DISCLOSURES BE MADE-MAKE SURE THIS INFORMATION IS INCLUDED IN THE PARTICIPANT INFORMATION SHEET AND CONSENT FORM

All processes of this research and any data collected will be confidential. However, it is the intention of the researcher to show, in public environments, the models developed as a result of the research. This will only be done with the consent of the participants and the models will not be named or reference the participants in any way.

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RESEARCH APPROACH AND METHODS

HOW IS THE RESEARCH TO BE CONDUCTED-WHAT IS THE DESIGN? HOW, WHERE AND WHEN WILL DATA BE COLLECTED?

WHAT FACILITIES/RESOURCES WILL BE REQUIRED AND WHO WILL PROVIDE THEM?

This research will be guided by the hermeneutic philosophy prescribed by Gadamer (1986). This is not a relativist philosophy, that there is no objectivity and therefore there is a relative nature to truth systems. The researcher agrees with Gadamer in believing that all truth is historical but that there is a world outside of our culturally conditioned perception of it. However, because we can never have more than a perspective we cannot achieve a full picture of the world. We interpret points of view/perspectives but these change, both ours and others, as we search for common ground; understanding has a dialogical basis. Wachterhauser (1994) describes this epistemological approach as perspectival realism

The methodological approach undertaken in this research project has no precedents to draw on.

Gadamer's contribution to hermeneutic research was purely philosophical and he left no methodological approach to follow. To a point the researcher will follow a combination of the approaches prescribed by Ausgard (2012) and Fleming, Gaidys and Robb (2003)¹. The researcher agrees with both approaches' steps towards truthfulness and validity. However, neither path goes further than the accepted conclusion for hermeneutic research, that of interpretation of text into text.

Gadamer described text as meaning which had 'undergone a kind of self-alienation through being written down' and it was the transformation back into meaning that he considered to be hermeneutic. It is the intention of the researcher to attempt to gain this understanding through meaning found within the text but then, still involved in the dialectic movement between the text, participant and himself, to seek an alternative means of interpretation. Gadamer describes this action of dialectic movement and transformation as 'play'.

¹ The points that Fleming, et al (2003) and Ausgard (2012) make break down into five main points:

- The initial area of interest needs to be congruent with the aims of hermeneutic study, that is it the phenomena in question needs to be open to new perspectives, the potential of discussion and interpretation
- The researcher needs to show his prejudice. This is often known as 'fore-grounding' and requires the researcher to make his position known both epistemologically and in regards to his understanding of the research topic itself. This process will be periodically reviewed throughout the study.
- 'Gaining understanding with the participants' (Fleming, et al, 2003). This process is done through conversation and dialogue; it's not a question and answer session but an attempt to reach a mutual understanding by working together. It is important to remember on this point that in hermeneutic philosophy it isn't possible to see from another's point of view and that one can never fully understand how it feels to be someone else. Fleming, et al (2003) note that the researcher should also be aware that meaning and conversational understandings are transient being situational and historical meanings can change. It is therefore necessary to reaffirm meanings with the participant at different junctures in the process.
- 'Gaining understanding through text' (Fleming, et al. 2003). Using thematic analysis, looking for basic patterns in the text (Van Manen, 1997) allows the researcher to provide the accuracy and structure to the text based analysis required. The researcher should be aware of the hermeneutic process and look for changes of understanding within the text as larger themes develop and also document any interpretative acts clearly.
- Establishing trustworthiness. Trustworthiness in hermeneutics is established by maintaining honesty to the participant's voice (being faithful to the text). The researcher needs to provide a clear structure to the research and during its progress provide explanations to all decisions/interpretations made. As any conclusion to hermeneutic research is going to be the interpretation of the researcher it is only by showing the process as transparently as possible that the integrity of the research can be maintained.

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It is in this sense of involved, interested, imaginative participation that the research will be undertaken following a hermeneutic methodological path adhering to Gadamer's philosophy and his writing on the arts and aesthetic understanding (Gadamer, 1975, 1986, 2008).

On approval the first action will be to conduct an initial study of the proposed process involving one participant. This will allow the researcher to understand and evaluate the intention and proposed strategies in greater depth and will help define the exact number of participants required to complete the study. At this current stage the target is a maximum of four to six participants.

Although there is no ideal number of participants (Englander, 2012, Kvale, 1994), Eisenhardt (1989) suggests that between four and ten would be desirable for theory building or where the researcher is looking for an in-depth investigation and rich description rather than theoretical replication and cross-case comparison. Whilst 'the phenomenological method in human science recommends that one uses at least three participants' (Englander, 2012), Denzin and Lincoln make a recommendation for six participants within a phenomenologically based study in the Sage Handbook for Qualitative Research (2009).

This research sits within the hermeneutic tradition and as such 'is not concerned with the repeatability of an explanation' (P.Darke et al., 1998). The value of any explanation in the context of this research will be judged in terms of the extent to which it allows others to understand the phenomena and makes sense to those being studied (Walsham, 1995).

This research will follow what is known as the hermeneutic cycle (fig.1) where the researcher will reassess and reflect on data collected throughout the process, re-evaluating his understanding of the phenomena and applying this to his analysis of the data. This process enables the researcher to maintain the principles of analytical rigour, a persuasive account and participant feedback prescribed by Laverly (2008).

The data gathered will follow through four stages:

- the initial conversation, where the researcher will attempt to come to an understanding with the participant about their experience of reality.
- the visualization process with participant, where the researcher will deepen and develop his understanding of the text with participant involvement using images and visual metaphor.
- the model making process.
- meeting with participants and models, where the models meanings will be interpreted and discussed.

The model making process will be the only one not to directly involve the participants although it will be discussed with them.

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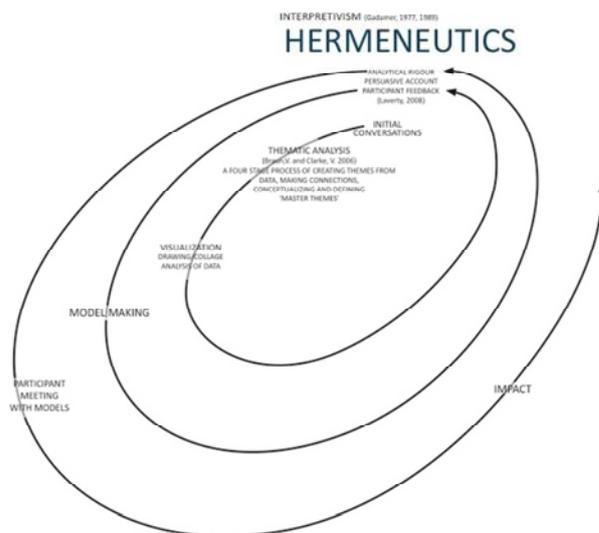


fig.1: Hermeneutic cycle within research context.

STAGE ONE THE INITIAL CONVERSATION

Stage one will involve one-on-one conversations lasting up to two hours with the participants. An idiographic conversational approach was chosen as the means of data collection to allow the participants the freedom to discuss their interpretation and understanding of their experience of the phenomenon openly in a private environment whilst allowing the researcher to focus on the conversation, prompting the participant where necessary to gain a deeper understanding. The researcher will follow a prescribed path (Braun and Clarke, 2006, Biggerstaff and Thompson, 2008) and collect data from open, in-depth and semi-structured conversations.

The focus of the conversation will relate to the participants lived experience in relation to their environment. How they feel about and interact with objects and how RA impacts on their everyday. Although the researcher will initially lead the conversation with a few main themes for discussion, it is not intended to be prescriptive or limiting in the sense of overriding the expressed interests of the participants. The desired outcome is to let a conversation develop with the participant taking the lead. This process also allows for a greater comprehension of and involvement in the research by the participant, which will involve creative processes outside of common practice.

A latent, theoretical, thematic analysis will be used as prescribed by Braun and Clarke (2006) to extract and understand the data; theoretical as the research is 'driven by the researcher's theoretical or analytic interest in the area' (ibid), whilst a latent approach would seek to identify the features that gave it that particular form and meaning. Thus for latent thematic analysis, 'the development of the themes themselves involves interpretative work, and the analysis that is produced is not just description, but is already theorized' (ibid).

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The conversations will be used as a means to engage with a sufferer of RA face to face, allowing the participant every opportunity to communicate their experience, an 'insiders' point of view, focusing on the subjective experience of living with and in spite of the illness and, through dialogue, to build a meaningful understanding of their perspectives, interests and concerns regarding the research topic.

The aim of the conversations is to interpret in detail and understanding the perspectives offered by the participants themselves as opposed to making a general claim regarding the subject.

Rooms on University of Brighton premises will be used for all meetings with the participants, the conversations and the visualization meeting and the final meeting (with models), which are convenient for the participants but not their direct place of work. The conversation will be recorded using a digital voice recorder.

Also, with consent of the participant, two, variously placed, digital camcorders will be used to document the hand gestures during the conversation. The researcher is interested in the hand's movement in space and gestural forms as a means of communication. The reason for this number of recording devices is to maximize the amount of data collected during this process. This footage will be used in conjunction with the discourse to help interpret the data with an understanding of the psychology of nonverbal behaviour (Krauss et al (1996)). Any irrelevant information (backgrounds/clothing/bodies/etc) will be digitally erased from the video. Participants will be invited to view the video post editing.

This approach also sits well with phenomenological understanding where the body can be understood as 'the outward expression of a certain manner of Being-in-the-world' (Merleau-Ponty, 2002, p.55). Physical gestures, understood here as any movement that expresses or emphasizes an idea, sentiment, or attitude, and the spoken word and are a form of articulation and both, according to Merleau-Ponty (2002), are a gesture and a language and therefore are open to interpretation.

The use of video recording equipment has the potential to greatly increase the understanding of the data gained during the conversation but the researcher is aware of the inhibiting nature of such equipment and therefore will not put any emphasis on this and will take the participants lead prior to commencing. The video recording will be focused on the hands and, by default, the upper body. The faces of participants will be excluded or digitally erased during editing as this data is not required by the researcher and, also, will protect the participant's anonymity.

The participants will be informed that all data collected at the initial conversation will be confidential and at every stage they will remain anonymous. This will be explained from the outset and in order that an informed consent can be given the participants will be provided with a written information sheet as well as an oral explanation, which will include the research outline and aims, details regarding the meeting-place, time frame, why they were chosen and what is expected from them, as well as an explanation of their rights to withdraw from the process at any time without having to explain and without penalty in accordance with the National Patient Safety Agency guidelines (Nrls.npsa.nhs.uk, 2015).

STAGE TWO THE VISUALIZATION PROCESS WITH PARTICIPANT

Stage two will involve the participants in a second meeting to discuss the themes of the thematic analysis that represent the researcher's understanding from the initial conversations. The purpose of this meeting is for the participant and researcher to create visual analogies and references of the

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data, a conceptual mood board, which, at a later date, the researcher will interpret through further drawing and collage into designs to aid the model making process. This process could be understood as similar to the role of a storyboard artist in movie making, creating visual images to help the director and production designer communicate their ideas.

During the meeting the participant and researcher will discuss keywords from the themes in terms of imagery and metaphor with the researcher drawing sketches and showing images from the internet. Any images taken from external sources will only be used in conjunction with existing copyright laws and permission will be sought if required. Any preparations for this meeting (including pens, paper, internet access, etc) will be made by the researcher. All drawings and processes required during the meeting will be undertaken by the researcher. Refreshments will be offered and available.

It is important to note that this is not an act of bringing something to the text but a realization that the text elicits something from its analysis, understandings that 'strikes us as significant' (Karnezis, 1987. p.3) which continuing dialogue 'serves to bring forth [a recognition of new meaning] into a sharable, intersubjective realm' (ibid).

STAGE THREE THE MODEL MAKING PROCESS

In the third stage the researcher will analyse his understanding of the discussions through model making, exploring materials and techniques to create a design which, with close attention to detail, interprets this understanding of the participant. There will be no participant involvement during this stage.

The process from interview to completion of model with the first participant will be conducted before the MPhil/PhD transfer, acting as a pilot study, with the following participants involvement coming after.

STAGE FOUR MEETING WITH PARTICIPANTS AND MODELS

This stage of the research process will involve the each participant seeing the complete collection of finished models (those of all participants including their own). The participant and researcher will discuss meanings they derive from the collection of models, seeking connections/differences between experiences and interpretations, looking for new meanings.

In line with Gadamer's philosophical hermeneutics, the researcher sees art (i.e. the models) as language, a process of discourse. Art is intersubjective, requiring both the artist and viewer's involvement to be fully realised; 'the being of a work of art is play which needs to be perceived by the spectator in order to be completed' (Gadamer, 1986. p.146). Both the creative act (the role of the maker) and the viewing act are part of the process of understanding, a part of play, from which meaning can be found.

This meeting will also be an opportunity to evaluate the participant's feelings towards the process and outcomes of the research resulting in an overall evaluation of the process regarding the interpretation of participant's description by a researcher through model making which will be described in the final thesis.

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Participant feedback is considered by the researcher to be another quality trail that Hermeneutic Phenomenological research needs to pass before reaching its audience since it helps to best represent the participant's intentions within the interpretive process (Lavery, 2008). This meeting will take place in a private room within the University where the models of all participants will be presented. Because of the requirement to have all models displayed the researcher will book the room in advance and request that participants travel to it. This meeting will be arranged for a time most suitable to the participants and will be scheduled to last for up to two hours. This meeting will be recorded using a digital voice recorder and notes will be taken by the researcher.

DATA STORAGE

HOW ARE DATA TO BE STORED TO ENSURE PARTICIPANT PRIVACY AND COMPLIANCE WITH THE DATA PROTECTION ACT?

All the information collected during this process will be anonymized- any names or other forms of identification, such as place of work, etc. will be removed to protect privacy. This process will take place before anyone other than the researcher views it.

All personal details regarding contact will be kept separately from the research data. Research data will be stored on a computer hard drive and laptop that have passwords only known to the researcher.

No data, discursive or video footage, will be shown publicly or outside of the context of the research (e.g. for purposes of assessment) without the understanding and consent of the participants.

All digital written data will be held in a safe and secure place for five years before being destroyed unless for evidence within papers or exhibition purposes to explain process and then only with the consent and understanding of the participants.

WHERE WILL DATA BE STORED?

All data will be stored at the researcher's home address. Digital data will be stored on a portable hard drive and on a laptop both with a password known only to the researcher. All analogue material (drawings and models) will be stored in a locked plan chest at the researcher's home. The research will mostly be conducted at home which has been the researcher's permanent address for more than three years. Models will be made in the workshops of the School of Architecture and stored in the researcher's personal office. As these will have no direct reference to any person/participant this is not considered to breach any participant privacy.

WHO WILL HAVE ACCESS TO DATA (SUPERVISORS MIGHT WELL HAVE SIGHT OF THE ANONYMISED DATA AND THIS SHOULD BE STATED CLEARLY AND MADE KNOWN TO THE PARTICIPANTS).

Only members of the researcher's supervisory team will have access to the anonymized data, when the researcher is present.

HOW WILL THE DATA BE TRANSFERRED FROM ONE SOURCE TO ANOTHER?

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Data will be stored on the researcher's laptop and backed up onto a portable storage device. Original data from all conversations will be transcribed by the researcher onto these devices. Once copied to the computer any information on the digital camcorders will be wiped clean.

HOW WILL THE RISK OF DATA LOSS BE MANAGED?

Digital data will be backed up regularly on a portable hard drive. Analogue material will be photographed, scanned and copied to provide a digital, secure record. Once this process is complete the analogue data will not need to be referenced on a regular basis and will remain in a locked plan chest.

ANALYSIS

In using a hermeneutic methodology it is important that the researcher and participants work together in order for the researcher to come to as full an understanding as possible of the participant's reality with the researcher remaining open to new ideas throughout the study. The help of the participants through arranged meetings at various stages in the process will allow understanding and interpretation to develop. The use of such an emergent approach is consistent with hermeneutics and vital if any interpretation of the participant's perceived reality is to have any validity.

Initial conversation: The reason for the initial conversations is to seek understanding from someone with first-hand experience. The research is not looking to create narratives around personal experience or to use specific personalities as witnesses to the researcher's understanding. RA is a very subjective experience and the researcher is aware of the need to have a mutual understanding with the people who participate, keeping the individuals understanding in context and not generalizing any information purely to make the analysis of data simpler. Using a latent, theoretical, thematic analysis (Braun and Clarke, 2006) will provide the means to analyse the structure and content of the discussions without 'disembodying' the data from the source by categorizing it.

THEMATIC ANALYSIS (Braun and Clarke, 2006):

Post interview, the recording will be transcribed with meticulous accuracy, including, for example, indications of pauses, mis-hearings, apparent mistakes, and even speech dynamics where these are in any way remarkable. Thematic analysis is a cyclical process where the researcher proceeds through several iterative stages:

- Stage 1:

The transcripts will be analyzed in conjunction with the original recordings and the visual recording from the camcorder in order to begin to identify themes. The researcher will keep a reflexive diary to record any details of the nature and origin of any emergent interpretations, making notes of any thoughts, observations, and reflections that occur while reading the transcript including any recurring phrases, the researcher's questions, emotions and descriptions of, or comments on, the language used.

- Stage 2:

The text is re-read to identify themes that best capture the essential qualities of the interview looking for possible connections between themes.

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- Stage 3:

The aim, at this stage, is to arrive at a group of themes and to identify categories that suggest a hierarchical relationship between them, thus providing an overall structure to the analysis by relating the identified themes into 'clusters' or concepts.

- Stage 4:

The fourth stage is to develop a 'master' list of themes. It is important to locate these themes in an ordered system that identifies the main features and concerns identified by the research participant and that best captures the essence of their thoughts and emotions about their experience of RA in the hand.

The researcher will use the master list of themes obtained from the first conversation to identify more instances of these themes in the subsequent meetings, while also being alert to the possibilities of new themes, which as part of the cyclical process will be tested against earlier data. It is important to note that in a hermeneutic inquiry there are no right or wrong answers; contradictions and differences may arise and the researcher sees his role to interpret these through whatever variables or multiples he sees necessary to convey an account truthful to the understanding he reached with the participants.

A second meeting with the participant arranged at the end of the thematic analysis process will revolve around a discussion of the themes the researcher has developed as an understanding from the transcriptions of the first conversation and an explanation of where the themes came from. The participant and researcher will use this discussion to analyze the themes further; deepening the researcher's understanding using drawing and collage to develop a visual language and metaphorical links to aid the design process. This meeting will also be recorded using a digital voice recorder but will again remain confidential and anonymous.

Whilst sketching will be used by the researcher to anchor the conversation in a visual domain, the use of collage, digitally cutting and pasting images, will allow the participant to use 'ready-made' images, endowed with semantic and cultural references relevant to themselves, to visually explain and describe with little or no creative abilities. Nicholson (1990) explains that "like all maps, collage can exist as a guide to what exists on the ground or it can prompt a new set of thoughts suggested by interconnections of terrain and cities. When considered from this angle, the collage becomes a transcription that can accelerate the way one understands the everyday world and how it comes together, without necessarily being an expert of any particular field of knowledge" (ibid, p.17). The researcher will respond to metaphors or descriptions given by the participant by searching Google images and manipulating these through Photoshop to the participant's specifications in a process similar to that of facial composites in Police investigations. This process will take place during the conversation using the researcher's own laptop computer and a sketch pad with pencils provided by the researcher.

Halling (2009) argues that this approach to idiographic phenomenological research can identify general structures of experience when researchers engage with the experience alongside reflection on themes common to the phenomenon and more universal, abstract aspects of being human.

This aspect of the research process is important to allow the researcher to begin formulating the

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models. The researcher sees drawing as integral to the design/creative process. Even though “a major value in making models is to ask questions and thus develop ideas and concepts” (Glanville in Ayers, 2012. p.47) the making process is not an immediate one. The researcher accepts the time constraints on the participants but also feels that the conceptual leap from idea to image/drawing is at first easier to grasp than trying to directly visualize materials or objects into anything other than what they are.

Going through this process will enable the researcher to pursue the design of the models within the constraints of a visual and material palette determined in consultation with the participants, ensuring that their voice is not lost in the creative process.

At this point of the process the researcher will also begin to relate the designs to the logistics of manufacture and other practicalities (their scale, potential for interaction, etc).

ANALYSIS THROUGH MODEL MAKING PROCESS

Systems are theoretical tools which can be used here to explain the creative process of reflexive model making. The element is the starting point of the system, although it can be basically anything physical, complex or simple. Elements have properties, some more relevant than others to the understanding of the system. The relationships, the interaction between different elements in the system, can affect or be affected by these properties. Varying within the system, these relationships may be time or space dependant, active or passive, etcetera. Bringing different elements together activates certain properties of each; therefore only in a certain relation does a certain property of an element become relevant as information. Wharton (2009) sees any informative intention not as an attempt to modify a viewer’s thoughts directly but to modify their cognitive environment—a manifestation of memories, facts, associations and assumptions we are already aware of alongside those which we are capable of becoming aware of due to our cognitive abilities and the environment we reside in. On a cognitive level it is not an intention to produce a particular response to something but an intention to make manifest or more manifest to the user/hearer a set of assumptions *relevant* to something.

In model making terms we can understand the elements of a system as the materials used, wood, metals, plastics paper and so on. These elements have both syntactic and semantic properties. How the material element is composed, whether it is large, small, light or dark, is a syntactic difference yet how that object is understood or labeled is semantic; for example a blue glass bottle ribbed and grooved denoting poison. Whether understood through linguistic description or through a cultural context, this conceptualization of objects and things allows for interpretation, with each individual element becoming meaningful as part of a system.

STATISTICAL OR QUANTITATIVE METHODS SHOULD BE STATED WITH A BRIEF OUTLINE DEMONSTRATING UNDERSTANDING OF THE PROCEEDURES AND OR STATING TRAINING THE RESEARCHER HAS UNDERGONE TO ACQUIRE COMPETENCE IN HANDLING THESE PROCEEDURES.

There are no statistical or quantitative methods involved as this research sits within an Interpretivist, qualitative framework. The interest of this research lies in the interpretation of language and experience rather than statistical or numerical fact.

POTENTIAL OUTCOMES/IMPACT OF RESEARCH

PETER MARSH ETHICS SUBMISSION <https://mc.manuscriptcentral.com/fregc>

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HOW MODELS CAN TRANSLATE THE LIVED EXPERIENCE OF RHEUMATOID ARTHRITIS INTO MATERIAL AND FORM

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WHAT ARE THE EXPECTED IMPACTS OF THE RESEARCH?

By providing new perspectives on how those suffering from RA experience their day-to-day this research falls in line with the social model of disability. By increasing the awareness of how it feels to suffer from RA more can be put in place, to help those who do, to cope with the disease.

There are implications for the field of hermeneutic phenomenology where researchers search for more creative, expressive ways to convey their interpretations (Finlay, 2009) and, although not the prime intention of this research, the potential of material models as a means of communicating lived experience, and an understanding of the process, has an implication in the field of design at a time when the digitalization of the design process has begun to ignore the potential of materials beyond purely aesthetic qualities.

As stated the methodological approach undertaken in this research project has no precedents to draw on. The researcher's attempt to gain understanding through meaning found within an alternative means of interpretation to text will provide new insights in how hermeneutic research can be undertaken.

This research hopes to increase public awareness of RA through exhibitions and to promote discussion in the Health Profession community of the potentials of phenomenological models through papers, displays and conferences.

ARE THERE ANY BENEFITS TO THE PARTICIPANTS?

Through vocalizing their experience Hutchinson, Wilson and Wilson describes catharsis, self-acknowledgment, sense of purpose, self-awareness, empowerment, healing, and providing a voice for the disenfranchised as the sometimes unanticipated benefits reported by participants involved in research of this type (1994).

WHAT ARE THE RISKS TO THE PARTICIPANTS, RESEARCHERS OR ORGANIZATIONS IN WHICH THE RESEARCH IS TO TAKE PLACE? HOW ARE THESE TO BE HANDLED/ JUSTIFICATION AS TO WHY THIS RESEARCH SHOULD PROCEED AND THE COMPETENCE OF THE RESEARCHER TO REFLEXIVELY MANAGE PROBLEMS SHOULD THEY ARISE

At the beginning of the research process, before the interviews take place, the researcher will discuss the potential of distress in re-living their experiences with the participant. The researcher will recommend that between them (researcher and participant) they come up with a plan in case of such a scenario which will include the suggestion that the participant seek professional support, either by going to see their G.P. or the University's Occupational Health advisor in order to be referred to a counsellor.

Should the participant become distressed at any point during the research process the researcher will stop the proceedings either temporarily or permanently as the participant wishes. He will suggest that the participant seek the professional support discussed.

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The researcher and all participants will be following risk assessments prescribed by and using University of Brighton guidance on good practice in research ethics and governance policy (May 2010):

- Research should be carried out wherever possible to avoid risk to participants.
- At all times the safety, wellbeing, rights and dignity of research participants should be maintained.
- Research should be designed and carried out to high standards to ensure quality and integrity.
- Partiality or conflict of interest should be avoided where possible, or if unavoidable should be dealt with appropriately to ensure the independence of the research.
- In research involving human participants, wherever possible they should be fully informed regarding the aims, purpose and methods of the research, and the potential use and dissemination of its results. In particular they should be given information on exactly what their participation is likely to involve, including any possible risks and benefits.
- Participation in research should be voluntary, and participants should be free from any coercion or inducement to take part.
- Participants should be given adequate time to consider whether or not they wish to participate before being asked to make a decision.
- Consent to taking part should be obtained from participants wherever possible. Once volunteers have decided to participate, they should be able to withdraw from participation at any time without giving a reason.
- Confidentiality of information supplied by participants should be maintained, and their privacy respected, and where possible information provided by them should be anonymised.

Ackermann, E. (2001) "Piaget's Constructivism, Papert's Constructionism: What's the Difference?", *Future of learning group publication*.
 Adams, F. and Aizawa, K. (2001) "The Bounds of Cognition", *Philosophical psychology*, 14 (1) pp. 43-64.
 Adams, F. and Aizawa, K. (2008) *The Bounds of Cognition*, John Wiley & Sons.
 Adams, F. and Aizawa, K. (2010) "Defending the Bounds of Cognition", *The extended mind*, pp. 67-80.

The final pages have not been displayed to avoid repetition. They consisted of Bibliography and documents to be found in APPENDIX 2

11.3.2 FEEDBACK and RESPONSE to Ethics submission

RESPONSE TO REVIEWER 1

Dear Reviewer 1,

Thank you for the feedback, hopefully I've addressed the points you have raised. I haven't highlighted the changes as I believe it would make the document quite confusing to read as there are quite a few changes which are minor word changes, grammatical or changes by deletion.

The main changes include:

- The omission of the questionnaire as a means to record impact regarding the exhibition, as I agree that these did not sit comfortably within the project. The exhibition itself has been included in the proposal as a standard means of dissemination of results for an Arts based PhD.
- I have adjusted the wording of much of the document to highlight the hermeneutic approach I have adopted; for example, I have never been satisfied with the concept of 'an interview' believing that understanding will come through a dialogue, a conversation, and that will be the stance that I approach my participants with. I will 'search for meaning' rather than 'analyse data' and although these seem potentially trivial such wording does suit the way in which I will conduct the research.
- I did consider keeping the focus group, or (much better phrased) intersubjective community following the approach of the 'festival' from Gadamer's understanding of aesthetics⁴⁴ (the idea of a community formed around a shared interest in what an artwork could bring to the fore). However, after consideration I felt that if I were to be put in such a situation I'm not convinced I would be at all comfortable so why should I as a researcher expect this of

44 Gadamer, H. G. (1975) *Truth and Method*, Seabury Press.

Gadamer, H. G. and Bernasconi, R. (1986) *The Relevance of the Beautiful and Other Essays*, Cambridge University Press.

others? I therefore changed this stage of the research which I feel sits more comfortably with me ethically and still maintains the methodological approach I'm attempting. By inviting each participant individually to 'meet' all of the participant's models, the concept of festival is maintained but with a different focus. Rather than draw the participants as a community into the hermeneutic circle, the collection of models, individually and collectively will be. The dialogue between the participant and myself will continue undisturbed by any new dynamics/personalities. The inclusion of the model, especially those that are not the participants, will create the sense of community (not a lone voice, different perspectives, etc.). This approach will bring new understandings to the participant and, also, to myself by being able to have an open dialogue about them with someone so closely associated in the research and being able to see the work in a new light/setting (the idea of being able to stand back from the work here rings true. The work really would be making up the group/community, having to stand on its own for the first time and be *viewed*-which Gadamer believes completes the work, opening it up to true understanding, like a text being read).

Thank you once again for taking the time with this document and I hope this is an improvement.

Yours sincerely

Pete Marsh

Reviewer: 1

Comments to the Applicant

Thank you for resubmitting your application with revisions. I note this has been uploaded as a new submission.

HERMENEUTICS

420

HOW MODELS CAN TRANSLATE THE LIVED EXPERIENCE OF RHEUMATOID ARTHRITIS INTO MATERIAL AND FORM

The methodology does still remain very muddled/ Gadamerian Hermeneutics IS the methodology to study TEXTS yet - you constantly suggest that this research is in finding an alternative medium to represent and communicate the experience of people with RA. Surely symbolic interactionism would be a better methodology that gives you scope of interpretation and assess the process of making meaning through different symbols and other representations. This is mentioned as if you do situate this work in an inappropriate theoretical framework it will be rendered meaningless and thereby wasting the time of participants in the longer term.

How is a pilot study - compatible with phenomenology? Also, how is building theory consistent with phenomenology? Rather than a pilot why not work with PPI to design the study and rehearse your skills?

How does the proposed thematic analysis square with Gadamerian hermeneutics?

You mention all six participants meeting to discuss the results - is this a focus group to verify findings? Once again how does this square with phenomenology? How are you positioned to merge the findings from six different people and make a representation across those individuals? Once again, this is phenomenology!

The same applies to all the questions in the survey - again this type of questioning is inconsistent with Gadamerian hermeneutics.

Terminology corrected , survey omitted, focus group stage changed to individual participant with models.

ARTHRITIS

You suggest that you will recruit 3-6 people diagnosed with RA who are not undergoing physical treatment. This is extremely unlikely - have you checked how many people have this diagnosis who are not having any physical treatment from the NHS even if this is control through paracetamol or other anti-inflammatory medication? Will you exclude people who are using dietary control? If someone with RA is not undergoing treatment there are potentially two options a) the RA is so mild it does not require medication - or b) that the individual is resisting treatments and taking

alternative remedies / treatment choice - that makes them potentially unrepresentative of the population of people who have this diagnosis. c) People who feel / self-diagnosed they have RA but it is not yet formally labelled confirmed by blood samples, CT scan / ultra sound or biopsy. Medics are extremely reluctant to attach the label until it is confirmed / diagnosed - but then treat aggressively to delay / halt further deterioration. Have you consulted a rheumatologist about this issue? I recommend strongly that you do.

Requirement removed.

INTERVIEWS

You are stating you will not reimburse people for their time - but will you reimburse any expenses. If not, why not? Should participants be out of pocket because they take part in your research?

Reimbursement policy rectified.

The email invitation does not set out an exclusion criterion - therefore you are inviting responses from people exposing their diagnosis without realising they are to be excluded.

Now included

If you are recruiting by email how can this be anonymous - you are asking respondents to reveal who they are unless you give instructions as to how to hide their identity in replying to your email. Are there enough hours in the day to do this - you seem to be asking a lot of people.

Apologies-mistyping now corrected (~~anonymous-confidential~~)

What exactly will you be videoing - the way people use their hands when talking of the way they use their hands to do certain activities. Will participants see the video? If your primary source of data collection is video how can you destroy this at the end of the study. You should consent people to retain this as long as a transcript. Will you seek retrospective consent if you wish to use the data as illustrations / evidence in your thesis? You do not mention the use of video in your information sheet nor in your consent form.

Video approach now explained, digital data to be kept with written for same length of time, consent request added.

What is the impact of a chaperone on the interview and video? Will you take their consent or ask

them to sit silently and out of sight? How can you justify this time spent by a second party? Is this an act of cultural sensitivity or an other rationale? If it is please state this. Also you do not discuss the potential impact on the data from having a third party in the interviews.

Chaperone offer removed as criteria requirements for participants and opt in recruitment policy negate need.

How will you transfer data from University to home where it is to be stored? Will this be locked / password protected etc. Are the data more safely stored at the university?

Better digital security at home, also will be working from home so less transport of data over long term.

The information sheet identifies that you are seeking to interview people for up to 2 hours on four occasions - this seems to be an extraordinary amount of time. Also, what happens over the course of the longitudinal study the participants then enter a programme of medication / physical treatment with the NHS?

Time frame rectified in information sheet- three meetings up to two hours each over a one year span.

You assure participants confidentiality at all times. What happens in the event of a disclosure? You cannot state this as you will be required to make known to authorities anyone who declares they are risk to themselves or others. You should make this clear in the information sheet.

Confidentiality disclosure warning added to document and information sheet.

What kind of benefits do you think the participants will experience from being interviewed?

Potential benefits added to information sheet.

QUESTIONNAIRE

Appendix four lists ages that fall outside the recruitment range set out above

You introduce new criteria in the questionnaire (phenomenology????!!!!) that implies people either work in arts or health (what about scientists and social scientists). If they are to be excluded again you need to make this clear.

The question about models promoting lived experience a) what does that mean?

b) it is loaded to an answer yes/ no.

We only find at the end of the questionnaire this is a survey aimed at people visiting an exhibition - is this to the wider population of visitors if so who might they be.

Questionnaire removed from study.

You add something to potential benefits and describe catharsis on p 17 but this has not been transferred into the information sheet.

Information added to information sheet.

You do need to set out the risk assessments - not simply say you will follow policy on this.

University of Brighton guidelines now included in document.

RESPONSE TO REVIEWER 2

I've copied in the points you asked for in the email (noted in purple) but also the points/comments raised by Reviewer 1 in my Ethics resubmission that relate to my epistemological/methodological stance, which I've noted in red (A, A1, B, C, D, E, F).

Sorry if it's too long winded but my thinking was that I may need to feed it into my thesis...

Please provide evidence (literature and references) from those who follow Gadamerian phenomenology that the methods you are proposing (notably focus groups (a collective view point), questionnaires (is this how you capture essence?) and an evaluative survey (post exhibition) are consistent with the approach.

A: The methodology does still remain very muddled

Hermeneutic phenomenology, like Husserl's transcendent, is concerned with human experience as it is lived, but does not agree with Husserl's view of the importance of description rather than understanding (Dowling 2007). Hermeneutic phenomenology should not be seen as a method or a research approach but rather as an epistemological stance.

The Heideggerian concept of being-in-the-world used in hermeneutic research places the researcher in a different relationship to research participants than that in Husserlian phenomenology (Walters 1994). Researchers either bracket their understandings in studies guided by Husserl or incorporate these into their interpretation of participants' stories if following hermeneutics (Koch 1999). The researcher is using phenomenology from an interpretive perspective in this study and is not attempting to separate himself from the world to arrive at an objective description of the phenomenon under study. He is engaged in a process of reciprocal interpretation with participants (the hermeneutic circle) and the concept of 'contamination of their accounts' is not an issue (Bradbury-Jones, et al. 2008).

For both Heidegger and Gadamer truth isn't something that is constructed by distancing oneself from what is to be known (Polkinghorne 1983). Their phenomenology is based on the assumption that the observer cannot separate themselves from the world (Walters 1994) and that world isn't just embodied but also intersubjective⁴⁵ (Merleau-Ponty, 2002); so the possibility of creating a description of the lived world from the viewpoint of a detached observer isn't possible. An interpreter always brings certain experiences and frames of meaning (prejudices and traditions) to bear in the act of understanding and these cannot be bracketed (Koch 1996).

The researcher feels it important to note that although Gadamer's hermeneutics is against the concept of a Cartesian objectivity, a dichotomy of right and wrong, it also sees fundamental flaws in Relativist subjectivity (Bernstein, 1983). Rather, understanding could be seen as coming from a 'psychological empathy... the aim of which is to grasp the subjective intentions of the author of a work or text' (ibid). Understanding should therefore not be seen as a state of mind or a

⁴⁵ We are part of a system that includes the environment and others in it. Our self is "entangled in an undifferentiated communion with others" that only gradually becomes distinguished and differentiated. Being social makes us *us* (Merleau-Ponty, 2002).

psychological process. Meaning is to be found in the thing itself (the text –see ‘Text’, p.4). Meaning is not a self-contained essence but comes to realization only through the ‘happening’ of understanding, which, for Gadamer, occurs in language (Gadamer, 1975). To put it another way, understanding is based on the interpretation of phenomena rather than the description of phenomena and so, from this perspective, the concept of ‘capturing an essence’ is flawed as there is no single, definable foundation (an essence) to a thing/phenomena to describe. As meaning isn’t inherent, waiting to be exposed but is to be found in dialogue⁴⁶ or play (Gadamer, 1975) the researcher sees the need to engage the participants in a collective discussion within the context of the research (a continuation of the hermeneutic circle process) to bring greater clarity to his understanding.

B: You mention all six participants meeting to discuss the results - is this a focus group to verify findings? Once again how does this square with phenomenology? How are you positioned to merge the findings from six different people and make a representation across those individuals? Once again, this is phenomenology!

⁴⁶ **A1:** Surely Symbolic Interactionism would be a better methodology that gives you scope of interpretation and assess the process of making meaning through different symbols and other representations? As can be seen above the researcher’s methodological approach stems from epistemology rather than from a Social Science discipline. It is the researcher’s understanding that Symbolic Interactionism, as an interpretive method, relies on locating invariant properties in conversation with an understanding of the participant’s knowledge of symbolic meanings and social environment (Lowenberg, 1993), whereas the researcher sees symbolic meaning deriving from an analysis of the text with language providing ‘the mediation between individual cognitive processes and the social and culturally shared aspects of interpretation’ (ibid, p.65). For the researcher the meaning is in the text and not in the context. In this project the emphasis is on the participant’s perspective rather than a social construction of reality, a tradition shared by participant and researcher that could potentially prescribe or restrict any idiosyncratic interpretation/translation into material form. Although in future research he sees how this approach will become more relevant, currently the researcher feels it justified in following a hermeneutic methodology.

The researcher accepts that individual experiences are at the core of phenomenological research and that analytical emphasis is on subjective, idiosyncratic perceptions of the individual participant (Stewart et al. 2007), but that does not mean that group approaches are inappropriate. Spiegelberg (1975) and Halling et al. (1994), argue that a group approach does not exclude individual perspectives but finds them inclusive; if participants are given the opportunity to tell their story and are listened to each in turn then allowing for differing perspectives, insights stemming from the chance for participants to interact with the work in context of the research and their collective experience.

The group meeting prescribed in this project isn't to be used as a substitute or attempt to verify the analysis of the one-to-one interviews but an attempt to achieve a richer understanding of the phenomenon under study; a result of the participants reflecting on the process and sharing their understandings developing in keeping with Gadamer's concept of shared horizons, which was termed in the initial email request (above, p.1) as a 'collective view point'.

A group discussion with all the participants allows for a deepening of understanding both among participants and between participants and the researcher. This is not to imply an attempt to arrive at 'the truth', as clearly this is contrary to phenomenological philosophy but it is a means to find the most probable interpretation (Ricoeur, 1973), enhancing rather than hindering methodological rigour (Côté-Arsenault and Morrison- Beedy 2001).

C: How does the proposed thematic analysis square with Gadamerian hermeneutics?

Gadamer's contribution to hermeneutic research was purely philosophical and he left no methodological approach to follow. The researcher will follow a theoretic appreciation of Gadamer and Ricoeur established by Bernstein (1983) and Geanellos (2000) and, to a point, a combination of the approaches prescribed by Ausgard (2012) and Fleming, Gaidys and Robb (2003). The researcher agrees with the latter's approaches and their steps towards truthfulness and validity but neither path goes further than the accepted conclusion for hermeneutic research, that of interpretation of text into text.

Gadamer described text as meaning which had 'undergone a kind of self-alienation through being written down' (1975, p.411) and it was the transformation back into meaning that he considered to be hermeneutic. It is the intention of the researcher to attempt to re-gain this meaning through

transformation of the text but then, still involved in a dialectic movement between the text, participant and himself, to seek an alternative means of interpretation which will, hopefully allow easier application and understanding in the practical world. Gadamer (1975) describes this action of dialectic movement and transformation as 'play' and it is in this sense of involved, interested, imaginative participation that the research will be undertaken following a hermeneutic methodological path.

The points made by Fleming, et al (2003) and Ausgard (2012) break down into five main points:

- The initial area of interest needs to be congruent with the aims of hermeneutic study, that is it the phenomena in question needs to be open to new perspectives, the potential of discussion and interpretation
- The researcher needs to show his prejudice. This is often known as 'fore-grounding' and requires the researcher to make his position known both epistemologically and in regards to his understanding of the research topic itself. This process will be periodically reviewed throughout the study.
- 'Gaining understanding with the participants' (Fleming, et al, 2003). This process is done through conversation and dialogue; it's not a question and answer session but an attempt to reach a mutual understanding by working together. It is important to remember on this point that in hermeneutic philosophy it isn't possible to see from another's point of view and that one can never fully understand how it feels to be someone else. Fleming, et al (2003) note that the researcher should also be aware that meaning and conversational understandings are transient being situational and historical meanings can change. It is therefore necessary to reaffirm meanings with the participant at different junctures in the process.
- 'Gaining understanding through text' (Fleming, et al. 2003). Using thematic analysis, looking for basic patterns in the text (Van Manen, 1997), allows the researcher to provide the accuracy and structure to the text based analysis required. The researcher should be aware of the hermeneutic process and look for changes of understanding within the text as larger themes develop and also document any interpretative acts clearly.
- Establishing trustworthiness. Trustworthiness in hermeneutics is established by maintaining honesty to the participant's voice (being faithful to the text). The researcher needs to provide a clear structure to the research and during its progress provide explanations to all

decisions/interpretations made. As any conclusion to hermeneutic research is going to be the interpretation of the researcher it is only by showing the process as transparently as possible that the integrity of the research can be maintained.

D: Gadamerian Hermeneutics IS the methodology to study TEXTS yet - you constantly suggest that this research is in finding an alternative medium to represent and communicate the experience of people with RA.

TEXT

“Human behaviour becomes a text analogue that is studied and interpreted in order to discover its hidden or obscured meaning” (Leonard, 1989, p.52).

LANGUAGE AND DISCOURSE

The concept of text as the focus of study in Hermeneutics needs to be understood beyond the basic linguistic understanding. If we follow Gadamer’s understanding that language is the basis of understanding (Gadamer, 1975) it is through Ricoeur that we see that “it is in discourse that the symbolic function of language is actualized” (Ricoeur, 1973. p.92).

The premise of this research is to use meaningfully appropriated objects/models as a means to communicate lived experience in the ‘third person’. The researcher suggests that such models can and should be seen as text in that they follow the characteristics of discourse prescribed by Ricoeur and the underlying tenets of Arnheim’s concept of objects as a means of communication.

Benvéniste (1971) explains that the sign, whether phonological or lexical, is the basic unit of language whilst it is the sentence that is the basic unit of discourse.

Ricoeur (1974) points out four defining themes to discourse which differentiate it from language and then uses these to explain the hermeneutic principle of the text.

1: Whereas language is virtual and outside of time, discourse is realized in time and a present moment, something which Benvéniste calls the ‘instance of discourse’.

2: Discourse is self-referential, that is, it is always related to a speaker. Language is non-subjective.

3: As well as non-subjective, language has no 'world'; discourse is always about something, it refers to the world.

4: Language is the condition/requirement for discourse. The condition for discourse (communication) is an other/an interlocutor.

We can here understand that discourse as speech is an event in the world, relating to the world, it is fleeting, being of time and present and intersubjective in that it relates to the interlocutors.

It is precisely because speech is 'temporal and present' that we have a need to fix it to prevent it from disappearing. What is fixed, however, is not the event, the speaking or saying, but what is *said* and this is held by inscription, in text. It is in Ricoeur's understanding of text that we are to find the similarities between linguistic written text and model making as a means of communication.

UNDERSTANDING DISCOURSE

What we write down is the meaning, the noema, of the speech event, what is said. Ricoeur describes this act as "the intentional exteriorization constitutive of the aim". In understanding this act of speech, he goes on to explain how it can be described in three stages;

- the propositional, what is said in the act of saying. This stage is the simplest to exteriorize in text using language as a medium and signs as referents the meaning to those who know the language stays the same. For example: "Close the door" said Pete.
- the illocutionary, what we do in saying and the way in which it is said. This stage is less easily inscribed; the patterns of stress and intonation in a language, volume, the use of gesture and mimicry are all means to communicate during speech. However, in text we have developed certain grammatical and semiotic paradigms such as the subjective, imperative or indicative to make prosody readable: "CLOSE THE DOOR!!" growled Pete vindictively.
- the perlocutionary stage, what we do by saying-the contextual, emotive stimulus and effect of saying. This is the least discursive element of speech and is the most difficult to inscribe. Ricoeur describes it as 'discourse as stimulus'. If we understand discourse as between interlocutors we should not see the perlocutionary as an act of recognition of the intent of the speaker but as something 'energetically' direct (Ricoeur). It is the influence of emotion

and the affective dispositions of those involved in response to what is said *in context* (historical situation). For example: “CLOSE THE DOOR!!” growled Pete vindictively. The child’s eyes lowered as the door was quietly eased into the void in an atmosphere of mutual embarrassment.

It is these stages together that give rise to understanding and empathetic response in discourse and using all three stages when inscribing the discourse give the same meaning as the *said* and one which can be re-identified when seen out of context.

The written word has long been recognized as capable of inscribing living speech but models also have this capacity. Ricoeur in explaining how action can be understood as text, when ‘meaningful orientated behaviour’ (Weber, 1978. p.4) involves an act of interpretation, he explains how the term ‘understanding’ becomes ‘readability’ in hermeneutic methodology. Text here is the *who* or the *what* we communicate with rather than an inscribing of a phenomena.

Text, as a literary means of communication, should not be seen as a methodological requirement. The researcher has chosen to follow this prescribed path in conducting this research as an initial stage in developing his concept, to help him understand and explain how we can communicate abstract, emotional concepts in media other than the written word, and then how that meaning can be re-identified when seen out of context of dialogue.

E: this type of questioning is inconsistent with Gadamerian hermeneutics.

With the questionnaire, the researcher is not seeking validation/verification of his findings but is interested in those who show interest. However, he agrees that the questionnaire is too quantitative and that potentially a ‘visitor book with an invitation to leave comments’ approach would be more in keeping (?).

F: how is building theory consistent with phenomenology?

Man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an

interpretative one in search of meaning. It is explication I am after, construing social expression on their surface enigmatical. (Geertz, 1971).

The purpose of this research is to interpret meaning through three-dimensional media. In this context, the researcher sees his role akin to a translator; with materials (wood, metals, plastics, etc.) as language and model making (how you choose, shape, assemble and work with materials) as discourse (see Benvéniste, 1971, Ricoeur, 1973). In proposing this methodology as one of translation and interpretation, a hypothesis is presumed, claiming that people are capable of reading combinations of materials and form as visual metaphors with meaning. This hypothesis is questioned with the participant as a dialogue grows searching for a common understanding.

Questioning, Gadamer wrote, is an essential aspect of the interpretive process as it helps make new horizons and understandings possible:

Understanding is always more than merely re-creating someone else's meaning. Questioning opens up possibilities of meaning, and thus what is meaningful passes into one's own thinking on the subject...To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one's own point of view, but being transformed into a communion in which we do not remain what we were. (1975, p. 375)

When Gadamer talks of 'possibilities of meaning' here one can see it following four paths (Hansen, et al, 2008); the *historical or intended*: the original meaning of X in the time/context/place it was created, the *hidden* meaning of X of which the agent may be unaware (subconscious meaning), *Internal* meaning: the meaning that X has quite apart from its context at creation, which may differ from intended meaning of creator and the *scholarly* meaning: the meaning of X to the researcher (the contemporary world)-the significance of X to some application of it.

In this research the participant and researcher are searching for an understanding of the meaning of the description offered at the initial interview, (initially the *intended*, questioning the *hidden* and *internal*, leading to the *scholarly*) and this will involve the construction of hypotheses, a term that may cause alarm bells to ring in certain methodological circles.

A hypothesis is a tentative statement. It is not a statement of fact, but a claim that something might be true or worth considering (Shlesinger, M, 2009).

Basic hypotheses are explanatory. They are statements, which suggest probable explanations (causes, reasons, influences) for a given phenomenon.

The task of the researcher is often seen in the generation and testing of hypotheses. These hypotheses are taken to be possible answers to questions concerning the description, prediction, and explanation of natural phenomena. But there is also another kind of hypothesis, an interpretive hypothesis, the status of which is not as clear as that of descriptive, predictive or explanatory ones.

Descriptive hypotheses can be understood as a claim about how to describe something, how to relate it to/distinguish it from other things. It is specifically a claim about particular features that, one believes, are common to all instances of the thing described (categorization).

With predictive hypotheses, one proposes an idea that certain causal conditions lead to given phenomenon. One tests that idea by predicting that whenever these conditions exist, the phenomenon will follow, and then check how good those predictions are.

Interpretive hypothesizing is also predictive in that they implicitly predict that the adoption of a said claim will bring new understanding. However, interpretive hypotheses are conceptual conjectures about what something means: *the interpretation of X is hypothesized to be y*, or simply *X is interpreted as Y*. Such hypotheses have their roots in hermeneutics (Chesterman, 2008)."

Niiniluoto (1983) argues that that the basic method of hermeneutic research is indeed the presentation and testing of interpretive hypotheses, although the actual term "hypothesis" is not so fashionable in the current climate (G. Hansen et al, 2008).

In research the testing of interpretive hypotheses takes place in practice and not against empirical evidence: do they bring new insights, new understandings? Do they stimulate the researcher/participant to generate other hypotheses of various kinds? Unlike empirical hypotheses they are not falsifiable, however. They can be tested against data and discarded if they no longer have a value but they are not a truth beyond that which the interpreter gives them.

If we look at a phenomenological hermeneutic methodology through the language of Gile's sequential model of translation (2009) one can see two stages in the process, comprehension and reformulation. Although titled as sequential, this is not a linear path but a circular one akin to the hermeneutic circle from where it draws its inspiration.

Initially a meaning is assigned to the text based on preconceived understandings, historical, cultural and social awareness (prejudice). This is the interpretive hypothesis.

This is checked for plausibility (does it contextually make sense?). If so then this understanding is verbalized in the target language (reformulation) making sure that all relevant information is included and any extraneous information is excluded and that the target language version is correct in its terminology and style (In the context of this research this refers initially to the process of thematic analysis followed by the process of visualization both involving a dialogue with participants). This process will highlight flaws in the translation leading to a re-comprehension and revision of the hypothesis until the results are grammatically acceptable and plausible and the meaning of the text becomes clear, the most probable interpretation (Ricoeur, 1973).

ETHICS APPROVAL EMAIL

Monday, 9 May 2016 17:17:16 British Summer Time

Subject: Health and Social Science, Science and Engineering Research Ethics and Governance Committee
- Decision on Manuscript ID REGC-15-067.R1

Date: Monday, 7 December 2015 14:00:56 Greenwich Mean Time

From: Julie Scholes (sent by onbehalfof+J.Scholes+brighton.ac.uk@manuscriptcentral.com
<onbehalfof+J.Scholes+brighton.ac.uk@manuscriptcentral.com>)

To: pjm10@brighton.ac.uk, pjmkutya@gmail.com

07-Dec-2015

Dear Mr Marsh:

It is a pleasure to approve your application entitled "HOW MATERIAL MODELS CONVEY THE LIVED EXPERIENCE AND IMPACT WHICH RHEUMATOID ARTHRITIS HAS ON HAND FUNCTION." which has been approved by the Health and Social Science, Science and Engineering Research Ethics and Governance Committee. The comments of the reviewer(s) who reviewed your manuscript are included at the foot of this letter.

Please notify The Chair of FREGC immediately if you experience an adverse incident whilst undertaking the research or if you need to make amendments to the original application.

We shall shortly issue letters of sponsorship and insurance for appropriate external agencies as necessary.

We wish you well with your research. Please remember to send annual updates on the progress of your research or an end of study summary of your research.

Sincerely,

Prof. Julie Scholes

Chair, Health and Social Science, Science and Engineering Research Ethics and Governance Committee

J.Scholes@brighton.ac.uk

Reviewer's Comments to Author:

Reviewer: 1

Comments to the Applicant

Thank you for making these revisions. I do feel the research design is now more consistent with the methodology and well explained.

I have two minor issues that can be dealt with without further review.

1) the consent form has Yes/ No in the boxes - where as it is normal to ask the participant to initial each item and I suggest this is added to the form as well.

2) You do not specify Rheumatoid arthritis rather than leave this open to other diagnoses within the rheumatoid group - e.g. psoriatic arthritis or lupus. I am not sure if this will limit the recruits to your sample. You also do not seek confirmation that this diagnosis has been confirmed with medical markers - or whether individual's can determine if they believe themselves to suffer from 'arthritis'. This is a pedantic point but may affect the recruitment process. I do not wish to hold up any longer the start of the project but it is worth considering if you wish to state: have you been diagnosed with Rheumatoid arthritis by a medical practitioner?

A minor point for any publication - but RA 1/100 seems extraordinarily high - despite the NRAS reference - is this all types?

This email has been scanned by MessageLabs' Email Security System on behalf of the University of Brighton.
For more information see <http://www.brighton.ac.uk/is/spam/>

11.3.3 Email to supervisory team and school ethics advisor discussing revisions:

Hello all, Sorry for pestering you but I just wanted to talk over this ethics and participant thing if that's ok.

As things stand in regard to the ethics document the inclusion criteria stands as follows:

WHAT ARE THE INCLUSION/EXCLUSION CRITERIA? (INCLUSIVE OF A RATIONALE FOR THE CHOICES MADE).

In order to gather data to construct a hypothesis it is my intention to interview people who suffer from RA, in particular, those whose hands are affected by the disease.

It will be a requirement that none of the participants will be undertaking NHS treatment during the research timeframe. The research will focus on participants in the later stages of working life (40-60). The rationale for this lies in the "major impact [RA has] on economically active patients" (Steward and Land, 2009. P.24) and the fact that the "age of onset [of the disease] is generally between 40-60 years" (p.4). The researcher believes that a mature ability to verbalize and discuss personal issues relating to the disease will bring greater depth to the data collected.

Ideally the participants would have longer-term experience of dealing with their disease, therefore being in a better position to both explain their understanding and be comfortable with any discussions. The King's Fund noted that "patients reported that they had a low awareness of RA at the point of first contact but that ... they would become experts in the management of their own condition" (p,19). (226-238, p.6)

Obviously, the main point of concern in including someone who has responded with suffering "from RA in my knees and ankles," when I have said that my main focus would lie in the hands. On all other points this potential participant fulfills the requirements.

After conducting the case study, however, it has become obvious to me that the lived experience cannot be focused to any specific bodily point of reference, in fact any attempt to restrict the criteria in this way appears to me to bias the data.

The focus on the hand stems from the initial approach to the research which has become less and less relevant within the interpretive approach adopted and my growing understanding of just what the lived experience of something means and how truly embodied and all-encompassing RA is. The resulting models in no way reflect the body (form or function) as they draw on the text rather than any observational descriptions.

On top of which, as stated in the ethics document “The research’s main sphere of interest lies in how data can be interpreted through model making” (220, p.6) and I don’t feel that this main goal of the research is affected by these variations.

On a slightly different note, this being my first experience of PPI so this may be a common response or a little soft but, my inclination is to engage with these primary respondents, (the participant in question responded to the call within 4 minutes), not out of desperation, ‘will I get any more/better ones!!’, but more out of respect that these people have chosen to give some of themselves to this project and even thanked me for it! (e.g.: “Thank you for choosing to research this disease all help is to be gratefully received.”).

If I have to put this forward to ethics as a request, do you know what the procedure would be or if this would massively bite into my time frame/work load?

Sorry for the lengthy email!

Let me know what you think...

Thanks

11.4 APPENDIX 4

Certain key points to Gadamer's philosophy drawn from *Truth and Method* (2004) provided the steps necessary for me to develop with this project. Although an in-depth description of them was felt to be a diversion from the path of the thesis, I have included a description of them here for the interested reader. The elements included are:

- THE FUSION OF HORIZONS, Gadamer's concept of how we reach an understanding
- CONCENTRATION AND MEMORY, a conceptual description outlining the way in which we process and store information
- DESIGN AND MAKING AS HERMENEUTIC EXPERIENCE, a discussion about how design has been considered in the field of Hermeneutic philosophy, which leads on to
- GADAMER'S CONCEPT OF PLAY AS A DESCRIPTION OF THE DESIGN PROCESS, where I outline my understanding of how hermeneutic philosophy sits in the act of designing.
- PUZZLES AND HYPOTHESES originates through a conversation with the Ethics examiner about why the concept of hypothesizing anything is valid in hermeneutic study, and how the principle of puzzling is overlooked as an act of design.

11.4.1 THE FUSION OF HORIZONS

Metaphorically speaking, we occupy a standpoint from where we can look out as far as our prejudice allows—the horizon. This horizon is the range of vision that includes everything that can be seen from this particular vantage point, our present understanding (literally, our point of view). Jeff Malpas, professor of philosophy who has laid strong emphasis on the importance of place and space in appreciating hermeneutics, described “understanding [as always] *standing somewhere*, and it is this standing somewhere that underlies understanding itself” (Gander and Malpas, 2014, p.355).

This understanding, what we can see, is what we know in relation to our experience yet is defined by history, from authority and through traditions passed down to us. Beyond this horizon everything is unfamiliar and foreign.

Yet our horizon isn't fixed, new understanding broadens our horizons; horizons fluctuate depending on how far into the 'unknown' we are willing to explore. By engaging with something, our horizons

move to accommodate it, and the closer in from the edge of our perception it becomes, the less distorted it appears becoming easier to comprehend⁴⁷. We become able to compare it to other experiences, events within our horizon. In this way our perception of this new thing changes us, it changes our perception of this thing and also our perception of the other things within our horizon.

Gadamer felt that if someone were to have no horizons they would have nothing to offer, valuing only that which was close at hand and lacking any context or perspective that horizons bring (ibid. p.301). Gadamer also explained that there are limits to our horizons (2004, p.302) but he saw these as an opportunity to judge (compare and comprehend) things we see close up and far away; to understand within the context of our prejudices and situation. This understanding isn't quantifiable as no horizon or action can become objective knowledge to be defined, analyzed and used as it is conditional on us and our temporal and physical situation. Similarly horizons cannot be channelled or focused into an essence, as no horizons are the same in hermeneutic experience. We can only stand where we stand, and any attempt to change our horizon by forgetting our prejudices is impossible; our beliefs and knowledge cannot be unlearned just as we cannot be separated from our past.

Yet if we allow our horizons to expand, our perspective becomes richer, more attuned and the objects within view are more clearly seen in the context of others around them- our prejudice, our point of view becomes less dominant and phenomena become perceptible in the light of their own history and their connections to other phenomena rather than just their relationship to our own subjectivity.

Once aware of others, with the understanding that we are part of an intersubjective community, we are in a position to make conversation, to 'make a trade' in perspectives. We are able to describe our world and we are able to see the world from another's point of view. Gadamer describes this event as transposition. Transposition requires the acceptance that the other's view is different, an awareness that it is not one's own. Such actions account for our day-to-day intersubjective

47 Literally and etymologically the terminology of comprehension comes from something being physically within our grasp. (<https://www.etymonline.com/word/comprehend> [last accessed 28.11.18])

existence, but we actually learn little from them and understand, in the hermeneutic sense of the word, even less. We see these points of view from our perspective, an act that reinforces our prejudices. We would not benefit from abandoning our point of view, allowing another's subjective belief to subsume our own, nor would we gain anything from rote learning. Understanding involves a process of mediation with the familiar, our fore-knowledge and the unfamiliar sitting on the edge of our horizon.

In order for our horizons to expand, transposition is just a stage. True understanding requires dialogue. In this dialogue neither state remains unaffected, neither what we know nor what comes new to us. Our present understanding, our prejudice, is shown in a new context as we relate it to what we have newly discovered. By seeing the historical context of this encounter and allowing this to mediate with our prejudice, our horizons fuse in understanding; we compare what we knew to what is new and this experience allows us to compare what we now know to our prejudices, changing them.

It is this ability to see our own horizon when understanding another's in the context of our historical consciousness and then to *fuse* this with the wider horizon of history that allows our horizons to expand. History allows us to check and validate our prejudices, preventing us becoming lost in our own subjectivity, grounding our reality in a wider, intersubjective community whilst maintaining our sense of self.

It is our historical consciousness, our awareness of our history, which provides both a frame of reference to our present understanding, allowing us to understand in the context of a much broader historical vision, and an anchor, stopping our understanding from becoming lost or being distorted by this fresh perspective.

11.4.2 CONCENTRATION AND MEMORY

What Barsalou's theory did not consider is how we can create mental simulations to alter our conceptualization of our perception, how we can think in the immediacy of the moment, online, allowing our senses to dictate to our experience/memory, for example, when abstract visual metaphors reference but do not show both source and target together and meaning is derived only in an overall context. In his paper *Dynamically meshing perceptual symbols* (2009) Nick Davis

proposed the solution to this by drawing together Barsalou's concept of simulation (1999) with Glenberg's theory of meshing (1997).

In many ways similar to Gibson's affordances (1957), Glenberg considered "the phenomenological aspects of conceptualization, acknowledging that objects inherently suggest to the human perceiver what kinds of activities one could do with them" (in Davis 2009).

Naming these acknowledgments activity patterns, Glenberg saw them develop into two strands, automatically and manually attributed. Automatically attributed activity is a result of innate bodily potentials, our sensory embodied awareness of our environment, which he named 'projectable properties' (Glenberg 1997). Manually attributed activity relies on mental simulation, akin to Barsalou, and is goal orientated. Our memory is used to recall 'non-projectable' features of the environment based on previous encounters to seek out the best course of action. Glenberg proposed that this manual, or non-projective property, 'meshes' with projective properties to allow us to conceptualize (ibid.). This cognitive action of 'meshing' in a search for common proprioceptive qualities informs our Being-in-the-world (Davis 2009); if our goal, meshes with an object's automatic potentials then that object is seen in a new way, serving our need.

Where Davis (2009) saw the link, allowing for the conceptualization of image-based metaphors, is in the way we solve problems online, abstracting simulations to conceptualize what we perceive, a top-down cognitive act.

To process information as quickly as possible, Glenberg (1997) proposed that we subconsciously 'clamp' simulations. 'Clamping' (ibid.) refers to the process of holding on to only the most relevant perceptual symbols/projective properties relating to the immediate environmental situation allowing almost intuitive action. This could be understood in the light of Heidegger's concept of 'ready-to-hand' (Heidegger 1978).

However, 'suppression' encourages a more open mind, opening up a simulation to non-projectable properties, symbols and simulators from memory, outside of the immediate environment, questioning the object or action from different perspectives, looking for ways in which it could be used to achieve the desired goal. This could be thought of as concentration, making the environment present-to-hand (ibid.).

We can now understand perception as two levels of perceptual symbol simulation, bottom-up and top-down.

Bottom-up is unconscious, an automatic simulation searching for categorization. It seeks to verify that affordances based on proprioceptive information from the simulator are applicable to the word/image/object in question.

Top-down is a conscious, goal-orientated awareness which is normally 'clamped' to allow us to function as efficiently as possible in our day to day reality. However, when we concentrate, to interpret a word/image/object in a novel way, we 'suppress' the bottom-up, applying a conscious mental simulation in a search for different affordances.

11.4.3 DESIGN AND MAKING AS HERMENEUTIC EXPERIENCE

I wish to explain why and how hermeneutic theory can be readily applied epistemologically to the process of designing and the application of visual media in research through Gadamer's understanding of aesthetic experience. Gadamer's approach to aesthetic appreciation is phenomenological but he was not concerned with the types of subjective pleasure that one can derive from art instead he looked for art's position in our experience and understanding of the world; how do we engage with creative acts and gain from that process. I will consider the act of designing by making as an interpretive process involving the generating and discarding of hypotheses and as an act of play, a hermeneutic experience that allows those involved to lose themselves in the act and in so doing find meaning through what they are engaging with.

Snodgrass and Coyne in a paper 'Is designing hermeneutical?' (1996) made a case that "to design is to interpret" (p.4) building on the work of Donald Schön, a theoretician who has had much influence on current approaches in design education (Newman 1999; Bashier 2014), who considered design to be "a reflective conversation with the situation" (1983, p.163). Appreciating design as "a clear and straightforward account of the working of the hermeneutical circle" (Coyne, 2015, para.3) Snodgrass and Coyne stated that understanding through design should be seen as an interpretation of a situation. To be considered hermeneutic in nature the process of design, rather than the solving of a problem, could be compared with that of interpreting a text (1996).

Snodgrass and Coyne's approach has great value as it was the first, and is still the most noted attempt at grounding the actual practice of designing within a hermeneutic framework. Their understanding was that designers approach the text/situation with experience (prejudice), starting the process with a vague notion, a projection, of the completed product. As the process develops "understanding increases by way of an interpretation of the parts, the projected whole is modified, refined, clarified" (Snodgrass and Coyne 1996, p. 6). Thus, engaging in the process of designing was to enter the hermeneutic circle.

The designer enters into a dialogue with his anticipated concept; the designer questions the idea, the design situation questions the designer's prejudice, a process which brings about a fusion of horizons. The designer enters a hermeneutic circle through prejudice (with the particulars of the situation informing the conceptual whole) constantly reflecting and making readjustments. The result is a 'discovery', a disclosure of the designed artefact and a self-discovery through edification.

Yet I feel that this process maintains a mystique of design, the "debilitating...mystery" that Snodgrass and Coyne (1996, p.24) were seeking to unveil in stating that "designing is grounded in understanding and is nothing other than the explication of what has already been understood" (ibid).

"There is a minimal pre-knowledge necessary for understanding, without which the designer cannot begin to design" (ibid, p.26). This approach is a reinterpretation of Schön's claim that in designing one must "begin with a discipline, even if it is arbitrary" (1983, p.78). Snodgrass and Coyne consider this discipline as prejudice, the foreknowledge they need in their theory to allow them to place the process of design within the hermeneutic circle. Yet I feel this leads to a vicious circle; to begin to design one needs to know how to design, which comes from being a designer.

Snodgrass and Coyne attempted to resolve this by stating that novices however 'untrained' and 'raw,' have been "exposed from birth to the products of the design process" (Snodgrass and Coyne, 1996, p.26). Yet an appreciation that one is exposed to something requires some foreknowledge that what one is engaged with are indeed products of design. "But when designed objects (spoon, spanner, chair) function as they are supposed to they disappear, drawing attention rather to the task at hand (to eat, mend or sit)" (Coyne 2015). In other words, to appreciate a designed object some distanciation is necessary-seeing the object as an object and not 'simply there', 'familiar' and

'already understood' (Snodgrass and Coyne 1996, p.15)⁴⁸. Without this capacity to step back and see the thing as an object of design "our understanding of things in the lived world is not a matter of knowing objects but of taking them for granted" (ibid, p.16).

I agree that design is hermeneutic experience but find the concept of just entering into the "back and forth" (Schön 1983, p.78) process of the hermeneutic circle through a foreknowledge of design distorts the understanding of the way in which designing works.

So how does the act of designing come about if we accept, as I do, that one enters the hermeneutic circle in this process? Nicholas Davey, Professor of Hermeneutic studies, states that "the subjectivity of an artist cannot be an appropriate interpretive starting point" (2013, p.48); one cannot appreciate the meaning of a work on the basis of the designer's prejudice alone; establishing a critical, if disciplined distance places the design out of context, denying it the ability to engage with the observer in conversation integral to hermeneutic understanding.

Looking again at Schön's 'the Reflective Practitioner' we can see that he frames the starting point to designing as a question, "what if?" (1983, p.78) and so shapes "the situation in accordance to an initial judgment" (Malpas 2014, p.563). 'What if' requires no design discipline to ask, just an imagination and openness to alternate realities. It is a phrase full of possibilities, yet it still holds the

48This draws on the ready-to-hand concept of Heidegger who stated that being (one's sense of one's body perceived in the world) can only be 'ready-to-hand'. Reflection on an object makes it 'present-to-hand'. Ready-to-hand is a much fuller knowledge than present-to hand since it involves existential engagement rather than reflection. An object/ tool conceals itself when it is ready-to-hand. The tool must withdraw from our explicit attention. Tools have to be absent otherwise they are present-to-hand. For example, 'she cut the bread' as opposed to 'the knife was too blunt to cut the bread' where the knife, the object, becomes present-to-hand as she becomes aware of its inability to perform the function expected of it in her actuality. We communicate the action 'she cut the bread' without any reference to the knife, understanding that the knife is ready-to-hand, a means to her existential engagement with the world and not a relevant part of it.

process of design in the context of a situation needed for hermeneutic understanding. This dynamic imagining in a context is clearly recognized in the metaphor of 'play' as explained by Gadamer (2004).

11.4.4 GADAMER'S CONCEPT OF PLAY AS A DESCRIPTION OF THE DESIGN PROCESS

We learn when we play. Hermeneutically, to gain understanding in play, we relate the experience of play to our previous experiences, contextualizing this with our historical consciousness, making the event of play very similar to the fusion of horizons. The structure of play, the rules, tasks, the other players all allow for an evaluation of self-knowledge and the expansion of our horizons. The difference of play to a fusion of horizons lies in the fact that play is a *self-contained* purposiveness.

To play one needs to submit, to lose oneself in an act of de-subjectification. In other words, we do not protect our prejudices, our assumptions on what we believe instead we accept the experience given by the context of playing. This is a conscious choice of submission, an act of 'letting it go'. It is a willingness to yield to an other, to let one's prejudices be exposed and questioned. We know that what we are playing isn't 'real', that it does not follow the conventions of the reality we know but by accepting the rules of play, structures that contrast against our prejudice, we are able to question and validate our prejudice by seeing it in the context of the game and the other players.

We acquiesce to play outside of practical life and our present experience of being. To make sense of our everyday we rely on our prejudice, which inhibits our perception within the confines of our horizons; our appreciation of reality is based on what we believe to be real and possible. By entering into play, the structure of the game counteracts this requirement. However, our prejudice and historical consciousness are not abandoned in play and so we are still able to contextualize and understand; the game gives a framework in which to situate our historical consciousness allowing us to relax our reliance on it for our perceptions of reality. Play's aims reside within it but they are not isolated from reality and so we are able to see our reality from a more detached perspective.

Gadamer explains:

“The case of play-which refers phenomenologically only to the absence of strain-is experienced subjectively as relaxation. The structure of play absorbs the player into itself and thus frees him from the burden of taking the initiative, which constitutes the actual strain of existence” (2004, p.105).

Snodgrass and Coyne describe the design process as ‘repetitive and continuous’ (1996, p.23). This is similar to Gadamer’s description of play’s “to-and-fro movement ... [a process] that is not tied to any goal that would bring it to an end...it renews itself in constant repetition” (2004, p.103). Also holding relevance to both the act of design and that of the phenomenological experience of play is Snodgrass’s appreciation that designing ‘absorbs the designer’ (1996, p.26). Designers are ‘absorbed’ because, as Gadamer states, there is a ‘primacy of play’ over consciousness, the act of designing becomes reality in that moment not a distraction from it.

The question “what if?” (Schön, 1983, p.78) begins this act of play, and requires neither designers nor specifically design-able things to be asked. In placing design within the analogy of play, the designers are players and the design question around the object in context is the field of play. For Gadamer, “the players are merely the way the play comes into presentation” (ibid, p.98). In other words, the game is not defined by those who play it, one does not have to be a ‘designer’ with ‘minimal pre-knowledge’ to design, it is enough to ask ‘what if’ to bring design ‘into presentation’.

The term presentation in Gadamer’s terminology is both temporal and physical; it is something that is in the immediacy of now and something we are faced with. In discussing the arts, he explained that a picture is always there but its meaning, or our understanding of it, is only to be found in its presentation. This presentation is not on show but is always available; “presentation, by its nature, exists for someone” (2004, p.110) but we, the viewer, need to be present also. The same, I believe, applies to the objects around us; it is a conscious engagement when we choose to question an object’s role, its performance, its materials, colour or forms but the questions we seek to answer are always present in the object. This could perhaps be understood in the light of Schon’s initial definition of design as ‘a reflective conversation with the situation’ (1983, p.43) but the process isn’t one shared with a situation, it is *in* the situation, the structure of the game.

It is important not to see the field of play as having a special significance-it is the game, the playing of it that brings understanding and it is this that defines the structure in experience. “The playing field on which the game is played is...defined far more by the structure that determines the movement of the game from within than by what it comes up against-i.e.: the boundaries of the

open space-limiting movement from without” (Gadamer, 2004, p.107) By elevating the space over and above the game one’s prejudices are reinforced leading to the formation of pre-conceived opinions that limit experience to an acceptance of understanding, a transpositioning. In other words, one becomes aware of playing and not lost in play. Being conscious of designing, that one is applying design to a problem (a situation) restricts the ability to become involved in the act, to solve the problem. Such an act becomes defined (I am a designer designing) giving total self-knowledge of that moment, which as an experience, *erlebnis*, means that there can be no fusion of horizons.

Schön, in later years, went on to refine his thoughts of designing as “a conversation *with the materials of a situation*” (1992, p.3 my italics) and here we can begin to see how his appreciation of design allows for play. The situation is no longer separated; we are embodied and enacting within the situation. We are surrounded by the materials and forms with which we choose to interact and converse with in play. Understanding is still found in dialogue, through a conversation but the dialogue rests in the relationship with these materials when we see them as present-to-hand, in the context of tradition⁴⁹, history and collective memory, laden with meaning, yet inexhaustible in interpretative potential.

49 In a paper furthering Snodgrass’ hermeneutic understanding of design (1996), Jahnke also saw design as “to a large extent an embodied human experience” (2011, p.3) but he saw failings in using Gadamer as the philosophical grounding for the argument, in particular, highlighting Habermas’s critique of the role of tradition and authority which Habermas felt undermined reflection and distorted our reality. Jahnke criticized Gadamer’s reliance on tradition as a limitation when designing. Yet Gadamer readily accepts that tradition is not free of dogma. At no point does he refute that history contains bias, but he sees the potential of tradition in being a valuable (re)source of inspiration and critical insight. In understanding, meaning is developed through a critical reflection in dialogue. Tradition needs to be questioned, as should authority, so that they too can be revised. In true understanding neither the subject nor the object remains untouched. “Reason and authority stand in a basically ambivalent relation, reason being manifest in and through history and tradition, and therefore ‘dependent’ upon them, while at the same time dissolving part of that tradition and rebuilding it. (Gall, 1981, p.10).

Tradition and authority are rooted in insight (ibid.) allowing reflection through context. “Reflection is granted a false power when it is abstractly opposed to authority” (ibid.). Authority is not the ‘locking down’ of meaning

11.4.5 PUZZLES AND HYPOTHESES

In hermeneutics, in both research and design, it is in asking questions and in proposing answers that meaning is to be found (Gadamer, 2004). I believe the question 'what if' to be a hypothetical one. Designing as a process towards improving our situation, whether that be objects or our environment, is initiated by those objects asking questions of us, 'What if... 'I could function better, carry more, I was lighter, taller, a different colour, etc.?' Such questions are problems asking for a solution. However, Snodgrass and Coyne stated that the metaphor of problem solving destroys "the complexity, subtlety, and uniqueness of the design situation" (1992, p.72). I see the concepts of designing and problem solving as inherently related. In considering the concept of 'problem solving as design', I do not see it as a logistical, cybernetic matter of finding fault-fixing fault, "rule-like" (Simon, 1996), rather I see problem solving akin to the experience of a puzzle, a game of questioning, inquiry, discovery and fun; a phenomenological experience of the event of play.

The puzzle here is how to convey interpreted meaning through three-dimensional media. In proposing this, a hypothesis was made that people are capable of reading organized combinations of materials and form with empathy. This hypothesis is shared and questioned with the participants, teachers, friends, the models themselves and as a result a dialogue grows searching for a potential solution to the problem. The models will stand as the application of my hypothesis, the outcome of the conversation with the materials but they are also, in a sense, participants in the search for meaning, asking more questions than they answered.

Jahnke describes (2011, p.8), nor does it seek to create objectively valid results using history as a precedent. A critical attitude to tradition and authority leads one to question one's own horizon; an awareness of other's perspectives, in the context of analysing how tradition limits our perspective points to what tradition conceals. By failing to reference tradition, the designer falls into a constructivist trap. In other words, by understanding our belonging to a tradition we escape relativism and maintain the intersubjective basis of design; we accept that the other may be right, allowing ourselves to be questioned just as we question, to be reflective in the light of an historical consciousness.

“Understanding is always more than merely re-creating someone else’s meaning. Questioning opens up possibilities of meaning⁵⁰, and thus what is meaningful passes into one’s own thinking on the subject...To reach an understanding in a dialogue is not merely a matter of putting oneself forward and successfully asserting one’s own point of view, but being transformed into a communion in which we do not remain what we were” (Gadamer, 2004, p. 375).

In hermeneutic research, the testing of interpretive hypotheses⁵¹ takes place in practice. Niiniluoto (1983) argues that the basic method of hermeneutic research is indeed the presentation and

50 When Gadamer talks of ‘possibilities of meaning’ here one can see it following four paths; historical, hidden, internal and scholarly (Hansen et al. 2008). Hansen explains the historical or intended meaning as the original meaning of X in the time/context/place it was created (what the participant said). The hidden meaning of X, of which the agent may be unaware (the analysis of the transcribed text). The Internal meaning: the meaning that X has quite apart from its context at creation, which may differ from the intended meaning of its creator (the dialogue-as-text that stands alone from the conversation and its interpretation) and the scholarly meaning: the meaning of X to the researcher (the contemporary world)-the significance of X to some application of it (the models and their presentation).

51 Although generating hypotheses is not an act denied to the interpretive fields in research, it is a term that requires some justification in its use. A hypothesis is a tentative statement. It is not a statement of fact, but a claim that something might be true or worth considering (Shlesinger et al., 2009) and it is the goal of the claim that brings clarity to the role or type of hypothesis. For example, most claims associated with basic hypotheses are explanatory. They are statements that suggest probable explanations (causes, reasons, or influences) for a given phenomenon. The task of the researcher is often seen as the generating and testing of such hypotheses. These hypotheses are taken to be possible answers to questions concerning the description, prediction, or explanation of natural phenomena.

Descriptive hypotheses can be understood as a claim about how to describe something, how to relate it to or distinguish it from other things. They tend to be specific claims about particular features that, one believes, are common to all instances of the thing described; in other words, a form of categorization.

With predictive hypotheses, one proposes an idea that certain causal conditions lead to given phenomenon. One tests that idea by predicting that whenever these conditions exist, the phenomenon will follow, and then check how good those predictions are. But there is also another kind of hypothesis, an interpretive hypothesis,

testing of interpretive hypotheses. In the case of this current project the models are the hypothesis, a presentation. Hypotheses are conjectures that are incomplete without a response, and models and the process of model making provide a physical response, a reply in the form of a question in true hermeneutic style. These models are not falsifiable, they act as an intermediary, testing and questioning the interpretation both of the maker and the viewer. The models can and should be tested against data and discarded if they no longer have a value in application (in the world of praxis).

the status of which is not as clear as that of the descriptive, predictive or explanatory. Interpretive hypotheses are predictive in that they implicitly predict that the adoption of a said claim will bring new understanding. However, interpretive hypotheses are conceptual conjectures about what something means: the interpretation of X is hypothesized to be y, or simply X is interpreted as Y. Such hypotheses have their roots in hermeneutics (Chesterman, 2008). "Although the actual term 'hypothesis' is not so current...interpretive hypotheses are typical of hermeneutic research" (Hansen et al. 2008, p.49).

11.5 APPENDIX 5

11.5.1 PUBLICATIONS AND CONFERENCE ABSTRACTS

Funding to register and attend these events was applied for through various channels within the University of Brighton and was awarded on all occasions.

<p>2016 publication</p>	<p>A Gadamerian approach to interpreting pain: model-making metaphors through embodied cognitive theory</p> <p>Digital Creativity, special issue article 2016</p> <p>Marsh, P., Chubb, S., Saber-Sheikh, K., Hooker, C. and Moore, A., 2016. A Gadamerian approach to interpreting pain: model-making metaphors through embodied cognitive theory. <i>Digital Creativity</i>, 27(4), pp.347-357.</p> <p>ABSTRACT</p> <p>This paper will discuss how the conceptualization of embodied, abstract notions such as pain, which is multi-modal, non-visual and subjective, has the potential to be communicated visually using model making, as it is traditionally understood in the fields of architecture and design. We propose a new methodological approach to research where Gadamer’s [2004. <i>Truth and Method</i>. Continuum International Publishing Group] understanding of intersubjective interpretation used in conjunction with Simulation theory [Gallese, V., and A. Goldman. 1998. “Mirror Neurons and the Simulation Theory of Mind-Reading.” <i>Trends in Cognitive Sciences</i> 2 (12): 493–501] in embodied cognitive science, provides a strong framework in which to formulate a palette of materials and forms to visualize subjective experience. This novel approach to design research is currently being undertaken within the field of Health Sciences to produce metaphorically provocative, descriptive models of the lived experience of people with rheumatoid arthritis (RA) to help bridge the gap in understanding between the sufferer and the public. This paper seeks to</p>
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	<p>engage briefly with two questions integral to the research being undertaken: how does one understand another’s pain, and how can one conceptualize and communicate abstract notions such as pain visually using material and form as language?</p>
<p>2017 conference paper</p>	<p>An appreciation of the iconic superstructure in translating text to form.</p> <p>11th international symposium on Iconicity in Language and Literature. (A focus on ‘operationalization of iconicity’, resemblance mappings between form and meaning in language and in literature; primarily concerned with being able to define and describe different types and levels of iconicity as they appear in different media and modalities).</p> <p>Hosted by University of Brighton</p>
<p>2017 conference paper</p>	<p>Transposition of understanding when translating from the linguistic to the visual.</p> <p>Paper exploring how understanding lies beyond the implied meaning, that in order to make the unperceivable (i.e.: emotive experience) tangible, a simple substitution of media is insufficient.</p> <p>‘Beyond Meaning’ Conference, investigating language use and how it generates and conveys impressions of various kinds that cannot be explained in terms of the notion of meaning as it is classically construed.</p> <p>Hosted by the University of Athens, Université de Neuchâtel and the University of Brighton</p>
<p>2018 exhibition</p>	<p>How Material Models Convey the Lived Experience of Rheumatoid Arthritis</p> <p>Marks Make Meaning: drawing across disciplines</p> <p>Hosted by Hosted by Creative Futures and the School of Art, University of Brighton</p>

2019 conference exhibit	How Material Models Convey the Lived Experience of Rheumatoid Arthritis 'Blurring boundaries and crossing frontiers in social research'; Social Research Association Annual Conference Hosted by the Royal College of Surgeons, London
2020 conference paper	A discussion with case studies examining the role of metaphor in translating descriptions of living with rheumatoid arthritis into three dimensional models 'Metaphorical creativity in a multilingual world'; Research associates in Applied Metaphor (RaAM) Conference Hosted by Inland Norway University of Applied Sciences.