

**A psychological structure pertaining to the meaning of  
recreational programmes in the natural environment for those  
living with and beyond cancer**

**Submitted in partial fulfilment of the requirements of the degree  
of  
Doctor of Philosophy**

**School of Health Sciences**

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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 solid black rectangular box redacting the signature of the author.

Dated

**02/11/2020**

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## Abstract

In this study, a descriptive phenomenological approach was applied to discern the meaning of recreational programmes in the natural environment for those living with and beyond cancer. Over the past twenty years, significant healthcare strategies have been developed and commissioned to support the increasing numbers of those living with and beyond cancer. At present, there has been an increased effort to assist those living with and beyond cancer during the rehabilitation and survivorship phase of the cancer trajectory, with emphasis being placed on the recently established 'recovery package'. Whilst acknowledging the position that structured physical activity interventions and follow-up questionnaires now assume in this strategic development, this study followed recommendations to explore the contrary for the sake of increasing awareness of meaningful, alternative options. This involved undertaking a descriptive phenomenological study of unstructured recreational programmes in the natural environment facilitated by a civil society organisation (Burke et al., 2017).

Twelve participants were recruited and interviewed to extrapolate an essential description and psychological structure of their experiences of the 4 Cancer Group's recreational programmes. After analysing the data through a psychological perspective (Giorgi, 2009), six empirical constituents were identified as being essential for the participants' experience. The constituents included *awareness of the changes to one's reality due to chronic illness, a sense of openness to want to experience other opportunities, movements towards experiencing the present moment, renewed insight into one's physical potential, a willingness to engage with and listen to others living with and beyond cancer, and anticipation of the presence of the future*, all of which had experiential networks within. Firstly, the findings were critically examined in a manner that elaborated on the interplay of psychological *rigidity* and *openness*. The findings were then reflectively analysed through a phenomenological commentary and discussion of the scholarly literature to draw out a greater conversation of the philosophical and academic position of the study. The study concludes by presenting the originality of the findings, emphasising how a descriptive analysis has presented a psychological structure of meaning through the experiential givenness of recreational programmes for those living with and beyond cancer.

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## **Breakdown of thesis chapters**

### **Personal Preface**

The start of the thesis commences with a personal preface. The preface identifies how my academic and personal background inspired the motivation to engage with this area of study. Essentially, the personal preface allows the reader to understand the person who arrived at the start of the research collaboration between the University of Brighton and the 4 Cancer Group. It could also be argued that the personal preface is an initial movement towards engaging in a form of reflective practice, for had this preface not been included, the reader would not know the reasons why and how I came to this doctoral study.

### **Chapter One - Introduction**

Chapter one begins by conveying a considerable global overview of the qualitative characterisations and statistical trends of cancer. The chapter then proceeds to identify the effect of cancer in the United Kingdom before specifically recognising the healthcare strategies and ambitions that have been commissioned for cancer services in England over the past twenty years through the NHS. In particular, the chapter positions the third ambition, *Patient experience and QoL*, of the current strategy, *Achieving world-class cancer outcomes – a strategy for England 2015-2020*, as the focal point for the study. Moreover, after discussing the advantages of using physical activity interventions and post-treatment questionnaires to enhance and measure health and QoL, the introduction presents significant concerns about this approach of managing rehabilitation and survivorship for those living with and beyond cancer. Such concerns transform to articulate the necessity of undertaking a narrative literature review to identify if and how the unstructured recreational approach enhances the health and overall experience for those living with and beyond cancer.

### **Chapter Two - Narrative Literature Review**

The second chapter of the thesis is committed toward presenting the narrative literature review of the scholarly work that has, at present, been established for the area of interest. The chapter begins by communicating why a narrative approach

was undertaken before clearly stating the search strategy that informed this process. The narrative literature review then presents the three core themes that emerged from the process. The three core themes include *structured physical activity interventions and unstructured recreational programmes for the rehabilitation and survivorship of those living with and beyond cancer, environmental approaches for the restoration of health, and the measurement and understanding of health, quality of life, and well-being*. Once an extensive elaboration of the scholarly literature has been expressed, the chapter explicitly recognises the researchable question that will satisfy the gap in the literature that has been identified and, in turn, enhance the knowledge base in this specific area of interest. After expressing the originality of the study, the narrative literature review will conclude by introducing the following chapter, *Methodology and methods*.

### **Chapter Three - Methodology and methods**

Chapter three has been written to communicate three parts that aim to offer the reader a broad understanding of the qualitative and phenomenological underpinnings that support this study. Part one has been written to largely convey the epistemological, ontological, and historical foundations of qualitative and phenomenological research. Part two follows by engaging in the contemporary debates that surround applied phenomenological research, with Amedeo Giorgi's (2009) descriptive phenomenological method in psychology being positioned as the primary methodology and method that would address the *phenomenon of interest* that was identified throughout the narrative literature review. And lastly, part three concludes the chapter by addressing the contextual and procedural considerations that were exercised throughout the research process. For example, an extensive commentary has been written on how ethical principles were upheld throughout the entire process.

### **Chapter Four - Findings**

Chapter four is committed to presenting the findings of this study. Firstly, the chapter begins with an essential description of the meaning of the 4 Cancer Group's recreational programmes for the twelve participants who were involved in this study. Secondly, the chapter moves on to present three tables which exhibit the six essential constituents of the psychological structure that were established. The

tables detail each of the experiential variations that occurred, thus sharing an insight into the range of experiential possibilities and networks that were present within. Lastly, the chapter goes on to present an extensive commentary of the six constituents that made up the psychological structure with supporting quotations from the original interviews.

## **Chapter Five - Discussion**

Chapter five has been written to present a thorough elaboration of the constituents that were identified as being essential in chapter four. Rather than step into an immediate discussion of the comparisons that can be drawn against the existing literature, the first two parts of the discussion have been designed to discuss the psychological structure in greater depth and detail. Part one establishes a discussion of the psychological interplay that occurred between the six experiential constituents. Part two engages in a comprehensive philosophical discussion by using the lifeworld fractions discussed by Ashworth (2016) to explore the dimensions of the structure. The chapter will conclude by reviewing how and where this study locates its findings and subsequent elaborations in the wider literature and healthcare enframements which were situated at the start of the thesis.

## **Chapter Six - Conclusion**

Chapter six has been broken into various parts to identify and convey the significance and limitations of the study that has been presented. Firstly, the significance of the study will be expressed through a direct articulation of how the findings have made an original contribution to knowledge. Secondly, the limitations of the study will be drawn on from both a philosophical and scientific perspective. In doing so, the reader will be informed of certain characteristics of the study that limit its overall scope and interpretation. Lastly, certain recommendations have been provided to direct the reader as to how the study can influence other ways in which further academic research can be conducted in this area of interest.

## **Chapter Seven – Personal reflections on the research process**

Chapter seven has been written to communicate my reflections on the research process. How this chapter has been designed corresponds with Finlay's (2008) recommendation for reflective practice both during and after the process has

occurred. In some ways, chapter seven is a simple extension of the personal preface and concluding chapter due to its content being heavily immersed in expressing my experience of being responsible for the study during each step of the way. As there is no right or wrong way to communicate these issues, the chapter, for example, identifies how I overcame problematic moments throughout to fulfil the academic goals of the study. Overall, chapter seven is a personal presentation of how I managed each step of the study to ensure that I was not only learning about the phenomenon of interest but also expanding in my academic skills as a doctoral researcher.

## **References**

A comprehensive list of the academic and professional references that were used throughout the entirety of the thesis will also be presented after chapter seven.

## **Appendices**

The thesis officially concludes by offering a variety of appendices that present additional information (i.e. ethical application and data analysis procedures) for the reader's interest.

## **Personal Preface - Who am I coming into this study?**

Before arriving at an immediate introduction, it is important to address who I am coming into this study so the reader has an understanding of myself, the researcher responsible for this study. This initial text serves as a reflective exercise that was considered before the beginning of this doctoral study. Considerably more reflections will be presented throughout the entirety of the thesis, and in doing so, I aim to offer the reader an insight into how I navigated my sense of subjectivity and how I had an impression of the research process.

I am a doctoral candidate with a background of health science, exercise science and psychology, and more recently, experiences of evaluating public health strategies. Before the commencement of my PhD studies, my experiences of higher education by and large had been dominated by the study of human physiology and psychology through the natural sciences. For much of the duration of my undergraduate degree, I was confronted by the quantitative approach to observe, record, and objectify human beings in many different contexts. This involved studying human physiology, anatomy, and psychology in settings that were controlled to either confirm a hypothesis or predict behaviour, thereby naively following and adhering to the academic praxis of behaviourism without question.

However, it was during the second year of my undergraduate degree that I became aware of qualitative research and the philosophy that supports this branch of research inquiry. This experience was something in which I automatically engaged with and felt connected to. The opportunity to explore our subjective reality in this world was a way of moving beyond the laboratories and sophisticated technology that had otherwise reduced subjectivism to a position of inferiority during earlier phases of my higher education. As a consequence, this was a pivotal moment for my personal and academic development that enabled me to begin to ask questions which relied on human beings as a gateway for subjective knowledge as opposed to an object that can be manipulated and tested.

However, I was yet again confronted by the ways in which the natural sciences had continued to dominate the health sciences landscape during the year I worked as a research assistant at the University of Hull. I joined a team of academics and post-graduate researchers that had formed a research collaboration with the East Riding

of Yorkshire Council. The project aimed to qualitatively and quantitatively evaluate the public health strategies that had been designed and implemented across the region. This included various studies and evaluations being conducted that were targeting child and adult weight management, critical obesity interventions, exercise referral programmes, and wider behavioural change strategies. Initially, this type of work presented me with what I thought was a crucial opportunity to be and feel immersed in an applied setting of “real world” health psychology and health promotion.

Harnessing my passion and interest for qualitative research, I undertook a research study that was designed to explore the experiential nature of these programmes and interventions by those who were at the heart of them (i.e. patients, instructors, general practitioners). However, it was clear that the council’s priority remained with the quantitative evaluations that positioned measurement (i.e. weight loss or increased time being active) and statistical analyses at the centre of the perceived success or failure. This way of interpreting the services, I concluded, was only a fraction of what could be discovered, as my findings indicated that the pathways and designs of the services simply did not consider the patient to be a subject. In fact, the qualitative insights could have offered more detail and understanding of why non-adherence or drop-out rates were occurring, enabling the entire strategy to undergo small but effective changes to support the overall design. Of course, there was, and probably still are, individuals and families who hugely benefit from accessing such services. Yet, I came away from the experience feeling underwhelmed by the humanistic meaning that was lacking throughout the programmes and interventions that were being implemented for people who required clinical and personal support for their general health.

My desire to apply for a PhD studentship was, therefore, carefully considered as I did not want to be faced with another arduous task of attempting to promote the advantages and usefulness of qualitative research in a health science setting. However, the opportunity to collaborate with the 4 Cancer Group on behalf of the University of Brighton was an appealing prospect to study how the organisation, which is divorced from public health direction because of its status as a civil society organisation, attempts to enhance experiences of rehabilitation and survivorship for those living with and beyond cancer. At present, the NHS has developed and



implemented a rehabilitation and survivorship based recovery package that offers several different stratified follow-up pathways to support those affected by cancer, with physical activity being one of many pathways an individual can engage with. Although this is a crucially important step forward to support those after their treatment, my automatic assumption immediately arrived at a concern for how this style of rehabilitation is designed, delivered, and measured through the “recovery package”.

Consequently, a phenomenological analysis of how the 4 Cancer Group’s recreational programmes are meaningfully lived through was considered to be a study that would satisfy my concern for the current approach. What’s more, an understanding of the use of alternative approaches was considered to be useful for the sake of broadening the current strategies and ambitions to expand the range of post-treatment provision.

# **1.0 Introduction**

## **1.1 Background to the Introduction**

The following introductory chapter will begin by briefly undertaking a review of the biological and historical foundations of cancer. The chapter then proceeds to examine the contemporary qualitative characterisations and statistical trends of cancer (i.e. rates of survival) before moving onto the current political and healthcare strategy in England. Moreover, a specific emphasis is placed on reviewing the healthcare-based strategies to support the health of those living with and beyond cancer.

Following the broader contextual considerations, the introduction draws on the third ambition, *Patient experience and QoL*, of the recently developed 2015-2020 strategy, *Achieving world class cancer outcomes – A strategy for England*. Specifically, the introduction establishes how structured physical activity interventions and the measurement of QoL have been adopted by the NHS through ‘the recovery package’ and ‘the stratified follow-up pathways’ for those living with and beyond cancer. It is at this point during the introduction whereby this thesis, and the phenomenological interest that is driving the study, will be identified and elaborated upon.

The introduction will then conclude by introducing the next chapter, which is focussed on a review of the current academic and scholarly literature that has been undertaken on this topic. The review will establish how this thesis can expand both healthcare strategy and patient experience through a descriptive phenomenological study of recreational programmes in the natural environment for those living with and beyond cancer.

## **1.2 A historical and contemporary overview of cancer**

Cancer is defined as “a disease caused by an uncontrolled division of abnormal cells in a part of the body” and “a malignant growth or tumour resulting from an uncontrolled division of cells.” (Oxford Online Dictionary, 2017). Biologically, and in its simplest reduction, the condition of cancer arises in human beings because of a complex process that involves functioning cells converting into ‘tumours’ or ‘neoplasms’ due to genomic instability (Tobias, Hochhauser, and Souhami, 2010).

Changes in human DNA and exposure to physical, biological and chemical carcinogenic drivers, such as tobacco and processed foods, are two of the many risk factors associated with the onset of cancer (Tobias, Hochhauser, and Souhami, 2010; World Health Organisation, 2017; Wyatt & Bates, 2015). As opposed to functioning cells, which follow the process of 'apoptosis' or the cell life-cycle, carcinogenic cells do not die and are driven to reproduce and migrate to other areas of the body (Hejmadi, 2009). Cells that have converted into tumours, a swelling-like inflammation of bodily tissue, fall into two classifications. Firstly, cells that have become tumours but do not invade other areas of the body are classified as benign, or commonly known non-cancerous, whereas cancerous cells that do invade other areas and organs of the body are termed as being malignant (Weinburg, 2013).

The complex process that separates both classifications is called metastasis, which has been described as a biological invasion from the original site of the tumour (Weinburg, 2013). Moreover, metastasis is a multifaceted process that involves four stages of detachment, migration, invasion, and adhesion, whereby the once benign cells breach from epithelial tissues into the basal membrane and continue into the stroma, a connective tissue, subsequently becoming malignant (Weinburg, 2013). Once breached, the malignant cells can enter lymphatic systems, evading the immune system's response and causing considerable proliferation to other anatomical areas and the possibility of death if not medically treated (Hejmadi, 2009; Wyatt & Bates, 2015; WHO, 2017). Anatomical areas including the breast, prostate, bladder, cervix, colon, stomach, kidney, oesophagus and lung have been observed and recorded as being the common most cancer sites (Tobias, Hochhauser, and Souhami, 2010).

Before entering into a comprehensive overview of cancer in the modern-day, whereby it is possible to identify the causes which contribute toward the onset of cancer, a brief historical encounter of the condition is provided to convey its longevity in medical history. Mukherjee (2010) offers an insightful narrative that encapsulates the human effort to understand and overcome the long term health condition that is cancer. Expressed in a style and prose that has encouraged mixed reviews as he discusses his experiences as a specialist in haematology and oncology, Mukherjee's (2010) '*a biography of cancer*' deals chronologically with the

earliest recordings of cancer to the contemporary medical treatments that aim to treat cancer.

Mukherjee (2010) first cites cancerous lumps identified over 4000 years ago through medical observations found in Greek and Egyptian medical practice. Further chapters survey the medical procedures that evolved from this foundation, such as the identification and development of chemotherapy by Sidney Faber. A key theme throughout Mukherjee's (2010) work is the foundation of serendipitously discovered pharmaceuticals in the field of cancer research, emphasising how disciplined science and open-minded intuition have combined to generate contemporary treatments that are used today (Hargrave-Thomas, Yu & Reynisson, 2012). Mukherjee (2010) also writes extensively on central figures, such as Mary Lasker and Rudolph Virchow, who contributed directly or indirectly toward the contemporary scientific study, observation, and treatment of cancer.

Not surprisingly, Mukherjee's (2010) analysis conveys too much detail for this brief historical encounter, but his biography of cancer does communicate the essential advances in technology for cancer treatment over centuries, serendipitously discovered or otherwise. Importantly, Mukherjee's (2010) work also considers the people who have borne the burden of this specific malady, revealing extensive narratives that capture the essence of the experiential cost of cancer and the subsequent treatment they have received and lived with. Such narratives, therefore, include psychological detail to what is otherwise a sanitised and biomedical worldview, enriching the understanding of the sometimes taken-for-granted subjective world of living with and beyond cancer.

### **1.3 Contemporary Trends**

In the modern-day, cancer continues to affect the global population and is accountable for millions of fatalities worldwide, indiscriminate of age and gender (WHO, 2017; World Cancer Report, 2014). Increases in greater health surveillance methodologies have resulted in published reports that provide data on current cancer statistics and trends. Documents and reports such as GLOBOCAN (2012) and the World Cancer Report (2014) by Stewart and Wild have observed that incidence and mortality rates concerning cancer have continued to increase. 8.2 million fatalities worldwide were recorded in 2012, with this figure rising to 8.8 million

in 2015, directly effecting high, intermediary, and lowly resourced countries (GLOBOCAN, 2012; World Cancer Report, 2014). Incidence is high in the high resource countries of North America, Western Europe, pockets of Asia (Japan and Korea) and Oceania (Australia and New Zealand), intermediate in Eastern Europe, Central and South America, and South-East Asia, and lowest in the lower resourced Africa and South-West Asia countries or continents (World Cancer Report, 2014).

In the case of mortality and survival, this trend varies from one country to another. However, the technological advancement and greater understanding of cancer care in primary care settings, typically in high resource countries of western Europe and the United States of America, have observed lower rates of mortality and thus higher rates of survivors. However, low resource countries have generally recorded greater rates of mortality, raising concerns over access to clinical care designed for diagnosis, treatment and survival, with 20 million new cases of cancer affecting countries entering economic and social transitions (World Cancer Report, 2014).

#### **1.4 Cancer in the United Kingdom (UK)**

Observational trends in the UK have identified that as opposed to affluent areas, those who belong to an ethnic minority, are older, and who live and work in the most deprived areas of any given geographical region are more likely to be affected by cancer, reinforcing global statistics (Coleman et al., 2004; Public Health England, 2019). For example, Public Health England (2019) recorded that 70% of lung and cervical cancers and 25% of liver and stomach cancers will impact those living in what are described as deprived areas, with the consumption of affordable processed food as one example of causation (Tobias & Hochhauser, 2010).

Maddams, Utley and Moller (2012) produced four potential projections on cancer trends from 2010-2040 in the UK. Using the national cancer registry, Maddams et al. (2012) assumed that trends of incidence, mortality, and survival would continue to rise, with projections suggesting that by 2040 there will be over five million cancer people living beyond cancer. The projections also offer a break-down of the statistics for gender, cancer type, and age ranges. Whilst the outcomes may well be projections, Maddams et al. (2012) have emphasised the constant responsibility that must be taken by the appropriate governing bodies and healthcare commissioners

to provide healthcare strategies for present and future generations of those who will live with and beyond cancer (Maddams et al., 2012).

Taking into account the rise and severity of cancer statistics throughout England (Public Health England, 2019), extensive public awareness strategies and screening campaigns have been introduced to support and guide those who are at greater risk (NHS, Screenings Review, 2019). However, focussing simply on direct medical solutions have often been described as a small part of a multifaceted and complex process (Smith, Bambra and Hill, 2016). Often what determines the state of an individual's health has considerably more variables than what can be provided by immediate statutory healthcare legislature and policy, such as the conditions of workplaces or the accessibility, and cost of, local education (Smith et al., 2016). Multiple determinants have therefore been recognised when accounting for the risk of developing ill-health, especially in the historical and current context of cancer (Public Health England, 2019).

Socio-economic inequalities throughout the life-course, for example, have been identified as serious obstacles that affect many groups of the global population, let alone in the UK (Public Health England, 2019). Furthermore, the identification of disparities around statutory and tertiary education, financial income, social capital, geographical location, housing conditions, occupational exposures, and educational and cultural awareness have been recorded as having significant influence over the variation in cancer prevalence and incidence (Macmillan, 2019). For example, Karbani et al. (2011) identified cultural beliefs in South Asian women in the UK as a possible barrier which may prevent whole populations from accessing clinical guidance and support. Amongst all of the participants of the Karbani et al. (2011) study, of which there were twenty-four direct patients and fifteen significant others (i.e family), a general lack of awareness of cancer and associated symptoms featured heavily (Karbani et al., 2011).

Moreover, the participants spoke of their cultural barriers of communication, recalling their male counterparts' attempts to reject discussions of cancer due to a superstitious fear of speaking the word cancer as it could encourage symptomatic signs of cancer (Karbani et al., 2011). The study provides cultural insight into the different and meaningful ways people may respond to the threat of cancer and the

importance of understanding the beliefs people draw upon when making decisions about accessing services and throughout their experiences of living with and beyond cancer.

Concerns over the rise and projected impact of cancer have consequently generated wider consideration into the response by political institutions, healthcare providers, and the civil society for both direct and indirect solutions to support those living with and beyond cancer. What follows, then, is a brief commentary of cancer strategies that have been implemented throughout England over the past twenty years, including the newly developed strategy for 2015-2020. Within this commentary, this thesis locates its initial position in the field of rehabilitative and survivorship ambitions for those who are living with and beyond cancer.

## **1.5 Political and Healthcare Response**

At present, the strategy, *Achieving world-class cancer outcomes – a strategy for England 2015-2020*, has charted the strategic ambitions for the National Health Service (NHS) in England to support those living with and beyond cancer. Stressing the severity that cancer still poses in the modern-day, the strategy addresses clear objectives that have and are currently being implemented to manage the current and projected challenges associated with this specific condition. Moreover, the strategy has been continuously evolving throughout the past twenty years, with considerable efforts being directed towards reducing the number of those who are impacted by cancer, whilst also assisting the numerous health professionals who attempt to implement strategies and ambitions. Before delivering a commentary on this specific strategic plan for the sake of locating the basis of this thesis, an overview of the previous cancer strategies is necessary to articulate the complexity of managing this chronic illness that has affected millions.

## **1.6 Previous Cancer Strategies – 2000-2015**

Previously published strategies and ambitions included the *NHS Cancer Plan* (2000) and the *Cancer Reform Strategy* (2007), which established four divisional structures for different cancer-based initiatives. The divisional structures included the National Cancer Intelligence Network (NCIN), the National Awareness and Early Diagnosis Initiative (NAEDI), the National Cancer Survivorship Initiative (NCSI) and the

National Cancer Equality Initiative (NCEI). Each division aimed to coordinate and plan different agendas specific to separate areas of cancer diagnosis, treatment, and survivorship. Significant change throughout this period observed improvements (i.e. shorter waiting times) in secondary and tertiary care for cancer and greater intelligence (i.e. cancer registries) and earlier diagnosis targets being designed (Cancer Taskforce, 2015).

Further strategic development established the *Improving Outcomes Strategy* (2011) which coincided with the introduction of the health and social care act of 2012 and UK fiscal policies of austerity. Brown et al. (2014, p4) described the following three years as a broad “standstill” for much of the UK’s cancer services as a result of the national and local restructuring that was initiated. For example, the health and social care act of 2012, the most extensive reorganisation in the history of the NHS, saw NHS primary care trusts and strategic health authorities replaced by locally-led clinical commissioning groups (CCG). This involved general practitioners and supporting members (i.e. nurses) commissioning the most appropriate services for the local needs. Whilst criticisms of the new commissioning approach suggested that the NHS was slowly becoming privatised through contractual procurement through the private sector, Ham (2018) proposes that these claims are somewhat exaggerated. Yet, Ham (2018) does balance this argument by acknowledging that there was and still is a cause for consideration regarding leadership, governance, and patient experience because of such extensive reforms to the NHS’ system and structure that has caused fragmentation of patient care.

Furthermore, in their analysis of international economic policies of austerity, Bambra, Garthwaite, Copeland and Barr (2016) identified how the financial freeze of 2010 weakened and diminished social and institutional necessities for those living with a chronic health condition, such as cancer. This included financial weakening of the healthcare system, the housing industry, and social services, all of which contributed toward greater rates of morbidity and mortality in those diagnosed with cancer (Bambra et al., 2016; Brown et al., 2014). Brown et al. (2014) supported the expenditure analysis by Garthwaite et al. (2016), determining that outlay on ‘cancer and tumours’ peaked in 2009 and 2010 whilst fluctuating during the years that followed. The financial plateau created human and material resource discrepancies in the wake of increasing statistics in incidence, mortality, and survival rates of



cancer. Such changes had consequences for screening programmes, for example, with an NHS directed screenings review identifying many challenges in this area of cancer prevention. As well as identifying concerns for the accuracy of results and age-related concerns regarding access (Sarma et al., 2019), screening based services have encountered difficulties with operational, technological and overall governance on an institutional level, severely undermining functional capacity (NHS, Screenings Review, 2019).

Albeit inadvertently, the aforementioned service challenges can prevent those from making informed decisions about attending a screening. For example, whilst 89% the UK's public do think cancer screening is a good idea and 49% of the public would be tested if they had a concern (Sarma et al., 2019), the screening protocols in which these services are offered has been criticised (Wardle et al., 2016). Citing the letter of invitation as a significant barrier for those who are from a deprived background, there are clear literacy challenges that possibly prevent an earlier diagnosis and subsequent professional guidance on treatment planning or behavioural risk management (Wardle et al., 2016; Sarma et al., 2019).

Coinciding with the challenges associated with governance and uptake of screening programmes, the consequences of fluctuating financial support imposed on the NHS' services have created increased waiting times for newly diagnosed cancer patients to begin treatment. Identified by Brown et al. (2014), the 62-day waiting time between 2013 and 2014 for both the start of treatment and provider efficiency had fallen below 85% standard, with 84.4% of patients starting treatment and 61% of providers achieving targets within the 62-day expectation. Mixed-methodological evidence has also stressed the inconsistencies relating to less expenditure on medical staff recruitment whilst encouraging more patient screening referrals, with one interviewee discussing increases in bed capacity and plateauing in nursing availability (Brown et al., 2014, p.14).

As a consequence of the broad "stand-still" that has occurred, the financial fluctuation and instability for all those involved in cancer treatment and care not only reflected additional pressure onto healthcare strategists but also had severe implications for those living with cancer (Macmillan, 2017). The increase in time waiting for those requiring treatment, for example, has put an increased pressure

on staff to be efficient and cost-effective, potentially compromising a level of care and attention that is essential for treatment and the subsequent phases that follow for those living with and beyond cancer. What follows, then, is the latest strategy that has been developed and commissioned to respond to the fragmentations that have occurred in the previous strategies. One important element of the current strategy will be discussed to stress how increased fragmentation of care has had a subsequent effect those entering the 'rehabilitation and survivorship phase' of care. It is at this point that the emergent phenomenon of interest of this thesis will begin to appear, drawing specific attention to current issues of personalised follow-up care in the rehabilitation and survivorship phases for those living with and beyond cancer.

## **1.7 Current Cancer Strategy**

Although it has attempted to combine all previous strategies to cover a vast scope of care, accountability, and governance, the current strategy has been issued with "warning signs" regarding its commitment to meeting current strategic targets (Macmillan, 2017). Before addressing Macmillan's report, which has identified the causes for concern, it is important to provide a broad overview of the current strategy. The primary policies are as follows:

- *"Aligning with the principles set out in the NHS Five-Year Forward View."*
- *"Place stronger emphasis on the upstream and downstream elements of the cancer patient pathway, with more attention given to prevention, earlier diagnosis and treatment."*
- *"Acknowledge and plan for the increased demand we will see in the coming years, such that this is addressed proactively (and therefore cost-effectively) rather than reactively."*

To implement the newly developed strategy, the independent cancer taskforce, which is a specialist advisory group consisting of 16 members independent of the government, set three high-level ambitions with supporting practical initiatives. The initiatives would further frame and embed the aforementioned strategy within the NHS' and private cancer services.

The first ambition, *Cancer Incidence*, aims to reduce overall adult smoking rates and prevent an increase in age-standardised incidence by 2020. This currently involves

generating improved legislation on product packaging and prohibitions upon smoking premises, such as vehicles, whilst simultaneously introducing an integrated care system (Ham, 2018), relating to the efforts to manage both upstream and downstream policy. Intending to attain earlier detection and greater access to treatment, the second ambition, *Cancer Survival*, aims to increase cancer survival from five to ten years. The second ambition also underscores the importance of reducing variations across England, especially in the elderly population.

The third and last ambition, *patient experience and QoL* has been designed to be “more patient-centred” (P.13). Focussing on the overall cancer experience, the taskforce proposes continuous improvements in the development and measurement of long-term quality of life during and after cancer. This ambition emphasises the significance of the development of personalised care interventions and strategies for those who are living with and beyond cancer, which is otherwise known as the rehabilitation and survivorship phase. Recent developments have also focussed on introducing a QoL metric throughout this period of rehabilitation and survivorship. The QoL metric aims to assess via two questionnaires how adequately patients are supported through the third ambition of personalised care. Based on the information gathered within the questionnaires, health professionals can supposedly evaluate how or if further provision can be employed to manage the ongoing needs of an individual living with and beyond cancer.

Despite the current strategy placing greater importance on rehabilitation and survivorship, the third ambition has been subtly developing throughout previous strategies. Established in 2008 in the UK as a partnership between the NHS and Macmillan, the National Cancer Survivorship Initiative (NCSI) was designed after the development of the *Cancer Reform Strategy* of 2007. Moreover, the NCSI is focussed on the need to “support and enable cancer survivors to live as healthy and as good a quality of life for as long as possible” (NCSI, 2013, P.3) and has subsequently been drawn into the latest ambition as a way of extending and reinforcing the focus on long-term patient experience and QoL.

Following two comprehensive publications by the NCSI in 2010 and 2013, which focussed on the investigation of unmet needs of those living with and beyond cancer in England, the prioritisation of personalised post-treatment care has now been

considered to be as important as preventative campaigns and treatment strategies. As a result of the strategic expansion, the design and implementation of ‘the recovery package’ by the NHS and Macmillan has been commissioned for those in need of post-treatment support. Below features table 1.0 depicting the main features of the recovery package that is offered to those living with and beyond cancer.

<b><i>The Recovery Package</i></b>
<b>1.</b> <i>“Structured holistic needs assessment and individualised care planning.”</i>
<b>2.</b> <i>“Information on likely side-effects of treatment.”</i>
<b>3.</b> <i>“Potential markers on the recurrence of cancer and information on what to do in these circumstances.”</i>
<b>4.</b> <i>“A key contact point if recurrence markers are experienced or if serious side-effects become apparent.”</i>
<b>5.</b> <i>“Treatment summaries for patient and professional transparency.”</i>
<b>6.</b> <i>“Patient education and support events (i.e health and wellbeing events).”</i>
<b>7.</b> <i>“Access to and advice regarding health-based interventions for self-management.”</i>
<b>8.</b> <i>“Signposting to rehabilitation, work and financial support services.”</i>

**Table 1.0** - The main features of the recovery package (Macmillan, 2013).

Embedded within the recovery package are the stratified follow-up pathways. The pathways present a variety of specialist follow-up interventions for those who have or are continuing to live with the impact of cancer. Furthermore, the pathways, which are commissioned and supported by NHS England, Clinical Commissioning Groups, and Public Health England (NHS, 2015), prioritise biological recurrence awareness, signposting to social services, and the use of physical and mental health services (i.e specialist follow-up, self-management and group rehabilitation services) that can support high, intermediary, and low-risk individuals who are living with and beyond cancer (NHS Improvement, 2016). On a structural level, the pathways also aim to create a culture of cross-collaboration between various NHS services and different sectors of society, including the civil society.

Two examples will be used to bring the recovery package and the follow-up pathways to life to showcase their current depth and diversity. Firstly, in 2015, the

Ashford and St Peter's hospital foundation trust hosted a 'health and wellbeing event' that was attended by fourteen cancer charities and specialist professionals to provide a 'market stall' designed event to provide information, advice, and guidance to those who are living with and beyond cancer. Whilst Ashford and St Peter's hospital-based initiative was delivered to broadly incorporate most of the key principles within the recovery package for those who need guidance (i.e. financial and social support), other services focus specifically on other intricate features of the stratified follow-up pathways, such as structured physical activity interventions. For instance, the NHS commissioning guidance for the stratified follow-up pathways for those living with and beyond cancer (2016) cited the *Albion in the community* initiative hosted by Brighton and Hove Albion Football Club. This initiative is based on providing a structured physical activity intervention for "cancer survivors" to experience "less fatigue, improved mood, increased strength and fitness, reduced risk of cancer progression and decreased risk of recurrence" (*Albion in the Community*, Online). The initiative points towards the role that prescribed physical activity and lifestyle interventions now assume for the supposed enhancement of cancer rehabilitation and survivorship.

To summarise, the significant threat that cancer has and continues to pose to people in England has compelled healthcare commissioners to develop comprehensive strategies over the past twenty years. Specifically, the aforementioned strategies and ambitions have been designed to manage and frame the clinical expectations associated with inequalities in health, awareness and education, screening programmes, diagnosis, treatment, rehabilitation and survivorship, and end of life care for those living with and beyond cancer.

In relation to NHS England's strategic approach, the current ambition of *Patient experience and QoL* represents what Van Mazijk (2019) describes as "technological-scientific worldviews", which was originally discussed by phenomenological philosophers Edmund Husserl and Martin Heidegger. Both scholars critiqued the technological-scientific worldview of modern science by proposing that its underpinning logic and essence "has shaped the way things appear before us" and can sometimes be left unchallenged in disciplines of study and applied practice (i.e. psychology and the natural sciences) (Van Mazijk, 2019, p528). Whilst the third ambition of the current strategy has a clear direction to

support people through the recovery package and the stratified follow-up pathways, it is necessary to explore and challenge the worldview of the structured physical activity interventions and the measurement of QoL. In doing so, the ways in which this specific approach, or worldview, is designed and delivered for the needs of those living with and beyond cancer can be re-orientated to meet the human-world relationship that Husserl was concerned about being jeopardised through modern science (Van Mazijk, 2019). What follows, therefore, is a greater elaboration of the third ambition of the current strategy, drawing specific attention to the parochial worldview of structured physical activity interventions and the measurement of QoL for those living with and beyond cancer.

### **1.8 Phenomenon of Interest**

The third ambition of the most recent strategy, *Patient Experience and QoL*, is where this doctoral study finds its phenomenon of interest (Wertz, 2005). The ambition attests to the considerable shift in evidence over the rehabilitative influence of structured physical activity interventions for those who have experienced and undergone clinical treatment for cancer (Dimeo, 2000; Midtgaard et al., 2015; Burke et al., 2017; Macmillan, 2017).

Prior to the 1960s, bed rest was considered and advocated to be a suitable clinical approach for those with a chronic condition as it would not induce fatigue, breathlessness, and aggravation of a given health condition (Dimeo, 2000; Macmillan, 2017). Though rest is still advocated by many health professionals for contemporary health conditions, structured physical activity interventions are now considered to be a therapeutic method to aid the overall biopsychosocial recovery for those who have experienced cancer (Dimeo, 2000; Courneya, 2001; Feuerstein, 2007). Moreover, it has been recognised that without some form of therapeutic activity as a rehabilitative method, an individual living with cancer can experience “severe deconditioning” which can reduce the overall functionality of their health (Dimeo, 2000, p160; Ferioli et al., 2018). Moreover, disruptions in overall functionality can manifest in biopsychosocial side effects that can produce a psychological state of stress and physical suffering in those who are living with and beyond cancer (Sharpley, Bitsika & Christie, 2018; Parpa, Tsilika, Gennimata & Mystakidou, 2015; Lee 2008).

Cancer-related stressors can manifest in the form of chronic fatigue (i.e. cachexia), depression, financial challenges, loss of a social support system, work-related uncertainty, and existential anxiety (Folkman, 2012; Cobb, 2015; Feuerstein, 2007; Sharpley et al., 2018; Parpa et al., 2015; Lee 2008). Cobb (2015) expands these areas of cancer-related concerns by discussing the challenges associated with an individual's existential and psychological state of health throughout the entire cancer experience. Underlining the challenges of living with, and surviving, cancer, Cobb (2015) highlighted how psychological pressures of remaining healthy and realisations of potential mortality can occur, positioning an individual in a state of existential limbo.

Findings from a qualitative study of existential threats to those living with and beyond cancer by Baker et al. (2016) elaborated on the existential and psychological pressures espoused by Cobb (2015). Out of twenty-eight, seventeen participants had alternating views of identity continuity, with participants expressing views of feeling as positive and as physically capable as they did before the diagnosis of cancer. Yet, the participants also described an existential vulnerability due to the onset, and survival of, cancer (Baker et al., 2016; Cobb, 2015). As a consequence, those who live with and beyond cancer may experience periods of psychological instability, potentially triggering complex psychological reactions (Cobb, 2015; Feuerstein, 2007; Lee, 2008). This sense of existential limbo, which reflects alternating positions surrounding psychological continuity and stress, resonates with two dominant psychological theories of Post-Traumatic Stress Disorder (PTSD) and Post-Traumatic Growth (PTG).

Medically recognised in the last one-hundred years, PTSD is an anxiety-related condition caused by stressful, traumatic, or distressing events (NHS, 2018; Bisson & Andrew, 2007). Such events are eclectic in that they can differ from war and terrorist-related experiences to involvements in car accidents and sexual manipulation (Yehuda et al., 2015; Herman, 1992). PTSD typically manifests itself through psycho-somatic and neurotic stress-related symptoms that include anxiety attacks, emotional withdrawal, insomnia, and disruption of what can be considered 'normal life' (Yehuda et al., 2015). Ratcliffe, Ruddell, and Smith (2014) also use phenomenological research to expand upon both the individual and intersubjective experiences of trauma (i.e. torture), with considerable comparisons made to the

medical condition of PTSD. Ratcliffe et al., (2014, p.7) draw upon “loss of a meaningful future” to demonstrate how ontological insecurities impact upon a person’s beliefs, intersubjective relations, and future projects.

In the context of cancer, PTSD can be both acute and chronic, possibly disrupting the life of those affected for several months or perhaps years after diagnosis and treatment (Cordova, Riba, Spiegel, 2017). Cordova et al. (2017) identified 1637 qualitative studies that acknowledged the prevalence of PTSD of direct sufferers and immediate family members of those who have or are living with cancer. In several of the studies, nearly half of the participants experienced signs of traumatic stress, which was either self-reported or clinically diagnosed (Cordova et al., 2017). Factors associated with cancer-related PTSD have been identified as “pre-cancer diagnosis or lifetime trauma history, pre-cancer diagnosis of a psychiatric condition, low socioeconomic status, young age, limited or negative social support, advanced stages of disease, invasive treatment, dissociative symptoms as a result of a diagnosis of cancer, and repeated recall of the experience of diagnosis or treatment” (Cordova et al., 2017, p.4-5).

On the other hand, Post-Traumatic Growth (PTG) is a theory that also been associated with cancer-related experiences. Synonymous with terms such as adversarial growth, existential awakening, thriving, and resilience, Post-Traumatic Growth (PTG) is understood to be a psychological phenomenon of positive change through the experience of trauma and adversity (Hefferon, Grealy, and Mutrie, 2009; O’leary Adlay, Ickovicks, 1998). Typically, the occurrence of PTG is the antithesis of PTSD and is viewed as a psychological state that enables people to ‘rehumanise’ or ‘grow’ following an event that has caused significant physical or psychological trauma (Rosner and Powell, 2006; Lev-Wiesel and Amir, 2006).

A systematic review of the literature relating to cancer and PTG conducted by Hefferon et al. (2009) identified fifty-seven studies spanning over thirty-two years of publication. Seventeen of the studies focussed solely on the phenomena of PTG, whereas the remaining forty studies identified PTG as a serendipitous finding, reiterating what Hefferon et al. (2009) proposed as PTG being possibly overlooked or under-researched in the overall experience of cancer rehabilitation and



survivorship. The various dimensions and elements of PTG have been reported (Hefferon et al., 2009) as:

- Reappraisal of life and priorities.
- Trauma equals the development of the self.
- Existential evaluations.
- A new awareness of the body.

Since Dimeo's (2000) publication, considerably more academic and mainstream attention has focussed on the rehabilitative use of structured physical activity interventions for those who live with and beyond cancer (Midtgaard et al., 2015; Burke et al., 2017). As well as alleviating the associated symptoms of PTSD, such as social isolation and insomnia, physical activity interventions are now being recognised as an appropriate way of enabling the associated psychological effects of PTG. Such enablement comes in the form of increased social support, emotional resilience, and spiritual awakenings (Midtgaard et al., 2015; Burke et al., 2017).

Quantitative research studies that have also been conducted in this area of interest have supported the clinical safety, feasibility and health-related benefits associated with enhancing recovery and functional rehabilitation through physical activity interventions (Mishra, Scherer, Snyder, Geigle, Gotay, 2014; McNeely et al., 2006; Macmillan, 2017). In light of both the qualitative and quantitative evidence, the third ambition of *Patient Experience and QoL* has, therefore, found an empirical foundation, or worldview, for using structured physical activity interventions for the ways in which people meaningfully engage with their sense of living with and beyond cancer.

## **1.9 Research concern**

However, the third ambition positioned within 2015-2020 cancer strategy is currently being undermined due to concerns relating to political accountability, the design of the physical activity interventions, and measurement of QoL (Macmillan, 2017).

First of all, the current political and healthcare concerns regarding the lack of accountability and fragmented responsibilities for cancer services are jeopardising the standard of care and welfare for those living with and beyond cancer along the entire cancer trajectory (i.e. diagnosis to survivorship or end of life care) (Macmillan, 2017). Secondly, the dominance of structured physical activity interventions, and

how these are measured through questionnaires, that are being commissioned for those who currently receive personalised post-treatment care from the recovery package stratified pathways is a cause for concern (Macmillan, 2017).

The former of the two concerns relate to the substantial challenges facing the current strategy which was identified through Macmillan's (2017) "warnings signs" publication. This specific publication identified the existing "challenges to delivering the cancer strategy for England by 2020". Moreover, the report includes findings from a survey-based research study, with the overall purpose being designed toward understanding the confidence in the NHS' ability to deliver the 2015-2020 strategy (Macmillan, 2017). Drawing on seventy local NHS leaders and fifty-six Macmillan GP's as participants, the report identified five themes that emerged from the survey's findings. These included:

- Mixed confidence in delivering the cancer strategy.
- Cancer services under pressure.
- Unclear responsibilities, both locally and regionally.
- Financial and workforce problems constrain progress.
- Achieving transformation in cancer services will require excellent leadership.

Overall, the outcomes conveyed that statutory funds are being spent on "plugging gaps" rather than upgrading services despite statistical evidence and future projections underlining the rise in those who will be living with the physical and psychological implications of cancer. As a consequence, such outcomes suggest that there is a threat to the integrity of the strategies and ambitions that have been developed over the last twenty years (Macmillan, 2017; Maddams et al., 2012).

Compounding the pressure cancer services are under, it would seem that the 2012 reforms have continued to cause political fragmentation on a local and regional level, causing the NHS' cancer services to stretch well beyond financial and staffing capacity without any direct and obvious leadership (Macmillan, 2017). This, as a consequence, has for some time affected the overall cancer experience for those living with and beyond cancer. Macmillan (2009, p.12) asserts "...surviving cancer does not necessarily mean living well, and many people need ongoing support long after initial treatment ends. At the moment, a feeling of abandonment after initial treatment is common. Demand, therefore, is not just rising but changing. People

affected by cancer need new and different services, not only to bring new technologies to the frontline but also to support people to live as well as possible after treatment”.

The latter of the two concerns directs its attention to the demand for a greater diversity of post-treatment services from other sectors. The dominance of structured physical activity interventions being led by NHS trusts has been criticised as being too clinically rigid in the way that it attempts to promote and measure a meaningful relationship with rehabilitation and survivorship (Midtgaard et al., 2015; Burke et al., 2017). This critique explores the ways in the design and structure of such interventions represents a focus on physical rehabilitation and a degree of ‘responsibilisation’ for an individual’s health, which has caused controversy in other public health interventions (Midtgaard et al., 2015; Brown et al., 2019). For example, the Moreton et al. (2018) evaluation of the Macmillan physical activity pathway states that behaviour change is at the core of the focus of the intervention, with NICE guidelines for public health interventions serving as its scientific template and model of approach.

Understandably, this model of rehabilitation and survivorship has clear connections with addressing the lifestyle-based choices that can reduce the possibility of biological recurrence of cancer (Moreton et al., 2018). However, this would likewise suggest that cancer rehabilitation and survivorship interventions specific to physical activity are being based on what would be found in an exercise referral or weight management interventions, for example. This approach generally involves motivating the patient to receive lifestyle counselling (i.e. motivational interviewing) and exercise prescription with the expectation of making positive changes to their lives over several weeks or months. However, evidence suggests that the long-term effectiveness of this approach is modest at best (Moreton et al., 2018; Jepson, Harris, MacGillivray, Kearney, and Rowa-Dewar, 2006).

Indeed, the way in which the approach is presented also has commonalities with the common discourses and metaphoric language that are found in both strategic and media-based representations (Jerome & Pei, 2020; Oronsky et al., 2015). For example, ‘the recovery package’ and the societal campaign of ‘stand up to cancer’ are clearly intended to awareness of cancer amongst people. However, such

discourses do likewise encourage a certain worldview of how cancer should be managed and lived-through in a manner that portrays the individual as having to win the entire experience of cancer (Oronsky et al., 2015).

It is important, therefore, to question whether physical activity interventions led by an NHS that is under enormous internal pressure can offer a rehabilitative service in a meaningful way that will enhance living with and beyond cancer. At present, there has been additional research studies and syntheses committed to the meaningfulness of unstructured recreational services and programmes that are led by the civil society (Burke et al., 2017). Taking into consideration what has been discussed about the experiential cost of living with and beyond cancer, it is necessary to possibly broaden this “worldview” of rehabilitation and survivorship for those who may not respond to interventions that are aimed at “responsibilising” people, despite how subtle or strong this approach is.

This concern also expands to include the implications of using clinically standardised questionnaires to measure an individual’s health and QoL throughout this period. Despite being clinically and methodically effective in some ways, the following chapter discusses the limitations of this particular approach and introduces other ‘worldviews’ that may meaningfully capture a person’s general health, QoL, and well-being. For example, the following chapter, *Narrative literature review*, uses the alternative approach of phenomenologically informed well-being as an example of how different methods can be used to understand the experiential possibilities of living with and beyond a chronic health condition.

## **1.10 Conclusion**

In conclusion, the combination of the aforementioned concerns that relate to facilitating and measuring cancer-based rehabilitation and survivorship add to the complexity of developing sustainable care plans for those living with and beyond cancer (Keesing et al., 2015). In their systematic review of survivorship care plans, Keesing et al. (2015) stated that on a global basis the survivorship or post-treatment phase is still undergoing significant development, with inconsistencies occurring between the coordination and expectations of rehabilitative and survivorship plans (Macmillan, 2009; Keesing et al., 2015; Halpern et al., 2015). And whilst it is difficult to measure and compare personalised care plans against one another, the greater

the diversity amongst these services (i.e. design, delivery, content) not only offers more options for those living with and beyond cancer that need post-treatment support but also reduces the social and economic strain being placed on the NHS' services (Halpern et al., 2015; Moreton et al., 2018; Macmillan, 2017). However, what is now unavoidably clear is that there is a certain enframement of how rehabilitation and survivorship plans are being designed, delivered, and measured within England. This is not to propose that they are without benefits, it is important to explore and expand this worldview to continuously develop the ways in which people meaningfully engage the experience of living with and beyond cancer.

Living with and beyond cancer has sometimes been interpreted as a linear process that encapsulates the transition from being a cancer patient to what is considered as a 'normal and healthy individual' (Feuerstein, 2007; Macmillan, 2017). However, as this issue has been expansively researched, post-treatment and survivorship care have been divided into diverse areas which underline the support that various sectors of services can and should provide throughout the specific period of rehabilitation and survivorship (Feuerstein, 2007). Therefore, the necessity for a greater understanding of the variety and diversity of rehabilitative and survivorship plans is imperative for the success of the third ambition within the 2015-2020 strategy and beyond (Feuerstein, 2007).

The following chapter will offer a critical review of the scholarly literature that has been generated on the topic of the experiential nature of structured physical activity interventions and unstructured recreational programmes for those living with and beyond cancer. The review of studies and syntheses on the various approaches of facilitating rehabilitation and survivorship will then lead to other considerations that concern the use of the natural environment as a way of enhancing people's health. As a result, a substantial amount of scholarly literature will form the second theme of the review, which is based upon using the natural environment as a restorative setting for people living with and beyond chronic health conditions.

The review will include a critical review of the NHS' plans to measure the QoL of those who enter the survivorship phase. The third theme of the review will reflect on the deeply philosophical role that phenomenological studies of well-being can offer in this context. At present, there is a possibility for an increased phenomenological

depth that can enhance the current questionnaires being piloted for the measurement of QoL. The review will then conclude by communicating a researchable phenomenon that has been formed by assessing the current literature on alternative approaches to facilitate and measure cancer rehabilitation and survivorship.

Whilst I am aware of the phenomenological debates that surround the decision to incorporate a literature review within a body of research, the chapter that follows has been written to locate the study within the complexity of the scholarly field. However, this does not assume that the following research, theories, and frameworks will be automatically accepted. Rather, the decision to include a literature review corresponds with the phenomenological orientation to reflect on my pre-understanding of the area of interest. Chapter three, *Methodology and methods*, will elaborate on the notion of making my pre-understandings explicitly clear when I address the use of the phenomenological attitude.

## **2.0 Narrative Literature Review**

The following narrative literature review aims to adhere to the phenomenological principle of sensitizing and orientating oneself to the existing scholarly literature without performing a systematic review (Finlay, 2011). Contentiously, phenomenological projects have been commonly cited as being opposed to performing a systematic review as they are viewed as approaching the project, or phenomenon and area of interest, with an understanding that is too prescriptive and advanced, which is an ideal that is in contradiction of phenomenological attitude (please see chapter three) (Finlay, 2011; Dahlberg, 2006; Zahavi, 2018; Giorgi, 2009).

As a consequence, I thereby sought to use a narrative approach to present “a broad perspective on a topic and describe the history or development of a problem and its management” that captures a large area of academic interest (Green, Johnson & Adams, 2006, p.3). This decision was made in opposition to formulating a specific hypothesis or one singular, specific question, as this could force an approach for this specific study of a subjective, lived experience that does not appreciate the qualitative characteristics found in the phenomenon. This review consequently aims to adhere the Husserlian mantra of “to the things themselves”, whereby I, the primary researcher, can critically engage with the traditional theories and general research of the subject matter without an automatic acceptance of the work as being truly representative of the phenomenon of interest.

Furthermore, the narrative literature review conveys a transparent search strategy (please see 2.1) that seeks to offer the reader an understanding of the key terms used to find the relevant literature. In doing so, the review will establish a broad understanding of the philosophical, theoretical and practical knowledge base of the evidence that can address the concerns regarding cancer rehabilitation and survivorship identified in chapter one. The review likewise reduces the possibility of reproducing previous research designs that are no longer necessary and, in turn, offers a foundation of how this project establishes and builds upon existing research recommendations which warrant further academic study.

### **2.1 Search strategy**

An extensive search of online academic search engines (i.e. Google Scholar; Google Books; Medline; PsycINFO; ETHOS; EMBASE; PubMed) was initially undertaken using several keywords. The keywords were used to gather reading material for a critical evaluation of the literature that would establish a broad perspective of the topic of interest (Green et al., 2006). The keywords and variations included:

- Existential and subjective experience in cancer recovery and/or survivorship.
- Well-being and/or quality of life associated with recreational programmes in cancer recovery and/or survivorship.
- Exercise and/or physical activity interventions and cancer recovery and/or survivorship.

The keywords were considered to express the phenomenon of interest that was identified throughout the introductory chapter. To reflect the timeframe of the healthcare strategies that were discussed in chapter one, academic publications and literature from the past twenty years were deemed to be a suitable inclusion criterion when performing the search of the literature. The process was further enhanced through a review of different academic journals that were used throughout the narrative literature review. These specific journals included:

- Health and Place
- Leisure Studies
- BMC Cancer
- Journal of Cancer Survivorship

Upon finding an article that appeared to relate to the topic of interest, I would read the abstract provided to establish its applicability to this doctoral study. The articles deemed suitable were then assigned to a simple filing system for a further assessment of the academic content within. To improve the process of reviewing the academic literature located within and around this topic, I also used the CASP checklist for qualitative, quantitative and systematic review based studies. The overall quality of the identified research was therefore assessed and examined via the questions posed on the checklists to establish an understanding of the rigour and systematic approach taken in each of the studies philosophical grounding,



methodological protocol, and outcomes. Despite trying to include international literature to enhance the quality of the study, one critical judgement of the following narrative literature review can be that the literature cited is from that of developed countries and institutions.

## **2.2 Personal and professional interests**

Following recommendations by phenomenological researchers (Wertz, 2005; Todres & Holloway, 2004), I also have to make explicit my personal and professional interest and agenda as the doctoral researcher responsible for this narrative literature review. It is important to fulfil this intention because of my personal and professional embeddedness that is present in every stage of the study, something which cannot be avoided or substituted for pure objectivity. Rather, expressing my personal and professional assumptions which have been embraced throughout this process is a matter of being reflexive and grounded in the research process. Whilst I will offer a brief commentary at this point, considerably more reflections can be found in chapter seven which deals more directly with personal reflections of the entire research process.

Professionally, I have been educated and have worked in the field of health and exercise science for eight years. This includes evaluating the design of service provision and policy in public health initiatives, as well as presently working in a health advisory role for those who experience disordered eating patterns of behaviour. I have also had experiences of cancer within my immediate and wider family, therefore understanding the emotional and practical compromises one has to make during such a period. The subsequent review of literature will be guided by a narrative that is systematically flexible enough to identify a gap in the literature that can be addressed through a phenomenologically inspired study, whilst also being reflectively grounded in human concerns for human welfare (Todres and Holloway, 2004; Van Mazijk, 2019).

What follows is a brief introduction to the three emergent themes that were identified throughout the narrative literature review.

## **2.3 Introduction to the narrative literature review**

Initially, the narrative literature review focussed on grasping the nature of both the quantitative and qualitative literature that has been developed in this specific area of cancer rehabilitation and survivorship. However, concentrating largely on qualitatively underpinned research became a conscious decision insofar that I wanted to form a distinct understanding as to what subjective meanings those living with and beyond cancer attributed to their experience of physical activity and recreational programmes for the enhancement of their health, QoL, and well-being.

First of all, the knowledge base concentrating on the qualitative literature of structured physical activity interventions and unstructured recreational programmes for those living with cancer has been expanding. Two studies designed as a meta-synthesis (Midtgaard et al., 2015; Burke et al., 2017) were identified as collating the most recent evidence on the subject of using clinically structured interventions and unstructured recreational programmes for those living with and beyond cancer thus far. Both publications subsequently formed the core of the first theme of this narrative review. In response to the research recommendations of Burke et al. (2017), I began to expand into areas of research that acknowledged the study of the natural environment in which unstructured recreational programmes are situated for those living with chronic health conditions, such as cancer.

By doing so, I present and discuss the subjective and qualitative findings that have been established through various studies as a result of physical and psychological interactions with the natural environment for those with a chronic health condition, such as cancer. This discussion of how the natural world can facilitate and possibly enhance an individual's health thus formed the second theme of the review, emphasising the awareness and knowledge of the shifts in rehabilitation and survivorship that have and are occurring in these settings.

Consideration for how health, QoL, and well-being have been measured in both academic research studies and the NHS' recovery package informed the third and last theme of the review. Consequently, a critical analysis of the instrumentation used for patient-reported outcome measures (i.e. questionnaires and interviews) in the stratified follow-up pathways, which are embedded into the NHS' recovery package and overall cancer strategy, will be undertaken. Also, this will be supplemented by a critical examination of how the concept of phenomenologically

informed well-being has been developed to offer more depth and meaning into an individual's experience of their health. This, as a consequence, draws attention to how interdisciplinary researchers are now using subjectively grounded methodologies, such as phenomenology, to inform and broaden what we know of a person's general health and meaningful engagement with rehabilitation and survivorship.

## **2.4 Theme One - Structured physical activity interventions and unstructured recreational programmes for the rehabilitation and survivorship of those living with and beyond cancer.**

The first of two core meta-syntheses sought to understand the qualitative distinctions of what makes rehabilitative physical activity a safe, self-efficacious, and feasible option for those living with and beyond cancer (Midtgaard et al., 2015). Claiming to be the first to offer a meta-synthesis on the subject, Midtgaard et al., (2015) included eight studies which all focus on the experiential meaningfulness attached to this form of intense physical rehabilitation. The eight studies were explicitly focussed on controlled and prescribed exercise and physical activity interventions, led by qualified instructors, with Midtgaard et al. (2015) unequivocally stating that any studies with a focus on unsupervised and non-vigorous activities were automatically excluded from the synthesis. Midtgaard et al. (2015) offered three themes that represented the experience of clinically informed interventions for the participants involved. They are as follows:

- **Theme one:** *Emergence of continuity*  
**Sub-themes:** *New purpose, goal setting, and positive distraction.*
- **Theme two:** *Preservation of health*  
**Sub-themes:** *Social support, autonomy, and an affirmation of their health.*
- **Theme three:** *Reclaiming the body*  
**Sub-themes:** *Enhanced performance, Safety through professional supervision, and overcoming barriers.*

The three overarching themes that were interpreted by Midtgaard et al. (2015) contributed toward the meaningfulness of the traditional rehabilitative services within the studies that were appraised. Theoretically, the three overarching themes

in their findings tentatively supports the theory of Post Traumatic Growth for those living with and beyond the cancer experience, such as the effect of increased social support on one's sense of rehabilitation. Overall, the findings proposed by Midtgaard et al. (2015) suggest that the intervention can aid in helping an individual to accept an adjusted sense of reality that supports the reclamation of one's body and develop a new purpose that may have been lost during treatment. However, in the critical discussion of the synthesis, patient adherence to the prescribed guidelines after the intervention in each study was modest at best. This raises questions regarding whether such clinical interventions represent a realistic and authentic opportunity to rehabilitate an individual's physical and psychological health in the long-term (Midtgaard et al., 2015).

Despite the concerns over adherence to intervention guidelines, similar advantages have been identified by the UK cancer charity, Macmillan Cancer Support. The recovery package (2013) endorses the biological (i.e. preserving cardiovascular health) and psychological (i.e. goal setting) benefits that can be ascertained from participating in clinically structured physical activity interventions. For example, the Brighton and Hove Albion football club's *Albion in the Community* clinical intervention was cited by Macmillan and the NHS, with both approving of the rehabilitative advantages and service design that has been implemented by the NHS across the region of Sussex.

Macmillan's guidelines were further developed by academic researchers in 2017. The report, *Physical activity and cancer* extend the knowledge base by offering supporting evidence from various studies suggesting that clinically informed physical activity interventions can be useful for various stages of the cancer trajectory. For example, the report (2017, p5) acknowledges how physical activity has "potential benefits across the pre-treatment, treatment, post-treatment survivorship and palliative care phases" of care. As a consequence, the claims made by Midtgaard et al. (2015) and Macmillan (2017) indicate that the various biological and physiological benefits associated with these interventions can have meaningful implications across the entire cancer experience, let alone the rehabilitation and survivorship stages.

These claims were likewise supported in the literature review conducted by Ferioli et al. (2018). The review consisted of 249 journal articles, with Ferioli et al. (2018) proposing that there are physiological benefits of using clinically prescribed exercise and physical activity guidelines during and after antineoplastic cancer treatments. For example, statistical significance was indicated for the alleviation of symptoms relating to losses of bone density, reduction muscle and fat mass, cachexia, peripheral neuropathy, and severe cases of lymphedema through prescribed interventions that focussed on specific components of fitness (i.e aerobic, resistance, strength, impact training, and balance exercises).

However, Macmillan's (2017) report states that the findings were gathered from randomised controlled trials of clinically structured interventions. One may consider that the subjective meaning experienced by those living with and beyond cancer may be somewhat limited by the clinical restrictions in the design of the intervention that was being implemented (i.e. time limitations, supervised content, controlled environment and facilities). Likewise, the implications of using quantitative methods (i.e. randomised controlled trials) to measure the effectiveness of clinically designed interventions may inadvertently suppress a deeper understanding of the subjective rehabilitative experience. As a consequence, it is necessary to question this approach, one which is supposed to help people recover or move on from a chronic illness (Midtgaard et al., 2015).

In response to such concerns, recommendations for the contrary have been forthcoming. This has involved researching the meaning and experiential implications of unsupervised and less time-structured programmes used for cancer rehabilitation and survivorship (Midtgaard et al., 2015). Moreover, Midtgaard et al. (2015, p.616) state that "...more research is needed to demonstrate whether programs that are unsupervised by health professionals and less structured possess the same psychological qualities as the interventions examined for the purpose of this review".

The second of the two core syntheses that formed this theme was a meta-synthesis conducted by Burke et al. (2017). This review focussed on an analysis of forty qualitative studies that had employed both clinically structured interventions and unstructured recreational programmes in the natural environment as a means of

improving the quality of life of those living with cancer. Sharing similar concerns considered by Midtgaard et al. (2015), Burke et al. (2017) expressed a critical stance on the use of clinically structured interventions and the quantitative methods that were intended to capture the multi-dimensional nature of quality of life for those living with cancer.

From the 40 qualitative studies that were reviewed, Burke et al. (2017) expressed that physical, psychological, social and spiritual implications were all associated with the use of structured interventions and unstructured recreational programmes to enhance cancer survivors' quality of life. Moreover, the resultant themes formed to present a beneficial experience for those who were involved in the studies. For example, engagement through a physical commitment to a programme or intervention brought social opportunities, adapting or improving a psychological state that had been formed through a distressing diagnosis and treatment of cancer (Burke et al., 2017). Such findings, again, tentatively support the theoretical and clinical shifts that can occur between PTSD and PTG. What's more, the spiritual dimension of the Burke et al. (2017) analysis offers an overview of the existential engagement that occurred for the participants. The structured interventions and unstructured programmes used in the studies became a vehicle to experience normalcy, purpose, and meaning in the participants' lives, relating to the findings proposed by Midtgaard et al. (2015).

The study by Burke, Brunet, Wurz, Butler and Utley (2017) further enhances the experiential understanding described in the aforementioned synthesis. Seeking to understand if recreational cycling could or should be considered for children affected by cancer Burke et al. (2017) collaborated with cyclists fighting cancer, a registered charity committed to providing bikes for young children who are or have lived with cancer. After interviewing four boys who had participated in recreational cycling for three months, Burke et al. (2017) found that the programme enabled the participants to engage with physical and psychological opportunities, such as developing interpersonal relationships, as opposed to when they were being treated for cancer, which prevented personal and social development.

Returning to the forty studies that were included in the meta-synthesis by Burke et al. (2017), twelve were identified as being phenomenologically grounded in their

methodological designs. Within ten of the twelve phenomenological studies identified, there was a considerable emphasis on the use of Interpretive Phenomenological Analysis (IPA) and hermeneutical phenomenology (Burke et al., 2017). However, there was a general lack of critical discussion regarding the authors' choice and understanding of the philosophical considerations and scientific procedures involved in using these methodologies (Burke et al., 2017). Whilst there are word limitations when publishing within academic journals, there seemed to be little acknowledgement for why these choices were implemented. Only two of the studies were identified as having a strong philosophical understanding of the use of Heideggerian and Husserlian phenomenology. For example, both offered a critical analysis of the phenomenological concepts being used and other analytical procedures being presented to reinforce their methodological choices (Burke et al., 2017).

The remaining phenomenologically grounded research studies demonstrated an effective qualitative design and methodological procedure (i.e. thematic analysis) but did not address how and why their analytical procedures were phenomenologically informed (Burke et al., 2017). For example, the findings that were found in the ten IPA and hermeneutical phenomenological studies often relied on a thematic presentation of individual participants and did not engage in a descriptive or interpretative analysis of the essence of the findings.

In agreement with Giorgi (2009) and Zahavi (2019), this could also reflect a misunderstanding of phenomenology. Given its popularity in the social and health sciences, as well as many other developing disciplines, the mainstream application of phenomenology has indeed increased, as I have demonstrated in the meta-synthesis that was conducted by Burke et al. (2017). However, to use this approach has serious implications for philosophical claims and research practice. Phenomenology cannot be used in an unmethodical way of simply understanding "lived experience", which would quite simply require a thematic qualitative analysis (Zahavi, 2019).

Such concerns may have been reflected in some of the reported findings. For example, there was a lack of capacity to communicate theoretical and disciplinary perspectives and other philosophical groundings (Bradbury-Jones, Taylor, and

Herber, 2014). Twenty-five of the forty studies under review by Burke et al. (2017) did not state a disciplinary boundary or conceptual framework (i.e. psychological well-being), whilst thirty-three of the forty did not identify and justify a philosophical grounding (i.e. subjectivism or post-positivism). I would again propose that while some studies have offered a foundation upon which phenomenological knowledge can be generated, others have failed to do so, offering no more than a thematic qualitative analysis which has no disciplinary or philosophical claims within the context of cancer rehabilitation and survivorship. In accordance with Bradbury-Jones et al. (2014), there is a concern for how some of the qualitative studies have not visibly communicated their theoretical and philosophical positions, ultimately undermining the overall quality of the findings being presented.

Furthermore, though the studies included in the Burke et al. (2017) review corroborated the physiological and biological outcomes found in other reviews of cancer rehabilitation (Fong et al., 2012; Stacey et al., 2015; Ferioli et al., 2018), the majority of the studies in the two meta-synthesis reviews involved females who have lived with breast cancer as the primary participants. Midtgaard et al. (2015) stated that there was 68% of female participation, whilst Burke et al. (2017) identified 81% of middle-aged female participants. Research studies committed to understanding how men, senior citizens, and children experience clinically structured interventions and unstructured recreational programmes has been underwhelming in comparison to those who have lived with breast cancer. As a consequence, this does generate more interest in how men, senior citizens, and children would respond to the meaningfulness of rehabilitative and survivorship services in both structured and unstructured environments (Burke et al., 2017).

By the same token, clinically structured interventions appeared in seven of the eight studies within the Midtgaard et al. (2015) review, whereas the meta-synthesis by Burke et al. (2017) included both clinically structured interventions and unstructured recreational programmes in the natural environment to facilitate rehabilitation and survivorship. This included clinically designed rehabilitation interventions which focussed on dosage and frequency of gymnasium-based exercises (i.e. strength or cardiovascular training) and unstructured programmes and therapies (i.e. high-altitude trekking, dragon boating, Nordic walking; yoga interventions) that did not position structured physiological rehabilitation as the primary focus.



Overemphasis on clinical interventions can be problematic and challenging for those who are still living with the psychological effects of cancer (Midtgaard et al., 2015; Burke et al., 2017). Formal interventions can provide an appropriate clinical framework to restore physiological capacities throughout the survivorship phase (Burke et al., 2017). Simultaneously, however, this has been reported as creating a psychosocial dependency or dissatisfaction for those who attend short-to-medium based interventions (i.e 6-12 weeks of aerobic exercise classes), reinforcing previous discussions of how rehabilitative approaches in this context should be delivered for those living with cancer (Martiniuk et al., 2014; Macmillan, 2017; Brown et al., 2019).

Consequently, there is now an increased interest in the experiential implications of unstructured recreational programmes in a natural environment for those who are living with and beyond cancer (Burke et al., 2017). Burke et al. (2017, p22) explicitly state recommendations for future research to build upon the knowledge base that has been established within their review and the Midtgaard et al (2015) review. These are as follows:

- “Accordingly, further research is needed to explore if different types of leisure-time activities have a different meaning and utility for cancer survivors and how this might impact their experience.
- Another notable area for future research includes examining cancer survivors’ views on the setting in which the activity is delivered.
- Researchers need to closely examine other groups of survivors other than women (i.e men, adolescents, children, and the elderly) to gain an understanding of their experience along the cancer trajectory.
- Researchers may want to consider using more diverse qualitative methodologies to better understand the underlying processes of survivors’ experiences.”

To summarise and conclude, there is a wide range of rehabilitative possibilities that have been established for the enhancement of survivorship for those living with and beyond cancer. Quantitative research findings have recorded beneficial and statistically significant outcomes for using clinically structured interventions for the restoration and enhancement of physical and psychological capacities (Macmillan, 2013; 2017; Ferioli et al., 2018). These outcomes have also been corroborated by

qualitative studies that have established a growing knowledge base on the meaningfulness of unstructured recreational programmes in the natural environment for those living with and beyond cancer (Burke et al., 2017). Momentarily, however, unstructured recreational programmes will be defined as those that are “less supervised and inclusive of non-vigorous activities” (Burke et al., 2017). Yet, this definition will be further explored throughout the thesis so as to clarify what it is we mean by this and how this body of work may inform this understanding.

However, the use of interpretative phenomenological analysis and hermeneutical phenomenology in some studies, which have lacked consideration for both the theoretical and philosophical implications within their respective designs, have raised a cause for concern (Burke et al., 2017). Such concerns have also been expressed for (i) the overuse of women living with or having survived, breast cancer as the dominating demographic for many of the studies (Burke et al., 2017; Midtgaard et al., 2015), and (ii) the dominance of structured interventions in clinical settings that can reduce opportunities to holistically rehabilitate and subsequently enhance an individual’s sense of survivorship.

The following theme, *environmental approaches for restoring health*, will attempt to establish and build upon the existing evidence regarding if and how the natural environment can offer a meaningful experience for those living with a chronic health condition such as cancer. Scrutiny of the methods that researchers used to collect and analyse data will again feature heavily throughout. Whilst it is important to acknowledge the increased exposure that this area of research has received, how the findings of each respective study are analysed and subsequently interpreted can be a complex challenge.

## **2.5 Theme Two – Environmental approaches for the restoration of health**

The following theme has dramatically expanded its academic focus by offering a literature review of how the natural environment can facilitate a sense of restoration of health. Whilst this may seem to deviate from the focus of living with and beyond cancer, it was necessary to broaden this view to demonstrate the momentum of this

approach in recent years. The theme will subsequently address the foundational theories that support this movement before reviewing some of the most relevant studies that have been conducted in this area. Considerably more research studies on the various approaches used in the natural environment could have been included if the scope of the narrative literature had been much more comprehensive. However, the option to select and review the studies which offered a broad range of approaches was a conscious choice that was not exercised out of ignorance for other approaches that have not been cited (i.e. walking or gardening based studies). Rather, the studies that have been included aim to communicate how the natural environment is being used for a variety of mental and physical health issues.

The topic of human beings, their health and the natural environment has become a focal point of research due to several interrelated issues. One of the primary concerns has been the development of urbanisation in the UK as a result of the industrial revolutions throughout the 18<sup>th</sup> and 19<sup>th</sup> centuries (Van Den Berg, Joye, & De Vries, 2013). This has contributed toward the development of cities, with concerns arising from overpopulation density and environmental pollutants that have followed (Steg, Van Den Berg & De Groot, 2013; Kahn & Hasbach, 2012). More recently, increasing concerns regarding climate change and its detrimental effect on the earth's natural landscapes and its inhabitants has forced environmentalists and the general public to reflect on individual responsibility, larger social norms, and institutional policy and legislature (Steg et al., 2013). As a consequence, the discipline of environmentalism has been gradually developing as an inter-disciplinary topic, broadly encompassing the interplay between human beings, their health, and their natural surroundings since the 1960s (Steg et al., 2013; Seaman, 2018).

Furthermore, the use of the natural environment as a site for the maintenance and enhancement of sustainability, human well-being, and one's general health has been drawn upon within many academic disciplines. Geographical and environmental psychology, health psychology, eco-psychology, health promotion models (i.e Ottawa Charter), and health and social policy have all contributed toward this subject matter (Foley & Kistemann, 2015). Also, dominant psychological theories of restorative environments for an individual's health, QoL, and well-being have traditionally been divided into two theoretical explanations.

Associated with being a quick affect-driven, psychological process, *Stress Recovery Theory* (SRT) is defined as being:

“...concerned with restoration from the stress which occurs when an individual is confronted with a situation that is perceived as demanding or threatening to well-being” (Joye & Van Den Berg, 2013, p. 58).

*Attention Restoration Theory* (ART), on the other hand, has been described as a slower, cognitive process (Joye & Van Den Berg, 2013). ART was developed in detail by Kaplan and Kaplan (1989) and is defined as a theory that:

“...focusses on the restoration from attentional fatigue that occurs after prolonged engagement in tasks that are mentally fatiguing” (Joye & Van Den Berg, 2013, p.59)

The aforementioned theoretical explanations do offer a broad overview of how an individual can benefit from being immersed in a natural environment after being exposed to psychological and physiological stress. However, both SRT and ART may be too theoretically broad in the same way that can occur for the psychological theories of PTG and PTSD. This can occur when the theory is possibly too far removed from the experiential nuance that is embedded within such psychological experiences. Adding experiential detail to such theoretical explanations can therefore expand the understanding of how or if the natural environment can be an essential means for which humans can enhance their health, QoL, and well-being.

### **2.5.1 Nature-based solutions in healthcare**

To reiterate, natural environments have been recognised as sites that can enhance an individual’s sense of health, as well as increase awareness for the protection of the environment, with dominant theories emerging as a result (Seaman, 2018; Steg et al., 2013; Kahn & Hasbach, 2012).

However, nature, in the context of therapeutic places and the human connectedness that may emerge from an individual’s experience, has been and continues to be accepted, and sometimes romanticised, without critical engagement (Foley & Kistemann, 2015; Denton & Aranda, 2019). For example, Denton and Aranda (2019)

assume a sociological position for the argument that certain stigmatised bodies are not welcome in some specific spaces which are monopolised by the right bodies and the social norms that follow, reiterating concerns about cancer rehabilitation and survivorship being delivered in healthcare and leisure settings (Moreton et al., 2018).

Joye and De Block (2011) dissect the assumptive position to simply accept the natural world that we as humans are embedded in. Upon considering the deeply rooted evolutionary theory of Biophilia, which is defined as “the proposition that humans have evolved a biological affinity for natural environments” (Bell, Greene, Fisher and Baum, 2001, p.504), we must be careful not to simply assume that humans and nature have a default sense of connection, whereby every encounter with the natural environment will be beneficial. The embellishment of the connection that exists between humans and nature can subsequently create misleading expectations and raise beliefs that health and well-being can be automatically guaranteed if one is immersed in the natural world (Joye & De Block, 2011; Denton & Aranda, 2019).

Whilst romanticist critiques are a necessary balance, ‘Nature-Based Solutions’ have taken a significant place in political and healthcare responses to social and economic challenges that have severe implications for human health. Nature-based solutions is an umbrella concept which refers to the sustainable usage and management of the natural world, such as water safety, biodiversity research, and responses to climate change. The development and implementation of green (i.e. national parks) and blue (i.e. lakes, rivers, sea, and ocean) models of care, which have become embedded within nature-based solutions for human health, have emerged in recent decades (i.e. NEAR health project; Blue Health; Green Care Coalition in Nordic countries).

Both green and blue models of care use nature in a goal-directed manner to maintain and enhance people’s health and sense of well-being (Nature-Based Solutions, 2018). The three essential components of both green and blue care are community, action and of course, nature. Environmental psychologists have long associated green and blue spaces as therapeutic places that can alleviate the signs and symptoms of physiological and psychological stress, relating to the

development of the theories of SRT and ART (Nature-Based Solutions, 2018). Both green and blue models of care were also developed as a response to overburdened and underfunded public health care services, enabling health professionals, patients, and other interested parties to seek support from multiple organisations outside of the traditional model of healthcare (Nature-Based Solutions, 2018). Therefore, both models are appealing in that they can facilitate both institutional and individual needs.

To date, both green and blue approaches to care have been organised by primary care, local government, and the civil society throughout developed countries (Berget, Lidfors, Palsdottir, Soini & Homberg, 2012). Initiatives and interventions from a green perspective include, but are not limited to, health walks, gardening and horticulture, animal-based initiatives and outdoor recreation and education, while blue care can range from water-based environmental protection, community-inspired littering clean-ups, wild swimming, dragon boating, and sailing based activities (Berget et al., 2012; Britton, Kindermann, Domegan and Carlin, 2018; Allen-Collinson & Leledaki, 2015; Denton & Aranda, 2019; Foley and Kistemann, 2018).

Furthermore, the development of green care in Nordic countries is an example of how this model has been successfully implemented for those with chronic health conditions (Berget et al., 2012). More specifically, the expansion of the green care approach in Norway, Sweden, and Finland has increased the diversity of clinically structured interventions and unstructured recreational programmes that have and are being implemented. Similar to the rehabilitative approaches discussed in theme one of this review, structured interventions in the contexts of the studies have a specific clinical purpose, such as treating mental health concerns, whilst unstructured programmes offer recreational opportunities to increase informal social encounters whilst engaging in the natural environment (Berget et al., 2012). Blue and green models of care, which have shown to be quantitatively effective and qualitatively meaningful (Berget et al., 2012), have subsequently become embedded within the political and healthcare systems in each respective country (i.e. social prescribing), requiring regulatory processes to maintain quality of care for those using such services (Berget et al., 2012).

To deepen an understanding of the blue care model that is used in the UK, Britton et al. (2018) conducted a systematic review to determine if this was a feasible strategy for those diagnosed or suffering from a non-communicable disease, especially for individuals who were experiencing diminished psychological health (i.e. anxiety and depression). Focussing on examining "... the use of blue space in therapeutic interventions for the promotion of health and well-being" (p.2), the review established an evidence base of thirty-three studies ranging from 2004 to 2017, of which seven studies were focussed on breast cancer survivors. The number of participants totalled 2031, with considerable variations across gender and age demographics due to the multiple methodologies that were used throughout (Britton et al., 2015).

Also, there were differences amongst the studies as to how accessible blue space interventions are (BSI's). Patients either self-referred or were referred by a medical professional to civil society organisations (CSO), echoing recent developments in the NHS' strategy for the potential use of CSOs in the recovery package's follow-up pathways for those living with cancer. It is, therefore, important to acknowledge the role that the civil society assumes in the context of chronic health conditions before further elaborating on the findings within the Britton et al. (2015) review.

### **2.5.2 The role of the civil society**

Referred to as more than just the third sector but as the common good that connects various sectors of society, CSOs have been internationally defined as "organised and organic social and cultural relations existing in the space between the state, business and family, which builds on indigenous and external knowledge, values, traditions and principles to further collaboration and the achievement of specific goals by and among other stakeholders" (VanDyck, 2017, p. 1). CSO's within the community has also been associated as being well positioned in wider society to support the holistic needs of those living with long-term chronic conditions, especially those living with cancer. Providing emotional, social, and psychological support through evidence-based frameworks, they can help those who need it to "live well" (Independent Cancer Taskforce, 2015, p.16).

While the statutory healthcare system in the UK is important for the nation’s health, clinical-care, and overall welfare, it has been proposed that it is crucially important to seek support from other institutions to balance the service demand and capacity, which was apparent throughout the introductory chapter of this thesis (Bull, Joy, Bagwell, and Sheil, 2014; Macmillan, 2017). Moreover, CSOs have also been highlighted as having the adequate tools and positional influence of gauging public’s attention towards acute and chronic health conditions. Advice and information the primary, secondary and tertiary care cannot distribute to patients because of various challenges, CSOs are potentially able to relieve professionals and the entire system of the pressure of patient navigation due to their intermediary position (Bull et al., 2014). For example, Macmillan supports those affected by cancer either by financial grants or professional therapeutic assistance.

Furthermore, Bull et al. (2014) state that the role of CSOs in cancer care has opened an opportunity for statutory services to be carefully positioned onto registered charities, with little impact on the quality of care and finances. Chapter seven of the Bull et al. (2014) report, *Making scarce state resources go further*, reinforces potential collaborations and partnerships between statutory services and the civil society (Bull et al., 2014). As well as offering another layer of support, charitable services are in a unique and innovative position to enable greater financial security for further research and knowledge generation (Bull et al., 2014). However, the involvement of the third sector and CSOs in healthcare also brings challenges as well as benefits, which has been depicted in table 2.0 below.

<b>Strengths</b>	<b>Barriers</b>
Occupies a unique position between the system and the beneficiary.	The health system is becoming increasingly complex.
Ensures greater understanding of need.	The role of specialist providers is unclear in the new commissioning environment.
Provides joined-up, holistic support.	Spending cuts make it difficult to know how to influence commissioners and shift money to prevention.



Influences the design and delivery of services.	Charities struggle to make the case for their impact on health and lack data to do so.
Creates significant opportunities to save money.	Clinicians still need convincing that charities offer complementary expertise.
	A blueprint for the redesign of the health system does not exist.

**Table 2.0** – The key strengths and barriers of the third sectors involvements in healthcare in the UK (Bull et al., 2014).

To support the claims by Bull et al. (2014), the registered charity Cancer Research UK (2018) cited its position as a crucial mediator and facilitator between the general public and large public or private institutions. Take, for example, the promotion of the civil society (i.e. Macmillan) that is now being commissioned by the NHS through the recovery packages and stratified follow-up pathways for those living with and beyond cancer. In this context, the civil society mediates and creates an opportunity for those living with and beyond cancer to seek further support and guidance. Yet, this exists on a small scale, with rehabilitation and survivorships services primarily being led by NHS trusts that are under significant strain and pressure (Macmillan, 2017).

### **2.5.3 Overview of evidence of nature-based solutions for chronic health conditions.**

Returning to the review by Britton et al. (2018), it was determined that three aims were at the forefront of the evaluation. This included assessing and evaluating how a blue space intervention had implications for: (i) whether the intervention had alleviated signs or symptoms of a health condition, (ii) explore how it had impacted upon people’s health and well-being, and (iii) the overall lived experience of an individual’s participation. It was also understood that the review would seek to evaluate the academic methods were used to measure the health-based outcomes in the studies that were reviewed.

Britton et al. (2018) identified the study by Caddick, Smith and Phoenix (2015) as a sufficient example of a study that evaluated a cross-collaboration between members of armed forces and health services and the civil society. Caddick et al. (2015) aimed to subjectively evaluate if surfing, or “the blue gym”, alleviated the experiences of PTSD. The charity involved, *Surf Action*, was established to serve “the needs of military veterans (including TAs and reservists) and their families, especially those affected by PTSD and physical injuries or those struggling to re-adjust to civilian life” (Surf Action, online, 2019).

After recruiting fifteen male participants, semi-structured interviews, participant observation, and dialogical narrative analysis were undertaken to understand how, or if, surfing had a significant impact on the experiential nuances associated with PTSD. Based on the accounts of the participants, Caddick et al. (2015, p.82) identified that surfing prevented a “decline into a state of embodied chaos whereby the hopelessness of chronic suffering becomes unbearable.” The surfing initiative also enabled “positive emotions by going surfing and connecting with the ocean environment” for those who participated. The authors also positioned this form of therapeutic blue care to be as important as the therapeutically informed models used in traditional healthcare settings (i.e. psychological talking therapy interventions) for reasons relating to having access to an informal setting that supported different senses of trauma (Caddick et al., 2015).

However, in contrast to the Caddick et al. (2015) study, seventeen studies within the Britton et al. (2018) review did not identify their purposes for conducting their research. However, the remaining studies aimed to quantitatively measure or qualitatively thematise a psycho-social outcome, such as increased confidence or self-efficacy (Britton et al., 2018). Moreover, the findings from the review identified clinically beneficial responses for both the participants’ psychological and physical health. However, as indicated by Britton et al. (2018), the review did underline an important issue regarding a lack of depth and consideration for the qualities and subjective meanings attached to the natural environment in this specific systematic review (Britton et al., 2018). Van Den Berg (2013) proposes that the concept of ‘connectedness to nature’ has and can continue to deepen the understanding of restorative environments for chronic health conditions. The two reviews undertaken by Britton et al. (2018) and Burke et al. (2017) have both concluded that a greater

diversity of qualitative methodologies are required to draw out and understand the qualitative and subjective qualities that are attached to programmes in the natural environment.

Research that can substantiate and deepen understanding about the meaningful significance of connectedness to nature, as well as other meaningful implications of nature for those with health conditions, and those living with and beyond cancer is now a necessity (Britton et al., 2018; Burke et al., 2017). This need to study the subjective and experiential immersion of nature has indeed been slowly progressing, with recent studies using alternative methods through long-established methodologies to capture experiential depth that has been called for (Joye & Van Den Berg, 2013; Seaman, 2018; Blaschke, 2017; Allen-Collinson & Leledaki, 2015; Denton & Aranda, 2019; Throsby, 2013).

Through a unique qualitative method of “swim-along interviews”, Denton & Aranda (2019, p.5) interviewed six regular, healthy sea-swimmers to capture an embodied phenomenology of sea swimming. Like Britton et al. (2018) and Foley and Kistemann (2015), Denton and Aranda (2019) identify and acknowledge the interest that has been developing in blue spaces and the associated impact it has on health and well-being. Citing various studies that have reviewed the qualitative distinctions of why people position themselves alongside water (i.e. tourism-based coastal walks), Denton and Aranda (2019) sought to extend this body of literature with a focus on the phenomenological immersion of swimming. Denton and Aranda (2019) presented three, overlapping dimensions that emphasised the experiential interpretations that occurred when engaging in sea-swimming. These are as follows:

- Transformative
- Connecting
- Re-orientating

Each dimension was theoretically examined through Todres and Galvin’s (2010) theory of dwelling-mobility, which will be discussed as part of the third theme of this literature review. The dimensions and subsequent analyses presented by Denton and Aranda (2019) essentially offers a pragmatic and ontological analysis of the experiential immersion of sea-swimming. Using phenomenological philosopher

Merleau-Ponty to elaborate on their findings, physical and psychological embodied transformations due to the sea environment were highlighted as being essential for the participants (Denton & Aranda, 2019). This, too, was extended by discussions of how participants used the natural environment of the sea to disconnect from the natural happenings in their personal and work lives, whereby they can connect and transform in an environment that offers a contemplative space and interpersonal connection with others (Denton & Aranda, 2019).

However, within their discussion of the immersive experience of the sea, Denton and Aranda (2019) do acknowledge the risks that are involved with using the natural world as a vehicle to enhance a person's health and well-being. Such discussions underlined the unpredictable nature of the natural world, as well as emphasising the sociological realism of the ideal bodies that may dominate these contexts. Yet, this is not necessarily interpreted as a reason to reject the natural environment as a way of enhancing general health. It is, however, an understanding that the natural world could challenge the physical and psychological boundaries of the participants (Herman, 1992). Psychiatrist, researcher, and teacher, Judith Lewis Herman, identified the importance of disciplined and controlled exposure to physical challenges in the natural environment. Herman (1992) discusses this exposure is a way of channelling an individual's natural response to physiological and psychological fear, both of which can be diminished during a traumatic period. For example, Herman (1992) cites physical and recreational programmes as an opportunity to enhance one's energy and renew a natural sense of coping after experiences of rape or war-related PTSD.

Denton and Aranda's (2019) research does, therefore, share similarities with that of the nuanced implications (i.e. transforming an individual's sense of self) identified by Britton et al. (2018) and Caddick et al. (2015), whilst also adding further experiential and philosophical depth to the area of interest. However, the inclusion of "healthy" participants only offers one perspective. As this thesis is exploring the manifestation of the lived experience of those who have experienced a chronic health condition, it is necessary to further expand upon this specific area of experiential and philosophical depth.

Using a mixed methodological approach, Allen-Collinson and Leledaki (2015) phenomenologically conceptualised the qualitative outcomes from a two-year physical activity promotional programme based in Wales, named *Mentro-Allan* (Venture Out). The programme was designed to appeal to specific groups of the population (i.e. mental health patients) by utilising natural leisure activities (i.e. long-distance walking) in the outdoor environment (Allen-Collinson & Leledaki, 2015). Overall, the insights gained from the study related heavily to both visual and haptic connections to the surrounding environment. Moreover, the sensuous connection made by the participants concerning the environment was described as “intense embodiment”, with participants drawing upon the sight of nature and its stark contrast to man-made objects found in urban environments (Allen-Collinson & Leledaki, 2015). Other experiential haptic moments of “being-in-the-world” appeared to participants when being exposed to adverse but satisfying weather conditions, which is something that does not occur for clinically structured interventions (Allen-Collinson & Leledaki, 2015, p.10; Denton & Aranda, 2019; Midtgaard et al., 2015).

A phenomenological analysis was drawn upon by Allen-Collinson and Leledaki (2015) by reflecting on the concepts of embodiment by Merleau-Ponty’s and Leder’s (1990) dys-appearing body, which shared similarities with Denton and Aranda’s (2019) philosophical analyses of embodiment. Importantly, Allen-Collinson and Leledaki’s (2015) research enhances and characterises the connectedness an individual may experience within a natural environment or a specific location, adding phenomenological and existential depth to the aforementioned theories (i.e. SRT; ART; psychological measures of confidence; PTG; PTSD) that have been identified for those who live with chronic health conditions (Seaman, 2018). Henceforth, it is important to include a broad range of research methodologies and methods that are used to study the interplay between human health and the natural environment (Foley & Kistemann, 2015).

The use of and exposure to nature has similarly been applied to the context of those living with and beyond cancer (Blaschke, 2017). A systematic review and meta-synthesis of qualitative evidence by Blaschke (2017) explored and identified the various roles nature had in the lives of cancer patients. Also, Blaschke’s (2017)

review sought to determine whether encounters with nature had an impact upon the post-treatment process, as only one narrative review to date had directly attempted to capture this phenomenon (Ray & Jakubec, 2014). Whilst Blaschke (2017) did not discuss the philosophical groundings of the studies within their review, the synthesis offered a three-tiered engagement spectrum of experiential connection to nature for those living with and beyond cancer (Blaschke, 2017). This included “indirect engagement, e.g. views to nature and art depicting nature; incidental engagement, e.g. walking and resting outdoors; and intentional engagement, e.g. outdoor therapy” (Blaschke, 2017, p.2).

Within the synthesis, Blaschke (2017) did, however, identify potential methodological limitations (i.e audit trails and transparency) within each of the selected studies reviewed. Though this does raise questions over methodological processes that may have been overlooked by the original authors, it may be that such decisions could have been made purposefully, reiterating previous concerns in theme one regarding academic compromises (i.e word count limitations in academic journals).

The synthesis of eleven qualitative documents (ten articles and one doctoral thesis) revealed that out of two-hundred and forty participants, who varied in age and gender, twenty-two descriptive constituents were identified. These constituents were then used to develop seven subjective dimensions that identified how and why the participants connected with the natural world. Staying as close as descriptively possible to the original findings, the insights offered by Blaschke (2017) included:

- Connecting with what is valued.
- Being elsewhere – seeing and feeling differently.
- Exploration – inner and outer excursions.
- Home and safe.
- Symbolism – understanding and communicating differently.
- Benefitting from old and new physical activities.
- Enriching aesthetic experiences.

Compared to the Britton et al. (2018) review, which was based on interventionist approaches, Blaschke’s (2017) meta-synthesis offers a deeper analysis of the

experiential meaning that was ascertained through an unstructured approach of engaging in nature for the participants' health and sense of well-being. Moreover, the overlapping meanings that were established had connotations with that which was offered by Allen-Collinson and Leledaki (2015), whereby those living with cancer process the role of nature in their lives on an existential and spiritual plane (Blaschke, 2017).

The claims made by each study in Blaschke's (2017) review proposed that reality, which was grounded in post-cancer psychological adjustments, for each participant was navigated through fluid experiences of being in nature. In this sense, nature became a space in which the participants could find perspective about past, present, and future experiences of self (Blaschke, 2017). Indeed, the findings also addressed the important questions of 'does it work?' and 'should it be used?' that guided the review. Drawing on attachment theory to elaborate on the findings, Blaschke (2017) proposed that being in nature, whether that was indirect or direct engagement, assisted the participants to adapt to a "new normal" and manage what Cobb (2015) described as the "existential limbo" by being in the "here and now", thereby suggesting that exposure to nature is a sufficient way of helping those living with and beyond cancer.

It could be assumed that the methods and methodologies, which were heavily grounded in philosophical heritages (i.e. phenomenology and ethnography), facilitated a richer philosophical analysis of the psychological significance of nature, as opposed to a causal or interventionist based discussion of the participants' health (Britton et al., 2018). Furthermore, the interventionist approach by definition and content (i.e. the clinically structured approach) may be too prescriptive for the rehabilitation and survivorship of those living with and beyond cancer. This relates to clinical targets being measured in a manner whereby a participant is directed and possibly expected to experience a pre-determined outcome (i.e. increased time spent being physically active) from the respective service.

In social and health promotion theory, the interventionist strategy is often referred to as responsabilisation of health, whereby the individual must be the sole bearer of improving their health and well-being (Brown et al., 2019). Criticisms of this approach, and how they are evaluated, have been offered, suggesting that it is

morally ignorant and illegitimate to place full responsibility on the individual if that person does not have complete autonomy in the environment in which they live and operate (Brown et al., 2019).

Whilst the level of responsabilisation varies across many different clinical interventions (i.e. exercise referral, alcohol cessation, weight management), the stratified follow-up pathways that are embedded into the NHS' recovery package show signs of a 'responsibilised' approach. Chapter eight of the *how to guide: innovation to implementation of the follow-up pathways for those living with and beyond cancer* place an emphasis on the patient to become responsible "for optimising future health and well-being" (p. 79) during post-treatment. The guide cites the 2011 publication by the health foundation titled, *Helping people help themselves*, in which information provision and technical skills inform a behavioural change approach as its guiding template for those living with and beyond cancer.

In relation to theme one, an individual may then attend and follow a structured physical activity intervention, which is designed and delivered in a clinical setting. The physical activity intervention then aims to enhance and measure (i.e. less fatigue or increased confidence) the physiological and psychological responses that may be gained throughout their time on the service. However, with the knowledge and understanding of environmental approaches for the enhancement of health in this context, it is important to question whether interventionist or responsabilised-based strategies and the subsequent approaches taken to measure an individual's health should be designed in such a way for those who require a holistic approach for their cancer rehabilitation and survivorship. Blaschke's (2017) findings emphasise and highlight the diversity in methods that can be used to understand the implications of indirect and less structured exposure to the rehabilitative and survivorship experiences of the natural environment.

The literature identified in this review has thus far offered considerable evidence regarding the usefulness of restorative settings and environments for people's health, QoL, well-being (Foley & Kistemann, 2015; Britton et al., 2018; Denton & Aranda, 2019; Allen-Collinson & Leledaki, 2015; Blaschke, 2017). Whilst Britton et al. (2018) discussed several indicators of psychological benefits that were identified in their systematic review (i.e. increased self-esteem, psychological resilience,



social confidence), the research of Foley and Kistemann (2015) establishes the existential and subjective meanings that can be derived from natural environments that are not as easy to definitively measure. Both the personal symbolism and group-based implications that can be derived from the natural environment is now being acknowledged as being as important as clinically structured interventions for post-treatment programmes for those living with and beyond cancer (Blaschke, 2017).

## **2.6 Summary**

To summarise, there is a broad scope of approaches which include the natural environment to support those with chronic health conditions (i.e. green and blue care) (Foley & Kistemann, 2015; Britton et al., 2018; Denton & Aranda, 2019; Allen-Collinson & Leledaki, 2015; Blaschke, 2017). This analysis has also incorporated a critical engagement with the methods that are used to collect and make sense of the experiences and insights of those who use and meaningfully engage with such services (Foley & Kistemann, 2015). As a result, I can conclude that a diversity of methods do now faithfully represent what can be experienced in this context.

What is apparent, though, is that the methods employed in the current provisions for those living with and beyond cancer to evaluate one's health and QoL are overly concerned with quantifiable measurement. For example, the methods to understand the rehabilitative and survivorship phase is currently being done by way of PROM based questionnaires. Although this approach does have an important role within a public health evaluation, a closer assessment of the literature is necessary for the sake of assessing how a loss of subjectivism may hinder the post-treatment process for those involved, such as oncologists and patients. The proceeding theme will provide a review and critical discussion of the current QoL questionnaires being used in this context. For the sake of balance, however, there will also be a review and critical engagement of the academic and practical developments that have taken place within subjective and phenomenological well-being, which aim to offer a deeper reflection of a person's general health.

## **2.7 Theme Three – The measurement and understanding of health, quality of life, and well-being.**

The third and final theme of this narrative literature review seeks to critique the current use of patient-reported outcome measures (PROM) for those living with and beyond cancer. Moreover, this will be done by discussing the two questionnaires being used to capture and assess patient QoL. However, whilst the questionnaires may be helpful for clinicians, patients, and auditing purposes, I will introduce how the concept of phenomenologically grounded well-being can add additional depth and balance to the existing ambition of measuring and recording patient QoL in the recovery package's stratified pathways.

The ways in which it is possible to measure and evaluate how effective or meaningful public health-based initiatives has been developing over the years (Smith & Reid, 2018). As discussed in the introductory chapter, the NHS has committed to initiate the monitoring of patient QoL during post-treatment and survivorship through quantifiably orientated questionnaires. The questionnaires partly aim to evaluate how the recovery package and the stratified follow-up pathways (i.e. physical activity intervention) have been effective for the QoL of those living with and beyond cancer.

However, the approach taken to evaluate the QoL of those who are in this specific phase of the cancer trajectory does have an inherent flaw. The use of questionnaires as a means of understanding the quality of an individual's life has prevented what could be a fluid and experiential understanding into a statistical reduction which offers little subjective elaboration (Smith and Reid, 2017). Much like the interventionist approach in the design and setting of clinically structured interventions, the current questionnaires shift what is an inductive opportunity of subjective evaluation to a deductive process, whereby meaningful experience is delineated to a pre-determined measurement (Smith & Reid, 2017). The third theme of this literature review therefore seeks to understand and dissect the concepts of QoL and well-being, and how they can and have been used to understand an individual's health.

Drawing on the work of Greenhalgh et al. (2018), the use of patient-reported outcome measures (PROM) is a common procedure in healthcare practice, especially oncology (Cancer Research UK, 2015; Corner Wagland, Glaser, and Richards, 2013). It is this procedure, writes Greenhalgh et al. (2018), which can

support and enhance a patient's communication with health professionals and influence the subsequent care they receive. Discussing some of the key assumptions for and against the use of standardised and individualised designed PROMs (i.e. questionnaires and interviews), Greenhalgh et al. (2018) propose that PROMs are simple in that they can allow a patient to engage in self-reflection about their current state of health, and also raise awareness of their ongoing issues amongst health care professionals. Using a realist synthesis to identify, test, and refine these claims, Greenhalgh et al. (2018) analysed and critically reviewed forty-two academic articles that used either individualised or standardised PROM for healthcare settings (i.e. palliative care or psychological services).

The outcomes of the synthesis did not propose a shift in the current explanations that have been theorised around PROMs (Greenhalgh et al., 2018). The synthesis did, however, offer insight into the complex position that PROMs assume along the trajectory of a treatment or care process for patients. Whether it is a psychological or oncological based PROM, 'the how' and 'the "when' of using a PROM, such as a questionnaire, was found to be more important than the "what" of the process (i.e. gathering data) (Greenhalgh et al., 2018). The medicalisation of outcome measures, therefore, can be problematic, whereby health professionals and patients alike can experience the mechanical and sometimes impersonal nature of using questionnaire-based measures. However, if used in conjunction with patient and health professional consultation, questionnaire outcome measures can serve to enhance an understanding of problematic symptoms that are of a physical or psychological nature (Greenhalgh et al., 2018). Greenhalgh et al. (2018, p. 5) succinctly describe the importance of clinical communication by articulating that "...the presence of a tumour is a biomedical fact that was hitherto unknown to the patient whereas the insight revealed from a distress questionnaire is dependent on what a patient chooses to disclose; disclosure that, it is argued, could also occur through open dialogue".

Before engaging with any further critique of this specific PROM, it is important to first consider and discuss the foundations of QoL. This will be offered before I propose the concept of phenomenologically informed well-being as a suitable

means to equal or share the platform that the aforementioned questionnaires do currently hold.

### **2.7.1 Quality of life in cancer care**

QoL's emergence began between the 1930s and 1960s as a result of a desire to measure the output of developing healthcare systems for patient health (Karimi & Brazier, 2016). Furthermore, QoL is generally accepted as a concept that seeks to represent the physical, social, mental and spiritual functioning of the human condition (Karimi & Brazier, 2016; Pinto, Fumincelli, Mazzo, Caldeira & Carlos-Martins, 2017). Similar to that of other conceptualisations of health, defining QoL is often difficult because of its many interpretations and disciplinary tensions, with Karimi & Brazier (2016) citing qualitative and phenomenological analyses (i.e. Burke et al., 2017) and objective measurements appearing to use it as a foundation for differing projects. The conception of 'Health Related Quality of Life' (HRQoL) has further complicated matters due to its many definitions, with Karimi et al. (2016) citing four. What's more, HRQoL only focusses on the factors that are associated with an individual's health and nothing more. This, it would seem, does not entirely add anything original to the concept of QoL or health other than that it tends to focus considerably on a person's subjective assessment (Karimi et al., 2016).

Furthermore, the World Health Organisation defines QoL as "individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns." However, while acknowledging the subjectivity and expressivity that is found within the concept of QoL, the World Health Organisation (1997) continue to develop 'tools' and 'instruments', which are commonly questionnaires, to systematically measure the impact of chronic diseases and conditions. The questionnaires used, according to the WHO, are an attempt to bridge the mechanical model of medicine that sometimes stifles the humanism involved in an individual's evaluations of their health. Examples of the various questionnaires relating to QoL and various health conditions include EQ-5D, AQoL-8D, King's Health Questionnaire and NYHA Scale.

The NHS (2017) concede that while there is a general level of satisfaction with measurements of cancer care and treatment offered in the UK, there is no measure

“...to assess how well patients are supported after treatment”. To determine this, two questionnaire metrics (EQ-5D-5L and EORTC-QLQ-C30) to measure QoL are being trialled to become the primary tools of instrumentation (NHS, online, 2017). Before or if the questionnaire metrics are to be rolled out across the UK, a pilot project spanning across five different regions (Cheshire & Merseyside, Northern Cancer Alliance; East of England; North Central & North East London; Wessex) is currently underway to assess the feasibility of using these methods to capture the survivorship and rehabilitation phase of the cancer trajectory. If deemed feasible, the two questionnaires will be adopted as the primary form of instrumentation to measure QoL throughout post-treatment and into personalised follow-up care.

The first of the two, the EQ-5D-5L questionnaire, is a “standardised measure of health status developed by the EuroQol Group in order to provide a simple, generic measure of health for clinical and economic appraisal.” (EuroQol Research Foundation, 2015, p.4). The questionnaire consists of two pages, with the first section covering an individual’s response to five dimensions of quality of life that are answered in accordance to how they feel at that present time (mobility, self-care, usual activities, pain/discomfort and anxiety/depression). The second of the two pages incorporates a visual analogue scale (VAS), whereby a respondent has to assess and score the state of their health with zero being *‘the worst health you can imagine’* and one-hundred being *‘the best health you can imagine’*. Both pages are to be answered in accordance with how the respondent describes their health on the day of the questionnaire being administered. Upon being analysed, the questionnaire, therefore, provides a quantifiable measure of an individual’s QoL.

Developed in 1993, the second questionnaire, the EORTC-QLQ-C30, has been specifically designed to assess and understand the quality of life that is specific to those affected by cancer. Due to the many manifestations of cancer tumour sites, the EORTC-QLQ-C30 questionnaire has various modules (i.e prostate, breast, colorectal). Respondents are expected to answer thirty questions that consider the state of their quality of life during and over the past week. Moreover, questions one to twenty-eight are designed to measure health-related dimensions (i.e worry and feelings of nausea) from a scale of one (not at all) to four (very much). Questions twenty-nine to thirty address an overall rating of health and quality of life from one

(very poor) to seven (excellent), providing, again, a quantifiable description of an individual's QoL at that time.

Whilst this approach toward understanding QoL may indeed capture and create a broad statistical foundation and offer medical professionals a brief insight into a person's post-treatment progress, there are several potential issues of using the two questionnaires as the primary means of exploring what it means to be well or have a form of quality in one's life (Boyer, Baumstarck, Guedj and Auquir, 2014; Greenhalgh et al., 2018; Corner et al., 2013). Acknowledged as valid and reliable to assess a person's state of QoL, the questionnaires practically restrict a person from fully expressing their sense or experience of what it means to be in a specific situation, and do, in turn, only create a space for pre-defined responses that risks removing any nuance of expressivity. It is important to consider what this quantifiable outcome measure is achieving and why does this form of instrumentation continue to dominate clinical feedback.

Boyer et al. (2014) extend this argument to suggest that there can be a resultant tension between clinicians and patients due to the medicalisation of QoL (i.e. questionnaires). Indeed, Costain-Schou & Hewison's (1999) explorative accounts of the cancer experience suggest that the tensions that can occur between clinicians and patients are a subsequent by-product of a strong approach to bio-medicalise every phase of oncological treatment, whereby any form of experiential meaning and psychological depth is absent from a questionnaire that is determining the quality of one's life. Oncological QoL in this manner, writes Costain-Schou & Hewison (1999), has been absorbed into the reductionist science in which cancer is successfully treated. It has even been suggested that this approach of instrumentation is a problem for patients in a way that "... effectively neglects the person" (p.153).

Furthermore, the work of McCabe, Begley, Collier and McCann (2008) has attempted to address some of these methodological issues regarding a person's well-being throughout the cancer experience. Though some of these quantifiable instruments have been revised to become more individualised (i.e EORTC-QLQ-C30; SEIQoL-DW; the PGI; the DT), the ultimate consequence is that the format of questionnaires does not reflect the abstract and complex nature that is involved with

experiencing a life-threatening disease or illness (McCabe et al., 2008). McCabe et al. (2008) draw attention to the necessity of incorporating a qualitative feature throughout patient feedback, citing various studies that have included mixed methodological approaches to attempt to facilitate greater psycho-oncological care for those who are adjusting to the trauma associated with cancer.

Issues relating to patient feedback have also been considered in other healthcare contexts (Jomeen & Martin, 2018). In their discussion of maternal health, Jomeen and Martin (2018) discuss and deliberate on the notion of using psychometric measures that include both qualitative and quantitative divisions to reflect the true nature of perinatal well-being and quality of life. Nordenfelt (2018) also approaches QoL through “a new stance”, calling on holistic theories of life to be considered for the entirety of person or persons receiving care in and beyond clinical settings. In his attempt to offer balance to the dominance of QoL, Nordenfelt (2018) further contemplates the risks that are possibly involved with constant usage of standardised measures, relating to Costain-Schou & Hewison (1999) discussions of misunderstanding patient’s needs.

To summarise, the NHS’ proposed questionnaires for patient QoL are indeed limiting. However, it would be ignorant to simply suggest that this method of evaluation is not worthwhile. Re-engagement with ontological nature of well-being and chronic health conditions has the potential to add further depth to what is at present an objectionable and mechanical way of measuring an individual’s health after cancer treatment (Nordenfelt, 2018). What follows, then, is a comprehensive discussion of well-being, with additional emphasis placed on phenomenological applications that serve as examples of the ways in which health, QoL, and well-being can be explored and conceptualised.

### **2.7.2 Well-Being**

Similarly to QoL, well-being has been and continues to be a highly deliberated topic within many disciplines (Dodge, Daly, Huyton, and Sanders, 2012; La Placa, McNaught and Vincent, 2013). Attempts to expand it within philosophical literature and define it through conceptual and measurable frameworks have, to some degree, made the task of understanding its essence considerably more challenging. The

inclusion of well-being, especially the phenomenological study of its essence, has been drawn into this narrative literature review to expand how we can comprehend and study the complexity of people's health in times of ill-health.

In simple terms, the Online Oxford Dictionary (2017) defines well-being as “a state of being comfortable, healthy, or happy”, while the World Health Organisation (2017, online) considers well-being to be a supporting characteristic of health by stating that “health is a state of complete physical, mental, and social well-being and not merely the absence of disease or infirmity”. NICE (National Institute for Health and Care Excellence) has also separated well-being through a substantial quantity of clinical reports (i.e. *mental health and well-being, social and emotional well-being in secondary education, older people: independence and mental well-being*), as well as several more reports that cover specific areas of the human life-course. Governing bodies' efforts to define well-being have the potential to undermine its position as a singular entity (La Placa et al., 2013). Perhaps understandably, then, well-being has been automatically included within the above definitions and conceptualisations of health and QoL. This automatic inclusion can consequently constrain well-being in a way whereby it is automatically associated with biomedical and positivistic terminology and measurement.

Furthermore, it is perhaps too challenging to find a singular representation or truth of what constitutes a sense of well-being, especially for those who experience cancer. The social, economic, political, military, ideological, religious, medical and geographical contexts that surround individuals vastly differ from one society to another, drawing attention to its complex and fluid nature of how it manifests differently for individuals and groups across the world (Dodge et al., 2012). In an attempt to understand well-being's potential, philosophical and theoretical foundations will first of all be reflected upon.

### **2.7.3 Philosophical and theoretical considerations**

Traditional philosophy typically confines well-being into broad and classical theories of hedonism and eudemonism (Dodge et al., 2012; Deci & Ryan, 2008). While explained as separate entities below, there is a considerable interrelation between these dominant theories. Lent (2007) describes the human life-course as one that is occupied with pursuits that encourage both forms of well-being, whereby



eudaimonic experiences well-being (i.e. feeling socially accepted) offers a route to and from hedonistic experiences of well-being (i.e. personal happiness).

- **Hedonistic theory of well-being**

In its simplest expression, hedonistic well-being is concerned with gratifying experiences being maximised while painful experiences being minimised, thereby placing 'happiness' or 'pleasure' as a central component for an individual's centre of their well-being (Deci & Ryan, 2008). Therefore, hedonistic well-being is often referred to as subjective well-being (SWB) because of its focus on the self as the site for a primary origin of well-being (Deci & Ryan, 2008).

- **Eudaimonic theory of well-being**

Considered as perhaps a more complex understanding of well-being, eudaimonia is regarded as fulfilling an individual's potential and living well, regardless of whether they are happy or satisfied with their current potential (Deci & Ryan, 2008). Well-being in the eudaimonic sense is a layered and fluid process of realising one's true nature and purpose, emphasising the conditions or environment that enable or diminish one's sense of well-being, as opposed to reaching one's greatest sense of pleasure or happiness (Deci & Ryan, 2008).

Furthermore, the development of well-being has been theoretically manoeuvred into contemporary theories, with underpinnings of its philosophical heritage present throughout each. The theories include the equilibrium theory of well-being (Headley & Wearing, 1989), homeostasis based well-being (Cummins, 2012), and the lifespan model of development (Hendry & Kloep, 2002). Indeed, the contemporary 'see-saw' theory attempts to consider and include all previous notions of well-being that has come before it, attempting to create a fluid definition of well-being (Dodge et al., 2012). However, while Dodge et al. (2012) are committed toward making well-being more "universally applicable" and "a basis for measurement" (p.231) for institutional use, efforts to define well-being's essence risk sanitizing, medicalising and politicising its fundamental core. This can reduce its essence to a superficial procedure (i.e a questionnaire) before any level of subjective well-being can be discovered.

Furthermore, well-being based questionnaires such as the *Basic Psychological Needs Scale*, *Ryff's Psychological Well-Being Scales* and *Quality of Well-Being Scale* have been developed. However, in the same manner of QoL, this also has experiential implications. If a person's experience of a significant or general event is reduced to a simple model or quantifiable description, the experiential richness and depth are perhaps lost, with little or no significant meaning attached to it. It is now necessary to understand other informed approaches which aim to explore how or if subjective evidence can provide an alternative lens to the dominant theories that have potentially monopolised well-being in the area of chronic health conditions.

#### **2.7.4 Phenomenologically informed well-being**

The subject of well-being has since transcended beyond traditional theoretical boundaries and has been conceptualised within a variety of contexts, especially in health sciences and social care (Galvin & Todres, 2018). Moreover, Galvin and Todres (2018) have discussed how a multi-dimensional form of well-being is needed, whereby the academic and applied understanding in professional practice are balanced through a combination of philosophically-informed methodologies without one approach dominating the landscape. Smith and Reid's (2018, p.817) discussion of "beyond subjective and objective" well-being opens the possibility for what is described as intra-action, which is a metaphysical position in which experiential phenomena are open-ended and beyond predetermined classifications (Barad, 2007). In this sense, well-being inherently offers itself to phenomenology, whereby the concept emerges as a fluid process as opposed to a fixed 'truth' of one's health which can be easily measured (Smith and Reid, 2018; Blaschke, 2017).

Drawing heavily on the phenomenological influence of Van Den Berg, Burwood (2018, p.133) examined "the existential situation of the patient" as a site of discussion for the fluidity of well-being. After discussing some of the basic assumptions of ill-health, Burwood (2018) describes the experiential challenges that can occur in times of chronic disease or illness. Burwood (2018) extends his philosophical analysis to propose that those who experience chronic ill-health embrace an adapted and heightened sensitivity to "the little things", such as how we use our bodies, while "the well" concern themselves with matters of the everyday attitude with little attention focussed on the sensory details present in one's day-to-day life (p. 134). According to Burwood (2018), ill-health can be just as important to

well-being as good health, for it has the potential to produce readjustment to significant changes in one's immediate life and the wider environment (Baker et al., 2016).

Furthermore, Eatough's (2018) hermeneutical-phenomenological reflection of "Elsa's continual experience of Parkinson's disease" resonates with Burwood's philosophical reflections of ill-being as a constituent of well-being. Elsa's reflections of her life of living with Parkinson's disease express an ongoing adjustment of living with her new identity (Eatough, 2018). Moreover, Elsa's dialogue underlines the balance she endures on a constant basis throughout ill-being and ill-living, as she presents a gallows humour about her daily predicaments. This includes difficulties dressing, encounters with health professionals and the healthy visitors who come to call, whilst acknowledging the existential reality of her future (Eatough, 2018). It is possible to see a connection between what was experienced by Elsa and those living with and beyond cancer in both Blaschke's (2017) and Cobb's (2015) studies, whereby phenomenology affords a greater degree of understanding of deeply seated experiential meanings that are present.

Galvin and Todres' (2018) theory of dwelling-mobility is a stable grounding for a greater phenomenological reflection of the subject of living with or beyond a chronic illness. Through dwelling-mobility, the findings presented by Baker et al. (2016), Cobb (2015), Burwood (2018), Eatough (2018) and others cited in this thesis thus far can offer a deeper understanding of those living with and beyond chronic health conditions. Informed by Heideggerian considerations of ontology, specifically, the work on *Homecoming*, the philosophical concept of *Gegnet* and Svenaeus' (2000) work on understanding health, dwelling-mobility seeks to understand the experiential variations that can emerge from one's sense of well-being (Galvin & Todres, 2018).

Citing Boss (1979), Toombs (1993) and Gadamer (1996) as influencing the notion of mobility, Galvin and Todres (2018) acknowledge that an ontological realisation of, for example, a chronic health condition, while anxiety-provoking, can present restless energy to fulfil one's desires and possibilities, creating existential mobility that inspires "a feeling of flow, aliveness and vibrant movement" (p.86). Well-being in this phenomenological sense relies on accessing one's existential potential to

activate a “movement” of one’s potential (Galvin & Todres, 2018). Dwelling, on the other hand, is related to finding acceptance in one’s mortality, whereby meaning may be explored and found in the current quality of one’s position in their lives. Galvin and Todres (2018, p.87) explain that the ontological positioning of dwelling is not free of suffering, pain, or any negative emotional reaction for that matter. It is, however, the acknowledgement of what is there in that moment that surfaces the dwelling in one’s sense of well-being at that time (i.e. Eatough, 2018) (Galvin & Todres, 2018).

The phenomenology of chronic pain by Lum (1997) and Marilyn French’s (1999) book, *A Season In Hell*, exemplify the existing relationship that brings both dwelling and mobility together as a fluid unity, with the latter publication contextualising a sense of how cancer survivorship manifests. In chapter two of French’s (1999) book, she discusses the intense anxiety and instability that followed when trying to ascertain whether or not she had a diagnosis of cancer. Also, French’s (1999) concluding chapter offers a rich and descriptive account of her post-treatment attitude towards her present and future projects. She writes:

*“Losing the future is the best thing that ever happened to me. It altered the context of my desires, which are now limited to the present and the immediate future – that is, a few hours hence. Stuck in the present, I can devote myself to it: daily pleasure, pleasure in the moment, pleasure in everything (or almost everything) I do. Luckily, my work has always given me huge pleasure, as do my social encounters – my children and my friends. I also love excellent food, and I do my own cooking despite my difficulty with standing for a long time. I move through the day from pleasure to pleasure like a woman walking through the halls of a great gallery.*

*I no longer have large-scale desires. I no longer wish for or expect undying love, perfect harmony within my family, a life in which everything is right (which, however absurd it may be, I did desire and kept anticipating before). I only have small desires – for glass of cold orange juice, a good book, a visit with someone I love. Not only do I have no large desires for myself; I no longer have them for the world. Coming up against the absolute limit of death destroyed my fervent belief that an ideal world could be created if only people would do X and Y, believe what is before their eyes, let themselves be happier. It destroyed my absurd and unconscious belief that*

*because I could see the ideal, I had a responsibility to help others see it, to create it. The weight of responsibility was heavy, and carrying it made me angry. I was also angry because I was frustrated that no matter how simple it all was, it was not happening.*

*Coming as close to death as I did engraved on my consciousness the understanding that the ideal is not going to happen, that it was always a delusion, the daydream of a wilful child, engraved upon my body by yearning and helplessness like the fault tattooed on one's body by acid-dropping needles that prick it as the sinner is turned around and around on a huge rotisserie, as in Kafka's the penal colony. Coming against failure in so absolute a fashion calmed my anger and cooled my ambition. I am no longer driven. I no longer imagine that I can do much to help bring about the millennium of the humane ideal, or that I can change anything at all. I have relinquished my painful freight. I am free. I am permitted to enjoy myself. I have noticed that my laugh has changed, is more spontaneous, deeper. I am almost serene.*

*I cannot say I am happy I was sick, but I am happy that sickness, if it had to happen, brought me to where I am now. It is a better place than I have been before. I am grateful to have been allowed to live long enough to experience it.”(P.254-556).*

Reflecting upon the excerpt from French's (1999) concluding chapter, there is congruence between the evidence that has been gathered throughout the entirety of this narrative review. Philosophically and theoretically, Todres and Galvin's theory of dwelling-mobility (2013), and the other qualitative evidence that has been reviewed (Cobb, 2015), offer a way of understanding this type of reality as a fluid process. Rather than the fixed psychological positions that are reflective of PTSD and PTG, the above excerpt by French (1999), qualitative studies in both theme one and two, and phenomenological theories underline the experiential reality that can occur for those have experienced a chronic health condition such as cancer.

What can be learned from French's (1999) excerpt about those living with and beyond cancer also has practical implications. The reflection by French (1999) does exemplify the necessity to allow one to articulate their state of health, QoL, and well-being before reducing their experience to a theoretical or statistical explanation. This

could perhaps suggest that amendments to the current PROM based questionnaires to enable a greater degree of expression could be made. This, for example, could include a brief section that encourages an individual to reflect on how the overall experience has informed their thoughts, feelings, and behaviour, allowing clinicians and oncologists to delve further into the lives of those who have impacted by cancer.

Survivorship and the rehabilitation services (i.e. structured or unstructured approaches) used to enhance this phase of the trajectory and experience are thus a complex phenomenon that cannot simply be measured without critical reflection. This thesis, therefore, provides a critical reflection of how engagement with phenomenological methods can enhance our understanding of what it means to live with and beyond cancer in a specific context.

## **2.8 Summary**

To summarise, both QoL and well-being aim to conceptualise areas of health and describe the human condition through both objective and subject means (Pinto et al., 2016). However, the identification and implementation of both the EORTC-QLQ-C30 and 5Q-5D-5L questionnaires for the measurement of QoL within the NHS' strategic ambitions could reduce an individual's health to a pre-determined and pre-conceived form. The option to go beyond this quantitative reduction employing phenomenological methods offers a direction that can afford a greater understanding of the fluidity of how individuals meaningfully live with, through, and beyond cancer (Galvin & Todres, 2018).

The philosophical and theoretical discussions of well-being provided reflect the meaning of experience in a way that acknowledges the adaptability and fluidity of its philosophical grounding. The scholarly literature has also contributed towards understanding the subtle and broad meanings attached to chronic and ill health within a person's sense of well-being, as opposed to the broad-brushed theories that offer a certain truth or one sense of statistical reality. This isn't to dismiss the traditional models and theories of well-being, however. The phenomenological reflections simply offer and stress the importance of the depth of experiential well-being, reaching further into what kinds of experience underpin a specific moment in a person's life when living with a chronic health condition.

Cancer, especially the unique and challenging phase of post-treatment rehabilitation and survivorship, is thus a specific period to learn more of the experiential and taken-for-granted realities of chronic health when considering how many people in this era will live with and survive the condition (Maddams et al., 2012). It is the interest of this study to understand the phenomenological implications of unstructured recreational programmes in the natural environment for those living with and beyond cancer.

## **2.9 Conclusion of the narrative literature review**

Based on the evidence that has been gathered within both the first two chapters of this thesis, it is clear that cancer has a direct impact on the overall health of those who have or are living with the condition, causing considerable existential and psychological challenges. The existential repercussions associated with cancer have been reported as being severely debilitating, such as the experience of feeling existing in a state of limbo (Cobb, 2015). Moreover, research studies have drawn attention to the ongoing implications of psychological and physical deconditioning that can occur throughout the entirety of the post-treatment phase.

The challenges associated with the strategies and ambitions have also been identified as playing a major role in this process (Macmillan, 2017). Although access to screening facilities and treatments has improved since the turn of the century, the current operational climate in the healthcare system continues to prevent people receiving the treatment and care they require at any point throughout the experience. This has been compounded by the design, structure, and implementation of post-treatment strategies and ambitions that use structured physical activity interventions as one of many ways of enhancing 'patient experience and QoL'.

However, this narrative literature review aimed to delve further into this area of rehabilitation and survivorship to understand if structured interventions of physical activity are the most effective and meaningful way of facilitating rehabilitation and survivorship (Midtgaard et al., 2015; Burke et al., 2017).

Research has supported how physical activity in structured settings and the recreational programmes in unstructured settings, specifically the natural environment, can be physically and physiologically beneficial as well as psychologically and socially meaningful for those living with and beyond cancer. It has been shown to offer continuity, a sense of normality, and assist those living with cancer to reclaim a sense of their body after treatment (Midtgaard et al., 2015). Yet, there were recommendations to understand how unstructured recreational programmes, which have been under-researched in comparison to clinically structured interventions, are meaningful for a wider demographic of individuals living with and beyond cancer (Burke et al., 2017).

Based on the research that was gathered in the review, unstructured recreational programmes which are facilitated by the civil society in the natural environment have been identified as a provision that can meaningfully enable those who continue to live with the impact of cancer, as well as other chronic health conditions. However, both the programmes and environments in which those living with and recovering from cancer have become a focal point that warrants further study. The current evidence base surrounding the relevance and meaning of connecting with the natural world for those living with and beyond a chronic health condition, such as cancer, has thus far suggested that it can have both indirect and direct benefits for a person's life, unburdening them from their experiences of treatment by allowing them to live in "the here and now", for example (Blaschke, 2017).

What's more, small scale studies of unstructured programmes and activities like recreational cycling for children with cancer (Burke et al., 2017) have identified that it can assist in control over their lives and their social and emotional development, which was felt to be in contrast to their experiences of cancer treatment. Though the study was not focussed on cancer, recreational activities such as surfing have been reported as meaningful for war veterans with PTSD through how they prevented decline into a state of embodied chaos whereby their psychological suffering had the possibility to become unbearable (Caddick et al., 2015). Moreover, the participants identified how they were enabled to feel positive emotions through surfing and connecting with the ocean environment, that was just as meaningful, if not more, than the traditional forms of therapy (i.e. psychotherapy).



This review also indicated how engagement and connection with the natural world can take many forms, is not without risk and challenge, but can also provide possibilities for those living with trauma or a chronic health condition (Herman, 1992). For some, the fluid nature of their experience and connections with the natural world can offer a safe space upon which to find perspective about their past, present, and future experiences, which would otherwise be taken-for-granted if it was reduced to statistical analysis (Blaschke, 2017).

## **2.10 Researchable Phenomenon**

It was expressed by Burke et al. (2017) that there is a greater need for further study of how unstructured recreational programmes in the natural environment can enhance a sense of living with and beyond cancer. To make it explicitly clear, the meta-synthesis and subsequent recommendations for future research that were articulated by Burke et al. (2017, p.22) is the foundation from which this doctoral study has been prepared. To reiterate, the recommendations included:

- “Further research is needed to explore if different types of activities have a different meaning and utility for cancer survivors and how this might impact their experience.
- Another notable area for future research includes examining cancer survivors views on the setting in which the activity is delivered.
- Researchers need to closely examine other groups of survivors other than women (i.e men, adolescents, children, and the elderly) to gain an understanding of their experience along the cancer trajectory.
- Researchers may want to consider using more diverse qualitative methodologies to better understand the underlying processes of survivors’ experiences.”

The recommendations also resonate with the critique of the use of questionnaires and interpretive phenomenological analysis to measure or understand a meaningful engagement in structured interventions and unstructured programmes for those living with and beyond cancer. Specifically, the methodological approaches of IPA and hermeneutical phenomenology have, to date, offered a useful idiographic foundation to understand the qualitative features that occur. However, and in accordance with Giorgi (2009), the way the phenomenological methods were used

in the studies that were reviewed were often ambiguous and were heavily flexible in their approach to present phenomenological claims regarding the participants' experiences.

Such considerations encouraged me to seek to use a phenomenological method that has thus far rarely been used in this field of study. The descriptive phenomenological method, which is discussed more thoroughly in the next chapter, was identified as a method that would allow me to make phenomenologically grounded claims. Also, the descriptive method would allow me to recognise the essential experiential features of how men, women, senior citizens, and children encounter recreation in the natural environment (Burke et al., 2017).

Furthermore, by employing a descriptive perspective, it is possible to learn much more about the wider foundational implications that collectively occur throughout the entirety of the process. For example, there is a necessity to understand the essential characteristics that are involved for several people when engaging with recreational programmes. However, phenomenological essentialism will be explored in greater depth in the following chapter to offer the reader a greater understanding of this academic and philosophical pursuit. Yet, by committing to present an essential experiential structure, there will be a significant methodological and philosophical expansion in this specific area of interest that acknowledges what is meaningfully shared in an unstructured setting and context.

## **2.11 Delineation of the phenomenon of interest**

The following researchable phenomenon has undergone a reflective delineation through both chapters one and two. The underpinning strategies and ambitions, research findings, and philosophical considerations have all assisted in making the researchable phenomenon clear and worthy of study for both theoretical and practical purposes. Through these specific recommendations and considerations, the researchable phenomenon of interest that will be explored throughout the remainder of this doctoral study is:

- *A psychological structure pertaining to the meaning of recreational programmes in the natural environment for those living with and beyond cancer.*

As well as both chapters one and two, the researchable phenomenon has also been sensitively orientated by my pre-understandings of the subject matter. Yet, the following chapter will establish why I decided to engage the phenomenon from a psychological perspective as opposed to any other discipline of science. However, the entirety of the process of establishing the researchable phenomenon thus far has been a substantial task that has involved significant delineation. By doing so, the boundaries of the study are now clear and explicit, something of which is required for a phenomenologically-informed study.

## **2.12 Aims and Objectives**

This study, therefore, aims to provide an essential description and psychological structure of the meaning of recreation in the natural environment for those who are living with and beyond cancer. To do so, the objective that will be undertaken has been designed to interview men, women and children of various age groups who have used recreational programmes through a civil society organisation that can explicate this specific phenomenon of interest (Burke et al., 2017).

## **2.13 Original contribution to knowledge**

This doctoral thesis intends to provide a contribution of knowledge that is original in its commitment to practical and theoretical goals.

Theoretically, this thesis will continue to contribute to that has been cited through the aforementioned scholarly literature. Developing a phenomenologically grounded experiential structure can enable those living with and beyond cancer, clinicians, policy-makers, and commissioners to fully understand how the participants in this study experienced a recreational programme organised by a civil society organisation. In doing so, it is possible to identify and expand upon the essential and foundational processes that occur throughout the experience of engaging with unstructured recreational programmes.

Practically, the thesis will also reflectively comprehend how significant the civil society is for those living with and beyond cancer and the NHS. As a result, the thesis will partially address the concerns associated with how to alleviate pressure on the wider survivorship pathway of personalised care cited in chapter one. The intention to provide an experiential structure will likewise deliver a critique of the current questionnaire-based methods that are being employed by the NHS. The elaboration of the experience of living with and beyond cancer may result in recommendations for a change in how quality of life is measured and understood during the rehabilitation and survivorship phases of the cancer trajectory (Macmillan, 2009; Independent Cancer Taskforce, 2015-2020).

## **2.14 Call for methodology and method**

Achieving an original contribution of knowledge will involve implementing a methodology and method that can evoke and communicate the essential experiential properties of recreational programmes in the natural environment. As opposed to using a method that will present idiographic narratives or statistical analyses, I have chosen to employ the descriptive phenomenological method to understand the essential structures that are present in such experiences, thereby identifying what kind of essential meanings are being encountered by those living with and beyond cancer in this context.

The research study rests upon implementing Giorgi's (2009) methodology and method to present an understanding of the various kinds of experiences that are encountered during participation in unstructured recreational programmes. The following chapter will address the philosophical groundings and contemporary use of phenomenology in applied research before offering a detailed overview of how I have adopted the methodology of descriptive phenomenology to evoke an essential structure and description of unstructured recreation in the natural environment for those living with and beyond cancer. In accordance with Giorgi's (2009) methodological guidelines, the chapter will also deal more thoroughly with why I chose to adopt a disciplinary perspective of psychology for this study (please see sub-chapter 3.1.10)

## **3.0 Methodology and Methods**

### **3.1 Part One**

#### **3.1.1 Introduction**

Chapter three is designed to provide a clear rationale and justification for the use of a phenomenological framework for this doctoral research project. Part one of the chapter will offer a thorough overview of qualitative and phenomenological underpinnings, detailing both movements and their positions in contemporary literature and applied academic research. Part two is intended to establish how and why qualitative and phenomenological methodologies and methods are suitable strategies for this doctoral research study, thereby introducing and describing the context of the study. Lastly, part three, *Context, method, and procedural considerations*, describes the details regarding recruitment of the participants, ethical considerations, and the procedures undertaken to collect and analyse the participants' data to address the research phenomenon delineated in chapter two.

#### **3.1.2 Methodological approaches**

The terms 'ontology and 'epistemology' are not independent processes in academic research. Rather, both terms represent an interconnected structure that adheres to a philosophical set of principles regarding the world we inhabit and share with other beings (Taylor & Francis, 2013). Epistemology refers to the study of knowledge and how we constitute an understanding of any given phenomenon, whilst ontology denotes what exists in the world in accordance with reality (Taylor & Francis, 2013).

Importantly, a researchable question or phenomenon often determines what philosophical procedures should be employed to ascertain an answer that represents knowledge of a certain sense of reality (Giorgi, 2009). Often the method or procedure that is used to gather information about a certain reality falls within the paradigmatic boundaries of *positivism*, *constructivism*, or *subjectivism*, which is reflected through 'quantitative' and 'qualitative' research methodologies and methods. This study aimed to utilise a qualitative approach to continue to understand the essential and foundational features of those living with and beyond cancer when engaging and experiencing recreational programmes in the natural environment. In light of this, and what will come through subsequent discussions of

philosophical phenomenology, an epistemological and ontological foundation for this project can be found in and through subjective consciousness.

Methodological approaches from both qualitative and quantitative strategies include, but are not limited to, grounded theory, phenomenology, causal experiments, and correlational analyses. However, the distinction in philosophical and methodological orientations between qualitative and quantitative strategies is emphasised through the breadth versus depth debate, otherwise referred to as differences in epistemological and ontological orientations (Bahari, 2010). Quantitative questions attempt to identify causal relationships in human behaviour and other phenomena through objective, value-free analyses. However, qualitative questions are concerned with the meaning and subjective understanding of human phenomena, directing importance on the study of the experiential and the context in which the phenomena of interest is found (Bahari, 2010).

Though considerable friction can occur over what approach constitutes the nature in which knowledge can be generated, the research methodologies, designs, and methods involved are useful provided they have been applied appropriately (Giorgi, 2009). This study, using a qualitative and phenomenological approach, is concerned with the psychological meaning of the lived experience, placing considerable emphasis on the subjective consciousness of what is experientially given (Giorgi, 2009).

The philosophical and methodological principles define the method or technique researchers undertake to collect and analyse data. The quantitative question requires a researcher to apply a method that includes large-scale surveys, questionnaires, and natural experiments, all of which are randomised and can be applied to a statistical tool to test for significance or insignificance. Generally, qualitative based questions aim to place a researcher in close proximity with people or groups to try to understand the deep-rooted reality of the experiential phenomena being studied (Bahari, 2010). This is commonly achieved through in-depth interviews (structured, semi-structured, unstructured), group interviews, and observations, all of which serve to inductively understand the structures, meanings, and idiosyncrasies of individual or group experience (Kvale, 1996). In line with philosophical heritage that supports qualitative methods, I will be in close proximity

with the selected participants and, in turn, will study the experiential and psychological reality of those living with and beyond cancer when engaging recreational programmes by using phenomenological informed interviews (Giorgi, 2009).

More recently, mixed-methodologies have become common in inter-disciplinary research designs (Bahari, 2010). As the name suggests, the concept of mixed-methodology is a combination of qualitative and quantitative methods. For example, the use of interviews and survey-based analyses are often a choice exercised by researchers to gain an understanding of the qualitative meaning and identify a broader statistical base of evidence of the population being studied (Bahari, 2010). The underpinning philosophy behind the mixed-methods approach is known as pragmatism, whereby a researcher utilises the most suitable approach for the research question rather than personal appreciation.

I understand and accept the appeal and position of pragmatism, as there are many methods in which an academic and practitioner can learn of the disciplines they work within. Furthermore, I believe that a methodology does not come out of preference but is exercised by way of the research question. As a consequence, I do not locate myself in one specific camp of methodological loyalty. The findings of most research studies create qualitative and quantitative possibilities, whereby the choice to yield a greater understanding of phenomena can be achieved via numerous means. However, this is exercised in a manner that is truly considerate of the most applicable methodology as opposed to a choice that is congruent with a researcher's preference or speciality.

Having explained the epistemological, ontological and methodological considerations that commonly define the philosophical foundations of research projects, the task now is to offer a detailed overview of both qualitative and phenomenological principles, as they are the guiding methodological frameworks for this specific study.

### **3.1.3 Qualitative research**

Though its boundaries have undergone academic and practical expansion over the past thirty to forty years, consideration for qualitative research has been present in

philosophical texts for centuries (Babbie, 2014). The 17<sup>th</sup> century contained philosophical interest regarding the origin and nature of knowledge. The debates, writings, and criticisms by philosophers such as Descartes, Hume, Comte, and Kant eventually defined the paradigmatic boundaries of positivism, subjectivism, constructionism, and interpretivism (Snape & Spencer, 2003). What's more, those who sought to follow qualitative research questions included researchers and practitioners of disciplines such as psychology, sociology, and anthropology (Snape & Spencer, 2003; Denzin & Lincoln, 2018; Given 2008; Giorgi, 2009). For example, Giorgi (2009, p31-55) examines the work of six researchers from philosophical and psychological backgrounds, all of whom applied qualitative features in their research designs. William James (1842-1910), Edward B. Titchener (1867-1927), Frederic C. Bartlett (1886-1969), Gordon Allport (1897-1967), Jean Piaget (1896-1980), Robert Coles (B.1929) all contributed toward their respective disciplines by and through the use of inductive and descriptive methods to varying degrees.

Throughout both the 19<sup>th</sup> and 20<sup>th</sup> centuries, there were classical examples of anthropological research designs underpinned by a qualitative research design (Vidich & Lyman, 2000). Anthropologist research throughout this period, which has proved to be controversial by contemporary ethical standards, often involved western ethnographers researching the culture and customs of 'the other', often labelled 'primitives' or 'savages' (Vidich & Lyman, 2000). Inhabitants of colonised lands, 'the other' was subjected to physical, medical, and cultural observation and descriptions by explorers, missionaries, and administrators, compiling collections of 'facts' that could be exhibited as a "comprehensive description of the whole way of life of those who were being studied" (Denzin & Lincoln, 2018, p.39). Despite being morally disputable, arrogant in methodological approach, and later recognised as being heavily biased because of the religious, political, and social orientations of those who undertook such work, the early ethnographic work expanded the boundaries for the advancement of qualitative research (Vidich & Lyman, 2000).

Following what was the traditional or classical phase of qualitative research came several other qualitative developments (Denzin & Lincoln, 2005). The subsequent phases or movements included the *modernist phase*, *blurred genes phase*, *crisis of representation phase*, *the triple crisis phase*, *experimental ethnographic writing phase*, *post-experimental inquiry phase*, *the methodologically contested present*



*phase*, and now, *the present and future of qualitative research phase* (Denzin & Lincoln, 2018). Rather than representing a linear progression of developments that define contemporary qualitative research, the different phases and movements emphasise the diversity of methodologies qualitative researchers have and still undertake to address questions that inform an understanding of the experiential, subjective world (Denzin & Lincoln, 2018).

Reiterating its contested philosophical and historical heritage, qualitative research in contemporary literature has been described as a research methodology, approach, and tool that "...is not easy to define in a way that would be acceptable to everyone who does qualitative research" (Avis, 2005, p. 3). Drawing further on the definitional issues and contested challenges of qualitative research, Denzin and Lincoln (2018) contend that though qualitative research is now employed as frequently as other traditional research approaches, such as natural experiments in laboratories, it is still challenging to provide a linear explanation of its paradigmatic position (Applebaum, 2012). It is, to some extent, clear that the ontological and epistemological orientations of its purpose are directed towards understanding how individuals or groups of people experience, describe, and interpret their world (Bahari, 2010). Qualitative research is also a means by which researchers can explore and attempt to explain social behaviour, generating 'insider' knowledge from the periphery (Avis, 2005).

However, because there now exists an array of methodologies (i.e. grounded theory, ethnography, and phenomenology) and methods (i.e one-to-one interviews, observation, and focus groups) that have been developed to study the nuances of experiential human phenomena, there now exists a tension of what constitutes reliable and credible qualitative research. Often, such tensions result in inner and outer-community friction over what constitutes a reliable understanding of the experiential world (Denzin & Lincoln, 2018; Avis, 2005). Nevertheless, as qualitative research, and science as a whole, does not belong to one single discipline, the phenomena being studied will inevitably vary, evoking the necessity of multiple methodologies and methods that researchers utilise if it is philosophically justifiable (Denzin & Lincoln, 2018). Giorgi (2009, p.110) supports the diversity of options by stating:

*“The most simple and direct statement that one can make about science is that it endeavours to establish the most stable knowledge possible about phenomena of the world. However, since the phenomena of the world are so varied, science has to use different methods and strategies in order to come up with hierarchically arranged knowledge.”*

To conclude, researchers who pursue qualitative questions are confronted by the realities of every day, social world, subsequently forming an understanding of the structures of the phenomena that are being studied throughout groups or individuals. One such approach that has come to be commonly used for understanding the meaning and structural nuances of an individual's lived experience is phenomenology. What follows, then, is an introduction into the historical and contemporary development of phenomenology, before addressing how Giorgi's (2009) descriptive phenomenological method is going to be applied in this specific study.

### **3.1.4 Phenomenology - Philosophical heritage**

First and foremost, phenomenology has a deeply seated position in philosophy which dates back to the early 20<sup>th</sup> century. Since then, phenomenology has been further established as a research methodology in academic inquiries concerning subjective experience (Giorgi, 2009; Moustakas, 1994; Smith, Flowers, & Larkin 2009; Van Manen, 1989; Roy, Petitot, Pachoud & Verela, 1999). Within its philosophical history, phenomenology is concerned with several projects pertaining to the subjective consciousness and appearances of objects and subjects (Zahavi, 2018). Furthermore, phenomenology has been used to understand experiential structures within and through human consciousness and the meanings that are subsequently ascertained (Zahavi, 2018; Giorgi, 2009).

Phenomenology originated as a critique of the dominance of empirical methodologies undertaking reductionistic, objectivistic, and scientific methods used to study experiential phenomena, all of which inadvertently deprive the meaning that is often experienced by individuals (Zahavi, 2018). Giorgi, a psychologist committed to the phenomenological project, (2009, p. 4) further explains that phenomenology “seeks to understand anything at all that can be experienced through the consciousness one has of whatever is “given” - whether it be an object, a person,

or a complex state of affairs – from the perspective of the conscious person undergoing the experience”. Phenomenologists, therefore, are interested in the meanings that appear in experiential phenomena that we are conscious of, placing subjectivity and consciousness as the centre of epistemological knowledge and ontological reality (Zahavi, 2018).

In a similar nature to that of qualitative research, phenomenology does not belong to one particular philosopher, academic, or individual (Speigelberg & Schuhmann, 1994). On the contrary, phenomenology has passed through movements and schools of institutions, with each moment of its heritage developing and extending its reach in various ways. Initial beginnings appeared in Germany before spreading to France and other continents. Phenomenology is cited to have been originally established by Edmund Husserl (1859-1938) throughout the 20<sup>th</sup> century (Speigelberg & Schuhmann, 1994). A mathematician and philosopher, Husserl has been credited for being responsible for continuously developing the boundaries of phenomenology during his academic career (Speigelberg & Schuhmann, 1994). Inspired through Carl Stumpf’s (1848-1936) and Franz Brentano’s (1838-1917) work in psychology, Husserl radically developed much of the philosophic groundwork that had been accomplished before him in naturalism and psychologism (Speigelberg & Schuhmann, 1994; Moran, 2005). Moran (2005) proposed that Husserl expanded upon Franz Brentano's early philosophical conceptions, ultimately transforming what was descriptive psychology to transcendental philosophy of subjectivity.

Despite the phenomenological movement being deeply complex, and often heavily debated by those who follow its philosophic principles closely (Speigelberg & Schuhmann, 1994), the following text is devoted to the key philosophical tenets that are concerned with the underpinnings of philosophical phenomenology in greater depth. Once the key foundations of phenomenology have been established, the chapter then directs its focus to communicate how Husserl developed his transcendental philosophic method to understand phenomena that are presented to an individual’s consciousness. It is, therefore, necessary to first of all understand the phenomenological concept of intentionality, which, simply put, is the directedness of our consciousness to the world (Giorgi, 2009).

### **3.1.5 Intentionality**

To understand the nature of consciousness, the processes of mental activity must be discussed in the context of phenomenological philosophy. The basis for which all mental activity occurs is due to what Husserl terms as intentional consciousness, the fundamental feature of being conscious towards something in the world, such as an object, an unreal object (i.e. an idea or a dream), or an individual (Spiegelberg, 2012; Spiegelberg & Schuhmann 1994; Giorgi, 2009; Zahavi, 2018). Giorgi (2009) explains that the concept of intentionality was further developed to encompass the mind and body, as it is through the body in which one is also directed towards objects and other beings.

Husserl described this process of meaning-making that is embedded in intentionality as the correlation between *noesis* and *noema* (Giorgi, 2009). Simply put, Husserl's correlation between *noesis-noema* captures the distinctions between objective contents (i.e. something that we can see - noema) within our stream of consciousness (i.e. one of our senses – noesis). The presentation of intentionality is further extended to include sensory acts that are not directly perceived by touch or sight, for example. As a consequence, a thought and an idea, as well the capacity to touch and to see, in psychological phenomenology is a process of perceptual meaning-making (Giorgi, 2009). Such meanings are present in a person's *lifeworld*, or as Giorgi (2009, p.190) explains "an individual's space, time, body and world".

Before discussing the lifeworld, whereupon intentionality manifests further, Spiegelberg and Schuhmann (1994, p98-99) simplify the characteristics of Husserlian intentionality in four parts. The four parts are closely interconnected and offer a further breakdown of the noema and noesis. They are as follow:

1. Intentional objectivates – Commonly known as the interpretation of sense or hyletic data, Spiegelberg and Schuhmann (1994) propose that an object is presented to an individual's consciousness that pre-supposes any particular intuitive reference (i.e. thought or feeling).
2. Intention unifies – Once an individual acknowledges the object or sense data that has presented itself, they begin to unify its presence to a pole of meaning, whereby the establishment of its identity or characterisation begins to occur.

3. Intention relates – An individual then starts to connect all of the various components associated with the object or sense data to form a fulfilled interpretation of the meaning that has been intuited.
4. Intention constitutes – the act of intuitive fulfilment, whereby the object becomes constituted with a meaning that is congruent with an individual's reality of the world.

Giorgi (2009) synthesises this schematic process through his discussion of Husserl's theory of meaning, whereby acts of consciousness are processed by the person undergoing the experience. The schematic process follows a cyclical pattern of *signifying*, *fulfilling* and *identification* via 'free imaginative variation', which confirms or rejects the meaning that is being ascertained by varying the essential features of what is being identified (Giorgi, 2009). Simply, Intentionality, in its philosophical form, is the process in which an individual engages to clarify regions of experiential presences, confirming or clarifying the phenomena which are presented. Moreover, I have included detailed examples of how this particular method of ascertaining meaning was constituted by myself within this study during the analytical procedures undertaken.

### **3.1.6 Lifeworld**

In simple terms, the lifeworld is regarded as the everyday, common world that is central to the human stream of consciousness (Schutz & Luckmann, 1973; Giorgi, 2009; Ashworth, 2016; Zahavi, 2018). This world, as one comes to know it, is made up of objects and intersubjective encounters that become apparent to our existence (intentionality), whereby we slowly assume as "the natural attitude" or as a "pre-given frame of reference" (Schutz & Luckmann, 1973, p.5).

Before discussing the central constituents of the lifeworld, the lifeworld itself is a basis for discussing the philosophy of science, especially empiricism. Though phenomenology's project is not to replace the natural sciences and the methods used to observe and measure phenomena, phenomenologists would argue that the development of the natural sciences has lessened the significance of the lifeworld in its quest for pure objectivity through empiricism (Zahavi, 2018; Giorgi, 2002). As phenomenological researchers have experienced through counter-arguments of the phenomenological attitude, which will be discussed within this chapter, there is no

such position in which a person can be purely objective, as they are always in a position of tracing and enacting their sedimented historicity in their everyday encounters, which surfaces Heideggerian notions of '*being-in-the-world*' (Zahavi, 2018). Consequently, in whatever methodological approach a researcher assumes, there will be a sedimented presence behind any procedure they undertake, rendering objectivism to be a by-product of subjectivity and intersubjectivity in their lifeworld (Zahavi, 2018).

Drawing back to the central constituents of the lifeworld, Ashworth's (2016) analysis offers a brief overview of the potential fractions that can occur within any given experience. However, true to the nature of phenomenology, the fractions are not concrete structures that reduce conscious experience to separate classifications. Rather, they represent the fluid boundaries that can present an "aura" within an experiential region of consciousness (Ashworth, 2016, P. 24). I have presented the constituents as such to demonstrate the fluidity that exists amongst them. Within these fractions, I have also included additional examples from my experience and other phenomenological writings. The fractions discussed by Ashworth (2016) include:

- **Self-Hood** - A continuous narration or experiential sense of who we are in the world (Zahavi, 2012). The world in which we live relates to how we describe and identify ourselves. For example, we often base our identity on the outward relations and positions we hold (i.e I am a teacher or I am the brother of X, Y and Z).
- **Sociality, inter-subjectivity, discourse, and temporality** – Using both Schutz's sociological writings and Ashworth's psychological approach to phenomenology, each individual's lifeworld is formed with and through an intersubjective connection with others. Either directly or indirectly, the political, social, and familial (past and present) experiential horizon which we are conscious of creates behavioural understandings that we learn to employ in specific or general situations over time. Thus, as a person grows, in every human sense of the word, they build a "stock of knowledge" that is constantly aware of objects and intersubjectivities that are present to our consciousness, forming a natural attitude of doing or being (Schutz & Luckmann, 1973).

Schutz and Luckmann's (1976) analysis of language is a sufficient example of the interplay between sociality, inter-subjectivity, discourse, and temporality. A child, for example, experiences a pre-linguistic reality that bears an impact on their behaviour through objects and intersubjective encounters, be it facial or bodily expressions. This process is then transformed into language through speech production, generating a socialised reality that forms the experiential lifeworld fractions over time. Examples of how this socialised reality to manifests in social situations can be accessed through Ashworth's (2016) 'gift-giving' and Schutz and Luckmann's (1973) sociological discussion of mastering 'the situation'. Humans essentially attain a phenomenological script that is intuitively internalised (memory) and externalised (body language; facial expressions) when encountered by various situations that one participates in on an everyday basis, relating back to Husserl's theory of meaning. We subsequently begin to trust or reject the cognitive, visual and haptic experiences within a given lifeworld that we have become exposed to.

- **Embodiment, project, and spatiality** – The role of the body has become an important fraction of the lifeworld, drawing attention and focus to the conceptualisation of embodied consciousness (Merleau-Ponty, 1945). Take, for example, the paradoxical position of the professional athlete or sportsperson. Some of their most memorable achievements in their careers have been achieved by embodied adaptations (i.e physiological and psychological). It is the body, however, that can start to cause severe diminishment of well-being through acute injury or post-career chronic pain. The body, therefore, for an athlete, or anybody for that matter, has a fundamental influence over the world and reality that one exists within, drawing greater attention to the phenomenological work of Merleau-Ponty (1945). In greater depth, Parkhurst et al. (2014) study of older citizens in rural areas and Dyck's (1995) study of women with Multiple Sclerosis offers an insight into the lifeworld of those who see a personal connection to environmental space as a potential challenge or threat to an individual's well-being and previous sense of lifeworld.

The lifeworld thus extends Husserl's theory of meaning and his overall project of phenomenology as a study of real (those existing in time and space) and unreal (those existing experientially) objects. Consciousness, when examined through phenomenological underpinnings, offers a route to and from epistemology and ontology, whereby a philosopher or researcher can make claims of truth from the subjective world (Giorgi, 2009). The lifeworld tenets cited above will be used within this study to explain and discuss the findings of the experiential consciousness within the participants' experiences. Yet, what follows is a discussion of the phenomenological concepts of experiential constituents which unify to produce an essential meaning of a given experience.

### **3.1.7 Essential experiential structural constituents**

The concept of structural constituents and experiential essences, which are referred to as universal essences in philosophy and exact essences in mathematics, is a crucial feature in the study of phenomenological consciousness. Essences, writes Dahlberg (2006), "could be understood as a structure of essential meanings that explicates a phenomenon of interest. The essence is what makes the phenomenon to be that very phenomenon" (p.11).

Recognised as possibly being overly complicated (Dahlberg, 2006; Natanson, 1973), structural constituents, in the context of everyday experiences, is the way in which a person perceives 'things', be it an intersubjective encounter, an idea, or an object. Moreover, essences are present to the consciousness of the experiencer in the style, form, characteristics of 'objects', 'things' or 'persons', whereby to lose or add a characteristic would result in a change of identity, purpose or meaning (Dahlberg, 2006). Simply speaking, a person understands what separates a dining table from a desk or a distressed facial expression from one of elation or happiness, suggesting that each one has a distinct set of essential properties. On a complex level, Wertz (2010) proposes that structural constituents that represent phenomena are constantly subject to change through time. What it means to be a part of civilisation has significantly changed from medieval periods of time to the contemporary, present day. Yet, there are some essential features that remain the same, such as the use of clothing for protection against the environment.



Such experiential structures or variations are experienced every day in perhaps a nonchalant or subconscious way, reinforcing both the theory of meaning within intentionality and the pre-reflective, natural attitude we assume throughout our existence (Schutz & Luckmann, 1974). Therefore, in the context of descriptively underpinned phenomenological research, it is understood that a researcher seeks to decipher the essential constituent structures that appear through experiential happenings and how they connect to form an essential meaning. Thus, constituent structures of a phenomenon can be considered to be an inseparable or interchangeable part of the lifeworld and our consciousness. One cannot exist without the other without a phenomenon losing its eidetic integrity (Dahlberg, 2006; Wertz, 2010). Philosophically, this is sometimes referred to as ‘wholes and parts’ but I will elaborate upon this concept during the analytical discussions of this study (Sokolowski, 2008).

Husserl sought to develop a philosophical method to understand the essential constituent meanings that an individual identifies in their conscious natural attitude toward the world. It is within the natural attitude that the aforementioned dimensions of a person’s consciousness (i.e. intentionally, the lifeworld fractions, experiential structural constituents) become absorbed into their horizons, whereby acceptance of the conscious meaning becomes second nature or taken-for-granted (Zahavi, 2018; Schutz & Luckmann, 1976). Consequently, what Husserl sought to achieve was to reduce the subjective experience of reality (i.e. an individual’s natural attitude to the world) into an investigation of the experiential structures of consciousness to discern what is given in specific moments. What follows is Husserl’s transcendental phenomenological method for doing so.

### **3.1.8 Husserl’s philosophical method of transcendental phenomenology**

The transcendental philosophic method of Husserlian phenomenology is firstly assumed through the phenomenological attitude, which is a reflective position assumed by an individual intending to understand a subjective phenomenon that is separate from the natural attitude described above. The phenomenological attitude, Giorgi (2009) writes, was dissected and expanded by Husserl into distinct philosophical reductions. The “transcendental phenomenological reduction” means

disengaging from the natural attitude to learn of subjective phenomena, wherein we can learn of universal levels and essences of meaning of the experiential structural constituents that form to make any given phenomena that specific phenomenon (Giorgi, 2009, p.90). Secondly, the “phenomenological eidetic reduction” refers to a philosophical attitude of reducing a phenomenon to its simplest and descriptive essence (Giorgi, 2009).

Both reductions have philosophical goals in mind that essentially aim to investigate phenomena as they are consciously experienced on a universal and essential level. Giorgi (2009) continues to acknowledge the attitudinal shift, known as ‘the epoche’, that also has to occur for one to fully discern the universal and essential meaning of subjective consciousness. Engaging in the epoche involves the ‘bracketing’ of past knowledge to allow the phenomenon to present its experiential possibilities without any contamination being brought upon it (Giorgi, 2009). The epoche is sometimes referred to as a separate step of the phenomenological reduction. However, for the sake of this study, the entire process will be expressed as the phenomenological attitude.

Spiegelberg and Schuhmann (1994) offer a substantial counterargument to those who have scorned this philosophical reflection as idealistic and unachievable. Spiegelberg and Schuhmann state (1994, p.77):

*“Sometimes free from presuppositions (engaging in the phenomenological attitude) has been misinterpreted in the sense of a pretence of total rejection of any beliefs whatsoever, and of a program to start the philosophic enterprise from absolute zero, even without language and logic. While a full clarification of this issue would presuppose and deserve considerable discussion for its own sake, it will suffice here to point out that in Husserl’s case the phrase ‘freedom from presuppositions’ stands for the attempt to eliminate merely presuppositions that have not been thoroughly examined, or, at least in principle, been presented for such examination. It is thus not freedom from all presuppositions, but merely freedom from phenomenologically unclarified, unverified, and unverifiable presuppositions that is involved.”*

Like Spiegelberg and Schuhmann (1994), Zahavi (2018) is a contemporary phenomenological author and scholar who assists in making Husserl's project and the phenomenological attitude more accessible and philosophically clear. Zahavi (2018) states that the phenomenological reduction and the epoche (the phenomenological attitude) have been contorted in such a way that it now represents a flick-of-the-switch procedure. The phenomenological reduction and epoche, however, is a philosophical attitude that aims to suspend the dogmatic beliefs we have regarding phenomena of the world that has been reduced to a taken-for-granted perspective (Spiegelberg & Schuhmann, 1994; Zahavi, 2018). The attitude, as a result, reinforces the need to closely examine the common-sensical and complex positions that we assume as being valid and reliable without question or inquiry, reinforcing previous concerns over the enframement of knowledge and reality. Giorgi (2009, p90) underscores the importance of the phenomenological attitude by stating that "the speed and habituality of such acts (of consciousness) often make us ignore presentational aspects of the given that are important or make us posit as existing certain characteristics that do not warrant such positing's".

Zahavi (2019) has also extended this argument in an attempt to propose that the phenomenological attitude, or the epoche, should not be exercised by researchers or philosophers constantly, and should, on the contrary, be employed when only necessary. Zahavi (2019) asserts that numerous researchers engaged with phenomenology simply accept the use of the epoche because of its perceived importance in the literature. Likewise, Giorgi (2009) acknowledges that the phenomenological attitude has other words that have been associated with its meaning in contemporary academic literature, such as "bridling" (Dahlberg, 2006). Giorgi (2008) has been critical of the contemporary expressions that are becoming synonymous with the phenomenological attitude that was espoused by Husserl. Giorgi (2009) suggests that the significance of the phenomenological attitude can be distorted by shifting attitudes of different disciplines, ultimately overlooking the philosophical heritage that underpins the concept.

Reflecting upon Giorgi (2009) and Zahavi's (2019) concerns for the phenomenological attitude, I believe it is necessary to engage with Husserl's philosophical attitude and reflection as a matter of remaining faithful to the original

phenomenological project. I also believe it is necessary to engage with the phenomenological attitude because I, personally, have not experienced living with or beyond cancer and thereby cannot attempt to speculate or theorise the experiential nature that is a part of this very complex phenomenon. Therefore, I must engage with each area of participants' experiences openly and without my own theoretical or professional assumptions in order to formulate an eidetically sensitive psychological description and structure.

Of course, this does not then suggest that I am starting from what Spiegelberg and Schuhmann (1994) describe as an "absolute zero". On the contrary, the management of the phenomenological attitude involved being open to what I believe is true of the subject matter. This process involved considerable reflective exercises that I had to engage with before and during the data collection phase of the study. It is this sense of truth which I hold that has been suspended throughout the duration of the study insofar that I do not abandon my personal and professional beliefs, but I rather attempt to become aware of what is given and true to the participants in this study.

Husserl's phenomenological method, therefore, is a three-step attempt to discover the transcendental essence of any subjective experience that is presented to our consciousness or lifeworld (Giorgi, 2009). This explicitly involves assuming the phenomenological attitude to study a certain phenomenon, using free imaginative variation to discover the phenomenon's most essential meaning and presence, and finally, describing the phenomenon in all of its foundational parts and features that honours what was presented. Like most philosophical thought, Husserl's phenomenology was, and still is, subjected to criticisms of its fundamental features, especially the phenomenological attitude, ultimately leading to the development of other projects based on the philosophical foundations of Husserl's phenomenology. I have, therefore, included a commentary on the subsequent phases that have been developed to offer the broadest philosophical scale of phenomenology.

### **3.1.9 Post-Husserlian phenomenological movements**

For reasons relating to dubiousness and criticism of the phenomenological attitude, philosophers such as Martin Heidegger (1889-1976), Jean-Paul Sartre (1908-1980), Maurice Merleau-Ponty (1908-1961), and Emmanuel Levinas (1906-1995) adapted

the philosophy of phenomenology to fulfil other philosophic projects, such as hermeneutical and existential phenomenology (Spiegelberg & Schuhmann, 1994). An overview of the aforementioned philosophers and researchers will be presented to locate the depth and diversity that exists in phenomenological philosophy. The overview will likewise allow the reader to identify the philosophical groundings of the methodologies that were cited in the narrative literature review (i.e. IPA).

Martin Heidegger, assistant to Husserl from 1919 to 1923 at the University of Freiburg, recognised the significance of understanding phenomena of the experiential world. Yet, Heidegger asserted that it could be accomplished through a stance contrary to Husserl's position of suspending a pre-conceived understanding of a given phenomenon (Cerbone, 2014). Heidegger's phenomenology, therefore, shifted from the scrutiny of the consciousness of any given phenomena to movement to understand experiential phenomena through exploring the nature of being, otherwise referred to as *dasein* (Spiegelberg & Schuhmann, 1994). In doing so, Heidegger's phenomenological project attempted to emphasise the nature of being without the Husserlian feature of the phenomenological attitude, as he would go on to argue that we are all beings in the world and cannot escape the presuppositions and historicity we have come to understand through various phenomena (Wright-St Clair, 2014; Van Manen, 2016; Spiegelberg & Schuhmann, 1994; Mulhall, 2013).

Mulhall (2013) succinctly described the nature of enquiry to support the Heideggerian school of phenomenology. For example, when we ask questions, we are already a part of the process, thereby rejecting the doctrine that we can present an interrogation of thought as a presuppositionless basis for understanding phenomena, and so rejecting the Husserlian phenomenological attitude. Furthermore, amongst the academic debate that can confuse the differences between Heideggerian and Husserlian schools of phenomenology, Spiegelberg and Schuhmann (1994) explain the philosophical dichotomy that exists between the two. Husserl espoused the "...wonders of all wonders is the pure ego and pure consciousness, whereas Heidegger's position underlines that "man along of all existing things... experiences the wonder of all wonders: that there *is being*" (P.347). Philosophically, this emphasised the shift in focus regarding their respective ontological and epistemological stances. Heideggerian phenomenology

subsequently recognised the ontological significance of a person's relations with phenomena as opposed to what we come to understand from their experiential consciousness, which was the epistemological project of Husserl.

Influenced by both Husserlian and Heideggerian perspectives, the emphasis of the phenomenological project was further developed by French philosophers (Spiegelberg & Schuhmann, 1994). Similar to those that came before him, Jean-Paul Sartre did not claim to be a phenomenologist. Concerned with political and philosophic questions, Sartre's plays, critical essays, and novels centred on the topic of existentialism. Spiegelberg and Schuhmann (1994) underline the importance of Husserlian and Heideggerian phenomenology in Sartre's development of 'subjective-freedom' and 'objective-being' inasmuch that both philosophers served as a stimulus rather than a leader from which he was a disciple. An overall appraisal of Sartre's phenomenology offers a revival of Husserl's project of subjectivism, whereby he brought existentialism to the forefront of French philosophy. However, despite Sartre's liberation of phenomenology through creative analyses, he did not critique the philosophical methodology employed to understand the phenomenal field of the lifeworld, partially failing to deliver an overall critique of phenomenology (Spiegelberg & Schuhmann, 1994).

Another figure within the phenomenological movement who identified both Husserl and Heidegger as key figures in his writings was Maurice Merleau-Ponty (1908-1961). Merleau-Ponty sought to understand phenomenology's philosophical complexities. Merleau-Ponty was similar to Sartre in that he did not consider himself a disciple but one who shared a critical standpoint with certain features of phenomenology's past and present concepts. Despite being considered as philosophical comrades in their understanding and study of existentialism, Merleau-Ponty's project began to deviate from that of Sartre's path in the 1950s. Spiegelberg and Schuhmann (1994) are clear in their analysis of the difference between the two, with alternative views emerging in dialectics regarding the dualism between the mind and body. Furthermore, Merleau-Ponty's efforts were further developed through and in his *Phenomenology of Perception* (1945), criticising the mainstream philosophic traditions of empiricism and intellectualism (Spiegelberg & Schuhmann, 1994). As Husserl had put intentionality as his centre-piece, Merleau-Ponty's project essentially sought to place the body as one that is on par with intuitive

consciousness, for its sensory stimulation cannot be relegated to that of a secondary object (Spiegelberg & Schuhmann, 1994).

To conclude, phenomenology has a deep and rich philosophical tradition dating back to the 20<sup>th</sup> century, with numerous individuals offering philosophic applications of varying degrees. To disregard phenomenology as misguided, as many have done (Speigelberg & Schuhmann, 1994; Zahavi, 2018), would be to ignore its usefulness upon illuminating the qualitative distinctions found in everyday phenomena. What follows is a synthesis of the transformation of philosophic phenomenology to applied phenomenology through different academic disciplines and researchers. This commitment to communicate applied phenomenology will subsequently set the scene for the arrival of how descriptive phenomenology will guide the phenomenon of interest of this doctoral research study.

### **3.1.10 Phenomenology as an applied research methodology**

Both Husserlian and Heideggerian variations of phenomenological philosophy have been adapted to meet contemporary, academic projects (Finlay, 2011). Finlay (2011) extensively covers how Giorgi's (2009) Duquesne school of the Husserlian descriptive method, the Dallas school of thought (Garza, 2007), the open and reflective lifeworld approach of Dahlberg, Dahlberg, and Nystrom (2007), the dialogal approach by Halling (2006), the embodied enquiry approach of Todres (2007), Van Manen's school of Dutch phenomenology (1990), and Jonathan Smith's IPA method (2009) all contain underpinnings from phenomenological philosophy despite being hotly contested.

Though followers of Husserlian and Heideggerian philosophy have alternative views on how the method should be applied to researchable phenomena, the above approaches practically aim to place a researcher in a position that aims to capture the essential meaning of an individual's experiential world. It is, however, the philosophically-informed methodical procedures that have often caused controversial disagreements (Zahavi, 2018). By way of example, I will provide a brief overview of Amedeo Giorgi's, Max Van Manen's and Jonathan Smith's approaches of applied phenomenology. The three approaches have been commonly used for different disciplines to study human psychology and pedagogical sciences.

Considered to be a classical Husserlian approach to phenomenology, science, and psychology, Amedeo Giorgi's Duquesne school of descriptive phenomenology is considered to be a rigorous and systematic methodology. Staying close to Husserl's effort of developing a scientific strategy for philosophy, Giorgi (2009) sought to develop a methodology and method that would respect the investigation of psychological phenomena that would equal that of the reductionistic methods he had previously been trained in. Critiquing the control of environmental conditions in psychological laboratory-based research, Giorgi (2009) respects the subjective and qualitative dimensions that are present in the individual lifeworld. In response, Giorgi's phenomenological project is a commitment to human reality and an answer to the positivistic quest for causality and generalisability.

Consequently, Giorgi (2009) explains that human psychology can become its own discipline through engagement with phenomenological science. Mainstream psychology, Giorgi (2009) claims, has followed the philosophical and methodological frameworks of the natural sciences which aim to test and manipulate 'real objects' in controlled environments. Further, Giorgi (2009) has critiqued the method and setting in which humans and animals have been studied in mainstream psychology, resulting in a distorted reality in ways that would not produce the same behaviour or causal explanations in a heavily contextualised setting (Applebaum, 2012).

Without repeating previous discussions, the positivistic, reductionist research design relies heavily on a laboratory-based setting to study phenomena of the world. The laboratory is often associated with experimental procedures that offer causal laws, facts, and universal truths regarding phenomena that range from microbiological organisms to human behaviour (Giorgi, 2009). However, Giorgi (2009) identifies the inherent flaw of attempting to understand the psychological praxis of human experience within a laboratory setting, as the variety of contexts usually attached to an experience have significant and important implications on the meaning that is ascertained. Giorgi (2009, p.115) underscores the necessity of understanding the context or situated position in which the human "stream of consciousness" is exposed to outside conditions that can easily be controlled or repeated.



Broome's (2011) descriptive phenomenological study of police officers using deadly force while on duty is a sufficient example of the importance of meaning in a context that is not pre-controlled. Broome (2011, p.77-78) addresses the complications of ignoring context by suggesting "it is the plucking out of the psychological phenomenon (along with the person in whom it is inherently found) from its natural habitat and forcing it into the contrived context that imposes the greatest threats of 'contaminating' it prior to its analysis and subsequent understanding".

Using interviews as the method to understand a specific phenomenon, Giorgi's (2009) phenomenological analytical procedures are a step-by-step process which aims to meet scientific (systematic, general, methodical, and critical) and philosophic (Husserl's theory of intentionality) criteria. In brief, the method is first of all based on assuming the phenomenological attitude before (1) reading for a sense of the whole that is posited in the raw description of a phenomenon (i.e. phenomenological interview and transcript), (2) determination of meaning units within the descriptions, (3) transformation of participants' natural attitude expressions into phenomenologically sensitive expressions, (4) synthesising the transformed meaning units into an essential description of the phenomenon, and (5) determination of constituents that comprise the eidetic and experiential structure of the phenomenon being studied (Giorgi, Giorgi, & Morley, 2017; Giorgi, 2009).

Giorgi (2009) does explain that the whole process must be discipline-specific and is subject to the constitution of the researcher undertaking the study. Giorgi (2009, p.191) states that a psychologist engaging in the phenomenological method "has to come up with the psychological meaning of the details, which is a type of invariance that is different from the philosophical essence". This, consequently, keeps it within a scientific perspective, as moving beyond a specific disciplinary boundary would involve performing a transcendental study of universal essences, which was Husserl's philosophical project (Giorgi, 2009).

Staying firmly aligned with Husserlian principles, Giorgi's approach has been criticised as being "underwhelming" because of its systematic nature, with further assertions that his step-by-step approach does not fully respect the anti-reductionist approach that phenomenology seeks to critique and possibly avoid (Zahavi, 2018; 2019b). Yet, Giorgi (2009), who undoubtedly is in a minority of phenomenologically

informed psychologists, proposes that his method and overall approach has to answer the positivistic claims for validity and reliability that is sometimes unconvincing in qualitative research, whereby the entire process may be unsystematically naive and lacking in scientific rigour (Applebaum, 2012).

Considered to belong to the Dutch school of phenomenology, Max Van Manen's hermeneutical approach to phenomenology "... consists of the ability, rather the art of being sensitive – sensitive to the subtle undertones of language, in the way language speaks when it allows the things themselves to speak" (Van Manen, 1990, p.111). Claiming to follow primary literary sources in phenomenological philosophy, Van Manen (1990) explains that his phenomenological project is to understand lived experience, whereby an individual would understand 'what something is like' by engaging in the phenomenological attitude to understand the essential features and structures of a given phenomenon. Van Manen (1990), like many other qualitative researchers engaged with phenomenological philosophy, does not propose an overly complicated methodology at this point in that it respects the original components of qualitative research and the philosophy of phenomenology.

However, Van Manen's straightforward approach toward phenomenologically underpinned research becomes complicated and has been criticised for breaching into Husserlian, Heideggerian, and his conceptions (Zahavi, 2019; 2019b; 2020). Despite claiming not to be overly technical in his project, Van Manen proposes a philosophical engagement with twenty-one procedures (nine reductions, five methods and seven heuristic moves) that ultimately make the entire process complicated and possibly unapproachable to those who are not fully immersed in phenomenological trainings (Zahavi, 2019; 2019b). The procedures, which are suggested to be of his conceptualisation (Zahavi, 2019b), cross philosophic boundaries and do not, at times, represent the philosophers (i.e. Husserl and Heidegger) who wrote extensively about their respective projects. However, like Giorgi (2009), Van Manen (1990) does harness the lifeworld for an investigation of a chosen phenomenon if one can adopt the complex procedures involved (Zahavi, 2019).

Contrary to Amedeo Giorgi's and Max Van Manen's respective methodological projects, psychologist Jonathan Smith developed his methodology and method of

*Interpretative Phenomenological Analysis* (IPA), which featured heavily in the literature review of this study. Originating in the discipline of psychology, Smith's method, he proposes, follows the Husserlian proclamation of 'back to the things themselves' to understand subjective phenomena before it is confined to a theoretical model of knowledge that is accepted as truth without critical enquiry (Smith et al., 2009). Where IPA differs from Husserlian phenomenology, Smith and Osbourne (2007, p. 53) write, is that "it attempts to explore personal experience and is concerned with an individual's personal perception or account of an object or event, as opposed to an attempt to produce an objective statement of the object or event itself". Consequently, the entire IPA process has been proposed as being overly concerned with idiosyncratic science rather than focussing on the shared essential constituents and experiential regions of a specific phenomenon (Zahavi, 2019).

Smith and Osbourne's (2007) IPA stresses the importance of clarifying the phenomenon in which a participant has originally attempted to describe or articulate. In turn, a researcher would attempt to interpret the potential ambiguities throughout the analytical process, which has been described as 'double hermeneutic' (Smith et al., 2009). Similarly to most qualitative and phenomenological frameworks, the process then follows an analysis of identifying structures within the experience without attempting to offer a general claim, which is what is found in Giorgi's (2009) methodology.

Yet, the approach of IPA has undergone criticism, with claims proposing that its foundation crosses several philosophical boundaries that are not originally compatible (Zahavi, 2018). Furthermore, Smith's project faithfully attempts to acknowledge the founding pillars of phenomenology due to its focus on the idiosyncratic and subjective nature of experiential phenomena. Yet, Zahavi (2018) continues to criticise the method by asserting that it does not incorporate phenomenological science into the design of IPA (i.e. free imaginative variation). Smith et al. (2009) do, however, reject any such limitations of the methodology, asserting that its place amongst other methodologies is justified. Whilst I do not criticise Smith's methodology of IPA, it was challenging for myself to fully grasp how a systematic and procedural method has been incorporated in the various studies that used the methodology and method of IPA cited in chapter two.

Finally, the practical and analytical means of how phenomenological work is fulfilled in applied research has deepened the debates between the aforementioned researchers. For example, when using Giorgi's or Van Manen's approach to phenomenology as a method toward understanding experiential phenomenon (i.e. interviews on a specific phenomenon), it is expected that the researcher will attempt to harness the phenomenological attitude to develop an understanding of the essential experiential structure of those who are expressing the phenomenon. In typical phenomenological research, for example, interviewing an individual about their experience of certain phenomena, a researcher would attempt to ask questions that are not leading or directly focussed on providing a specific answer that you would find in a questionnaire or a structured interview. Rather, it is expected that a researcher would ask questions that require more clarification or description of the previous answers the participants have provided (Englander, 2012; Zahavi, 2018).

Moreover, the phenomenological interview becomes the personification of the phenomenological attitude, whereby the consciousness of the participants leads the direction of the interview whilst the interviewer resists the urge or temptation to accept conversational-like responses. In comparison with what may be experienced in a generic qualitative interview, the phenomenological interview may initially be a challenging process for both the interviewer and participant. The interviewer may feel under pressure to be sensitive when eliciting further description from the participant for what may seem like commonsensical responses. In turn, then, the participant may feel as if they are not offering an adequate response if they are being probed for greater depth and insight. As was the experience of this study, this challenge occurred initially before settling into a rhythm or flow that was bound by the depth that was being requested by myself throughout the interview.

However, if a researcher seeks to explore a phenomenon from the angle of an interpretative phenomenologist, it is not uncommon to employ the use of a semi-structured interview guide (Pietkiewicz & Smith, 2012). The guide, according to Pietkiewicz and Smith (2012), supports the interview by offering several topics to cover throughout. The option to exercise the use of a guide does, however, suggest opposition to the notion of the phenomenological attitude, relating to the acknowledgement of the historicity people carry into an experience (Mulhall, 2013),

as well as Smith's (2009) position of being responsible for interpreting the participants' interpretation.

The three aforementioned methodologies differ in their respective attempts to either describe, interpret, and explain human phenomena. This is not to suggest that the three are flawless in their approach to applied phenomenology and qualitative research. Critical analyses by both Zahavi (2019) and Paley (2018) offer a way of understanding the challenges and difficulties that are present within each methodology and method. Whilst Zahavi (2019) is concerned for the overall quality of phenomenological work that is undertaken because of the complexity of the underpinning philosophical concepts, Paley (2018), on the other hand, is content on a constant critique of Giorgi, Van Manen, Smith, and others, without offering his project for phenomenology.

To summarise, descriptive phenomenology as a methodology and method stays close to the concrete descriptions of an experiential phenomenon, whereas interpretative phenomenology attempts to uncover meaning and translate the ambiguities that appear in descriptive text or writings, subsequently transforming the description of the phenomena beyond the original expression. Each of the three researchers' methodologies and methods does not always translate into clear and distinct approaches that are fully representative of the original philosophical movement (Zahavi, 2018; 2019), with challenging technical principles applied to each respective approach being cited in all three. Finlay (2011) critically surveys the applied phenomenological field by suggesting that phenomenology is not as simple as utilising one method over another. Rather, Finlay (2011) diplomatically calls for phenomenology to be exercised as a continuum or system of classification, whereby exploring a phenomenon can be descriptively grounded through an interview, whilst applying a theoretical framework to delineate the nature of its meaning in the stages of interpretative discussions.

As for the methodological grounding of this study, the appeal to use Giorgi's (2009) descriptively grounded phenomenological approach was exercised because of the foundational stance of the study that was articulated in chapter two. The recommendations proposed by Burke et al. (2017) established that other unstructured recreational approaches for those living with and beyond cancer are

now necessary to increase the awareness of the diversity of post-treatment rehabilitation services. Therefore, to comprehend the essential components of other settings and activities that are being used, a descriptive approach is thought to be suitable and relevant. By using this approach, the experiences of men, women, and children can be recognised and constituted into an essential structure that comprehends the essential ‘parts and wholes’ that generally underpin the experience (Giorgi, 2009). Yet, considerably more justification will be offered in part two of this chapter.

### **3.1.11 Summary**

Throughout part one of this methodological chapter, I have offered an extensive overview of both qualitative and phenomenological traditions. As well as addressing both the philosophical and applied features of phenomenology, I have also demonstrated how one of the aforementioned academic methodologies can be applied to a study of human experience, providing it fits the criteria for such an endeavour. Therefore, what follows is a thorough overview of the context of this study, introducing why and how Giorgi’s (2009) descriptive methodology of phenomenology has been applied to this doctoral thesis. Importantly, part two will establish why and how an eidetic description and psychological structure were incorporated to fully discern the meaning of recreational programmes in the natural environment for those living with and beyond cancer.

## **3.2 Part Two - Application of descriptive phenomenology**

### **3.2.1 The 4 Cancer Group**

As a means of engaging with a CSO to explore how the third sector supports those living with and beyond cancer through recreation in the natural environment, I collaborated with the 4 Cancer Group on behalf of the University of Brighton. Established in 2001, the 4 Cancer Group is a UK registered charity (1090133) and their mission is to help the whole ‘family unit’ manage the impact of living with cancer. This includes:

- “Creating memories for affected families which last a lifetime. ”

- “Promoting an active lifestyle to help lower cancer incidence and assist in recovery.”
- “Strive to improve the standards of ‘end-of-life’ cancer care.”
- “Fostering ‘Fortis in Adversis’ (Courage in Adversity) in everything we do.”

The 4 Cancer Group is split into five divisions, which include Sail 4 Cancer, Run 4 Cancer, Bike 4 Cancer, Ski 4 Cancer and Trek 4 Cancer. Each division has a two-fold purpose, with one half committed to raising funds through the particular activity it represents, while the other half is committed to providing and organising recreational programmes that serve as “respite” for those living with and beyond cancer. Also, the 4 Cancer Group represents five core values. These include:

**1. “Be Courageous** - Dealing with a cancer diagnosis requires immense courage; for the whole family unit. Our recreational programmes build confidence and provide time-out to carry on the fight. As a charity, we believe that courage should drive everything we do. We trust in one’s own abilities and we see change as an opportunity. ‘Fortis in adversis’– Courage in Adversity.”

**2. “Embrace Creativity** - Creativity underpins everything we do; it is our lifeblood. We strive to learn and push to improve every day. We always try new things and we try new approaches to old things. We’re never afraid to try something new because no one else has done it before. Through innovation and belief in our colleagues, we strive to accomplish things that no outsiders think we can.”

**3. “Choose Positivity** - We always approach tasks in a positive and optimistic way. We never criticise or condemn team members, suppliers or partner organisations. If we’re unhappy about something, we communicate in a respectful, constructive and professional manner. We see the good in every action or reaction and make a point of sharing genuine appreciation.”

**4. “Growth Is Good** - We believe in pushing the boundaries. Internally, this means we are prepared to take calculated risks and step outside of our comfort zones. We strive to help more people every year and to grow our impact. For our supporters, we strive to create events which inspire people to raise funds. Similarly, our recreational activities will enable people to do the things they thought were no longer

possible. Growth is not a numbers game; it affects everything we do (people, memories, skills and impact alike).”

**5. “Listen to Understand** - We recognise the importance of understanding a person’s motivations, whether that person be a fundraiser, supplier or beneficiary. For some people, simply helping the charity will not be enough. By understanding the true value to each stakeholder, we can build sustainable relationships which foster long term growth.”

### **3.2.2 Initial collaborative considerations**

Whilst it is now clear that I have used Giorgi’s (2009) methodology and method to address the phenomenon of interest, I want to briefly address other methodological frameworks which I initially considered employing.

After conducting a scoping exercise, which included observing the 4 Cancer Group’s recreational programmes, I believed that an ethnographic stance would be experientially invasive as it would interfere with the participants’ experience of their recreational programme. Using an ethnographical stance would also imply that the participants are a part of a formal, cultural group, with historical and social purposes, which was not applicable for the specific nature of this study. Also, grounded theory or a narrative approach did not meet the desire to comprehend an experiential structure that could be ascertained from the phenomenon of recreational programmes for those living with and beyond cancer. Ultimately, I rejected the option to employ both grounded theory and narrative approach of inquiry as the study is focussed solely on the experiential structure of the experience rather than (i) testing an existing hypothesis to generate a theory, and (ii) focussing specifically on the ‘personal story’ of how this lived experience manifested for one specific person or separate individuals.

These choices were also informed by the themes and findings that are located in the narrative literature review. To reiterate, a substantial amount of idiographic and narrative inquiry has been achieved through Smith’s (2009) IPA methodology and other hermeneutical approaches. However, the studies that had used the methodologies and methods of IPA and hermeneutical phenomenology did not fully



convey a transparent explanation of how they adopted phenomenological tenets described in part one. Therefore, to faithfully apply the scientific tenets that are attached to phenomenology and address the phenomenon of interest, I chose to engage with Giorgi's (2009) descriptive methodology and method.

After engaging with Giorgi's (2009) phenomenologically informed approach for psychology, I understood that this methodology would enable me to expand the literature through an eidetic generalisation and structure of the phenomenon of interest. Furthermore, Giorgi's (2009) methodology and method allowed the participants' to express what was intuitively given to their experience, thereby distinguishing structures of the experience that were meaningful to them. By choosing this methodology, I have also offered another phenomenological lens through which this particular phenomenon appears, subsequently deviating from the common use of Smith's IPA method that is dominating this area of research cited in the narrative literature review.

In keeping with the philosophical heritage that is attached to the word *phenomenon*, I am committed to understanding the meaning of this project through the participants' expressions (Mulhall, 2013). To elaborate, the phenomenon of engaging in recreational programmes in the natural environment for those living with and beyond cancer is not something that willingly displays itself, but rather remains consciously or subconsciously concealed (Mulhall, 2013). Giorgi (2009) clarifies this further through his deliberations of the importance of the expressions of the participants' experiential worlds.

Giorgi (2009, p.107) explains that "...unfortunately, there is no access to this world so it has to be accessed indirectly through some form of expression. There are many forms of expression, from concrete behaviour to artistic, and each has its own peculiar difficulties with respect to the assessment of the participant's experiential world. Of course, one of the major forms of expression is language, and it holds that privileged, but not exclusive, place with respect to the determination of the world of the other". It is through the participants' expressions of their recreational programme in which I established of the essential experiential structure, therefore placing subjective consciousness of both the participants and myself at the heart of this epistemological and ontological project.

Furthermore, the aforementioned discussions of intentionally, whereby various acts of meaning are intuited and imaginatively varied through consciousness, has formed the basis of how I discerned the phenomenon of interest (Giorgi, 2009). This approach involved evoking lifeworldly descriptions of how the participants experienced their recreational programme, encouraging descriptions of an experiential presence and appearance of the recreational programmes. Whilst doing so, I engaged with what has been described through the Husserlian principles of the phenomenological attitude. This is often performed by acknowledging and reflecting upon one's position in this process, as well as adhering to what Finlay (2011) describes as "disciplined naivete", whereby the phenomenon can be evoked without theoretical or personal contamination.

Before data collection, I did not automatically assume to know of the participants' experiences despite learning of the services that the 4 Cancer Group offers. This was a conscious decision to committedly engage within the phenomenological attitude of being a presuppositionless researcher. For example, one of the first opportunities to engage with the phenomenological attitude was to stop referring to the 4 Cancer Group's recreational programmes as 'respite' during the interviews and, in turn, allow the participants to simply talk of their experience without any level of abstraction. To use the word respite as a means of describing the participants' experiences is a level of interpretation that has not been directed or articulated by the participants themselves, but by the 4 Cancer Group, as this is what the organisation aim to offer their beneficiaries.

Similarly, the participants involved in this study have not been referred to as cancer patients or cancer survivors for the same reasons that have been described above (Mullan, 1985; Khan, Harrison, Rose, Ward and Evans, 2012). Building on the work by Mullan (1985), who experienced a diagnosis of cancer, Khan et al. (2012) have identified that the terminology (i.e. cancer survivor) and discourse (i.e. "journey" or "recovery") that is used for those who are recovering from cancer is and can be politicised, medicalised and heavily reductionistic. In their study of interpretation and acceptance of the terminology used for those who are recovering from cancer, Khan et al. (2012) discuss the many linguistic forms and variations. Accepting that the usage of "cancer survivor" and "sufferer" can be used as a factual and emotive

description, the participants, of which there was forty people ranging in various diagnoses, also discussed the social, psychological and biological implications attached to the terminology. Interpretations suggested that there was always the possibility of biological recurrence and a person's identity is simply not defined by having an ongoing or previous diagnosis of cancer (Khan et al., 2012).

Also, the resultant themes suggest that an individual can find their own description and interpretation of their "recovery" without being enveloped by the common or politicised discourse. A step back from the common discourse and terminology is not a rejection of the term cancer survivor but it is a phenomenological orientated reflection of the fluidity of what it means to be reduced to a medical and chronic health condition. For the remainder of this study, and when it is appropriate, the individuals involved in this study will be referred to as participants or those living with and beyond cancer.

### **3.2.3 Philosophical and psychological claims**

It is important to provide a coherent argument for the chosen disciplinary perspective that is advocated by Giorgi (2009) and the subsequent epistemological and ontological claims that will emerge from this study. In doing so, I make an explicit argument for how this research study will use a psychological perspective to comprehend the phenomenon of interest in its broadest capacity, as well as the epistemological and ontological claims it will provide through the findings of the research.

It has been acknowledged I must adopt a disciplinary perspective to present the most essential structure of the phenomenon of interest (Giorgi, 2009). The perspective is necessary because Husserl's phenomenological philosophy sought to achieve a universal essence of any given phenomenon, which represents the transcendental nature of his project. This does, however, transcend any scientific discipline of interest, which is where this thesis takes its point of departure to follow Giorgi's (2009) scientific method. As I am not a philosopher, but a student and practitioner in the health sciences, I have assumed a disciplinary perspective of psychology to determine the phenomenon's essential experiential structure, which will now be referred to as the psychological structure.

The disciplinary perspective of psychology stems from my educational and applied background. Whilst I am not a psychologist, I have, and currently am working in a clinical setting that requires the elicitation of experience from people regarding their weight management and disordered eating patterns of behaviour, which is laden with psychological characteristics and processes. Moreover, in my work as a health advisor, I have employed certain methods (i.e. questionnaires) that aim to capture the experiential lifeworld of the patients who I aim to support. However, this can have an impact on clinical assessment and treatment as such methods can restrict patients from verbalising and articulating something particularly important to them that relates to their health and sense of well-being. The application of psychological phenomenology was, therefore, an opportunity for myself to engage with a philosophically-informed method of enquiry that would help inform and develop my qualitative and professional proficiency by using the phenomenological attitude to allow the phenomenon to speak for itself.

The option to select psychology as the disciplinary perspective also serves as a means of critiquing the mainstream approach and use of experimental psychology (Giorgi, 2009). By using phenomenologically informed psychology, a wider critique of the discipline of psychology can be yielded to attempt to re-orientate its humanistic concerns that have faded in the quest for empiricism by the natural sciences. The same would apply if I was from that of a sociological or anthropological background. The disciplinary perspective of psychology within Giorgi's scientific phenomenological method, therefore, steps back from Husserl's search for philosophical essences, as philosophising in this way would not fully disclose the psychological meaning of the phenomenon (Giorgi, 2009).

In addition to the disciplinary perspective, I must also provide an epistemological and ontological grounding for the study. By following a descriptive phenomenological design, I am focussed on the conscious study of the lived experience of the participants who consented to be involved in the study. Therefore, I am going to be making epistemological claims regarding the participants' ontological reality of recreational programmes in the natural environment as they are living with and beyond cancer. As I am engaging with the phenomenological attitude, as opposed to a theoretical or conceptual model, the study's claims can

only stay within the boundaries of the given data, neither adding nor subtracting from the subjectivity from which it originates. Epistemologically, then, I would stress that I have remained with the subjective world of the participants to present the experiential constituents that form the psychological structure found in chapter four.

However, once I had discussed the psychological and eidetic generalities of the participants' experience in chapter four, I was obliged to go beyond the empirical data and subsequently immerse myself back in the natural attitude by discussing the data alongside other scholarly work. This was a conscious decision to discuss the implications of the data alongside the literature that has been identified in the narrative literature review. This does not in any way distort the descriptive grounding of the experiential givens as the psychological structure will have been delivered and discussed by this point of the study. Researchers and academics are interested to further develop their respective fields of knowledge, and in this instance, I have followed the same agenda. However, in order to do this, I first engaged with the scientific phenomenological attitude to provide an essential description and psychological structure of the phenomenon of interest before reflecting on the wider implications of the outcomes. Philosophically, then, the research study is two-fold. The primary stance was to offer a phenomenological analysis of the psychologically lived through experiences of the participants of this study, before re-engaging with the wider scholarly literature to discuss how this study has implications for healthcare strategy and those living with and beyond cancer.

### **3.2.4 Summary**

To summarise, I adopted Giorgi's (2009) scientific and descriptive phenomenological method to ascertain the essential psychological experience of those living with and beyond cancer when engaging in recreational programmes in the natural environment. The initial findings of this study begin by offering an eidetic description of the meaning of recreation for the participants before moving on to elaborate on the structural constituents that form the structure. This analysis will be further developed by re-engaging with the natural attitude to understand how the findings relate to the wider academic context in the area of cancer rehabilitation and survivorship that was discussed in the introduction and narrative literature review.

Overall, the study has provided a psychological structure of the meaning of recreational programmes in the natural environment for men, women, and children, which is something that has not yet been fully expressed in the academic literature. What follows is an articulation of how I practically applied Giorgi's (2009) method of the descriptive phenomenology for this specific study. The discussion will include the reasoning and rationale that supported the procedural decisions that were made to study the phenomenon of interest.

### **3.3 Part Three – Context, method and procedural considerations**

#### **3.3.1 Ethical Approval**

Ethical approval for the study was granted by the cross-school ethics committee for life, health, and physical sciences at the University of Brighton on 09/04/2018 until the proposed end date of the project, 01/10/2020. The appendices exhibit the various forms and assessments that were applied to ensure participant rights and full transparency of the doctoral project. However, the entirety of part three has been designed to communicate all of the ethical and practical considerations that were undertaken to carry out the study. What's more, I have explicitly communicated how I negotiated the collaborative design of the study in an ethically responsible manner. For example, the following recruitment procedures identify how I established contact with the participants' without going beyond my role as the student representative.

#### **3.3.2 Recruitment strategy and considerations**

Recruitment strategies are often determined by the research phenomenon that is being explored. As opposed to quantitative questions, which seek to randomly recruit large samples of the population to meet universal laws of empiricism, such as empirical generalisability, phenomenological researchers frequently utilise maximum variation sampling strategies to fulfil eidetic claims of knowledge (Giorgi, 2009; Englander, 2012; Wertz, 2010).

Maximum variation sampling is simple in that it aims to recruit participants from differing demographics (i.e. age and gender) in order to understand the eidetic constituents of any given experience (i.e child-birth, experiencing a stroke, and

cancer) (Englander, 2012). However, sampling in a phenomenological study is not about the sociological elements of the participants who are included, but rather the psychological meaning of the phenomenon that is of interest (Englander, 2012). Therefore, in the overall design of this research project, I used maximum variation to recruit a variety of participants who have had a direct experience of cancer and have participated in the 4 Cancer Group's recreational programmes. Table 3.0 (see below) details the variations in participant personal information to exhibit how maximum variation was applied.

<b>Participant</b>	<b>Age</b>	<b>Gender</b>	<b>Cancer Diagnosis</b>	<b>Recreational Programme</b>
1	17	Female	Medulloblastoma	Sea Sailing
2	56	Female	Pancreatic neuroendocrine tumours	Riverboat Sailing
3	15	Female	Germinoma brain tumour	Riverboat Sailing
4	15	Male	Leukaemia	Sea Sailing
5	43	Female	Breast cancer	Sea Sailing
6	55	Female	Breast cancer	Sea Sailing
7	59	Female	Breast cancer	Sea Sailing
8	62	Female	Breast cancer	Sea Sailing
9	53	Female	Breast cancer	Sea Sailing
10	67	Male	Ocular melanoma and liver cancer	Sea Sailing
11	32	Male	Non-Hodgkin lymphoma	Sea Sailing
12	47	Male	Bladder cancer	Skiing and Riverboat Sailing

**Table 3.0** – Participant demographics to demonstrate maximum variation.

The recruitment procedures were initiated by managerial, administrative and coordination staff from the 4 Cancer group by emailing or sending letters to participants who have used the 4 Cancer Group's recreational programmes. The

members of staff were briefed about the ethical procedures before recruitment had commenced through team meetings that I was invited to join as the student collaborator. The participants who had been selected to be sent a letter had been involved in at least one of the 4 Cancer Group's recreational programmes. Though the 4 Cancer Group is split into a variety of distinct divisions, the recreational programmes mainly consist of sailing and skiing programmes and activities due to seasonal restrictions. These include activities and programmes that are designed for individuals, families, and groups living with and beyond cancer.

To make the process less coercive and more systematically rigorous, the 4 Cancer Group's official patient coordinator contacted potential participants who had indicated that they would be willing to receive updates and charity information in the future via their pre and post programme survey response. The 4 Cancer Group, therefore, committed to maintaining their position as the gatekeeper and intermediary during the initial phases of participant recruitment for the study. All personal information and details of the potential participants remained with the 4 Cancer Group during this period of recruitment to uphold confidentiality and anonymity.

After initial contact had been made and the participants were comfortable to proceed with the next stage of recruitment, their contact details were then passed on to me. Initial communication between myself and the participants included details of the purpose of the project, ethical considerations, participant information sheets, and reassurance about anxieties or ambiguities the participants' may have regarding their involvement. For the participants who were under the age of 18, I communicated with themselves and their parents as a way of safeguarding their well-being.

From that point onwards, the participants decided if they wanted to be involved in the project. If they did wish to proceed and participate in the study, they were asked to sign an informed consent declaration form and were encouraged to organise a date and time for a potential interview. Again, for those under the age of 18, the participants and their parents signed the informed declaration form and attended the interview with their parents. Those not wanting to take part were thanked for their interest, reassured that their decision would not affect their position with the charity and that the researcher would make no further contact with them.



### **3.3.3 Number of participants**

Twelve individuals were recruited to participate in this study (Please see table 3.0). Often debated amongst those who engage in phenomenological research, there is no precise number of participants who should be involved in the research process (Giorgi, 2009). It is generally accepted that the number of participants should not match the large numbers that would normally be included in quantitative research (i.e survey studies or clinical trials) (Finlay, 2011). The basis for such a decision stems from the philosophical and theoretical nature of performing qualitative and phenomenological research.

Wertz's (2010) discussion of eidetic analysis for psychological research elaborates on this topic of participant sampling. Empirical generalisations and universal absolutions that are found in quantitative research are recognised as facts that are extended to wider populations (Wertz, 2010). However, eidetic generalities, that of which are at the heart of this phenomenological project, make no absolutist claims but do rather focus on experiential structures of a given phenomenon (Wertz, 2010). The phenomenon of interest that will present itself within the findings of the study will subsequently offer one phenomenological analysis that is context bound to recreational programmes for those living with and beyond cancer in the natural environment. This can, therefore, be revised and presented differently through further eidetic analyses, upon which the essential experiential meanings may expand or offer a different sense of psychological givens (Wertz, 2010).

### **3.3.4 Inclusion and exclusion criteria**

For inclusion in the project, participants: (1) must have had an experience with the 4 Cancer Group's recreational programmes (2) directly experienced (i.e. diagnosis and treatment) the condition of cancer, (3) be from any ethnic background but able to communicate their experiences through the English language, (4) be in a physically and mentally comfortable disposition to discuss their experiences at length, and (5) be no younger than 12-years-old.

Participants were politely and professionally excluded from the study if they were unable to provide informed consent due to the severity of their current condition. This included diminished physical or psychological health and well-being. The participants' care team (i.e friends, family, and health care professionals) were

responsible for assessing whether potential participants were able to proceed throughout the data collection process (Groundwater-Smith, Dockett, and Bottrell, 2014). Practically, this involved members of the 4 Cancer Group communicating with members of the participants' 'care team' if there were concerns for the participants' welfare. Therefore, the 4 Cancer Group used their experience and discretion if they needed to execute such decisions.

Also, a potential participant was not directly contacted for recruitment by the 4 Cancer Group if the members of staff knew or discovered that their current condition was known to be too debilitating to participate in the project. Again, this was performed by contacting family members or friends (i.e. the care team) of the potential participants to discover if this was so. Yet, if a participant's condition worsened during the data collection period of the project, they would have been excluded from further interviews to prioritise their health, well-being, and overall care (Groundwater-Smith et al., 2014). In the event of this occurrence, the participant's care team would have been fully briefed and informed by managerial staff of the 4 Cancer Group so they were aware of how and why the participant would be excluded. However, participants' were not be completely excluded from the study if they were to withdraw at some point after they had contributed toward an interview. If deemed ready by their care team, participants would have been informed about the current stage of the study and reminded that they can still participate provided they could fully consent toward participating.

### **3.3.5 Data collection - Interview organisation**

The interviews were scheduled at the convenience of the participants who volunteered to be involved. As the study included participants who had a direct experience of cancer, there was the potential that some or all of the participants were still attending specialist clinical reviews or readjusting to life during or after cancer treatment. This was taken into consideration, allowing those who had expressed an interest in the study to meet with me when it was most suitable for them. Under the guidance of my supervisory team and the management staff at the 4 Cancer Group, it was estimated that the process of data collection would last a minimum of six to twelve months. However, because of the nature of the study, the time allocated for the interviews was adapted to meet the needs of all those involved.

For example, an additional three months was allocated for the last participant to organise and participate in an interview.

### **3.3.6 Phenomenologically informed interviews**

Once organised, each interview began with an initial experience evoking question that subsequently informed the entire duration of the interview. I began with a question that encouraged the participant to offer a description of the experience of their spent time engaging and participating in their recreational programme.

I then preceded to follow what Todres (2005) describes as clarifying the participants' descriptions and experiences through open-ended questions, rather than driving or steering the given responses towards a theoretical position or personal bias. Each participant, accordingly, became the source through which the phenomenon derives, whilst the researcher rejects the natural attitude that would normally be present during ordinary, conventional conversations (Moran, 2000; Giorgi, 2009; Schutz & Luckmann, 1973). In this instance, the natural attitude that I would engage within would be to possibly draw comparisons from my stock of knowledge that potentially aligned with the participants' experiences (Schutz and Luckmann, 1973). However, upon using the phenomenological method and engaging with the phenomenological attitude, I refrained from doing so and in turn allowed the participant to continue clarifying and describing their experience in descriptive detail (Giorgi, 2009). Yet, it should be noted that each of the participants' responses was met with an empathetic response from myself (i.e. body language) that was intended for the participant to feel at ease and comfortable.

Furthermore, engaging in the phenomenological attitude had similar connotations with what I have encountered before in my work as a health advisor for an NHS weight management and disordered eating service. Rather than assume or arrive at an immediate reduction over the reason for a patient's referral (i.e. inadequate dietary habits, lack of exercise or general mobility, psychological diagnosis of depression) and try to immediately correct the missing link, I suspend my personal and professional beliefs and allow the patient to speak for themselves (lifeworld) through open dialogue. Therefore, I hold or suspend the natural attitude of making quick assumptions of the patient's lifeworld and reflect upon the deeply rooted issues that the patients express, which is usually related to significant psychological

challenges as opposed to dietetic patterns and an inability to exercise. The attitude, in both cases of work and study, appears through open-ended dialogue and affords the opportunity to not start afresh but to understand the lived experience through disciplined naivete (Finlay, 2011), or as Giorgi (2009, p.28) writes, clarifying “the meanings of phenomena experienced by human persons”.

As the interviews in this study were designed to be unstructured and phenomenological, there was no necessity for a structured guide. This did not mean that I did not have to prepare for the interview; rather, it means that there was no structured instrument or predetermined format needed. In an unstructured and descriptive phenomenological interview, neither structured, semi-structured, or closed-ended question guides are required (Giorgi, 2009). This is due to the concept that one never knows what form the dialogue is going to take as it is the participants’ conscious and reflective intuitions that guide the dialogue. Neither I nor the respondent knows what result this interaction between us is going to generate. Importantly, because phenomenology is focussed on the conscious reflection of a specific phenomenon, it is therefore important to know how the participant experiences the world or any situation, and why this is so, without prompting any presuppositions or assumptions on the interview process (Todres, 2005; Giorgi, 2009).

This approach would subsequently serve as a response to the third theme and research consideration that was developed through the narrative literature review, which related to post-treatment outcome measures. By choosing to exercise an unstructured and descriptive approach, I was seeking to assist the participants to express their experiential world, rather than reduce it to a statistical measurement or a structured format.

After the initial experiential evoking question was asked, the interview was then directed towards eliciting further description regarding the participant’s experience. From that moment, the dialogue was guided in accordance with the participant’s answers and did not deviate from their experience. Included below is a small sample that offers an insight into what open-ended phenomenological questions were used during the interviews:

- “Please can you describe in as much detail as possible this situation you just talked about?”
- “In what way do you reflect on the experience now?”
- “What do you believe was at the centre of that particular moment you described?”

Throughout the interviews, I also employed the use of probes to allow for more depth during the interview process when it was deemed necessary. There is a small sample below that establishes what probes I used to achieve the phenomenological depth required.

- “Can you elaborate on that please?”
- “Can you give a specific example please?”
- “If possible, can you go into more detail on that point please?”

If, after the first interview, I believed it was essential to learn more of the participants’ experiences, it was planned that a second or third interview would be scheduled (Todres, 2005). I thus had the option to engage in several interviews with the selected participants as a systematic method of understanding their experiences, if it was necessary. Each participant was briefed that they could either contact me directly or the 4 Cancer Group to arrange the next interview. The opportunity to schedule another interview occurred only once with participant number twelve. This decision was made to gain further insight into some of how the participant had described his experience. For example, the participant used several metaphors to describe some of his experiences. However, I sought to investigate these further to learn more of the depth behind these experiences.

The ways in which I facilitated the one-to-one interviews varied between two options. I facilitated eight interviews in person and four interviews over the telephone, all of which ranged from sixty to ninety minutes. Both approaches were deemed suitable, as I have experience performing both styles in academic and clinical settings. Theoretically, it could be criticised that a telephone interview would not facilitate a deeply-descriptive conversation about the participant’s experience due to a lack of rapport and physical understanding (i.e. body language). While this could be argued, I believed that both approaches of ascertaining data were more than

satisfactory as each participant was able to offer a thorough and deep description of their experience on each occasion. On a practical note, the four participants interviewed over the telephone found this helpful as they were occupied with either medical appointments or work commitments on a regular basis, expressing how it was a challenge to commit to a physical one-to-one interview. This was also a suitable strategy because I interviewed participants that were considered to be a long-distance from the University of Brighton, Sussex.

Furthermore, an additional but brief commentary is necessary for the group interview that was facilitated for participants five to eight. Whilst the remaining participants each had their one-to-one interview in person or over the telephone, I scheduled a group interview with the four women who were a part of a cancer support group in Northamptonshire, England, that had used the 4 Cancer Group's recreational services. This was necessary for both experiential and practical reasons. Again, I deemed that it was appropriate to facilitate a group interview as organising four separate interviews for participant five to eight proved to be a logistical challenge for the participants due to their work and medical schedules. A group interview was agreed upon and subsequently established a unique process for each of the women to describe their lived experience (Bradbury-Jones, Sambrook, Irvine, 2009). This was not planned as part of the original approach, yet it was identified as a way in which the study could facilitate greater inclusion of participants and adhere to the initial timeline that had been proposed at the beginning of the study. In accordance with Bradbury-Jones et al. (2009), the incorporation of a group interview was also an opportunity to expand the phenomenon of interest because of the communicative atmosphere that is established through this approach.

Whilst all four of the participants had participated in the same recreational sailing programme, each participant was able to describe the implications of this experience in ways that respected their individual experience. Naturally, there were occurrences whereby the participants shared similar responses, but there were instances whereupon the participants had formed a different understanding to their counterparts. This, I believe, did not deter the participants from sharing their perspective of their given experience, which was interpreted as an advantage to avoid what is commonly known as groupthink.

However, it could be argued that the group interview was not suitable for two reasons. Firstly, a chief concern of using a group interview in phenomenologically underpinned research is that it breaks the philosophical boundaries endorsed by Giorgi (2009) and other prominent philosophical phenomenologists. For example, the participants may inadvertently 'contaminate' one another's responses in a way that does not allow them to share their given experience that is essentially true to their consciousness. Indeed, this could also suggest that the participants may not have felt confident to confide in expressing a deeply personal account of their lives. Yet, when engaging in the group interview, I believed that this did not occur due to the personal depth that was explored and expressed by the participants. For example, personal disclosures of cancer-related mental health issues were openly discussed by two participants to describe how their experiences had affected them, whilst other participants openly declared that they had not experienced the same reaction.

Secondly, there is an unavoidable argument relating to the ethical concerns and issues of using a group interview. Hypothetically, one of the participants may have wanted to withdraw from the study after the group interview had taken place due to the sensitive nature of the topic of interest. Yet, the participant may have felt pressured to resist the option to withdraw because of their prior commitment to the group interview. However, before the commencement of the study, the participants were made aware by myself that if one participant of the group wanted to withdraw from the study before the analytical phases of the study had started, they could do so without having to justify their actions. If this did occur, the remaining participants were made aware that they would be offered an opportunity to participate in another interview either over the telephone or in-person again as the group interview would have to be permanently deleted. Therefore, an ethical procedure was installed in the event of having to implement an action plan for the withdrawal of a participant during a group interview.

Recently, Zahavi (2018; 2019) has critiqued the suitability and positioning of a descriptive and unstructured interview in phenomenological research. Citing the common misuse of the phenomenological attitude and the phenomenological reduction, Zahavi (2018) is right to be cautious over what is and what is not the correct use of this reflective attitude. In his attempts to redirect the focus of how

phenomenological interviews should be conducted, Zahavi (2018) shifts the emphasis onto using the EASE-scale (Examination of Anomalous Self-Experience) for phenomenological researchers to divert from misusing the attitude. This approach, according to Zahavi (2018), does not detract from Husserlian principles and offers more options to elicit lifeworldly descriptions through its semi-structured approach. Although I do agree with Zahavi's (2018) concerns over the misinformed use of the phenomenological attitude, the EASE-scale was not used in this study. This was supported by my informed belief that the implementation of Giorgi's (2009) method cannot be performed without engaging in the Husserlian phenomenological attitude. On the contrary, the EASE-scale could distort the open-ended nature of the interview for the participant and subsequently restrict the phenomenon that was formed through analytical procedures.

### **3.3.7 Data Analysis**

Once the data collection phase had been completed, each of the participant's audio-recordings were transcribed verbatim and analysed in accordance with Giorgi's (2009) analytical procedures, which have been adapted from Husserl's transcendental, phenomenological philosophy. In this sense, the lifeworldly and naïve expressions that were recorded became phenomenological expressions that are constituted by myself to form a psychological description and structure of the lived experience of recreation for those living with and beyond cancer.

What follows is a step-by-step commentary that explains what procedures I addressed to satisfy each step of the descriptive phenomenological analysis. Firstly, however, table 4.0 has been created to exhibit the rigour and systematic approach that is essential to constitute the naïve expressions into essential psychological constituents of experience through Giorgi's (2009) approach.

<b>Analytical Procedure</b>	<b>Amedeo Giorgi's Commentary</b>
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<p><b>Step One – Reading to get a sense of the whole.</b></p>	<p>“The first (practical) step is to read through the written descriptions provided by the participants all the way to the end. In order to do a proper analysis, one must know how the described lived experience ends.” (Giorgi, Giorgi &amp; Morley, 2017, p.186; Giorgi, 2009). Also, Broome (2011, p.11) reminds the reader about the engaging in phenomenological attitude when reading the naïve expressions, saying that “the phenomenological attitude is different than the natural attitude or everyday way of understanding the world. In the phenomenological attitude, the researcher “brackets” his or her everyday knowledge to take a fresh look at the data”.</p>
<p><b>Step Two – Constituting meaning units.</b></p>	<p>“Since the ultimate goal of the phenomenological analysis is the meaning of experience, the parts to be established should be sensitive to that goal. Consequently, the aim of this step is to establish some “units of meaning” that are contained within the description. Since the analysis is also meant to be psychological, the meaning units to that perspective are also required.... As one begins to reread the description, one makes an appropriate mark in the data every time once experiences a significant shift in meaning.” (Giorgi, 2009, p129-130)</p>
<p><b>Step Three – Transforming the everyday expressions into phenomenologically sensitive expressions.</b></p>	<p>“Once the meaning units are determined, the task of the next step is to transform the meanings contained in the description in phenomenologically sensitive ways. Thus, the attitude to achieve this task requires one to not only be in the attitude of the phenomenological (scientific) reduction but also that one be sensitive to the meaning of what is being expressed” (Giorgi, Giorgi &amp; Morley, 2017, p.187)      “In this third step, one once again goes back to the beginning of the description that is now delineated into meaning units. Then the researcher starts interrogating each meaning unit to discover how to express in a more satisfactory way the psychological implications of the lifeworld description. In other words, for a psychological analysis to be fruitful, the psychological dimension of experience has to be highlighted. In a certain sense what is to be expressed is constituted by the phenomenological psychological attitude of the researcher. The psychological dimension is not just lying there fully blown, ready to be picked out. It has to be detected, drawn out and elaborated.” (Giorgi, 2009, p.131).</p>

<p style="text-align: center;"><b>Step Four – The synthesis of transformed meaning units.</b></p>	<p>“Structures are obtained by examining the last column of transformed meaning units, and with the help of imaginative variation, determining which ones are truly essential for the phenomenon to present itself to a consciousness. One should be careful here not to be too empirical as one reviews the transformed meaning units. The transformations of meaning units are determined by examining parts of the description; the structure has to be mindful of the whole. Consequently, the description of the structure itself could be different from the way that the meaning units themselves were described. It is not a matter of simply listing the meaning units together but of bringing a holistic perspective to them...” (Giorgi, 2009, p.200).</p>
<p style="text-align: center;"><b>Step Five – Determination of variants of constituents that comprise the experiential structure.</b></p>	<p>“The structure should provide a deeper insight into the unified dynamics taking place across varied experiences, and it serves as the basis of essential communication. But with the insights provided by the structure one can return to the raw data and make better sense of the variations contained therein. One can also give examples of the essential insights and help flesh out the sometimes more abstract points contained within the structure.... It is a way of understanding why diverse facts and concrete details can belong to the same phenomenon.” (Giorgi, 2009, p.200).</p>

**Table 4.0** – Amedeo Giorgi’s (2009) descriptive phenomenological analysis.

### **3.3.8 Application of Amedeo Giorgi's descriptive phenomenological analysis**

#### **3.3.9 Step one: Reading for a sense of the whole**

Engaging with the phenomenological attitude is a reflective process and it exists in the first step as the initiation so a researcher, academic, and practitioner can understand their unreflective and subjective understanding of the phenomenon being studied. Further, the attitude is about being open to the lived experience that has been presented, as opposed to immediately classifying or theorising its presence and contents.

The second key purpose behind the step of reading for a sense of whole applies to every qualitative researcher and practitioner, regardless of the methodological framework one is using. Reading the description of the phenomenon to simply understand what occurred within the participants' experience is all that is required at this early stage. The impulse and option to constitute any of the implications in the dialogue were reserved for subsequent steps.

Therefore, to begin the analysis, I:

- Assumed the attitude of the scientific phenomenological attitude as opposed to the transcendental attitude.
- Assumed a chosen disciplinary perspective - psychology.
- Was sensitive to the implications of the data for the phenomenon being researched.
- Read each transcript to understand the fluidity of the experience from the start to the finish.

#### **3.3.10 Step two: Constituting meaning units**

Once I engaged the analysis through the first step, the process of constituting meaning units began. This involved reading the transcript to determine when a shift of meaning occurred in the participant's lifeworldly and naive expressions, which was then marked as a meaning unit using a forward slash. For example, a whole paragraph can be a meaning unit or eight or nine sentences within a paragraph can

be distinct meaning units (Giorgi, 2009). The example below from participant number nine demonstrates how this was completed during step two of the analysis.

P9: Ok, so... in June 2017, I noticed some changes in how I felt physically and I went to go see my GP to get it investigated but I already had some degree of knowledge that some of these changes were associated with breast cancer / I saw a doctor and was referred under the two-week rule to a Hospital. That was on a Thursday and by Monday I was having an emergency mammogram and, erm, a biopsy/ I was told, the exact words, "this might be something sinister". Those words then played on my head for the next week and a bit whilst I was waiting for the biopsy results to come back / Erm, at that point, I was and am a single mum. I've been a single mum for my children since they were small. At that point, I had two teenagers of 14 and 16. The eldest was going through exams at that time, so I was trying to, sort of, not let on to them that anything was going on until I knew for sure / I then had an appointment with an oncologist to discuss the results. They confirmed that I had quite an aggressive and invasive lobular carcinoma of my left breast / which was, obviously, very, you know... I had a feeling the news was coming but, erm, it was delivered by an oncologist in quite a matter of fact way / Luckily, I saw a breast cancer specialist nurse straight after, who was lovely. So, although I had feared the worst and thought I was prepared for it, having those words said to me was hugely shocking and devastating... my whole world rocked underneath me / Erm, I've always been quite a strong independent person, bringing up my girls by myself. My youngest doesn't see her father, so she has only got me. I've also got an elderly mother who I look after... no brothers or sisters, so I've always been quite healthy up until then/ Quite a strong person and I've always worked/ And suddenly, it was like, oh right... (laughs)... I've got to look after myself here but what is ahead? What about my children? What about my mother? What about my job? How am I going to pay the bills? Clearly, a thousand questions went through my head / Literally my whole world turned upside down...

Each transcript was constituted through this process until each description had been broken up into respective meaning units. I performed this exercise three times for each transcript as a means of challenging the previous meaning units that had been constituted. This task was not practically laborious but did require a degree of reflection and attentiveness toward the data to ensure that the units were representative of a specific meaning without breaching into others.

### **3.3.11 Step three: Transforming the everyday expressions into psychologically phenomenologically sensitive expressions.**

In agreement with Giorgi (2009), the third step of transforming every day, lifeworldly expressions into psychological, phenomenological expressions was by far the most extensive and systematically rigorous of the analysis. To break it down, I will discuss

the theoretical and philosophical heritage that was drawn upon to undertake this procedure before moving onto my experience of fulfilling this specific process.

First of all, a table consisting of four rows (please see the following example) was created to replicate the process used by Giorgi (2009). The table represents Husserl's (1970) philosophical theory of meaning, whereby a meaning unit is subjected to a rigorous process of discriminating its most invariant and essential meaning. Philosophically, this involves using free imaginative variation to decipher the signifying, fulfilling, and identification acts of consciousness that were present in the unit of data. In practice, this involves testing the structure of the meaning unit that was expressed various times to extract and transform it into a clear psychological expression. Giorgi's (2009) method, in this step of the process, is a careful attempt to constitute the data into a psychological transformation that is respectful to the original expression, whereby the concept of free imaginative variation aims to vary and test the structure of the meaning unit. This is not achieved immediately and is "detected and drawn out" several times to fulfil the most appropriate expression of the data (Giorgi, 2009, p131). Therefore, to render this part of the analysis as a simple step or procedure does not respect the fluidity and reflection that was required to satisfy this phenomenological goal.

However, I had to be careful and considered throughout this step of the analysis. Whilst this procedure involves a transformation of the data into a psychological and phenomenological expression, it is important to stay close to the original expression of the participants lived experience. It would be easy to go beyond the data and confidently interpret the data through sophisticated terms used in psychology, or any other disciplinary or theoretical lens, rather than remain with what has been expressed by the participant and what is conscious to me, as it is I who is constituting the essential psychological structure (Giorgi, 2009). As expressed by Giorgi (2009, p.181), "I am making a psychological interpretation of a lifeworld event. That would be true, but I am doing so by means of a descriptive method."

Table 5.0 below demonstrates a transformed meaning unit that expresses the psychological meaning of participant number nine's experience when talking about her cancer-related experiences with another participant during her recreational programme. The transformation, in this case, may seem simple but it ascertains the

act of identification through the use of free imaginative variation, ultimately transforming the meaning to exhibit its most psychologically revealing form.

Original description of lifeworldly expression.	Third-person description of lifeworldly expression.	Psychological sense of the expression	Transformation of the expression.
<p><b>P9: Because we'd (P9 and two other women) been through very similar experiences, I think we felt quite open to talk about treatment and, erm, you know, the things we found scary, you know, the things like our body image following cancer. We were talking about relationships (laughs)... I found myself having quite personal conversations with them. But I felt very ok about it...</b></p>	<p><b>P9 states because they'd (P9 and two other women) been through very similar experiences, she thinks they felt quite open to talk about treatment and the things they found scary... the things like their body image following cancer. P9 says they were talking about relationships (laughs)... P9 says she found herself having quite personal conversations with them (the two women). P9 says but she felt very ok about it...</b></p>	<p><b>Stating that she felt ok about it, P9 acknowledges that she and two other ladies were having personal conversations about body image, relationships, and the things they found scary, as they had shared experiences.</b></p>	<p><b>Stating that she felt ok about it, P9 acknowledges that she and two ladies were having personal conversations about body image, relationships, and the things they found scary.</b></p>

**Table 5.0** – Step three of Amedeo Giorgi's (2009) descriptive phenomenological analysis: the transformation of a meaning unit.

This process was repeated for each meaning unit of each transcript (please see appendix C for two examples of this process). The time spent committed to this step of the analysis was between three to four months, emphasizing the rigour and systematic nature of this specific step. The following fourth step identifies how I managed and synthesised each of the meaning units together to form a psychological description for each participant that was respectful to the eidetic generalities of the experience.

### **3.3.12 Step four: The synthesis of the transformed meaning units**

After establishing the transformed meaning units that I constituted in step three, I performed step four of Giorgi's methodology and method (2009). I addressed this stage of the analysis by adopting a two-step holistic approach to synthesise and imaginatively vary the entirety of the meaning units that were transformed (please see appendices for final synthesised descriptions).

In practice, this procedure, first of all, involved moving all transformed meaning units from the far right column of the analytical table into a new document for each respective participant. Upon doing so, I began to constitute and create a transformed and synthesised description for each of the participant's experience, with emphasis on the psychological implications that occurred throughout. However, I did not simply list the meaning units and stop. Rather, I adopted the holistic approach encouraged by Giorgi (2009), which involved ordering the meaning units into a coherent description that remained faithful to the lived experience that had been constituted by myself. This approach involved carefully moving meaning units into an ordered description that respected the original expression, as opposed to leaving them as a simple list of transformed expressions. Furthermore, the description that was synthesised was subject to another process of transformation, as some units clearly stated the same meaning as others. Consequently, some meaning units were subsumed into others to avoid any repetition.

Secondly, I created a final description for each participant based on the meaning units that were synthesised and ordered in the first step outlined above. This was completed to, again, reduce the description to a finer psychological account of the main psychological constituents that were present in the data. Ultimately, the remaining text was a shorter description of the participants' lived experience. However, depending on one's confidence and competency to follow the procedures, the shorter version did not sacrifice the richness and overarching psychological meaning that was originally expressed by each participant (Giorgi, 2009). All of the meanings expressed in the interview are explicitly and implicitly present in the synthesised description for each participant. To offer an example, participant number nine's original transcript of ten pages of her lived experience was synthesised to two-and-a-half-pages which captured the psychological meanings of

her experience. This was then transformed for the last time to a one-page description that identified the essential psychological constituents of the experience that was present within all twelve of the participants' original interviews.

However, to fully complete Giorgi's (2009) fourth step, I then had to unify each of the synthesised descriptions to form an eidetic generalisation and experiential structure that is psychologically sensitive. It is important to address the philosophical concepts that support this stage found in step four. Drawing upon Broome (2011), Sokolowski (2008), and Giorgi (2009), the essential constituents and participant variations that appear in the synthesised descriptions represent what is known as "parts and wholes" in philosophy. Parts refer to the variety of meanings and moments that are present within each of the synthesised descriptions, while wholes refer to the key constituents that are interdependent of each other throughout the description. Consequently, what is eventually presented is an eidetic generalisation and structure of the experiential phenomenon which highlights the psychological wholes and experiential parts that are bound within (Broome, 2011). This approach did not, however, offer a causal explanation that would ultimately lead one to make a nomothetic claim of absolute or universal truth, as this study is grounded in a specific context (Broome, 2011; Wertz, 2010).

This process involved re-reading and marking each of the synthesised descriptions that were constituted to demarcate where each of the descriptions share comparisons, thus imaginatively varying, unifying, and identifying psychological constituents of the experience. The constituents, therefore, offer an explicit geometric-like insight into what it is like to meaningfully 'live through' recreational programmes for the twelve participants in this study, while the parts found within the constituents offer different ranges of meaning.

As such, the synthesised descriptions, eidetic generalisation, and psychological structure form together in a way that clearly shows what is essential in this meaningfully lived experience. The synthesised descriptions reveal the variations that were present in the participants' experiences, revealing the parts that made up the whole of the constituents, whilst the structure and generalisation transcend the descriptions to present the key essentialities of the experience. For example, it was possible to identify that all of the participants were involved in certain ways of



intersubjective encounters with other people in their synthesised descriptions. The descriptions of each participant subsequently reveal the variations that formed the fifth constituent, or whole, *A willingness to engage with and listen to others living with and beyond cancer.*

Similar to previous analytical phases, the process of the fourth step was not achieved on the first attempt. Rather, I attempted to establish an eidetic generalisation and psychological structure of the key constituents over three attempts, with each attempt refining the final presentation of findings. The first attempt was too reductive in its overall description and structure. This resulted in a psychological structure and eidetic generalisation that revealed three constituents. While this was not considered to be a failed attempt, the first structure simply bypassed too many of the experiential moments found within the transformed meaning units, resulting in a loss of nuance and depth. The second attempt subsequently aimed to break up the three key constituents that had been established in the first attempt. However, this resulted in a generalisation and structure that included too many essential constituents which did not offer the depth that was quite clearly contained within. The third and final attempt was deemed a success as this eidetic generalisation and psychological structure sought about grouping some of the clashing constituents that were established in the previous attempt. To facilitate this process, I created three tables (please see 4.3) which identified the constituents and variations amongst the participants. The tables were drafted through several attempts to capture the eidetic generalisation and psychological constituents that were apparent in each of the synthesised descriptions.

### **3.3.13 Step five: Presentation of dynamics that comprise the eidetic generalisation and psychological structure**

Whilst step four of the analytical method carries the responsibility of identifying the eidetic generalisation and psychological structure, the fifth step presents the final opportunity to display the overall dynamics that are involved in both. The fifth step was achieved by firstly writing a description to convey the eidetic generalisation of the lived-through experience of all twelve participants (please see chapter 4.2). The second and last part of the step was achieved by constructing three tables (please

see chapter 4.3) to display the participants' variations and key constituents of the psychological structure. This was created to display the depth of the meanings that were expressed by the participants'.

The reliability and rigour of the entirety of Giorgi's (2009) analytical framework rest upon phenomenological philosophy and science. As described throughout the chapter, this approach bases its goal of ascertaining a 'knowledge of truth' through consciousness as the entity in which reality is given, intuited, and true. Amedeo Giorgi's (2009) methodology and method follows the same philosophical and scientific goals of phenomenology, whereby the method and analytical procedures are general, systematic, critical, and methodical, all of which have relations to empirical science. Giorgi's (2009, p128) method also establishes a greater sense of credibility, reliability, and rigour as he described how the analytical procedures, and the findings that follow, can be directly checked by the critical other because of the method's clear effort to communicate what was consciously given by the participants' and intuited by myself.

However, if judged by empirical laws of philosophical science, the descriptive method that Giorgi has pioneered will be difficult to interpret as a science because of the lack of objectivity, for example (Applebaum, 2010, 2011, 2012). However, in accordance with Giorgi (2009) and Applebaum (2012), if the methodology and method are judged in relation to phenomenological philosophy and science, the findings of a given study can be verified by simply following the steps of the analytical procedures backwards to the original expressions that were articulated by the participants. Therefore, is it necessary to judge the rigour and reliability of this study, or any given study that has used Giorgi's (2009) methodology and method, by its attempt to closely adhere to the original consciousness of the participants, without unaware contamination or theoretical assumptions being brought into the study.

### **3.4 Summary and conclusion**

This chapter has provided a detailed rationale for the use of descriptive phenomenology as the primary methodology and method that has addressed the aforementioned researchable phenomenon posed in the previous chapter. Throughout, I have provided a considerable level of transparency about how the

data has been systematically constituted by myself to offer a faithful eidetic generalisation and psychological structure of the participants lived experience.

The following chapter, *Findings*, will therefore communicate the essential generalisation of the phenomenon of interest, the key constituents forming the psychological structure, and the experiential ranges of the participants' experiences that were constituted. The findings will allow the reader to fully grasp the 'conscious givens' of the twelve participants who have been involved in this study. The findings will also be supported by the original lifeworldly expressions that were recorded throughout the data collection phase to provide original evidence for how the findings were intuited, transformed, and constituted.

Before the findings are subjected to a thorough presentation, a short text will communicate the eidetic generalisation of the phenomenon of interest. This will present the eidetic apex of the psychological structure of the twelve participants in this study.

## **4.0 Findings**

### **4.1 Introduction**

Chapter four presents the findings of this study as an essential eidetic description and a psychological structure of the phenomenon of interest. Specifically, the presentation of the findings adheres to Giorgi's (2009) phenomenological method in psychology. This includes presenting the participants' subjective givens without adding or subtracting from the givenness of experience that was constituted by myself during the third step of the analysis. Such a descriptive presentation of the results is an extension of the phenomenological attitude, whereby I suspended the intention to clarify or interpret any of the given meanings that could be ascribed to the participants' experiences.

The chapter will provide a retrospective account from the analytical phases that were described in the previous chapter. For example, the first part of the chapter will consist of a phenomenological description of the experiential phenomenon which details the key and essential psychological meanings that were given for each participant in this study. The essential description will also be supported by three tables which establish the explicit constituents and the empirical variations amongst the twelve participants.

The essential description and tables of the most invariant key constituents with participant variations provides an insight into the resultant phenomenon. However, what follows will be an extensive text of each explicit constituent with the original descriptions to guide the reader through the phenomenon. The text will identify the subtle and strong parts of each constituent that was constituted by myself during the third and fourth phase of the analysis. As a result, the reader will find a range of meanings that are pregnant within each essential psychological constituent which united to form that specific region of the structure.

Ultimately, what is presented is an eidetic map of the psychological meanings that were identified through Giorgi's (2009) steps of analyses, illuminating what recreational programmes in the natural environment mean for those living with and beyond cancer. It is also important to state that the essential constituents are presented in a way that respects how the constituents of the experiential territory

unfolded, thus sharing the psychological ranges between the various parts and wholes of the psychological structure.

## **4.2 Essential description of the phenomenon of interest**

One kind of lived experience of recreational programmes for those living with and beyond cancer is characterised by an understanding of the significant shifts that occurred for the participants' past, present, and anticipated experiences of themselves. An initial consideration was made by the participants regarding how their lives had changed due to a diagnosis and treatment for cancer. This process was acknowledged as holding both negative and positive connotations, with the participants identifying how their chronic illness and possible mortality caused a multiplicity of emotional and behavioural reactions. Such reactions instigated an awareness of a diminished and/or heightened sense of self. Through this sense of self-awareness, the participants expressed an openness to want to experience opportunities that would challenge themselves, control negative thoughts, and/or expand their comfort zone. This sense of openness to seek to experience new opportunities was then actualised through and in the context of the 4 Cancer Group's recreational programmes.

The programmes provided a temporary sense of reflection and reprieve, whereby the development of the participants' openness to experience new opportunities could be realised. This sense of openness was expressed by the participants as an acute awareness of their immediate experience at that present time. Emphasis was placed on the explicit or implicit acceptance of their lives in that very moment, with or without a significant other in their company.

The unfolding of the participants' immediate experience also involved engaging in physical tasks and acts that were facilitated by trustworthy, genuine, and encouraging instructors. The expression of their physical involvements established an experience wherein the participants could either move beyond a previous sense of insecurity and/or re-identify with their physical capabilities. The participants' physical involvement in the programme were also reinforced and enhanced through interpersonal communication between those who have experienced living with and beyond cancer. Through such interpersonal encounters on their respective programmes, the participants could engage in open dialogue regarding anything

significant to them. For example, some participants did not reveal personal details about their experiences of ill health as they were there to lose themselves in the programme, whilst others discussed everyday topics of conversation relating to themselves, such as their educational experiences or what was happening in their lives during that time. Others engaged the topic of their cancer experience tactfully. This ranged from delicate discussions about cancer treatment to deeply personal topics of their appearance and relationship concerns, which was described as informal therapy and/or peer support.

Despite the temporary relief of the recreational programmes, there was a recognition of the anticipation of experiencing life beyond cancer to be that of a vulnerable and fearful existence. This sense of regression or rigidity ranged from the fear of losing a sense of positivity, feeling considerably vulnerable about cancer recurrence, and/or trying to develop a sense of normality in the years that have passed whilst living with a sense of cancer survivorship.

### 4.3 Tables of key constituents

**Table 6.0 – Variations amongst participants one to four.**

<b>Key constituents</b>	<b>P1</b>	<b>P2</b>	<b>P3</b>	<b>P4</b>
<b>An awareness of the changes to one's reality due to chronic illness.</b>	Experiences of being bullied and judged because of her diagnosis and treatment for cancer.	Feeling deflated as she didn't know what her life expectancy was before discovering that her condition was terminal.	Understanding the challenging process of cancer diagnosis and treatment.	Recognising how his feelings of being close to death adjusted his mindset to see things through an open and confident mindset.
<b>A sense of openness to want to experience other opportunities.</b>	Finding a sense of security in the idea of the recreational programme after initial nervousness.	Terminal cancer concentrating her mind, whereby she does not say no to things that challenge her comfort zone.	The recreational programme is a way of trying something new that would help her adjust to her sense of a normal life again.	The recreational programme is a means of expressing everything that he has been through and a way of building his confidence.

<b>A movement towards experiencing the present moment.</b>	Being with family and new people in an environment that was calm, happy, and fun.	A sense of feeling present with her husband as they sailed for the day.	Being and feeling free in a natural environment with her mother and sister as opposed to the hospital environment.	Learning new life skills with existing and new friends.
<b>Renewed insight into one's physical potential.</b>	Being encouraged by instructors to be involved in a new activity that she could do without feeling fatigued.	Instructors gently encouraged and inspired her to be involved in the technical skills despite initially anticipating that she would not be involved.	Learning to feel safe with instructors who taught her new sailing skills.	Guidance from instructors that helped him to feel confidently involved to the point whereby he could motivate others to participate.
<b>A willingness to engage with and listen to others living with and beyond cancer.</b>	A sense of talking about everyday topics of conversation whereby there were no awkward silences and she is not judged by the others.	Sensitively sharing experiences about each other's cancer experience whilst enjoying the sailing.	Feeling comfortable listening to her mother talking about their personal and ethnic background.	A sense of opening up and learning about other people in a short period of time.
<b>Anticipation of the future</b>	Did not identify experiential possibilities about the future.	Did not identify experiential possibilities about the future.	Did not identify experiential possibilities about the future.	Did not identify experiential possibilities about the future.



**Table 7.0 – Variations amongst participants five to eight.**

<b>Essential Constituent</b>	<b>P5</b>	<b>P6</b>	<b>P7</b>	<b>P8</b>
<b>An awareness of the changes to one's reality due to chronic illness.</b>	Recognition that her mind demands a lot of time from her due to pre and post-cancer-related anxiety.	An awareness of being stuck in a routine due to recent cancer treatment.	An acknowledgement that her sense of normality and attitude has changed.	An awareness of how depression affects her and how she did not know what to expect from cancer.
<b>A sense of openness to want to experience other opportunities.</b>	An understanding of how she now wants to accept her fears and do things that challenge her.	Recognition of the recreational programme as a means of challenging her normal routine.	Awareness that the recreational programme was an opportunity to push her outside of her comfort zone.	Recognition that the recreational programme was a way of developing her comfort zone.

<p><b>A movement towards experiencing the present moment.</b></p>	<p>A sense of reflecting on moments when she could be herself on the recreational programme.</p>	<p>A sense of feeling different throughout and by the end of the programme.</p>	<p>A sense of recognising that she didn't have to attach a deeply layered meaning on the experience, whereby she could acknowledge that her life is comfortable.</p>	<p>Recognition of a movement away from depression because someone noticed her smile.</p>
<p><b>Renewed insight into one's physical potential.</b></p>	<p>A collaboration with the instructors who not only encouraged her to be involved but shared their personal stories of cancer.</p>	<p>A sense of being scared and worried about the physical demands of the programme due to recent treatment.</p>	<p>Recognition that the instructors never made her feel stupid or inadequate when learning how to sail the boat.</p>	<p>Achieving a sense of a morale boost by getting on the boat and working with the instructors who tailored their manner for her.</p>
<p><b>A willingness to engage with and listen to others living with and beyond cancer.</b></p>	<p>Recognition of the diversity amongst the group insofar that cancer is a commonality between the group but it doesn't define their characteristics.</p>	<p>An understanding that cancer brought the participants together whilst moving onto understanding each person as a whole person.</p>	<p>After two separate experiences of cancer support groups, P7 is aware that there some need to talk about while others don't need to mention it.</p>	<p>Reflects upon the recreational programme as a way of allowing herself and others to see diversity in survivorship.</p>

<b>Anticipation of the future</b>	Identified that she wants to keep harnessing her positivity and energy.	Did not identify experiential possibilities about the future.	A sense of understanding that cancer will never leave her.	An understanding that cancer will always be there but not wanting it to be the focus of her daily life.
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**Table 8.0 – Variations amongst participants nine to twelve.**

<b>Essential Constituent</b>	<b>P9</b>	<b>P10</b>	<b>P11</b>	<b>P12</b>
<b>An awareness of the changes to one's reality due to chronic illness.</b>	Acknowledgement of how her diagnosis of cancer caused her to worry and lose sleep.	Cycles of crying and negative thinking due to the terminal status that is broken up with controlled positivity.	An awareness of making sense of negative thoughts and depression through writing a journal.	A fluid process of being healthy again while having a sense of fear at the back of his mind that makes him feel like he wants to reach out for support.
<b>A sense of openness to want to experience other opportunities.</b>	Recognition that the recreational programme is an opportunity to spend time with her daughter.	Using the recreational programme as a way of controlling the things that he can do and think about.	Understanding the recreational programme as a way of challenging his thoughts and assimilating into a new culture.	Using two recreational programmes to help him understand there is a sense of support and a sense of reduction in his cancer-related fears.

<p><b>A movement towards experiencing the present moment.</b></p>	<p>A sense of soaking in the day in an environment with her daughter, whereby cancer is not the dominating theme.</p>	<p>An appreciation of losing himself in an activity and new environment with his son.</p>	<p>Accepting the experience without having to put too much mental energy into it.</p>	<p><b>1<sup>st</sup> Programme:</b> An opportunity to have a bit of “me time” to forget about the doom and gloom.</p> <p><b>2<sup>nd</sup> Programme:</b> An opportunity to spend time with his family to relax and do nice things together.</p>
<p><b>Renewed insight into one’s physical potential.</b></p>	<p>Feelings of incredible happiness due to instructors investing time and confidence in her daughter and herself.</p>	<p>Achieving a state of immediate physical benefit by being hands-on during his time spent sailing.</p>	<p>Participating in the recreational programme surprised him in that it helped align his mind and his energy levels.</p>	<p><b>1<sup>st</sup> Programme:</b> A sense of enjoying an activity that he considers to be aligned to his personality.</p> <p><b>2<sup>nd</sup> Programme:</b> No physical involvement but rather an opportunity to be with his family.</p>
<p><b>A willingness to engage with and listen to others living with and beyond cancer.</b></p>	<p>A deeply layered style of communication with others about personal topics of conversation.</p>	<p>A sense of trying to read the signals and be careful about what he spoke about with others.</p>	<p>Talking and sharing similar experiences relating to treatment for one of the first times.</p>	<p><b>1<sup>st</sup> Programme:</b> Openly talking about his cancer experiences to create awareness.</p> <p><b>2<sup>nd</sup> Programme:</b></p>

				Deliberately chose not to talk about cancer-related experiences as it was about being with family.
<b>Anticipation of the future</b>	Living with and feeling controlled by fear about the future.	Trying to be positive about the future without knowing what will happen.	Did not identify experiential possibilities about the future.	Feelings of fear and vulnerability about the future.

## **4.4 Essential constituents of the psychological structure of recreational programmes in the natural environment for those living with and beyond cancer.**

### **4.4.1 Awareness of the changes to one's reality due to chronic illness.**

The participants in this study expressed a sense of how their lives had changed and how their sense of reality had been elevated to an immediate experiential surface due to being diagnosed and treated for various manifestations of cancer. Furthermore, the range of experiential possibilities within the first constituent consisted of strong and subtle meanings which explicitly and implicitly suggested how the participants became aware of the immediate recognition of this change. The meanings spanned from encountering significant loss of a sense of who they were before their diagnosis and experiencing a sense of personal and environmental insecurity. However, this was different for others, with some participants acknowledging how this experience presented an opportunity to engage in a sense of self-reflection for the betterment of themselves and their respective situations.

P9, P10, P11, and P12 described both linear and cyclical processes that involved experiencing challenging psychological reactions to their illness that were related to past and present concerns regarding how they had or currently were, experiencing living with cancer.

Despite being prepared for the diagnosis, P9 revealed in great detail how such an experience was shocking and devastating for her. Explaining how it rocked her world underneath her, P9 discussed how she was scared, apprehensive, and terrified about a lot of personal issues. This resulted in P9 asking herself numerous questions regarding financial matters and her responsibilities as a mother. This change manifested itself further through nightmares and sleeplessness, with P9 worrying that she would not survive her treatment. Through her work at a local hospice, P9 acknowledged that she was both fortunate and unfortunate to have an understanding of chemotherapy treatment. P9 identified that she knew kind medical professionals who offered her guidance, whilst also witnessing women living their last days at the hospice. However, P9 recognised that her friendships were a way

in which P9 could find help and support through practical and emotional engagement.

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*“My whole world rocked underneath me. Erm, I’ve always been quite a strong independent person, bringing up my girls by myself. My youngest doesn’t see her father, so she has only got me. I’ve also got an elderly mother who I look after... no brothers or sisters, so I’ve always been quite healthy up until then. Quite a strong person and I’ve always worked. And suddenly, it was like, oh right... (shocked laughter)... I’ve got to look after myself here but what is ahead? What about my children? What about my mother? What about my job? How am I going to pay the bills? Clearly, a thousand questions went through my head... literally my whole world turned upside down. Luckily and unluckily, whichever way you see it, I work for a hospice with nurses and they are incredibly caring, but at the same time, I also see people in the inpatient unit who are in their final days because of cancer. You know, ladies who are a similar age to myself. So, although people were saying “this is treatable”, I also knew that it wasn’t always successful. So, yes, I was very scared... ” – P9.*

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P10 revealed how living with terminal cancer had left him living in a dream-like state of mind. P10 described this process as a nightmare, understanding that he tried to approach this sense of reality on a day-to-day basis without professional psychological support, as he had his way of managing his emotional reactions. P10 recognised that he expressed his negative thoughts that he experienced through cycles of emotional releases until he could live with this sense of reality again. P10 described this cycle as a natural occurrence that appears in a way that he has to have a moment to himself as he cannot fight the emotions that he lives with. P10 was aware that once it is over, the process repeats itself to the point whereby he has to wait for the next emotional release. Understanding that his death will be inevitable, P10 reflected on how he has moved closer to his immediate family to make it easier for them.

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*“...but what you can’t do is avoid the psychology that is going on... every cancer sufferer, or whatever you’d like to call them, must have or go through these dark thoughts I am talking about... thinking about the future and thinking about how one day you won’t*

*be here... not knowing when that is going to happen is a real difficulty as well... this weekend just gone was very stressful and in the end, I had to give in to it, I had a little cry to myself... once you have that release, you are much stronger and better for it.” - P10*

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P11 explained that the cancer diagnosis was a shock to him, stressing how everything in his world was subsequently destroyed after he found out. P11 recalled that this was announced to him two weeks after he had married his wife, which meant they could not go on their scheduled honeymoon. P11 acknowledged that this state of living was reduced to a continual cycle of thinking about his illness and what type of future may lay ahead of him. Subsequently, P11's state of living was reduced to the point whereby he could not eat or communicate his thoughts with anybody. P11 understood that he fell into a depression during his aggressive treatment, which included experiencing a sense of spiritual injustice. And yet despite his experience of depression, P11 identified that he managed to expand his state of awareness by writing a journal from 2017 to 2019 as a way of managing his emotions. P11 explains that the style and expression of each chapter of the journal were split into two. P11 states that an introductory passage reflected the philosophical significance of his situation, whilst the remainder of each chapter was written in a humoristic style about the dilemmas he was facing throughout the entirety of his experience.

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*“I did the chemo(therapy) and the first two months indicated that I was already in remission, so I should've been happy afterwards but somehow, I went into a depression. I don't know exactly why... I felt like it was an injustice that was happening to me and how this world works... perhaps god had planned it... something like that. But, eventually, I managed to crawl myself out of this depression by making a schedule, working every day, and writing.” - P11*

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P12 recognised that at the time of his diagnosis he was living a busy professional life that had put him in a position of not being able to relax. In that sense, P12 described how the diagnosis did not hit him immediately as he had the physical and mental energy for it. P12 explained that it was an amazing process to take on board as he didn't know whether he was going to live. Yet, P12 identified how his reaction changed the following month as he was receiving his initial immunotherapy



treatment. P12 recognised that he was then suddenly aware of the financial and emotional responsibilities that he had established through his family and self-employed business. P12 described how he began to feel like he was in a state of being on auto-pilot as he had no choice or time for other issues, recalling how he felt like he was losing his mind as he waited three months to know if the initial immunotherapy had been successful. P12 explained how this was one of three incidents that caused him to cry uncontrollably, which resulted in P12 taking antidepressants to manage his emotional instability.

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*“I would say that the treatment is, forgive me for being so personal, for most a massive worry. You start to worry three days beforehand and then it just happens... you have 19 inches worth of tubing put into you and it’s just not pleasant. So, as I say, your emotions are difficult through that and I think that what tended to happen is that you’re almost on auto-pilot in the sense that you’re just having to deal with it, quite honestly. You’ve got no choice, no time for issues, you’ve just got to get on with it... I was coping, to a point. It is the waiting to find out to know if the type of tumour has gone into the muscle or not. I would say that it took around three months before they knew anything regarding that. Obviously, I had to go through various tests and biopsies, and in that time, the three months, that’s the time when you’re losing your mind. Yeah, that’s the point where you are really worried from that point of view. That if this has got into the muscle and spread, it could be the start of something horrible. A five-year process of treatment that can be really horrible.” – P12.*

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P2 and P4 identified and discussed how living with and beyond cancer had similarly caused them both to initially experience distressing, emotional reactions. Yet, both participants balanced such distressing experiences by describing how they recognised these moments as an opportunity to project their lives in a positive direction. For example, P2 acknowledged that while her terminal cancer had left her feeling deflated, she noticed how much bolder and passionate she was becoming throughout her experience with cancer. Moreover, P2 emphasised how she would have just accepted life as it was before her diagnosis. Likewise, P4 realised that his sense of reality had been thrown into a state of disarray by his symptoms and diagnosis, before going on to describe his treatment as a huge journey that caused him to feel like he was close to death. However, P4 states that this sense of being

close to death increased his confidence and enabled him to develop an open-minded approach to his life.

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*“It just flipped my world upside down because it changed my routine completely. I mean, before then, I was never going to go for head boy at my school. Like, in year 9 or 10, I was, like, no I am not going to go for it whatsoever and my grades weren’t the best either. But then, after going through the treatment, it made me realise how close to you are to death. Your life is short and you’ve got to live it. You only live once. So, in a way, it boosted my confidence tremendously. At the end of that very year, year 10, I did go for head boy and I managed to get it. It’s improved my grades tremendously too. When it flipped my world upside down, it had, like, a positive impact on me, if that makes sense.” – P4*

*“Not a lot of people know about it (P2’s type of cancer) and you just accept it. But now, I’m quite passionate about it. So when I was sending out emails to professionals who I deal with about endocrine cancer, I included the dean of education and the assistant dean (work colleagues)... I would not have done that before, I would have never dreamed of it... but because I was bold, they have now asked me to do a talk at the end of a lecture in cancer week... and yes, I will do that (laughter).” – P2*

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Similarly to P2 and P4, P5 and P8 acknowledged how experiencing a cancer diagnosis and the subsequent treatment had allowed them both to see other sides of themselves that may not have been evoked had they not been confronted with this sudden change in their reality. However, this sense of reflection was different than what was evident for P2 and P4. Both P5 and P8 described how their sense of reality before their respective cancer diagnoses and treatments had already been encapsulated by intense experiences of anxiety and depression. For example, P5 identified how her life was tightly controlled by anxiety, whilst P8 recognised that the world did not have a bearing on her life due to a sense of depression she had been living with prior to her diagnosis. In this sense, both P5 and P8 acknowledged how both of their respective treatments for cancer awakened an understanding of how their mental health had affected their lives.

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*“I suffer from anxiety and before I had cancer it was really bad to the point where my world was a very small world where I didn’t do very much. We didn’t drive very far, everything was very controlled and the thought of going on water, which to me is out of control, was a massive zero. Having cancer put everything in perspective for me hugely and has made me want to take on new challenges.”*  
– P5

*“Prior to my cancer diagnosis, I suffered a lot with depression, perhaps not so much anxiety but definitely depression. I live alone. I sometimes feel I live a very, very insular little life and the outside world doesn’t impinge on me very much. The opportunity to do something again, out of the comfort zone, doesn’t come along very often”* – P8.

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P1 and P3 described how their senses of security in their lives had been disrupted by the diagnosis and treatment of cancer, with both participants identifying explicit examples of how this had caused them pain, exhaustion, and confusion. Despite being supported by family, friends, and medical professionals during her diagnosis and treatment, P3 recognised that it was difficult to comprehend everything that was going on at the time. P3 also recognised how her sense of security was disrupted by having to stay in the hospital for much of the time, describing how the medical injections she received were painful and had caused her to distinctly identify these moments as challenging memories to think about. Similarly, P1 described a sense of physical and mental exhaustion that she experienced during her treatment. As well as having to spend time in different places, such as various hospital appointments, P1 explained that the exhaustion manifested through experiences of being bullied whilst she was at school because to her condition. P1 explains that this sense of insecurity in her educational surroundings caused her to move schools and become cautious about telling others about her cancer diagnosis and treatment.

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*“Yeah... like, when I was at school I didn’t have a good experience because people... like, I got bullied for being poorly... I didn’t have any friends at school or anything... people didn’t make my life very easy. So, because I wasn’t well enough to move schools so, erm, it was all the way through year seven, eight, nine, and halfway through year ten... but then I was well enough to move schools at this point. When I moved schools, I didn’t tell anyone about being*

*poorly because I didn't want anyone to know... there was the odd person, but I told them they weren't allowed to tell anyone..." - P1.*

*"During the treatment, it was hard... but not as hard as the process of diagnosis. it was getting familiar with the systems and, like, beginning to get and feel familiar with everything. so, after that, the treatment was hard... but the diagnosis is hard because it's difficult to understand what is going on. After that, the treatment had its own hardships as well because it was painful, it was hard to cope..." - P3.*

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P7 revealed that she experienced very minimal emotional suffering during both of her experiences of cancer diagnoses and treatment. Yet, P7 recognises that her second cancer diagnosis and subsequent treatment had changed her sense of self-awareness, with P7 describing how she is aware of living with a different sense of normality in herself. And lastly, P6 described how her very recent treatment for breast cancer had left her in a position whereby her routine made her feel like she was stuck, emphasising how she does most things by herself as a consequence. P6, therefore, encountered a sense of everyday reality that did not move beyond the immediate reality of going to work and coming home, suggesting that she recognised how her life had changed as a result.

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*"I was in my little routine of work, home, bed, work, home, bed, not particularly doing much or going anywhere." - P6*

*"I think it's... I feel a little bit differently in that my original cancer diagnosis was a long time ago and it's something I've lived with now for 19 years. It did change me; I mean I was working full time when I first had cancer and I carried on doing that and I said at the time it kept my sanity whilst I was going through all the treatment. I couldn't think of anything worse than just talking and thinking about cancer the whole time. For me, it was good that I worked and it got me through. When mine came back for this second time, I'd completely changed my life in how I worked and I think my attitude to things has changed because of the cancer." - P7*

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#### **4.4.2 A sense of openness to want to experience other opportunities**

Constituent one had significant implications for the actualisation of constituent two. Although the former captured a sense of what the participants experienced regarding their immediate sense of reality about their diagnosis and treatment for cancer, the latter was essentially characterised by an openness of how they moved beyond this fixed position. This process was, again, recognised as being filled with strong and subtle meanings that identified when and how this openness and movement had occurred. Within this experiential movement, the association with the 4 Cancer Group's recreational programmes was present in both direct and indirect ways. For example, some participants expressed how they engaged with the organisation to express their sense of commitment towards this sense of openness, whilst others had already acknowledged this sense of movement within the first constituent (i.e. being more self-aware, developing an open mindset, choosing to be more active on a weekend). Consequently, both constituent one and two coalesce together in a way that emphasises a change that had occurred to move beyond the point of cancer-related fixity that was occurring in the lives of the participants.

P1 and P3 both subtly expressed how they found the idea of the recreational programmes to be an opportunity to find a sense of security in their lives again. As opposed to the aforementioned constituent, P1 identified how the programme changed the physical and mental exhaustion she had experienced in and through an environment that helps her express enjoyment and meet new people who don't judge her. P3 expressed that the programmes she attended helped her achieve a sense of normality, explaining that the programmes are based in the natural environment and separate from the hospital she had attended while undergoing treatment. P3 also stated that the recreational programme aligned with the post-treatment guidance she had received from medical professionals regarding the use of physically orientated activities to help her achieve her sense of normality in her physical capabilities.

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*"It's (cancer) physically and mentally exhausting I think... mentally because I've got to deal with the fact, like, that I'm not very well and the fact that people are not being very nice to you... and it's just in your head... and physically, because you've, like, got to be at the hospital, at school, everywhere... and like, yeah... it's just*

*exhausting... the trips change, like, change that though... the fun of the sailing, meeting new people, and hearing about other people..." – P1.*

*"So it (the recreational programme) felt, like, good because it was outside the atmosphere of the hospital... so, that made it more, like, nice. It was in nature and a part of nature... the views were beautiful... it wasn't like being surrounded by a hospital with the nurses and the doctors... it was more, like, natural... that's what I meant by getting back to normal life..." – P3.*

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P5, P9, P10, P11, and P12 all expressed how the opportunity to engage with the recreational programmes were closely associated with being able to control and distance their negative thoughts for a period of time. This process was characterised as being a significant part of a wider perspective that was based on moving beyond the negative changes they became anchored to during their diagnosis and treatment of cancer. For example, P5 stated that she was aware that the recreational programmes were a cause for concern as she knew that they would intensify her anxiety and fear of participating in new challenges. Yet, P5 accepted the fear of being in a position and environment that would cause her to feel anxious. P5 expressed that she understood how these new opportunities allow her to acknowledge and evaluate how she responds to the changes in her life. P5 is aware that this insight is due to her cancer diagnosis and treatment, describing how it has helped her experience her life differently because she had to consider and reflect on her mortality.

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*"...those opportunities are often, I feel, of real true benefit. It's a shame that other people can't have that. I don't ever want them to have cancer, but I sometimes want them to have their eyes wide open which is what I feel happens often for many people when they've had cancer... is that your eyes are wide open that you see things or feel things that others may never have... you've had to stare at your own mortality. So, when you're then given opportunities beyond your norm, your normal life is changing. The event wasn't about cancer, and our group isn't about cancer either."*  
– P5

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P9 understood how the programme she attended was as therapeutic as other formal therapeutic events she has been involved in throughout her cancer experience. P9 recognised that this was a part of a wider process of self-reflection, whereby P9 acknowledged that she is remoulding herself, as she would have made an excuse to refuse attending social events before her diagnosis and treatment for cancer. Recognising how much she can worry and react to stress, P9 stated that she is aware of how cancer has changed the way she thinks and reacts when managing some of the less significant issues in her life.

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*“I’m much more, you know, less worried about the little things and, erm, whereas before I wouldn’t be bothered to go out after work, and I would make every excuse to not do something. I now think no; I’ve had a scare... I’ll now go out. I might not stay really late, but I’ll go out. I’ve now moulded myself to start doing more things. My calendar is now full of things as opposed to when I was pre-cancer...”- P9.*

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Similar to P9, P11 also shared a similar stance of how he now decides to view the less significant issues that can appear in his life. P11 described that this openness and shift of perspective was directed by being aware of what is going on in the present moment of his life. P11 acknowledged how his sense of perspective was then brought to life through his cancer specialist nurse, who encouraged him to participate and be involved in the recreational programme with the 4 Cancer Group. As well as using it as an opportunity to engage in a new culture as a legal immigrant to the UK, P11 recognised that the recreational programme could alleviate the occasional troubles that go on in his mind and thoughts. P11 described cancer as an emotional experience and an unnecessary suffering that can be made a lot worse in his head.

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*“When you go through this type of experience you tend to not give a damn about the superficial stuff. For example, when a normal person gets upset about breaking their phone or something like that, it is difficult, but when you go through this, you tend not to care about the things like how you look. I don’t care about how I want to look or anything like that. I just want to be healthy. It is very difficult to say because when my nurse proposed it (the recreational*



*programme) when I was having treatment but I was in a very positive state of mind. That is an interesting point because I was always really negative and it was difficult to be optimistic. But when I had learnt that the cancer had returned for the second time, I got over it a lot quicker. I developed my different perspective and became confident without having any doubt... so, when the nurse presented me with this opportunity, I was generally very positive. I decided that if I was well enough at that moment to go then I would go and it didn't really cross my mind that I might feel depressed or it would be difficult or anything like that... I guess even if you are depressed this kind of stuff can help and forget about all of your troubles.“ - P11.*

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P10 stated that he directly chose to attend the recreational sailing programme as a means of having some degree of control over what he does in his life because of his terminal status. Moreover, P10 was at that time aware that his recent medical scans indicated that his tumours had continued to grow and spread to other areas of his body. As well as choosing to contact previous work colleagues to share his news of terminal cancer, P10 was explicit in stating that this opportunity was deliberately chosen to help him continue setting personal targets for himself to help whilst he waited for the next phase of medical results from a clinically trialled drug.

*“...you're making targets for yourself as you wait... I've got no control over it... that's where the sailing programme comes into it because I've got some degree of control about what I do with my limited time here. But that is another strange thing because a lot of people say, “remain positive” (laughs)... it's much easier to say it than do it... and the other one people say is “you are strong, you can beat this” (laughs)... ” – P10.*

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P12 understood that the recreational programmes offered by the 4 Cancer Group could alleviate his experiences of feeling vulnerable as he described going through a challenging time with his treatment. Explaining that it gave him a sense of recognition and a feeling like there is a lot to look forward to, P12 acknowledged that his decision to engage with the programmes was a way of having what he described as scaffolding around him to support him, which is what he also experienced through support from family, friends, and business associates. Yet, P12



expressed an awareness of this sense of scaffolding was a temporary reprieve from the cancer-related fear that he is also accustomed to think about.

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*“The charity certainly fits into that position of support too; you know with what I talked about with the skiing and sailing. Like, for example, it never made me feel like I was in a position of needing help from a charity. It’s not so much that, it’s more of the opposite in that it filled with joy and realisation that there is so much to look forward to. It might be a daft thing to say but you’ve got used to all of that love and help... that goes on, yeah. But yeah, the second part of that was about the fear of it coming back.” – P12*

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P2, P4, P6, P7, and P8 expressed a perspective on how their decision to participate in the 4 Cancer Group’s recreational programmes was a positive opportunity to move beyond their previous sense of comfort zone and personal mindset after or during their cancer-related experiences. Other than P4, who directly engaged with the programme as an opportunity to express his open mindset to release everything has been through, P2, P6, P7, and P8 all expressed how this was a moment to be a part of something that would be regarded as being beyond their comfort zone before their cancer diagnosis and treatment. In turn, this involvement in a completely new opportunity removed participants from a boundary that rigidly defined them as the people they once saw themselves as.

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*“I approach things with an open mind. Always an open mind. A smile on my face and be positive. I just feel like everything should be approached with an open mind. It may be losing a rugby match against the hardest team in the county or going through a tough time with school but you’ve always got to go in with an open mind of you can do it or you can win. Even though you might be the second-best at something, you’ve always got to have that mindset because it’ll get you far in life, and that is what I believe now. That you have to go into everything with that mindset now. Like, knowing how to sail, it might get me somewhere in life now. Yeah, so if you’ve never tried something before and it does seem interesting, then why not? I just like to think of it as, like, an opportunity to learn new things. The amount of things I’ve done now because of it is just ridiculous when I think back to how shy I was. The mindset chooses who you will be.” – P4*

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*“Well if you know you’re dying... you don’t want to sit on your backside watching the television... there are other things to do. Living in London, there are great things to do. We have had a policy since then of making sure every weekend, or nearly every weekend, we (P2 and her husband) do something.” – P2*

*“...so for me to actually put my name forward and do something that was out of my comfort zone as well was a big challenge and I found it to be good.” – P6*

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To summarise, both constituent one and two delivered a broad scope of awareness about the experiential changes the participants had encountered and experienced whilst either living with or beyond cancer. As presented, the range of possibilities spanned a wide-ranging spectrum of how the participants’ had responded to the dramatic changes in their everyday sense of reality, such as how they emotionally engaged with their diagnoses and treatment of their condition. This sense of awareness then shifted to an understanding of how and why a psychological openness to experience new opportunities had occurred, with the 4 Cancer Group’s recreational programme being an actualising component in the process.

What follows, then, is a comprehensive characterisation that establishes further experiential insight into the participants’ experiences of participating in the 4 Cancer Group’s recreational programmes.

#### **4.4.3 Movements towards experiencing the present moment.**

The participants’ experiences that comprise constituent three both explicitly and implicitly illuminated how the recreational programmes were an opportunity to be closely associated with living and being in an environment that offered a space to connect with what was in their immediate experience. Such a conscious awareness of the immediate experience allowed a number of the participants to see themselves beyond their pre-conceived boundaries. Yet, this immediate awareness did not present itself as a moment of understanding something that was once incomprehensible but did, on the other hand, simplify their state of being by living through the exact moments of their recreational programme. For other participants, the recreational programme was an opportunity to feel and become immersed in a

new environment with a significant other, sharing the possibilities of the experience with a relative or an entire family unit.

P4, P5, P6, P7, P8, P9, and P11 expressed how the recreational programmes facilitated an opportunity to be in a new environment whereupon they could move beyond the expectations of themselves that they had been living with before and/or during their cancer diagnosis and treatment. Moreover, the recreational programmes were experienced as a way to respond and recognise an immediate reality for a period of time without having to prove their sense of worth or have to consciously banish their negative thoughts. This was described as a sense of stretching beyond their original capabilities without deliberately clarifying the experience by both P7 and P5. Consequently, the opportunity to be immersed in the recreational programme enabled a sense of acceptance of the immediate experience, which was of significant value to these individuals.

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*“There was a moment on there and I probably only could have found that in the weather. We had that norming and storming, that group bonding. It was stormy weather and we got the moment of norming when we were coming in at the end and I just sat on the corner of the boat and I was covered like this. I had literally that much face showing. I had puddles all over me, I was covered in puddles, freezing cold. I’ve never been so cold in my life ever I don’t think. I had my hands just tucked in and I would see everyone was as they should be, they were fine and I was just so happy and I can’t explain that absolute pureness of moment. I know that sounds a bit... I can’t even describe it. A sense of just... well-being. I was so content at that moment. I didn’t want it to end and I needed that. I only realised it when I had it how much I needed that moment in my life because I had cancer. I just sat there and I didn’t want it to end. I closed my eyes at one point, I thought I don’t want to close my eyes, I want to keep looking. I want to keep looking forwards it was just magic. I’ve held on to that and I keep clocking back into that. For me to find that quietness, that silence, not the bells ringing and the whistles blowing, that silence of nothingness of pure calm was lovely. That’s the sweet spot.” – P5*

*“I do spend a lot of my time depressed, sadly, and obviously I don’t show joy and love of life very often but two people picked up on the fact that my face was actually showing that I was loving what I was doing and that was quite important, I think, to me.” – P8*

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*“...I didn’t have the chance to think about what might happen or how the treatment will go or how will the next transplant go. I just went on that boat and accepted the experience. This happened without me having to put any mental effort into it...” – P11.*

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Similarly, P1, P2, P3, P10, P12 acknowledged an openness to the experiential immediacy of the natural environment in which the recreational programme were situated. However, as opposed to offering a deep reflection of how this immediate sense of reality had moved or transformed themselves from their original capacities, which was described above, the participants identified the meaning of their immediate experience to be associated with the company of significant family members or friends in strong or subtle ways. For example, being with a family member or significant other created an initial sense of togetherness and comfort for the participants. This sense of comfort and security was a way in which the participants could then meaningfully engage with other elements of their respective programme. Sharing this experiential moment with a significant other was, therefore, understood to be an essential component for the participants' sense of security and comfort in this particular context.

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*“It felt more natural than being stuck in the hospital in a bed... you felt more free... because in a hospital you can’t really enjoy yourself because at any moment there is going to be a treatment or an injection... so, on the boat, I felt free and I didn’t have to have an injection... it was much more relaxed. Like, taking the pictures with my mum... she brought a digital camera with us and we took pictures. We posed on the boat and we took pictures of the wildlife as we sailed down the river... it’s nice to look back on them...” – P3.*

*“...it was just one of those experiences that even if the weather had been miserable or not so good, it would not have mattered because we (family) are all there together, joining in, having fun, and laughing” – P2.*

*“She (member of staff) kindly offered me it, which was nice because that particular event is nice in the sense that you can take your family with you and you can have that time together. And possibly in times of hardship, whether that is emotionally or financially, you*

*don't necessarily think about doing it but it was nice to be offered it because it brings home to you that feeling of family time.” – P12*

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Overall, this phenomenological movement was characterised by the experiential possibilities of placing oneself in a unique environment which had the potential to allow the participants to accept or be open to the immediacy of their experience, with or without a significant other. Therefore, the movement which was established evoked a trust in their sense of the experience of the present moment, which is something that had been a challenge for some during the diagnosis and treatment of cancer.

#### **4.4.4 Renewed insight into one's physical potential**

The participants' openness toward their experience transformed into an acceptance of their involvements in physical acts of their respective recreational programmes. For some participants, the possibility of the physical experience was gently encouraged by the instructors of the programme, thus bridging a connection between the movement to want to experience new opportunities (i.e. moving beyond their comfort zone). Other participants, however, recognised that the instructors had facilitated a sense of involvement to the point whereby they could quickly embrace the physical nature of the programme as they had used their minds and bodies in this way beforehand. Similarly, the range of experiential possibilities extended to acknowledge the implications of how the physical nature of the programme supported accompanying family members, as well as allowing a sense of re-engagement with the sensory experience of using their bodies. The sense of renewal, therefore, had many layers that ultimately brought the participants back to a position of physical and embodied engagement again.

P1, P2, P3, P5, P6, P7, P8 all identified how they formed a trusting and confident relationship with the professional instructors who were present throughout their recreational programmes. The foundation of this bond was established through the instructors gently encouraging the participants to feel as involved as possible in the technical manoeuvres without causing them to feel inferior or inadequate. Whilst being as physically involved as they were was an unanticipated prospect, the collaborative manner in which it was delivered enabled these participants to experience a sense of achievement, and thus expand their sense of competency,

security, and comfort zone. This, too, had the possibility to extend beyond a simple physical collaboration, with P5, for example, describing how the instructors also engaged with her about their personal experiences of cancer.

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*“...and I would’ve imagined that you needed weeks of training to do it (sail the boat)... but they expected us, in a nice way, to do it... they had confidence in us all to do it and they even walked away while I was doing it (laughter)...” – P2.*

*“They talked amongst us and actually one of the guys (instructor) was very open about the fact that his wife has just been diagnosed with breast cancer. I felt that he was getting something from talking to us. Not only was it from the sailing point of view that they were helping us, but we were speaking to them. It was a real collaboration.” – P5*

*“I can understand that people obviously would still find that a challenge because of their general health or the fact that we know that treatment wipes you out and leaves you tired and feeling weak but the fact that you can do it is then quite a morale boost. I was quite pleased to even just get on the boat in the first place.” – P8*

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P4, P10, and P12 expressed a stance that emphasised how the recreational programmes were an opportunity to be completely immersed in the physical possibilities of the tasks that were presented to them. And whilst the instructors did guide the participants on the technical skills required to complete the necessary tasks, each of the participants acknowledged that this type of involvement was a natural part of their identity and sense of who they are. For example, P4 recognised that once he had become comfortable with his surroundings, he was capable of motivating his fellow participants to make sure they were all working in synchronisation, whilst P10 stated how the physical potential of the programme aligned with his previous experiences of being physically active, whereupon he finds that he achieves an immediate physical benefit. Lastly, P12 recognised that his recreational skiing programme was something that he felt very attached to as he had always considered that type of activity to be closely aligned with his interests since he was a child.

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*“Well, in the midst of the sailing, I was encouraging everyone but not telling them what to do. But, like, to compare, whenever I am playing rugby, I always try to motivate my teammates. So, when we were on the boat and we were putting up the sail, I was trying to inspire the guys by saying “come on guys, we can do this”. So, I was that motivating figure.” – P4*

*“I was winching and helming the craft under the strict guidance of the skipper. It was really hands-on, as they say... but it wasn't a problem as I'm quite a physical person” – P10.*

*“I spent three and a half days out there skiing with this group and it was just incredible. One day, and without being arrogant, I had a day of just skiing with the instructor because I was able to keep up with him and his standards. It was lovely, really. We just had a laugh and it was all very social. You come away thinking that you've made a strong bond with someone.” – P12*

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P11 expressed an awareness of how the recreational programmes were a significant opportunity to use a physical activity as a means of pushing himself through his ongoing treatment to align his mental and physical capabilities. P11 reflected and elaborated on this statement by identifying how the instructors encouraged him to engage and learn intricate sailing skills, whereby he had to use his dexterity skills for the sailing manoeuvres used throughout the programme. P11 understood that the finer details of his sensuous involvements were essential for his experience of using the recreational programme to help him understand his sense of dexterity once again. P9, on the other hand, recognised how the instructors invested a considerable amount of confidence and trust in both her and her daughter's involvement with the physical tasks of the programme. Such confidence in her daughter's capabilities had caused P9 to feel a sense of satisfaction as a mother again.

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*“It was really demanding and I was really surprised to see that I could all of that stuff. Even though I was a little bit tender afterwards, it was great and try to be physically active again... so that helped so much. It was really healthy to be active and to push yourself, it allowed me to push myself during this ongoing treatment. I didn't*



*realise that I had that strength in me before... my mind didn't adjust to the energy levels that were growing within me. And of course, the doctors do not always advised me to try not to do too much. Working with my hands was a good feeling... most of us these days are very digital what with computers and mobile phones but it was nice to take a break from that and use your hands, especially if you enjoy that feeling.” - P11*

*“They asked my daughter if she wanted to steer the boat, go into the lock, everything associated with what we had to do. She was very quiet at first but, obviously, they've had such good experience at being with children and teenagers in this situation. They got her on the boat. I've got pictures of her steering, looking very happy. That was nice for me as well because, you know, when you're going through all of this (cancer), you worry about your children as well. You worry about how they're feeling and coping. It was nice for me to see her having a good time. The crew were just so caring and lovely with her. In all seriousness, though, I think seeing someone show confidence in her really boosted her (P9 daughter) confidence which, in turn, then makes me feel incredibly happy.” – P9*

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Constituent four, *a renewed insight into one's physical potential*, offered an understanding of the meaning that was taken from the instructors' ability to instil confidence in each participant to be as involved as they or their significant other/family member could be. The instructors, therefore, were acknowledged as being essential for the facilitation of the participants' physical involvements in their respective programmes, which was a surprise for some because they did not envision this sense of responsibility. The participants' awareness of their physical potential in the programmes consequently encouraged them to reflect on their wider potential and purpose, such as being a mother or being a physical person again. Consequently, their physical renewal was elevated to a psychological renewal, resurfacing who the participants are as people.

#### **4.4.5 A willingness to engage with and listen to others living with and beyond cancer.**

Each participant explicitly expressed how they chose to engage with other people throughout the time they spent on their respective recreational programme. The range of possibilities that was described by each participant was a part of a broad spectrum that was essentially characterised by finding a comfortable ground to



communicate their thoughts and feelings of any given topic. For some, deeply personal encounters with other participants was achieved naturally, whilst others expressed a careful and sensitive approach to discuss some but not all of their personal experiences. The range of conversational possibilities did not solely fixate its position on the topic of cancer either. Several participants expressed how cancer could initiate a potential opportunity to learn more about that person as a person, rather than someone living with cancer, or to simply discuss everyday topics of conversation.

P12 recognised that his engagement and communication with other participants on his first programme was focussed on raising awareness about cancer as he was the only one present who had experienced and lived with the condition. P12 also stated that he was aware of how this type of conversation can make people react, recalling how the instructor on his first recreational programme did not engage in the discussions of cancer, whilst others were happy to listen to him. However, on the second programme, the recreational sailing event, P12 was aware that he made a conscious decision not to talk about anything relating to his cancer experience because he didn't want to share his hardships with anyone. This, too, was extended by P12 to explain that the point of his attendance was so he and others, which included his family, could forget about their experiences of the hardships of cancer.

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*“What I did find interesting, if one was to try to analyse it all, was that on that particular event (2<sup>nd</sup> programme) it wasn't as if everybody was sat around talking about their cancer experience in a doom and gloom way. Erm, I remember there was another young lady who attended with her two little kids. She looked like she had a lot of things on her mind. But we didn't all sit around and talk about it. It wasn't an atmosphere of sitting around and doing that sort of thing. It was more of putting it all behind you and having a lovely day together.” – P12*

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P1 and P3 identified that their experiences of engaging and talking with other people on the programme about everyday topics of conversation in a non-judgemental environment helped them both feel secure and safe. Similarly, P5, P6, P7, and P8 described that the engagement and communication amongst the participants were important for them in that it was an opportunity to see and hear about characteristics

and qualities of people other than that of cancer. Each one of the four participants did acknowledge that someone in their support group may need to talk about their experiences of diagnosis and treatment. Yet, the diversity amongst the group of individuals on their programme was recognised as being important for the sake of allowing one another to meet and communicate with people beyond the immediate years that follow cancer treatment. The four aforementioned participants, therefore, emphasised the importance of meeting, as well as listening and talking, with others that were at different phases of the cancer trajectory.

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*“We just talked about our lives and what you have been up to... if you are at college, what you are doing at college, what you are doing at school... normal stuff that you can talk about with normal people, who don't judge you.” – P1*

*“So, perhaps for older people coming to the group who can then take part in these kind of days out, you then do see somebody that's been through it and come out of the other side of it. There is that opportunity to see sides to people other than the people in the chemo suite. It's like the adverts which actually are not very inspiring I don't think. It's that opportunity to see more than one side of the same story I think.” - P8*

*“Well, the importance of the sailing point of view for me was to not just put people in a room to talk about cancer but to give them something that would be useful, or challenge or whatever. Otherwise what you can end up having is an AA meeting where you're just sitting. We did that for our very first meeting, it was the worst thing I've ever done was to have people sitting around and introducing each other to themselves. That totally struck a chord with me... having that feeling of needing to see somebody else that's had cancer that looks normal. What we see on the television is not like that here and when you're put into that club, I used to say, I don't want to be in this club. Walking through the doors for cancer was horrendous.” – P5*

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Both P2 and P10 stated that throughout the duration of their recreational programme they sensitively and carefully engaged with other people who were living with and beyond cancer. This sense of engagement did include exchanges of communication that recognised one another's medical and personal narratives but was achieved in a manner that respected the social acceptances of being sensitive and emotionally

intuitive in those particular situations. Consequently, both P2 and P10's experience of communicating with others underscored the fluidity of their recreational programme insofar that they could both tentatively engage with others whilst returning to their meaningful moments of the programme.

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*"I did talk with one woman... she must've been in her late 30's and we discussed our situations. ... I was attempting to read the signals and I was trying to be very careful about what we spoke about... I wouldn't sit there and talk to other people about our condition because I felt like most of us were there to lose ourselves in the situation and the activity..." – P10.*

*"...you don't want to be intrusive but, for example, there was a lady and her daughter who both had cancer and... it was an amazing story really... and erm, it was nice that they opened up and told us about it... in those situations, you don't know how much you can ask." – P2*

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Similar to that of P2 and P10, P4, P9, and P11 engaged and communicated with others that were present throughout their programmes. However, this was done in a manner that went beyond careful discussions and conversations of their circumstances. Rather, all three participants exchanged personal details of themselves and their lives in deeply meaningful ways.

For example, P9 specifically described an encounter she experienced with two other women on her recreational programme. P9 explained how the three of them flowed from one conversation to another, emphasising that the topics ranged from comedic to serious discussions which subsequently formed a natural bond and connection between them which didn't feel like an attempt at impromptu counselling. P9 stated that the serious topics of conversation related to their thoughts about body image and intimate relationships, as all three women had faced the reality of having to undergo reconstructive surgery after their respective mastectomy procedures for breast cancer. On the other hand, P9 recognised that this personal engagement with the two other women also encompassed a sense of black humour that related to situations that they cannot express to anybody else.

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*“I mean, it’s difficult sometimes because with my close friends I can tell them anything but with a complete stranger... to open up and talk about cancer, the treatment and the things you have been through, erm, it is quite difficult... but, you know, one of the ladies, came up to me and introduced herself and we just got talking. We were sitting on the deck of the boat, watching the world go by. We shared one conversation after another... before we knew it, there was three of us ladies sat there chatting away about all our experiences. It was a long day out, so we just sat there and started to get to know each other. I began to feel very, very comfortable with them. Because we’d been through very similar experiences, I think we felt quite open to talk about treatment and, erm, you know, the things we found scary, you know, the things like our body image following cancer. We were talking about relationships (laughs)... I found myself having quite personal conversations with them. But I felt very ok about it. We all talked of how the mastectomy damaged our body confidence. We also had a bit of laugh about the things people say to you, were they mean well but sometimes you think oh god, please don’t say that to me. You know, when people say, “I bet you’re glad it’s all over” and “oh, how are you now?” – P9*

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P4 recognised that it was a while before he and the other participants began to engage with each other on the recreational programme. After establishing the physical roles and responsibilities of the team, P4 reflected upon how they began to communicate with each other, explaining that he opened up and got to know each person in a short space of time. As well as enjoying each other’s company, P4 states that he opened up about the details of his brain tumour, which consequently shocked some of the participants. Such was the connection between the participants during this particular programme, P4 stated that there was a legacy effect on the group. P4 explained how they were going to meet to spend time together after the programme, describing their bond as something powerful between them.

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*“We’re meeting in Exeter soon and we’re just going to hang out for the day. It’s funny because I don’t think we all would’ve been friends if it wasn’t for the cancer. We’re all very different people and we all come from different walks of life, but we share in something that is very powerful and it becomes, like, a family feeling. We all have such a strong bond together.” – P4*

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Lastly, P11 couldn't talk about his cancer-related experiences before his recreational programme as it made him feel too emotional. P11 cited an example whereby he had once refused the opportunity earlier in his treatment to speak with another patient about his experiences. However, on the programme, P11 talked with the team of instructors and also engaged with a younger participant, recalling how they both shared how they had been through near-identical experiences during their treatment. P11 stated that despite his previous reluctance to engage in such a direct way of communicating his experiences, the time spent talking with the younger participant felt natural, explaining that it is now easier to talk about cancer.

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*“But I then talked with the teenage boy who is living with cancer. We talked for a while about that. He actually had the same side-effects as I did during the transplant stages... you know, the digestive system and the difficulties swallowing. He had the same experience... actually it was the first time I talked properly with another person who had been through this.” – P11*

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Constituent five produced an insightful range of ways in which interpersonal communication and engagement were meaningful for the participants in this study. The psychological meaning that was derived from this constituent is based on the recreational programme being an open-ended and receptive space to explore and exchange experiences with others if they were willing to. There is, therefore, the importance of being able to feel capable of sharing personal information about oneself in a manner that is not forced or in any way planned. Rather, the voluntary nature of the programme enabled some participants to share what they may have otherwise kept to themselves had they been placed in an environment that was directly or forcibly focussed on sharing cancer-related experiences.

#### **4.4.6 Anticipation of the presence of the future**

Constituent six established a range of experiential possibilities that extended to present how the participants continued to live with the short and long-term experiential consequences of cancer. Of the twelve participants in this study, six participants were strongly aware of how cancer had continued to change their sense of reality, whilst the remaining six participants did not explicitly disclose during the interview process how or if this had happened to them. Constituent six, therefore,

had a close connection through what was established in both constituent one and two regarding the deeper and broader psychological implications of their experiences of living with and beyond cancer.

Compatible with what was expressed in constituent one, P9 and P12 discussed how a sense of fear had manifested in their lives after their respective treatments. And whilst the recreational programme had momentarily stalled this process of fear, and had, in turn, encouraged them both to navigate their negative thought processes for a time, it was clear that the manifestation of fear was controlling how the participants envisaged their long-term future. Specifically, the implications attached to a potential recurrence of cancer was causing both P9 and P12 to feel vulnerable and in need of seeking help from those around them with those who may or may not understand their fear.

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*“Every day I have to live with the knowledge that if I get a twinge or a pain I start thinking ‘has it come back’. You have to live with it and that fear never, ever goes away. You worry about it and you try not to. You’re not over it when the chemotherapy and radiotherapy stops. Even when somebody says there is evidence or an indication that there is no cancer in your body, you are still controlled by it. I found that however caring people are in your life, whether that is a friend or family, only someone who has been through it can really understand that...” – P9.*

*“I start to worry about my own circumstances because it might be well and good now, you know with your family and friends thinking that you’re ok, but yet in the back of your mind there is that worry that I’ve got it, despite it being medically under control. But will it come back? And if it does come back, will it be limited to the same area again or is it going to come back in a different area? Like your kidneys, for example. That’s the real concern. the fear of it coming back and some of the other things I have explained is there all the time. It doesn’t matter about the circumstances that you’re in, it is always there in your mind. Like last night, for example, I was at a party and having lots of fun with family and friends but suddenly it just sprang up in my mind. So, yeah, I don’t just forget about it. It is always there, just ticking over slowly. I suppose this worry for me is, erm, there in many different ways. So, I described the fear of it coming back, but if I am being crude for a minute, even using the toilet has become a worry.” – P12*

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P7 and P8 echoed similar concerns about how they had learnt to process and live with since their respective treatments. However, as opposed to an immediate and sharp sense of fear that had been experienced by P9 and P12, both P7 and P8 articulated a subtle acceptance of the role that cancer now plays in their sense of normalcy. Both participants acknowledged how they had established a way of understanding how cancer continues to appear to them during the years that had passed since their treatments. P10, on the other hand, understood that family members were attempting to remain positive about his predicament. Yet, P10 recognised that he had no control over whether his recent treatment would alleviate and cure what was at that point a state of terminal cancer, reflecting back to his intense emotional reactions he experiences regularly.

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*“well, I hate to argue with them but I’ve really got no call on any of it and the disease will take its course and there may well be a temporary hold through the trialled drug I am taking... It’s delicate because they (family) don’t necessarily understand but they’re trying to support you, trying to boost you, trying to make you feel better and you have to understand that...” – P10.*

*“I guess the bottom line is you’re never going to actually leave it behind completely but do you want it to be the focus of everyday life... no, definitely not.” – P8*

*“There is a normality. Normality changes. Normal for me is different now to how it was but it’s getting on with your life and I’d like to think that as much as you get out of it personally. Maybe as well it helps others in the group to see that you can live with it. I won’t ever say get over it but you can learn to live with it and carry on with all the things that you want to do”. – P7*

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P5 understood how the recreational programme she attended had caused her to begin to question how she attempts to manage the anxiety that she has been living with for many years of her life. Recognising the beneficial impact that the recreational programme has had on her sense of energy and mindset, P5 acknowledged how she wants to channel her experiences to help her manage other areas of her life she had feared.



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*“I love to do things; I just can’t get there. When I get there can I handle it? I haven’t flown since I was 20 and that’s my absolute nemesis. Before I wouldn’t travel by boat, it’s all about control. So it’s (the recreational programme) already had a physical and emotional impact on me to go why are you not doing these things? Look what happened when you did. I’m really trying to harness that energy and positivity and use it because I’m just so fed up with being scared of things. I now want to keep going and keep going. I don’t want to lose that” – P5.*

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Other than what was identified through both constituents one and two, which identified how a change in their sense of reality had created a sense of openness and movement, the remaining participants did not explicitly identify a way in which cancer had continued to permeate their ongoing sense of reality after they had discussed their experience of engaging in their recreational programme. This was not, then, accepted as a way of recognising that no short or long-term problems were considered by these participants after their recreational programme. Rather, it was accepted that it was their decision not to discuss how this experiential possibility had manifested due to the unstructured nature of the interview.

The final constituent thus reflects a range of experiential possibilities that refer to an awareness of how a number of the participants viewed a sense of what is ahead of them. This sense of anticipating the future had both negative and positive connotations of how cancer had changed a sense of normality and, therefore, their sense of time. For some, this sense of anticipating what may lay ahead could also be linked back to the first constituent, whereby the participants found themselves anchored or fixed to a certain way of living (i.e. fear or vulnerability). Others, however, acknowledged their sense of anticipating the future as a process that they manage on a daily basis, which can then be used to nurture a sense of hope and positivity.

#### **4.5 Conclusion**

Throughout this chapter, I have presented a descriptive phenomenological analysis of the essential constituents of the 4 Cancer Group’s recreational programmes. Grounded through Giorgi’s (2009) phenomenological method in psychology, I have presented both empirical and psychological senses of what type of reality appeared



through the consciousness of the participants, which was then constituted by myself during the data analysis. Consequently, six constituents were identified as significant psychological wholes that formed the essential meaning of the experience.

Furthermore, the constituents that were established and presented emphasise a sequence of events that draw one out from the other, exhibiting both the interrelationships that occurred and the singular distinctiveness that was present within them. Yet, this does not suggest that the findings are similar to what one may find in the natural sciences, whereby there is a cause-and-effect sense of reality that represents a psychological truth. Rather, the sequence of events represents what Giorgi (2009) discussed as to *how* the experience manifested between the participants and the worldly objects that were before them.

The following chapter, *Discussion of the findings*, will continue to examine and communicate the essential relationships and interplay that exists between the constituents. This commentary will be delivered in a style that expresses how key features of the constituents were actualised in this specific context. The discussion will also draw upon the lifeworld tenets that were expressed by Ashworth (2016) to offer a greater phenomenological depth of the psychological structure. Beyond the phenomenological commentary, I will seek to discuss the findings from this study against the existing scholarly literature that was reviewed in both chapter one and two. By doing so, I can locate how this study can expand and deepen what we already know about this subject matter, providing important contributions to academic, practical, and theoretical interests.

## **5.0 Discussion of the findings**

### **5.1 Introduction**

Chapter five has been designed to communicate a critical examination of the psychological structure that was presented in the previous chapter. Before engaging in what could be considered to be traditional discussion in part three, the first and second sections of the chapter have been written to expand and elaborate upon the essential psychological and phenomenological meaning of the constituents. This approach was inspired and informed by the methodological guidance of Lindberg, Osterberg, and Horberg (2016), whose critical essay focusses on discussing the phenomenon of interest in ways that do not bypass or take-for-granted the depth that is within. Whilst Lindberg et al. (2016) use reflective lifeworld research in their essay, the use of Giorgi's (2009) method in this study does not detract from the main purpose of remaining with the psychological and philosophical properties that are contained within the findings.

Firstly, in keeping with the eidetic nature of Husserl's transcendental phenomenology and Giorgi's (2009) phenomenologically grounded method in psychology, part one of this chapter examines the psychological constituents of the structure. Moreover, part one of the chapter will be discussed to critically expand the interplay between the psychological constituents that were constituted by myself through Giorgi's (2009) method. In doing so, I am exhibiting the empirical and psychological properties that were expressed through the participants' subjectively lived experience in the specific context of recreational programmes for those living with and beyond cancer. Moreover, the critical commentary does not discuss the 'good' or 'bad' regions of their experiences but does, on the contrary, aim to critically engage with the psychological depths that was constituted by myself and presented within the previous chapter. The parts and wholes of the phenomenon will, therefore, be elevated to a level of discussion that will engage with the psychological senses of 'rigidity' and 'openness' that were contained within.

Part two of the discussion is committed toward using the lifeworld fractions to deepen the psychological constituents that were presented in the previous chapter (Ashworth, 2015; Schutz & Luckmann, 1974). In comprehending a lifeworldly discussion of the phenomenon I am providing a richer ontological analysis of the philosophical threads that were present in the experiential meanings. Engaging with the lifeworldly provinces of reality (i.e. temporality, self-hood, or embodiment) of the phenomenon will thereby concentrate on the characteristics that were subjectively and phenomenologically real for the participants involved in this study. For example, the temporal and embodied arrangement of the phenomenon will feature heavily as a way of communicating how reality shifted in different temporal locations and embodied contents for the participants. As a consequence, the commentary that features in part two continues to reinforce the phenomenological nuances of how the participants encountered their sense of reality.

Lastly, the third part of the chapter conveys how this study locates its position with the wider scholarly literature that was identified in the introduction and narrative literature review. This part of the discussion thus examines how the practical and theoretical findings of this study influence the broader conversations that surround this subject. By re-engaging with the lifeworld and the wider literature, I accept how this approach moves beyond the philosophical guidelines that were articulated by Giorgi (2009). This movement involves a voluntary act of engaging back in the natural attitude, which, in turn, can possibly compromise one's commitment to the phenomenological attitude and the subsequent epistemological and ontological claims that are being made.

However, I am satisfied with committing to a wider discussion of the literature as the essential description and psychological structure of the phenomenon has already been carefully articulated throughout the previous chapter, *Findings*, and part one and two of this discussion. Moreover, a discussion with the wider philosophical and scholarly literature can facilitate a richer and greater critical examination of the aforementioned commentaries found within the narrative literature review and introduction, something of which academic researchers are committed to achieving.

## **5.2 Part One – The interplay of the constituents**

The findings that have been established within this study have endeavoured to determine the essential ways in which recreational programmes, which are facilitated by the civil society in the natural environment, are meaningful for those living with and beyond cancer. As opposed to using a method of reductionism in the natural science framework (i.e. a questionnaire) to understand this experience, the participants in this study were encouraged to speak freely of their subjective experience. In doing so, I could use Giorgi's (2009) descriptive phenomenological method in psychology to address the research interest of developing an eidetic description and essential psychological structure. Consequently, six psychological constituents were identified which encapsulated the variety of experiential ranges within this specific phenomenon of recreation for those living with and beyond cancer. The commentary that features below presents a psychological discussion of the six constituents in a way that displays a process of the shifting emergences and regressions of self and the wider lifeworld that were expressed by the participants.

### ***5.2.1 The Interplay of Awareness of the changes to one's reality due to chronic illness and A sense of openness to want to experience other opportunities.***

For a meaningful engagement in the recreational programme to occur, the participants firstly identified and acknowledged the changes they had been confronted with upon their diagnosis, treatment, and overall experience of cancer. Without reiterating the various characterisations that occurred for all twelve participants, the initial constituent reflects a situation in which the participants had been confronted by the rigidity that comes as a result of being exposed to a sudden and alternative way of living their life due to diagnosis and treatment for a chronic illness. For example, the language used and various exemplifications that were described throughout the first constituent were concerned with a sense of being rooted or anchored to the situation before a sense of psychological openness occurs. It was recognised that this rootedness to the change in their reality was characterised by a range of implications that were detrimental for their health, before entering into a perspective in which they could begin to accept or acknowledge an openness of living with and beyond cancer.

For example, the participants initially communicated detrimental characterisations that depicted internal and external upheavals. These characterisations included but were not limited to, experiences of sleeplessness, nightmares, emotional cycles of crying, persistent thoughts about the disease, a readiness to understand existing challenges with mental health, feeling and being on auto-pilot, experiencing a closeness to death, trying to remain focussed on work, and exposure to school bullying. The repercussions of these changes reflected a fragmented sense of self in which there was a violation of one's autonomy and independence to varying degrees. As opposed to what one would find with a victim of abuse from another individual, the violation comes from within that subsequently splits the participants' sense of self into two over various senses of time (i.e. P10's emotional cycles of crying before starting to try to live all over again).

Yet, after increased exposure to this sudden change in the participants' reality, there was a shift for each participant that indicated that one could begin to function, adapt, and potentially accept such dramatic changes to their lives. This again ranged from taking prescribed anti-depressant medication, writing journal entries about ongoing treatment and overall experience, engaging with family and friends for support, moving schools and cautiously entering new friendships, and generally increasing a sense of self-awareness. Therefore, the rigidity that had contained the participants to think, feel, and behave in a manner that would not be considered functional for their overall health, QoL, and sense of well-being had begun to ease in many different ways and at various times.

This process of becoming unrooted from the rigidity of the first experiential constituent was thus further characterised through constituent two, which explored the openness of seeking opportunities for themselves. As was emphasised in the previous chapter, this insight was two-fold in that it rotated around both the flow of broader psychological changes and the participation in the 4 Cancer Group's recreational programmes.

Drawing upon the various examples communicated by the participants, a projection and movement of oneself occurred as a result of being confronted by the ways in which they lived with a chronic illness. This sense of awareness facilitated an adaptation of seeking or exploring the possibility of new opportunities in an

environment that could offer a sense of internal and external security, emphasising a sense of psychological and physical movement. Yet, this sense of openness did not then disregard the rootedness that had occurred, as it is the previous constituent that has been fuelling this sense of experiential openness and movement. P5's understanding of how the recreational sailing programme would intensify her sense of anxiety as well as encourage her to see how her life and experiences of anxiety are changing (i.e. "eyes opening") for the better is an apt example of the overlapping that occurred between the two constituents.

Consequently, the initial shifts that occurred in the participants' psychologically grounded experience, such as adjusted comfort zones and open-mindedness, trust in one's environment, new interrelationships, and distancing oneself from negative thoughts, encouraged what could be considered an initial step from rigidity towards a sense of psychological openness.

### ***5.2.2 The Interplay of Movements towards experiencing the present moment, Renewed insight into one's physical potential, and A willingness to engage with and listen to others living with and beyond cancer.***

As I have reflectively integrated constituents one and two, the third, fourth, and fifth constituents will be presented together to communicate the subjective and psychological flow that exists between them. Once again, this approach does not detract from the singular uniqueness from which the constituents were originally circumscribed. Rather, the three constituents coalesce together to present an empirical and psychological whole of how the participants experienced their respective recreational programmes, with each constituent adding its own phenomenological depth and direction. Moreover, the three constituents that will be discussed have a distinct focus on the context and environment in which the participants were involved with the 4 Cancer Group. The range of psychological possibilities are subsequently discussed in a manner that recognises the significance of how each recreational programme facilitated a sense of trust and openness for the participants.

The phenomenological and psychological direction that was presented within constituent three brought a movement and acceptance of the present moment of the recreational programmes experienced by the participants. The two supporting components that comprised the constituent were split between an emphasis on the participants' awareness of the immediacy of the present moment and being with a significant other, such as a family member or a friend, with some participants overlapping into both parts of the whole constituent.

Upon studying the language that was used to describe this dimension of the experience, it is possible to identify the importance of the immersion of the immediate experience. The language expressed a sense of being "freed" from thoughts and experiences "without having to put much mental effort into it" which the participants could "hold onto" for reflection. This sense of importance also reflected onto sharing this moment with a significant other, with P2 reflecting on how the weather "would not have mattered because we are all there together, joining in, having fun, and laughing".

The character and intricacy of the constituent are based upon the psychological sense of being in an environment that encourages and actualises another degree of openness to live in the present moment as oneself with or without a significant other. On reflection, this is something that was initially causing a degree of disconnection from reality during constituent one for a number of the participants (i.e. the distressful immediacy of *thinking about the disease* and *sleeplessness*).

The recreational programmes are not then a safe refuge as such, but rather an environment that has broadened the participants' horizons of their lives. This includes the immediate experiential and haptic moments that can be found within it, which is then possibly shared with a significant other (i.e. P8 and her mother taking pictures of the natural environment together). Moreover, the impact of the present moment through the recreational programme takes on a sense of empowerment and control that has been undermined and compromised by living with and beyond a chronic illness. The internal and external conflict is subsequently suspended for a time whereby strong (i.e. thoughts of one's treatment) or trivial (i.e. inclement weather) matters bear no undesirable impressions on the immediacy of the present moment that is being held personally or with a significant other. The trust and

openness to experience other opportunities are consequently fulfilled through this encounter and engagement with another sense of reality for a while.

The awareness to engage in the immediate experience during the recreational programme represents a potential process of understanding the desire to consciously or subconsciously move beyond the psychological rigidity that had been formed throughout the reality of living with cancer by becoming more open to new possibilities. The loosening of this sense of psychological rigidity then underwent a further process of being actualised through the engagement or renewal of the participants' embodied and physical potential.

Whilst constituent three had a psychological sense of re-engaging with the experiential nature of being in the present moment, constituent four's essential psychological boundary was shaped by concrete experiences of security when engaging in the physical acts of the recreational programme. This sense of trust and safety to be physically immersed in each of their recreational programmes was a notion that was initially unanticipated by some of the participants. Yet, it was through the instructors' guidance and support that enabled the participants to access and actualise this opportunity. Exposing the participants to a sense of inclusion and immersion, the instructors created novel opportunities for the participants. It is then through this openness to their physical potential that enabled the participants to renew their involvements in the world again.

The recreational programmes, especially the instructors, were thus responsible for producing a literal sense of experiential transformation through bodily engagement and learning. The ranges of transformation are not dramatic in the sense that the participants were exerting themselves beyond their physiological and psychological boundaries. Rather, the transformation existed and occurred in a way whereby the participants are trusting their physical sense of self, with the underlying psychological process relating to a subtle or strong transference of 'passivity to activity', which will be explored in greater depth in part two. Yet, what is psychologically relevant is that by choosing to participate in the recreational programmes, the participants are willingly accepting an opportunity to engage with natural psychological challenges that have otherwise been subtly or strongly diminished as they are living with or beyond their respective experiences of cancer.



Constituent one confirms how the participants experienced a sense of being anchored to their respective situations that had either momentarily or long-lastingly caused them to be passive actors in the process (i.e. receiving treatment and waiting to learn of the medical results). Yet, this experiential constituent of the structure encapsulates many movements that strongly or subtly propelled the participants into a position of being active members of the recreational programme. For example, participants 11, 4, and 8 all articulated different movements that related back to a position of being given a sense of empowerment and control to fulfil a sense of their physical and psychological potential, which is something they had underestimated upon registering for their respective programmes.

Lastly, constituent five presented a significance that was directed towards engaging and communicating with other people living with and beyond cancer. As was highlighted in the previous chapter, the essential ways in which the engagement and communication occurred spanned a broad spectrum of styles that facilitated a sense of trust and respect for one another. For example, the space and time to speak of personal fears and vulnerabilities, engage in everyday topics of conversation, or the trust in the decision to completely avoid speaking of the subject of cancer was described in various ways.

However, the essential psychological root of this constituent was based on the acceptance of one another's presence and communication without having to justify it or formally therapize each other. There is a collection of commonalities and reciprocated empathies that were present for the participants throughout their respective experiences, whether that is distant understanding or an experiential closeness. What was then a psychological and physical experience of actively being in the present moment in the previous constituents becomes a process of gradual trust and safety in the company of relative strangers who had also experienced a sense of the psychological distress and rigidity.

For example, P11 disclosed how it was his first time that he had properly engaged with someone who could truly understand and reciprocate his experience, as this was something he actively avoided beforehand. P9 communicated her sense of vulnerability about her physical appearance and relationship concerns to two women who were strangers before they participated in the programme. P1 had an

opportunity to be welcomed into a group without being bullied or discriminated about her experiences of cancer. And lastly, P12 chose to move beyond the topic of cancer throughout his second recreational programme as he knew how difficult the hardships of cancer have been for those affected.

Consequently, there is greater tolerance and choice to unobtrusively communicate the internal and external difficulties that have occurred throughout the years before, during, and after the participants' respective cancer treatments during their time spent participating in their recreational programmes.

Upon integrating the constituents to establish the psychological implications that were formed, it is possible to understand the transition that had at this point occurred for the twelve participants in this study. The three constituents represent the essential psychological shifts that they have made to move beyond the original state that they had described whether that was subtle (i.e. P7) or strong (i.e. P9). However, what is essential to express at this point is that the essential flow of the constituents is completely open-ended, whereby the participants controlled what level of engagement they committed to throughout the 4 Cancer Group's recreational programme, as there was no strict agenda or format forced upon them. As a consequence, the constituents that were established are fluid and could be different for another twelve participants. Yet, what has been discerned from the twelve participants in this study is that communicating with one another, engaging in physical tasks and acts, and being in the present moment with or without a significant other was how the participants actualised their sense of openness to experience their recreational programmes, which had previously been damaged due to their respective diagnoses and treatments for cancer.

What is recognised at this point, then, is that the sequence of the psychological structure places a significance on the sense of having a place, space, and time to move beyond or control the rigidity that deprived the participants of the way of life they had known before their diagnosis and treatment for cancer. However, the following constituent of the structure offers a sense of balance against the essential psychological characteristics that have so far established the psychological openness.

### **5.2.3 Anticipation of the presence of the future**

Constituent six reflected the experiential shifts in reality that were expressed by the participants concerning how they anticipated or lived through the presence of the future. The range of experiential possibilities identified and acknowledged how reality for the participants had continued to change and did not simply return to a 'normal' state of existence as they live with and beyond their cancer experience. The six participants (P5, P7, P8, P9, P10, P12) that explicitly identified and articulated their sense of reality about the future could be understood to have been confronted with the psychological consequences of a clash in their evolving senses of reality.

Whilst the recreational programmes had stalled or suspended the psychological rigidity and had, in turn, enabled a degree of autonomy, empowerment, trust, and control for some time, the disruption to their psychological openness gains partial or full prominence again. This disruption of control and direction of the participants' lives is experienced as cancer continues to be a part of who they are. For example, this occurred as they move towards initial physical recovery (P9, P12), wait to receive test results to possibly reverse the terminal status (P10), continue to live with cancer as part of their ongoing identity years after the treatment (P7, P8), and contemplate the worry of losing the positivity and energy that has since been established after treatment (P5).

In this sense, then, there is a clash between the participants' experiences of being fully immersed in the richness of their lives again with the possibility of being consumed by the psychological rigidity that had disrupted their lives. Aside from P10 and P2, who openly acknowledged that their terminal cancer was more than likely to be the cause of their deaths, the aforementioned participants proceed back into a way of living that is difficult to negotiate after being confronted with their mortality. The psychological structure then has the possibility of returning to what was established in constituent one, whereby the reality of living with and moving beyond cancer can produce both another sense of rigidity and potential openness.

As I indicated in the previous chapter, the remaining participants (P1, P2, P3, P4, P6, P11) did not explicitly articulate a sense of 'normality' or reality after their participation in the recreational programmes like the other participants had done. However, it would not be speculative to propose that all aforementioned constituents

could continue to have an impression on the participants' sense of reality that they had expressed.

#### **5.2.4 Summary of part one**

Throughout the part one, I have presented a critical engagement of how various characterisations of how the participants' experiences coalesced into a temporal movement that flows back and forth, shifting in psychological directions which represent senses of who they are in their lifeworlds. Various examples from the previous chapter have been used to emphasise how reality in the essential psychological structure is not one of a linear and narrative process but one that has different phenomenological properties and manifestations that have substantial meaning for the participants.

Importantly, the psychological meaning of recreational programmes represents a temporary and neutral territory that momentarily stalls or enhances the direction of the broader psychological shifts for some time through the aforementioned constituents. It is thus the flow between psychological rigidity and openness that is one of the most dominant and essential characterisations in this study that emerges out of the eidetic description and structure. Moreover, the characterisations reflect a reality, whether that is strong, subtle, or in between, that is describing a sense of losing and regaining ontological security in the wake of living with and beyond cancer.

Delving further into an ontological analysis of this sense of living with and beyond cancer, the recreational programmes are an opening up of the world for the participants. Reality, in the sense of the world opening up, is a time, place, and space for the psychological and physical moments that can produce experiential movements (i.e. shifts in comfort zones and mindset) and reclamations (i.e. P10 reflecting on his participation programme being worthwhile as he is and has been quite a physical person) of the participants' worlds. Yet, reality, in the sense of the world closing down and becoming rigid again, was an important possibility that has been recognised and constituted. The participants acknowledged how the combination of the presence of cancer and the future can or does continue to pose a challenge to their senses of normality and reclaimed sense of autonomy.

The movements towards establishing a meaningful sense of living with and beyond cancer in this study are therefore far from the linear and heroic discourses often

depicted in typical strategic plans (i.e. the recovery package). The movements do, however, contain a complex and layered discussion which can improve strategy and individual QoL through phenomenological psychology. Yet, before a critical engagement with the literature and strategic documents that were cited in both the first two chapters can occur, I aim to evoke a greater ontological analysis of the psychological structure by using the lifeworld fractions that were previously articulated by Ashworth (2016).

### **5.3 Part Two - Lifeworld Commentary**

It is at this point where the attention of the discussion deals more sensitively with the lifeworld fractions (self-hood; intersubjectivity; embodiment; temporality; spatiality; project; discourse) that were described and discussed by Ashworth (2016) in chapter three, *Methodology and methods*. As a reminder, Ashworth's (2016) analysis of the lifeworld posits that each one of the fractions is not a separate experiential entity that can be studied in isolation. Rather, the lifeworld fractions are an interconnected group of experiential structures which overlap together to illuminate different areas of a phenomenon of interest.

Ashworth (2016) explains that one perspective of the lifeworld can be used to inform a phenomenological study. That is true but it would not respect the phenomenological attitude of letting the phenomenon speak for itself (Halling et al., 2020) which is at the heart of this phenomenological study under the guidance of Giorgi's (2009) methodology and method. However, what became apparent when the phenomenon speaks for itself is that, naturally, one or two of the fractions emerged as the dominant characterisations of the phenomenon of interest, whilst the remaining fractions subtly remained in the experiential background (Ashworth, 2016). Therefore, the following commentary will engage with the findings that were discussed in the previous chapter and part one of this chapter by using the lifeworld fractions to elicit a greater philosophical discussion of the constituents.

It is also at this point where the discussion becomes significantly more concerned with the existential and practical concerns of the study, drawing attention to how the lifeworld fractions evoke a greater understanding of the participants' ontological sense of who they are in their world of living with and beyond cancer.

### **5.3.1 Temporality and selfhood**

Within the findings of this study, there was considerable emphasis on the temporal unities and structures that expressed the flow of the participants' sense of selfhood. Yet, before engaging with the temporal contents of the sense of selfhood within the constituents, it is important to reflect on Zahavi's (2012) critical essay of how the self emerges through two types of temporality.

Zahavi (2012) discusses both a narrative sense of self and an experiential sense of self, which have been discussed as conflicting unities of temporality by different scholars and philosophers (Ricoeur, 1992; Husserl, 1962). The former refers to selfhood being a process of construction over time wherein there is not be a fixed reality but a constant sense of self-evolvement through reflection. The latter presents a first-person perspective that explores the experiential and subjective givenness of the world that is around us to form our sense of self, drawing heavily on the phenomenological analysis of experience. In agreement with Zahavi (2012), both perspectives are incredibly relevant in their exploration for how the development of self appears through time, and to disregard one for the other would be unreasonable.

The entire temporal flow of the constituents in this study supports both perspectives. Whilst each one of the participant interviews generally followed a step-by-step recounting of their narrative experiences of their sense of self, the meaning that was ascertained, which is reflected in the psychological structure, is different in that it does not reflect the narrative process of reality in which it was articulated and reflected upon by the participants. Rather, the essential meaning that has been established through Giorgi's (2009) method represents several constituents of their world that were experientially lived through together. Therefore, I have attempted to fulfil what Zahavi (2012, p16) discusses as a thorough exploration of "the temporality of perspective" through a descriptive approach of the experiential consciousness through an initial narration.

As a result, the personal narratives were transformed into psychological constituents of a larger structure which explored the givenness of the world to the participants. Through this experiential excavation, a temporal consciousness of selfhood and its relation to living with and beyond cancer was both acute and chronic. Both poles

reflected a sense of fragility and robustness of the selfhoods that appeared back and forth throughout time for the participants involved.

Moreover, the participants' sense of time does not respect and share the same qualities that are found in the natural attitude or an objective sense of time. Rather, the time that was described by the participants takes on a whole different meaning and experience in the context of living with and beyond chronic illness, such as cancer. Within the natural attitude, or how individuals approach their day-to-day life, deadlines or scheduled plans usually have a pre-conceived outcome that they are expected to manage and move on from. Yet, the participants in this study experienced both the rigidity and openness of being in a world of living with and beyond cancer whereby their existential sense of time is, and can be, unendingly present for days, months, and years after diagnosis and treatment.

Therefore, what was a factual way to describe the participants (i.e. either living with or beyond cancer) now becomes a phenomenological and psychological process that can endure indefinitely. Living with and trying to move beyond, or accept, cancer becomes a sense of self or identity involving a higher awareness of what is normal and natural insofar that there is both uncertainty and hope about the participants' assumptions relating to self and time. For example, though there was a sense of a loss of time (i.e. P12 waiting three months to learn of effectiveness of treatment), there was likewise a regaining of one's time in the world through the recreational programmes that were attended by the participants (i.e. being in the present moment with family or doing something that they had enjoyed as children).

The depth and location of time can therefore be both trapped and accepted in various experiential moments of structure. Each experiential moment provoked different senses of the self before, during, and after the participants engaged with their recreational programme.

### **5.3.2 Spatiality, intersubjectivity, and discourse**

The lifeworld fractions of spatiality, intersubjectivity, discourse, embodiment and project can also be used to draw out a firmer stance about how the recreational programmes facilitated the shifting sense of rigidity and openness within the six constituents of the psychological structure.

The space and place of the recreational programme offered an opportunity for the engagement of an altogether different discourse for the participants as individuals or as a group. In reality, the open-ended and unstructured nature of the programmes created an experiential space that does not imitate to what one would find in common discourses of health and cancer. On the contrary, the recreational programme was experienced as being a space to engage with others or be by themselves in a way that did not include any of the master narratives of identity that are strongly promoted and endorsed in public health and communication discourses (i.e. “stand up to cancer” or “lifestyle improvements”). Indeed, the spaces in which the participants accommodated did not communicate a phenomenon of experiencing ‘oppression to liberation’. Rather, the essential meaning that featured explicitly and implicitly amongst the experiential constituents concerned movements of being psychologically rigid and open, with neither one dominating the other. It was, on the contrary, much more balanced in that the experience was negotiated in this open space as individuals or as a group of compatible people.

Consequently, the psychological structure presented was not a ‘battleground’ of how living with and beyond cancer is ‘fought and won’. The wholes and parts of the structure described the recreational programmes as a space in the natural environment whereby the participants can communicate about what is meaningful to them. This includes fear of relationships and body image, talking plainly about what is happening in their lives, engaging with the natural environment through “closing one’s eyes to accept the silence and quietness of the moment”, and taking pictures of the natural surroundings with significant others. What is currently an enframement of changing behaviour through physical activity for the fulfilment of rehabilitation and survivorship thus turns into an openness and possible acceptance of living with and beyond cancer for the participants, relating to how different senses of self appears throughout their sense of time.

The space and intersubjective relations that occurred within the psychological structure did not, then, encourage a narrative of heroism and bravery. Rather, the space and intersubjective dimensions present a reality that reflects the participants’ lifeworlds, be it vulnerability, laughter, personal reflection, openness to inclement weather, and another sense of psychological state that was expressed.



### **5.3.3 Embodiment and project**

To reiterate, the findings of this study presented a variety of experiential moments that provoked different senses of self over time which shifted back and forth. The changes that the participants experienced concerning their psychological adjustments were quite clearly a very broad and fluid phenomenon that was difficult to completely manage and negotiate.

For a deeper exploration of the findings, it is necessary to contemplate how the experiential constituents were not purely psychological all of the time. Rather, the embodied changes that occurred over time were equally as important for the psychological sense of self that occurred. As discussed, the various ranges of experiences that were expressed emphasised a spiritual and psychological movement in order to live with and moved beyond their experiences of cancer. Within this movement occurred what has already been described as psychological movements that shift back and forth. However, the embodied sense of the experiential dimensions can be expressed as flowing from a sense of passivity toward the reclamation of activity, or an initial step to regenerate life's projects, whether these are substantial or small.

Although the embodied passivity that was expressed varied amongst the participants caused different reactions (i.e. being and feeling on auto-pilot, existing in a dream-like state of living, and trying to engage with work to forget about cancer), the alternative way of living essentially removed the participants from a pre-reflective direction that they were originally moving toward. The passivity stems from the confrontation of facing a loss of control over their lives, which, ultimately, left the participants "stuck" or without any sense of familiarity or certainty in what they had known of the world. Sharing both positive and negative qualities, this loss of the participants' projects created an embodied and psychological evaluation of the direction of the participants' health and lives, seeking out new projects to deliver a renewed sense of experiential movement and meaning.

The recreational programmes subsequently acted as the embodied space and place to fulfil the movements and openness that occurs in the first two constituents. Taking into consideration all of the experiential moments and variances amongst them, it is possible to state that the recreational programmes are, therefore, a reality that can

be physically grasped and harnessed for a sense of meaningful project without there being a strict agenda in place. A deeper analysis of the essence of the recreational programmes is accordingly based on a psychological and physical movement towards an environment that can generate and hold personal meaning. The recreational programmes are a flexible opportunity to fulfil both the broader and smaller movements in the lives of the participants.

This sense embodied fulfilment manifested in a multiplicity of ways for each participant. For example, participants expressed a desire to move beyond a certain sense of comfort zone, control one's physical sense of anxiety and depression, find security in a place where people are not judgemental, embody an open-mindset, re-align physical and mental energy, and re-engage with being a physical person again through recreation. Another crucially important example was P11's description of the pleasure of using his hands again and P8's morale boost of being able to get on the boat. Both resonate with what was described through Burwood's (2018) philosophical discussion of heightened sensitivity towards the taken-for-granted or less significant issues of our existence.

The recreational programmes are, in this embodied way, related to but different from what would be found in an intervention that has a psychological and theoretical foundation of behaviourism. The essential embodied meanings that have been ascertained by the participants are much more complex and personal than simply being an active respondent of a physical rehabilitation and survivorship initiative. On the contrary, the open-ended and unstructured approach of the 4 Cancer Group's recreational programmes enabled the participants to seek out a project that can satisfy their humanistic concerns of being physically connected to the world and its contents for a time. In this way, the recreational programme does not only give back a sense of time but also give back a sense of the body again.

### **5.3.4 Summary of part two**

It is important to reflect upon the participants' existence in the world as a way of concluding the lifeworldly commentary of the discussion. The worlds in which the participants exist has been exhibited as both broadened and narrowed by the various lifeworld characterisations that have been brought into focus during both the findings and discussion so far. The participants' involvements in the recreational

programme are not just simply about being active again or engaging in a form of physical therapy for their physiological recovery, quality of life, and sense of well-being. It is also much more about the space, time, intersubjective encounters, shared discourses, embodied projects, and senses of self that emerge throughout the entirety of the cancer experience that is of importance. What this study has illuminated has been how the programmes offered by the 4 Cancer Group partially helps navigate those emerging and colliding worlds of existence for the participants. Consequently, the recreational programmes are not a panacea for the psychological and existential concerns that occurred for twelve participants in this study, but are, instead, a vehicle that supports certain moments of the psychological processes that are involved in the complexity that is living with and beyond cancer.

The unique position that the civil society holds, and the services (i.e. recreational programmes) that can and are being offered, could now hold a stronger position for the way in which those living with and beyond cancer are supported after treatment. What is at present a method of encouraging individuals to manage their lifestyle after treatment can be expanded to include a wider variety of services that do not put pressure on a public health agenda but do, in turn, encourage individuals to explore and understand their various senses of self that emerge during and after their treatment. More importantly, the value of this research illuminates the significance of lifeworld-led policy reform. Reforming cancer strategies and ambitions through phenomenologically informed research can not only reduce the mechanical and bureaucratic nature of the pathways currently in place and, in succession, inspire a sensitivity to a greater humanistic agenda. Refusal or resistance to incorporate the subjective lifeworld could indeed intensify, and possibly worsen, what we already understand as the unmet needs of those living with and beyond cancer.

The third and last part that will follow has been committed toward locating and positioning the findings of this study against the literature that was cited in the first two chapters of the thesis. The purpose of re-engaging with the existing literature is to expand the current enframement of how rehabilitation and survivorship pathways are being modelled and commissioned in England. This is not to suggest a significant overhaul of the current model, yet the following discussion will seek to expand the approach as a way of satisfying the empirical, psychological, and

existential findings that have so far been presented within this study. By doing so, the current cancer strategy and supporting ambitions can be diversified for those who do not require or want to seek out lifestyle-based interventions.

## **5.4 Part Three – Re-engagement with scholarly literature**

### **5.4.1 Introduction**

The third and last part of the discussion is focussed on the re-engagement with the wider literature. This has been presented to provide a commentary of how this phenomenological analysis compares with the broader enframements of this topic that were discussed in the introduction and the narrative literature review. The comparison does not, then, spell out a rejection of the larger and broader enframements that were considered. It is, however, a reconsideration of where this study sits alongside other scholarly literature. Through this, I am addressing what Wertz (2010) explains as a critical dialogue with the literature, as no subject matter can ever be completely known, and must, therefore, be subjected to qualitative and phenomenological modification to continue revealing the phenomenon's essence over time.

### **5.4.2 A critique of current strategic enframement of rehabilitation and survivorship**

As discussed in the introduction, both Heidegger and Husserl shared the same concerns for western culture and humanity about the scientific developments of modernity (Van Mazijk, 2019). Husserl's concerns, which are important for this discussion, were directed toward the development of modern science and its control over things and phenomena to the point whereby philosophical science is consumed by fact-finding and idealistic positivism (Van Mazijk, 2019).

Through this paradigm of conducting science, people can be dominated by the technological and positivistic understanding of the world that can, according to Husserl, leave subjective and humanistic concerns unanswered and rendered commonsensical (Van Mazijk, 2019). To reiterate, Husserl acknowledged how the modern idea of mathematical and scientific nature of inquiry has its role and purpose to measure and record objects of the world. Yet, the overall dominance of this way of 'doing or seeing science' can create problems for the human-world relationship, forcing knowledge and reality into certain 'enframements' and ways of knowing the

world (Van Mazijk, 2019). The sense of enframement of the world and the various institutions and schools of thought that exist within it can create types of reality that are therefore deprived of experiential meaning or value. It was at this point that Husserl formulated and introduced his transcendental phenomenological philosophy to attempt to manage and restore a balance that would satisfy his concerns for science (Van Mazijk, 2019). However, the key and essential point to be taken from Husserl's critique and the findings of this thesis are to be aware of how the world and its contents can be 'enframed' and subsequently left unchallenged by ignoring the foundation of subjectivism.

To return to the core of this thesis, it is apparent how the current healthcare strategies and ambitions for those living with and beyond cancer have enframed an approach to enhance the reality of rehabilitation, survivorship, and end of life care. This enframement can have clear benefits for the many individuals that have and will continue to receive it, and it is not the goal of this thesis to question the entirety and integrity of the NHS' and Macmillan's long term ambitions to support those living with and beyond cancer.

It is, however, the 'enframement' of the way in which an individual who is living with and beyond cancer can be confronted by the 'technological-scientific worldview' that is embedded in the post-treatment pathways of the recovery package. To be specific, it is the prescribed physical activity interventions that have been one of the major concerns and critique of this thesis. As discussed in the first and second chapter, the vast majority of physical activity interventions used (i.e. supervised gymnasium interventions) follow a behavioural change model of care that encourages and perpetuates the concept of self-management through lifestyle interventions, otherwise referred to as "the responsabilisation of health" in public health ethics (Brown et al., 2019).

Of course, a degree of autonomy and awareness of lifestyle management is important for those living with and beyond cancer for the sake of managing potential recurrence and the physiological side-effects of treatment, such as cachexia. The six constituents of the findings of this study do, to some degree, support the notion of promoting self-management for these purposes (i.e. P11 realigning one's mental and physical energy through recreation and P3's use of physical activities to help

her get back to normal). However, to use such an approach for an entire generation of people living with and beyond cancer is simply too linear, one-dimensional, and can reduce individuals to being and feeling solely responsible for their health at a time when they can still be considerably vulnerable about who they are. This study has in part shown the complex nuances that individuals are confronted with in their approach to living with and beyond cancer, which is far beyond the remit of behaviour change models of physical activity interventions. As a result, I do instead propose that the conceptual enframement of self-management may be too challenging at certain times due to the various psychological difficulties an individual may experience.

Furthermore, this study chose to resist and suspend this dominant worldview of rehabilitation and survivorship and, in turn, learn of how the 4 Cancer Group facilitates a meaningful sense of rehabilitation and survivorship through recreational programmes. More specifically, within both the introduction and narrative literature review, it was identified that there was a greater scope for further research to understand the diversity of recreational approaches and services established to facilitate rehabilitation and survivorship for those living with and beyond cancer (Burke et al., 2017). In particular, the existing scholarship that surrounded this subject matter had identified that there was a greater need to understand (i) men, women, and children's experiences of different recreational programmes, and (ii) incorporate a broader range of methodologies to be used to understand this phenomenon.

Through this approach, I automatically resisted the assumptions, theories, and discourses that come heavily embedded in this enframement, such as PTG or the bio-militant discourse that is associated with chronic health conditions. The resultant constituents that were established offered a psychological reality of how and why the recreational programmes facilitated by the 4 Cancer Group were meaningful for greater awareness of the participants' sense of self and their positions in the world over periods of time that were not necessarily linear. All of the aforementioned psychological nuances move beyond the scientific worldview in a detailed phenomenological manner. There are lots of ways to engage this point of discussion but, for example, the findings partially show the phenomenological movements that can potentially occur between Post-Traumatic Stress Disorder and Post-Traumatic

Growth, suggesting that the psychological states involved in these types of experiences are not static but much more fluid and nuanced. Therefore, the findings do identify that it is much more complex to simply “recover” from or “stand up to cancer” in the days, months and years that lead to an individual’s death or psychological movement from the disease.

With this knowledge, it is possible to challenge the ongoing sense of enframement that exists within the strategic ambitions through an engagement with the findings of this study and the themes that were developed in the initial chapters. Hereinafter, part three of the discussion has been written to establish a link with the various literature and scholarship that was cited in the introduction and narrative literature review. Moreover, the literature and scholarship will be drawn upon to compare and contrast the various commonalities that were found in this study, and therefore attempt to subtly expand the current strategic and academic enframement of what it means to live with and beyond cancer.

## **5.5 Structured physical activity interventions and unstructured recreational programmes**

In the review of the literature, there appeared to be a developing emergence of the two approaches of using structured physical activity interventions and unstructured recreational programmes for the QoL, rehabilitation, and survivorship of those living with and beyond cancer (Midtgaard et al., 2015; Burke et al., 2017). This study pursued the option and recommendation to comprehend how unstructured recreational programmes in the natural environment influenced the senses of rehabilitation and survivorship of twelve participants either living with and beyond cancer. The findings in this study had direct and indirect commonalities with both the Midtgaard et al. (2015) and Burke et al. (2017) reviews presented.

For example, there was a resonance with the physical, spiritual, and social dimensions of both syntheses which reflected how the participants found various meaningful moments throughout their experiences engaging with the 4 Cancer Group. Also, as anticipated, some of the findings of this thesis did have a high degree of similarity with the psychological dimensions of Burke et al. (2017) synthesis. These included striving to achieve a sense of physical renewal, taking control, and focussing on finding relief from cancer-related thoughts and

experiences. Yet, in contrast with Burke et al. (2017), a number of the participants in this study did recognise how cancer had continued to be detrimental to their lives, suggesting that the recreational programmes were a temporary answer to the wider psychological challenges associated with living with and beyond cancer.

The option to employ a maximum variation sampling approach was another way in which this study has expanded the swell of literature and scholarly work in this area of interest (Burke et al., 2017). As discussed in the narrative literature review, the majority of participants included in previous studies have been middle-aged women living with or recovering from breast cancer (Midtgaard et al., 2015; Burke et al., 2017). This study included women, men, and children with a variety of ages (i.e. 15-67) and diagnoses of cancer. Not only does this body of work expand the Burke et al. (2017) call for a greater inclusion of participants, but it simultaneously follows the phenomenological pursuit for essentialism. In the case of this study, the twelve participants were subject to Giorgi's (2009) method to discern and establish an essential psychological structure and description based on their experiences. Consequently, the combination of twelve experiential accounts, all of which varied in age, sex, and diagnosis, identified the essential meaningfulness of the 4 Cancer Group's recreational programmes.

However, Midtgaard et al. (2015) questioned whether unstructured programmes and activities could fulfil the psychological need to enable individuals to achieve a sense of control and normalcy due to the apparent lack of clinical input, design, and setting. Yet, what is clear from the findings of the Burke et al. (2017) synthesis and the findings of this study is that the psychological implications reveal a greater possibility of sustaining a meaningful engagement with living with and beyond cancer that is perhaps more representative of reality than what would be established in a structured and clinical environment. This argument expands to include the limitations of the clinical settings that were discussed by Midtgaard et al. (2015). These were expressed as concerns relating to the limited "long-term adherence" due to a lack of "real life" settings when attempting to facilitate meaningful engagement with a structured physical activity intervention.

Whilst there were no significant discrepancies between the structured and unstructured approach in facilitating a meaningful sense of rehabilitation and



survivorship, there is now a plausible argument to underline the limitations of clinically supervised and structured interventions. Ironically, and probably inadvertently, the interventions may create further psychological dependency on the clinical staff and environment in which they are situated. Moreover, this dependency may reduce the likelihood of those who use these specific services to commit and adhere to the content of the intervention in the long-term because of the specialist consultation they receive for a relatively short period of time (Midtgaard et al., 2015). Consequently, the structured and clinical approach may be too controlled whereby the intervention loses its central and humanistic ethos of enabling those living with and beyond cancer to 'recover' by focussing primarily on using their bodies and minds in the right way to achieve an active lifestyle.

In this sense, both the structured and unstructured approach offers different kinds of experiential meaningfulness (i.e. physical/embodied, psychological, social engagement, and spiritual experiences) that can support "the unmet needs" of those living with and beyond cancer (Macmillan, 2017). For example, the structured interventions can produce a greater awareness and movement toward establishing a physical transformation (i.e. increased strength or cardiovascular fitness) that can help after an individual's treatment for cancer. Whereas the unstructured approach, based on the findings of this study, provides a natural space to engage in the experiential moment of the present in a way that does not conform to the master narratives of being heroic or brave for doing so. Furthermore, the unstructured approach is a setting that also expands psychological and physical "comfort zones", enabling those living with and beyond cancer to recognise a greater sense of self, detached from cancer or other health-related issues.

What's more, it is important to address and unpack the definition of unstructured recreational programmes that was referenced in the narrative literature review. Based on the findings of this study, it could be proposed that the previous definition offered is indeed valid in that the participants' experiences were not as heavily supervised or vigorous as what one would encounter in a clinically structured intervention. Yet, the definition could be expanded to identify that unstructured recreational programmes are an all absorbing encounter wherein the agenda does not enforce strict goals to attain (i.e. improving cardiovascular fitness). The 4 Cancer Group's programmes do, on the other hand, promote an openness to be reflective

and present in the environment and social setting in which the participants are situated, thereby expanding or renewing a sense of embodied or psychological comfort zone. Consequently, I would define unstructured recreational programmes as being less supervised and less vigorous opportunities that encourage a sense of openness and freedom to explore self-chosen goals which otherwise could be suppressed through a pre-determined intervention.

What's more, it could be argued that the essential underpinning characteristic of any successful programme is the promotion and delivery of a flexible agenda. Although there is a loose goal in place (i.e. sailing from one destination to another in an allocated time), the 4 Cancer Group's programmes are not micromanaged in a way that prevents freedom of choice or creativity. Rather, the programme's flexibility fosters a sense of independence to engage with spontaneity as a group or an individual, reducing the possibility of prescriptive disruptions to the natural flow or openness of one's experience.

The variety of approaches leads to a critical analysis of the ethical challenges of promoting health, QoL, and well-being for those living with and beyond cancer. The ethical challenge of this topic relates to how individuals are potentially responsabilised for their general health and life after cancer treatment (Brown et al., 2019). It was discussed in the narrative literature review that some of the ongoing clinical interventions (i.e. physical activity interventions) for those living with and beyond cancer share commonalities with other forms of responsabilisation-based initiatives or campaigns. These included weight management, smoking cessation, and alcohol cessation, all of which emphasise the ideal of turning the recipient of such services into a responsible individual who is capable of making the right decisions for themselves. It is through this approach of placing responsibility on the individual that raises moral concerns and questions for the suitability of this approach (Brown et al., 2019).

To illustrate, what are the consequences when an individual living beyond cancer attends a specialist physical activity intervention with the expectation of achieving a healthier lifestyle but then experiences a recurrence of cancer? Several participants in this study expressed fears and concerns about the possibility of recurrence and mortality in the future. This fear, coupled with the broader psychological changes to

the sense of self that were expressed throughout the findings, may well have the possibility to incur an even greater sense of vulnerability and self-blame if they cannot attain the lifestyle that is being promoted and endorsed (Brown et al., 2019). However, it is necessary to recognise that both types of provision do have their respective purposes and intentions without there having to be an outright discreditation of one particular method of attempting to enhance rehabilitation and survivorship. Therefore, engaging with other sectors of the community that can offer greater diversity and pool of services that are necessary for those who need or require different types of support after treatment.

Expanding the current strategic enframement is now crucially important. What is at present a suitable strategy for motivated individuals who are in a position to receive lifestyle guidance and advice through structured physical activity interventions could be improved by a model of care that also incorporates unstructured recreational programmes in the natural environment. These opportunities are beneficial and advantageous for the sake of enhancing different senses of how people continue to live with and beyond cancer. In this way, the natural environment can be used for those who seek to engage in a meaningful experience with the complexity of their way of living with or beyond their senses psychological rigidity.

## **5.6 The use of the civil society and natural environment as a restorative setting**

Through the interpretation of the findings of this study, there is evidence to assume that the role of the natural environment can and does have a significant role in the lives of those living with and beyond cancer for both practical and personally meaningful experiences (Blaschke, 2017). Through their unique design, the 4 Cancer Group's model of care and service provision has similarities with the Nature-Based Solutions approach, especially the model of blue care for those who have a chronic health condition (Foley & Kistemann, 2015; Britton et al., 2018; Berget et al., 2012; Allen-Collinson & Leledaki, 2015). However, to propose that the recreational services that the 4 Cancer Group offers provide a complete sense of restoration would be contrary to the experiential constituents that were presented in the findings. The constituents do not offer a completely optimistic sense of living with and beyond cancer, but do, on the contrary, reflect a reality that is true to

psychological fluctuations which the participants experienced (i.e. the back and forth of rigidity and openness). As a consequence, the concept of cancer survivorship should be comprehended as a multifaceted experience that is not necessarily linear but a complex range of experiences which include what could be considered to be oxymoronic expressions of vulnerability and relief. For example, the phenomenological insights of this study do suggest that the natural environments situated in the context of the 4 Cancer Group's services do provide a temporary restorative project that can either go beyond or engage the subject of cancer for a period of time.

Furthermore, the 4 Cancer Group's purpose and role in the community reinforces what Bull et al. (2014) discuss as patient and individual needs being carefully transitioned from statutory organisations to the civil society, providing it is economically viable and serviceable to do so. The findings of this study tentatively point towards the positive implications of how a grassroots and community-based organisation can fulfil the needs of people (i.e. engaging in informal peer support) and, therefore, reduce the economic and social strain on statutory services (Macmillan, 2017).

The sense of having a support and community-based network (i.e. P9 and P4 experiences) had similarities with what was found in Caddick et al. (2015) study of combat veterans. Both the organisations of Surf Action and the 4 Cancer Group are compatible in that they provide a range of tailored services for those who need or want support with a chronic physical or mental health condition (Britton et al., 2018). It could be suggested that the organisational space of the civil society may be more advantageous due to the organisational distance from statutory and institutional services. Both combat veterans and those living with and beyond cancer have spent a considerable amount of time in close proximity to institutional ways of living. In this sense, the individuals involved can become dependent on medical or militant ways of living, echoing concerns of being passive patients or Foucauldian notions of becoming 'docile bodies'. However, this study reminds us that informal community networks facilitated by the civil society are essential for those still living with the distress or vulnerability of cancer. Also, various examples from the findings suggest that the intersubjective opportunities offered by the 4 Cancer Group present openings that are beyond distress or vulnerability. Indeed, the intersubjective

encounters described in the findings presented hope and ways of living after treatment (i.e. talking about it for the first or discussions of reconstructive surgery).

Delving further into the experiential comparisons that have been established between this study and the existing literature, Herman's (1992) discussion of therapeutic benefits and Foley and Kistemann's (2015) 'active and passive' moments are applicable. Herman's (1992) therapeutic insights apply to this study in a way that highlights the shifts that appear in both psychological and embodied reactions that can occur when exposed to a natural environment that evokes natural reactions (i.e. psychological and physical sense of expanding a comfort zone), which may have been diminished during diagnosis and treatment (i.e. not being in the present moment and not being able to use one's body) (Foley & Kistemann, 2015). The scholarly comparisons, therefore, underline the importance of how an openness to experience other opportunities can pull an individual away from the rigidity of the previous sense of living with psychological distress, creating subtle movements towards autonomy.

Remaining grounded to the sensuous and somatic experiences of the participants, there were elements of the findings that resonated with the work and research of Allen-Collinson and Leledaki (2015). For example, there were moments within the constituents that illustrated how the participants engaged with the natural environment that was around them. This included assuming leadership responsibilities during the recreational programmes under the guidance and encouragement of the professional instructors, embracing inclement weather conditions, and experiencing the finer details of using one's hands in a way in which they have not been used for a while.

However, in trying to stay close to Giorgi's (2009) methodological guidelines, I have resisted the opportunity to overtheorize and engage in heavy abstraction, which is something that subtly occurs in the Allen-Collinson and Leledaki (2015) study, despite the authors downplay. It is important to acknowledge how the participants in this study came to be 'in-the-world' of the recreational programme and what ontological realities were attached to this awareness of time, space, and place. For example, the paragraph above expresses a meaningful engagement with being

leaders of their respective programmes and using their bodies in ways that expanded their comfort zones.

Yet, going beyond this to expand the phenomenon does not remain faithful to the philosophical boundaries that have been discussed previously (Halling, 2020; Giorgi, 2009). As a consequence, the heavily theoretical concepts of 'intense embodiment' or 'aliveness' that were described by Allen-Collinson and Leledaki (2015) were deemed to be too far removed from the constituents that emerged in this study. The rejection of heavy abstraction could also be considered for the broadly theoretical positions of ART, SRT, and Biophilia that were discussed in the narrative literature review. Quite possibly, there are elements of SRT, for example, that relate to how the immediacy of the present moment was a way in which the participants may have experienced less psychological and somatic stress. Yet, there was no way in which this was measured or recorded through a standardised test, which, therefore, corresponds with the phenomenological position of entering the study without any presuppositions or hypotheses.

Denton and Aranda's (2019) study of sea-swimming did, however, resonate with what was identified in this study of recreation in the natural environment for those living with and beyond cancer. Specifically, Denton and Aranda's (2019) third dimension of their findings, *Re-orientating*, shared similar experiential qualities relating to time and self that were presented in the findings and the lifeworldly commentary of this thesis.

The openness to the world and the broader psychological changes to self that were described in this study were shared by one of the participants in the Denton and Aranda (2019) study. Although she was classed as a healthy participant, *Beth* described how her day-to-day life had taken on a different meaning through her engagement with the natural environment of the sea. The result of this different meaning offered *Beth* a "bigger picture" to recognise and respond to, which clearly had a significant link with the psychological constituents that were described in the findings of this study. Whilst the fluidity within the structure brought some participants back to a place of psychological rigidity, the participants did at times describe the broader changes that occurred within their lives as they live with and beyond cancer. For example, P11 stated how he tries to not care about the

superficial things, whilst P9 was aware that she now attempts to fill her calendar with social activities to help her “not sweat the small stuff”. Re-orientating, as opposed to Allen-Collinson and Leledaki’s (2015) intense embodiment, is perhaps a more apt way of describing the essential way in which the recreational programmes supported the participants’ management of self and comfort zones, mindsets, or thoughts in the natural environment.

On reflection, it may have been useful to engage with a similar method (swim-along interviews) that was used by Denton and Aranda (2019) to gather greater access to the phenomenon that was identified through Giorgi’s (2009) descriptive method. Being an active member of the recreational programmes could have been another way of understanding the sense of re-orientating that had similarities with Denton and Aranda’s (2019) participants in their study of sea-swimming. Yet, I chose to engage with retrospective interviews grounded in a descriptive phenomenological approach as a way of enhancing the current literature and scholarship that exists on this subject matter.

To summarise, the 4 Cancer Group’s model of recreational services, which are based on inspiring ‘respite’ from the experience of cancer, share both commonalities and shades of contrast with the existing qualitative literature that has been published in this area of research. The findings and subsequent discussions have so far indicated that the natural environment should continue to be considered as a setting that can manage the psychological and embodied changes that occur as a result of an experience with cancer. Indeed, there has also been a tentative proposition for the use of civil society organisations as a way of alleviating the pressure that NHS cancer services have and are facing (Macmillan, 2017).

The following section engages with a critical discussion of the methods that are and have been used in academic and health care settings to make informed decisions regarding an individual’s experience and state of health and QoL. More specifically, the following sub-chapter will seek to critically discuss how the utilisation of Giorgi’s (2009) descriptive phenomenological method unified two of the concerns of this thesis that were presented in the narrative literature review.

Firstly, the use of Giorgi’s (2009) method has resulted in a greater diversity of methodological approaches used to ascertain the psychological essentialities of

what recreation means for the twelve participants who were involved in this study (Burke et al., 2017). The use of IPA, hermeneutical, and general thematic analyses have, until this point, established a foundation regarding the qualitative and narrative themes that are involved in this field of research. Yet, what will follow will expand upon how this method has explicated the psychological implications involved in this specific form of post-treatment support to make eidetic generalisations.

And secondly, the following sub-chapter goes on to establish a critical evaluation of how a phenomenologically informed approach could have significant implications for the current QoL questionnaires that are being piloted as one of the primary means of measuring and recording the health of those currently living with and beyond cancer. Much like the rest of part three, phenomenological concepts and previous scholarly literature will be used to elaborate on this subject in greater detail.

### **5.7 Discussing the phenomenological project and descriptive phenomenological method in psychology in the context of this study.**

It was one of the major considerations of this thesis that there had been an over-reliance on the use of IPA, hermeneutical phenomenology, and general thematic analyses, with or without supporting philosophical discussions in much of the scholarly literature that has been produced on this subject thus far. By following Giorgi's (2009) methodology and method in psychology, it has been one of the key features of this thesis to make phenomenological claims about the essential psychological implications of the meaningfulness of unstructured recreational programmes. The psychological structure and description that has been presented represent an eidetic generalisation relating to the essential constituents and properties that were involved in this experience for twelve participants. Previous research has established how the experience of structured and unstructured settings had unfolded via idiographic narratives or general qualitative themes, but there was very little elaboration of what transcends these perspectives or themes.

However, part one of this chapter has offered a psychological discussion of the experiential structure and description in a manner that presents an essential characterisation of the findings through 'rigidity and openness' of the phenomenon. The six constituents that were the key and essential components have thus been



transcended into these two psychological properties to show the participants' shared experiences. The phenomenon in this study was, therefore, allowed to speak for itself by suspending the intention to theoretically position it prior to the data analysis phase, which is something that may not occur through the other aforementioned approaches. And in doing so, for example, I did not immediately attribute the psychological structure and description to any other theoretical understanding that has been used in this area of research.

Consequently, this study engaged both philosophical and psychological phenomenology to explicitly understand the essential properties and meanings that are involved in this phenomenon of interest. In this sense, the body of literature has expanded from the purely subjective account of the lived experience, which, to reiterate, is something that has been used in this context at various times without much elaboration or understanding (Giorgi, 2009; Zahavi, 2018).

What was a critical way to broaden the diversity of research methodologies and methods was another opportunity to critique the applied clinical and healthcare approaches of using questionnaires to observe QoL of those living with and beyond cancer. Whilst it was understood that this “ground-breaking new approach” could support people after their treatment, it was highlighted that there was evidence to suggest that a purely quantitative measurement could fail to capture the complexity that is involved with cancer rehabilitation and survivorship (Smith & Reid, 2017; Boyer et al., 2014; McCabe et al., 2008; Jomeen & Martin, 2008; Nordenfelt, 2018; Costain-Schou & Hewison, 1999).

Throughout the third theme of the narrative literature review, a large body of scholarship was dedicated to the contemporary study of well-being to draw a comparison of how the experiential nature of health does not have to be reduced to a statistical method and measurement (Galvin & Todres, 2018). Specifically, the phenomenologically informed research of well-being was used as a way of illuminating the advantages that can be ascertained by allowing the lifeworld, or people’s experiences in general, to guide our knowledge of their health and well-being (French, 1999; Burwood, 2018; Eatough, 2018; Galvin & Todres, 2018; Lum, 1997; Nordenfelt, 2018).

Indeed, the experiential and psychological structure displayed in the findings of this study certainly cannot be captured by the two questionnaires that were identified as being suitable to capture QoL (Smith & Reid, 2017). For example, the two questionnaires require individuals to complete them about how they are feeling on the day of administration. Yet, the findings in this study emphasise that there is a possibility of experiencing several senses of self that can emerge at different times, drawing parallels with Todres and Galvin's theory of dwelling-mobility (2010) and the "existential limbo" that was described by Cobb (2015). As a consequence, the two questionnaires are probably only able to capture a small essence of the potentially larger issues which may be important for those who may need further clinical guidance. That being said, it is expected that such concerns could be remedied through patient-specialist consultation post-administration, as the questionnaires may only be used as a brief way of encouraging individuals to share an initial concern. However, the consequences of using the questionnaires as a bureaucratic exercise rather than a clinical opportunity to serve to support people can have serious long-term ramifications.

The incorporation of a qualitative 'free-text' feature in the QoL based questionnaires can complement the existing standardised measurement that has already been gained through a statistical reduction (Corner et al., 2013; Nordenfelt, 2018). Not only does this greater collection of evidence have the potential to feedback into the wider system about other strategic approaches (i.e. the 4 Cancer Group's recreational programme) that can be used for other people, but it likewise offers people space to, for example, highlight their fear of recurrence or any physical side-effects from treatment (Corner et al., 2013).

Phenomenologically informed psychology should not, then, be purely reserved for academic pursuits, but could, however, be employed in clinical and healthcare settings to address long-term issues that are not static and cannot be reduced to a statistical measurement (Smith & Reid, 2017). The following text has thus been designed and written to critically evaluate how the discipline of psychology can be benefitted by a closer familiarity of the philosophy of science (Applebaum, 2010; 2011; 2012). Specifically, the fourth section of part three is where this thesis intends to temporarily remove psychology from the limiting worldview of the natural sciences. In doing so, psychology can expand its reach through engagement with

the science of phenomenology, something of which is not often considered to be a normal way of approaching subjective phenomena of the world.

## **5.8 The wider conversations with the discipline of psychology**

Whilst brief in comparison to the previous parts of the discussion, this section is a reflective stance that expresses concern for how psychology has been misappropriated by the natural sciences. Moreover, this section of the discussion is supported by Applebaum's (2010; 2011; 2012) understanding of Giorgi's phenomenological method as a commitment for psychology as a humanistic endeavour that respects methodological rigour, subjectivity, and Husserl's theory of meaning. Specifically, I have chosen to engage with Applebaum's (2011, p522) reflection regarding the unexamined and internalised assumptions of natural science that are lived through in our natural attitude. Throughout this thesis and the methodological undertaking of descriptive phenomenology, I have engaged with Applebaum's reflection, using the experiential world of cancer and recreation to form a psychological basis of scientific knowledge.

The evidence that has been offered through this study does subscribe to Giorgi's commitment towards using phenomenology as a way of informing our understanding and use of psychology, which is at present a discipline that is commonly left unquestioned and methodologically regarded as the normal way of approaching science (Applebaum, 2010; 2011; 2012). This thesis in its entirety has contributed towards these broader conversations of what is and is not considered to be psychological research. To reiterate, the experimental method relates heavily to what was described by Broome (2011) in the third chapter of this thesis. Generally, this involves a using controlled tool (i.e. questionnaire) and environment (i.e. laboratory) wherein certain variables are manipulated or handled in a manner that will determine and explain human behaviour (Broome, 2011). This particular approach is often regulated and informed by the contextless laws of the natural sciences (i.e. generalisability and verification) that determines an objective assumption towards the ontological and epistemological realities in and of the world (Applebaum, 2012). The unquestioned stance of the natural sciences has thus been a critique throughout each chapter of this thesis through Giorgi's (2009) reflective

and equally scientific methodology, which revealed a psychological structure and its essential constituents.

This study is not, however, rejecting the empirically informed experimental method of psychology, and nor is it discrediting the interpretive frameworks found in other qualitative methodologies that vehemently reject any sort of mechanistic approach. Yet, by using Giorgi's methodology and method, I endeavoured to engage in the philosophical concept of science that respects rigour and reflection of subjectivity that does not relegate the human to the position of an object. Much like how Mukherjee (2010) included subjective commentaries of how people live with cancer in his intensely biomedical biography of cancer, this thesis opens up and explores psychology outside of its common territory of the natural sciences, subsequently pushing and reflecting on its disciplinary boundaries. It is important, therefore, to stress that as well as directly engaging the meaning of recreation for those living with and beyond cancer, this study has subtly evoked a dialogue with the breadth and depth of the discipline of psychology.

It is with this in-depth understanding of philosophy and science that can propel phenomenologically informed psychology into a position that can enlighten considerably more researchers to investigate phenomena of the world without reductive and objective procedures (Giorgi, 2009). As a consequence, the psychological field of research could dramatically expand its range of methodological possibilities, as well as offer a detailed and systematic approach to understand experiential phenomena that will not be classed as naïve or without rigour (Applebaum, 2012). In fact, the greater range of psychological methodologies and perspectives in the common pool of resource can assist those interested in exploring the change and adaptability of human nature over time. Like philosophical movements, psychological disciplines are likely to change if more exposure is granted towards constituting the lived experience differently, reiterating the importance of exploring 'the things themselves'. Psychology and those who study it, like any other academic and applied pursuit, must not walk unaware into the natural attitude of conventional empiricism without question (Applebaum, 2012).

## **5.9 Conclusion**

Chapter five, *Discussion*, has been split into three separate sections with each displaying a unique analysis of the psychological structure that was presented in the previous chapter. Whilst my previous experience has been to immediately compare the study's findings against existing literature, the approach taken in this study has been to expand the phenomenon to show all of its many psychological regions and phenomenological structures. Consequently, all three sections engage the subject matter in a way that continues to respect the phenomenological attitude of remaining close and faithful to the phenomenon before subtly breaching back into the natural attitude to discuss the wider scholarly and healthcare conversations.

Through this extended examination of the phenomenological structure, it is now possible to understand how the wider enframement that surrounds rehabilitation and survivorship has been theoretically expanded through this thesis. The following chapter, *Conclusion*, will encapsulate and summarise the significance of how this study has contributed an original way of understanding how strategic approaches for those living with and beyond cancer can be differentiated in psychologically meaningful ways to complement the current cancer strategy and ambitions. The conclusion will also seek to identify the limitations of this study that have become apparent throughout the entirety of the project. What's more, understanding the limitations of this study serves as another means of being truly reflective of the study's praxis and purpose. Moreover, it is through this reflective stance that can enable an opportunity to understand how this area of research can be expanded to strengthen its current scope and reach. Explicit recommendations will therefore be presented which will state how the study can be approached and extended from a theoretical and practical perspective.

## **6.0 Conclusion**

This thesis began by outlining the current statistical trends and qualitative characteristics that have been recorded and observed internationally concerning the chronic health condition of cancer. The thesis then proceeded to identify the healthcare strategies and ambitions that have, and currently are, being commissioned in England to support those living with and beyond cancer. Focussing solely on the rehabilitation and survivorship phase of the 'cancer trajectory', the direction of the thesis then concentrated its attention toward the use of structured physical activity interventions and follow-up questionnaires being used as two of the primary tools to enhance and measure an individual's QoL during this specific phase.

The scholarly and wider literature identified the advantages of using both approaches for managing the overwhelming amount of people who will live with and beyond cancer (Maddams et al., 2012; Macmillan, 2013; Midtgaard et al., 2015; Burke et al., 2017). Yet in equal measure, there was a substantial cause of concern regarding the limitations of structured physical activity interventions and quantitatively orientated questionnaires as the underpinning strategies for rehabilitation and survivorship pathways and ambitions in both chapters one and two (Macmillan, 2017; Burke et al., 2017). This concern was, therefore, an opportunity to seek to explore other means of facilitating meaningful approaches of rehabilitation and survivorship outside of clinical settings and in ways that would not reduce experiences of health and QoL to a statistical breakdown or an idiographic analysis (Burke et al., 2017).

The thesis then explicitly stated a phenomenon of interest that positioned the study in the context of wider academic scholarship and healthcare strategies. The phenomenon of interest unfolded by collaborating with the 4 Cancer Group, a civil

society organisation which provides recreational services as “respite” for those living with and beyond cancer in the natural environment. The collaboration was established to offer insights into how rehabilitation and survivorship services are delivered outside of clinical settings for men, women, and children. To elicit an experiential understanding of the meaningfulness of the 4 Cancer Group’s recreational programmes, a descriptive phenomenological approach was employed as the primary methodology and method (Giorgi, 2009). In doing this, an essential description and psychological structure were ascertained that established how and why this type of approach is psychologically meaningful for the twelve people who were recruited to participate. Also, the findings tentatively illuminated how rehabilitation and survivorship services delivered in the community can alleviate the NHS’ cancer services of the pressure of supporting those living with and beyond cancer (Burke et al., 2017; Macmillan, 2017).

After extensive periods of data collection and analysis, six psychological constituents were identified as being essential to the participants’ experiences of their recreational programmes. It is within the six psychological constituents, and the elaborative psychological and phenomenological discussions that followed where this study found its original contribution to knowledge. The original contribution to knowledge was also considered against the context of the academic and professional scholarship that was cited in the first two chapters of the thesis. The following text includes three comprehensive passages of how the study has contributed an original body of work, with each one specifically highlighting practical and theoretical implications attached to the wider contextual considerations of this area of study.

## **6.1 The essential and foundational constituents of this study**

Firstly, the descriptive phenomenological method in psychology (Giorgi, 2009) enabled me to produce an essential description and psychological structure of the meaning of recreational programmes in the natural environment for men, women, and children. This is important because if it is possible to draw attention to alternative approaches of delivering meaningful rehabilitation and survivorship services, it is necessary to comprehend the essential and foundational psychological properties that are involved in this process for those who have used such services.

The evidence and interrelatedness of all the constituents that were established in this study discerned that the reality of living with or beyond the chronic illness of cancer changed how the participants recognised the ways in which they confront the possibility of mortality, thereby living in a state of psychological rigidity and openness. This sense of change in reality, in accordance with the participants, can lead to the actualisation to seek new or different opportunities to engage in a meaningful project that occupies their thoughts, time, and ambitions for the future. As well as broader psychological changes (i.e. changing routines or development to oneself), the 4 Cancer Group's recreational programmes fulfilled this sense of actualisation through three essential constituents. The constituents included the recognition of being in the present moment with or without a significant other, a renewed sense of being physically engaged again, and a certain willingness to engage and communicate with others who were also living with and beyond cancer. However, the recognition of how the anticipation of the future held both negative and positive psychological implications for the participants was another way in which reality caused another sense of rigidity and openness to occur in the participants' lives.

Taking a foundational stance through descriptive phenomenology established that the experience of this type of setting is similar but not identical to what would have been identified as phenomenologically meaningful in clinical and structured settings. Therefore, the findings in some ways point towards how the wider inclusion of sectors of services and unstructured approaches can be meaningful for those living with and beyond cancer. If used for practical implementation, these findings can encourage greater diversity amongst the existing services used in rehabilitation and survivorship strategies in England.

## **6.2 Identifying alternative discourses and restorative environments for cancer rehabilitation and survivorship.**

Secondly, the six psychological constituents contained in the essential description and structure represent a broader psychological essence of rigidity and openness as the participants experienced their lives and their respective recreational programmes. The 4 Cancer Group's alternative way of approaching rehabilitation and survivorship does not offer an overly optimistic sense of "recovery" but does



present a reality that is phenomenologically true to the accuracy of the experiential nature of living with and beyond cancer, according to the twelve participants. For example, the constituents that were established through Giorgi's (2009) method presents psychological movements that surfaced various senses of self and the experiential world in which the participants had found themselves. The constituents do not, however, support or resemble the common discourses and NHS' strategy of using heavily prescribed physical activity interventions to "recover" from cancer, as it is much too complex than that simple reduction. More importantly, having access to post-treatment opportunities that do not undermine the capabilities of those living with and beyond cancer but rather subtly encourage them to live with the condition by themselves and amongst others is just as essential and necessary.

Consequently, the natural environment has the potential to be a suitable setting for rehabilitation and survivorship initiatives if regulated by a registered charity or organisation and supervised by the appropriate professionals. The community approach can, then, potentially alleviate the NHS' cancer services from being overwhelmed by the pressure to manage each personal care plan, given the severity of the governance and operational "warning signs" that Macmillan (2017) have previously published. However, this will largely depend on complex collaborative efforts being established to forge closer relationships between grassroots organisations, locally-led council services, and NHS cancer services.

As discussed, the practical implications of this study suggest that the findings do not discredit what has been established in the scholarly literature regarding the meaningfulness of structured physical activity interventions. Whilst this may seemingly be problematic, as the interventions were one of the main features of this academic critique, it is important to reflect positively on the comparisons between the structured and unstructured approach for the sake of expanding the provision of services for those living with and beyond cancer.

What's more, although the study has been contextually bound to the services that the 4 Cancer Group offers, the disciplinary stance of psychology suggests that the findings may move beyond the recreational activities that were used in this study. The constituents could, as a result, be applied to a wider range of activities, programmes, and services that are used in the green and blue models of care which

have been discussed throughout this thesis (Berget et al., 2012). Clearly, this type of proposal would need to be subjected to a wider phenomenological, qualitative, and quantitative analysis, but it is not without phenomenological reason and evidence to propose that it could inform the range of services used for rehabilitation and survivorship strategies. The community setting or model, which was discussed in comparison to the healthcare model by Moreton et al. (2018), could be a greater way of achieving a wider range of opportunities for those living with and beyond cancer and others that are involved in the process (i.e. healthcare professionals, leisure providers, cancer specialist nurses).

Also, the collaborative nature of this study, as well as others that have been cited throughout (Caddick et al., 2015), could inform the commissioning guidance into how small charitable organisations can form effective working relationships with healthcare services. As a consequence, not only is it possible to broaden the range of services for those who are living with and beyond cancer, but there is the possibility that a shift can occur in the theoretical ways in which such services are designed and delivered (Brown et al., 2019). The current interventions for those living with and beyond cancer have directly been compared to what is found in other chronic health interventions (i.e. obesity management, smoking cessation etc.). Yet, this study has illuminated the complex psychological ways in which people re-engage with their life during or after their respective treatments, directing considerable attention toward alternative theoretical and ethical positions that will drive similar strategies and ambitions for future generations of people. As such, healthcare strategists and commissioners should seek to develop a greater understanding of the various theoretical underpinnings of the approaches that are used in this context to promote health, QoL, and well-being.

### **6.3 Theoretical and philosophical expansion of the scholarly literature and healthcare practice**

And lastly, originality was recognised through the methodological use of the descriptive phenomenological method. Using Amedeo Giorgi's (2009) approach was original in the attempt to critique the use of questionnaires that are being employed to record post-treatment QoL for those living with and beyond cancer. The findings can firmly confirm that Giorgi's (2009) methodology and method reduces

the participants' experiential world in a systematic manner that respects the subjective details that were given and lived through meaningfully. In this way, the study has used a methodology that has an underpinning philosophy which is respectful of the positivistic plea for systematic rigour and the interpretative call for exploring subjective meaning (Giorgi, 2009). The implications of using descriptive phenomenology, therefore, can have an important theoretical implication for healthcare policy.

The theoretical advantages of using descriptive phenomenology can complement how health and QoL are measured by professionals who implement the strategies and ambitions. For example, the importance of remaining faithful and open to the phenomenon that has been expressed whilst suspending any personal and professional presuppositions is key for comprehending the experiences of others. Quite simply, then, the inclusion of a qualitative and subjective dimension in the questionnaires currently being used could enhance how those living with and beyond cancer can express the state of their health in the weeks, months, and years following their completion of treatment.

In an academic sense, using Giorgi's (2009) descriptive phenomenological method has complemented the volume of idiographic and thematic research that has been accumulated in this subject area (Midtgaard et al., 2015; Burke et al., 2017). By recognising the shared psychological properties that are found in each twelve of the participants' experiences, the use of Giorgi's (2009) phenomenological approach has simultaneously addressed the subjective-objective debates that are often contested. For example, the analysis, findings, and discussion of this thesis reflect an attempt to use both subjectivity and objectivity in a way which is faithful to Husserl's theory of meaning and free imaginative variation.

The study did not simply report the correspondence between the thoughts and feelings of the participants' experiences. Rather, Giorgi's (2009) methodology and method allowed me to transform the subjectivity of the participants' experiences into a shared description and structure that privileges a geometry of experiential invariance. By following this approach, I have communicated both a detailed presentation of the findings and discussion to illuminate the fulfilled meanings of what is given when engaging in recreational programmes for those living with and

beyond cancer. The participants' subjectivity did not then automatically reveal the phenomenon that has been presented. Rather, the participants served as the access to the phenomenon, whereupon I comprehended and constituted the eidetic description, the psychological structure, and the psychological dynamic of rigidity and openness that was discussed.

Also, by developing a closer theoretical relationship with phenomenologically informed psychology it has been possible to reconsider any scientific absolutisms about human behaviour and experience in the wider discipline of psychology. This is not to suggest that psychology as a whole discipline must acknowledge a change in its way of establishing knowledge. Instead, by introducing a philosophical movement such as phenomenology into this psychological study, it is possible to recognise other innovative ways of discerning the lived-through character of human reality.

#### **6.4 Limitations of the study**

As is the case with every study, many limitations may restrict the overall scope and reach that has been presented in this thesis. Importantly, though, if the findings of this study are interpreted from a natural sciences perspective, there are bound to be limitations that will restrict the essential meaning that has been communicated (Applebaum, 2012). Such traditional limitations relate to:

Sample size – The recruitment of twelve individuals may well be an angle of this study that is criticised as being restrictive and limited because it may not comprehend the phenomenon in its most complex and diverse ways. Yet, in accordance with what was expressed in chapter three, it is important to recognise that a relatively small sample of participants is necessary for both the practical and philosophical goals of performing qualitative and phenomenological research. For example, the methodology and method that has been applied to this study require the researcher to use a considerable amount of time to dwell with the data during the analytical phases to draw out the essential meanings that were being expressed by the participants. Including considerably more participants would require a greater amount of time to dwell, reflect, and analyse the data. Therefore, twelve participants were considered to be manageable for the philosophical goals and time allocated for the study. Also, no absolute or universal truths are being attempted to be

established through this body of work. On the contrary, the overall philosophical and psychological goal was to produce an eidetic generalisation and psychological structure, which can be revised and reconsidered through other phenomenological and qualitative research. Twelve participants were thus seen as an adequate amount of participants to begin this research process.

Lack of regard for objectivity – The concern with subjectivity and overall focus on interpersonal collaboration throughout this study will naturally cause concern in many scientific disciplines that are heavily committed to objectivity as the access for truth. However, in accordance with the phenomenological attitude, this particular study has engaged with the philosophy of phenomenology to suspend any attempts to replicate what would be found in a quantitative study, for example. However, what could be considered to be a study that lacks complete respect or regard for objectivity is balanced by a respect for consciousness as the centre of reality and what is discovered from it, thereby justifying the decision to be in close contact with those who are living with and beyond cancer.

Ethical considerations - Concerns regarding participatory coercion or collaborative bias because of the interpersonal design of the study could be considered to be another limitation that may otherwise limit the integrity of the findings. Yet, I have attempted to manage any overarching ethical concerns in numerous ways. Firstly, I successfully submitted an ethical review of my study in which I identified the risks and concerns that were reviewed and resolved throughout the entirety of the study (please see the appendices). Secondly, I managed the collaborative nature of the study through scheduled meetings with the 4 Cancer Group for the sake of directing the attention of the study in ways that would not introduce conflicts of interest. However, more personal reflections on the collaborative negotiation of the study are offered in the following chapter.

International application - Another significant limitation applies to the practical applicability of the entirety of this study. It may well be suitable for those countries that have the national healthcare and political infrastructure to implement strategies for those living with and beyond cancer. However, for those countries that are considered to be less economically, medically, socially, and politically developed in comparison, this study may well be unnecessary and westernised in its approach to

understanding the associated challenges of living with and beyond cancer. The implementation of post-treatment rehabilitative strategies as a way of enhancing a meaningful sense of survivorship is heavily reliant on several sectors of society functioning in harmony to produce a collaborative strategy. Yet, some countries that are faced with the reality of under-funded and inadequate primary care settings could interpret the contributions of this thesis to be irrelevant and unnecessary. If, for example, several countries cannot successfully manage the medical demands that are attached to the successful treatment of cancer, then how rehabilitation and survivorship can be delivered may well be meaningless and without perspective. Therefore, this study and the findings it has presented have to remain grounded and aware of its applicability to developed countries around the world that have the infrastructure and capacity to implement diverse approaches to enhance the lives of those who are living with and beyond cancer.

However, if interpreted and critically reviewed from a phenomenologically sensitive perspective, the reliability and credibility of this body of work can be scrutinised by arguing against the acceptance of the participants' consciousness being the essence of what the phenomenon is (Applebaum, 2010; 2011; 2012). In other words, a critique against this study would be to propose that the conscious descriptions of the participants may not fully represent a sincere and genuine representation of what is trying to be understood as essential to the experience. This argument is likewise applied to the use of descriptive phenomenology in the many movements and divisions that exist in the applied research movement of phenomenology. Whilst applauding Giorgi's (2009) methodology and method as being faithful to Husserl's original project, Zahavi (2018) simultaneously suggests that the approach may be too systematic in ways that do not respect phenomenology's scientific and philosophical divorce from the natural sciences.

Indeed, another phenomenologically sensitive limitation would be to probe how I constituted the participants' findings during step three of the analytical phase of the study. It could be recognised that it is at this point whereby the participants' natural expressions may be descriptively clarified in a manner that does not reflect the essential meaning that was being communicated. However, this stage of the analysis was substantially supported by the supervisory team in ways that would remind me of the methodological and philosophical obligations that are involved in

this method of descriptive phenomenology. And lastly, relying solely on subjectivity, or consciousness, as the access to the phenomenon, could be cited as another way in which the study was limited. Requesting participants to reflect and describe past experiences contains potential problems that relate to the participants' inability to fully recall the event or use the appropriate language to describe its complexity.

## **6.5 The rigour and reliability of descriptive phenomenological science**

As was discussed in chapter three, Amedeo Giorgi (1997; 2009) developed the descriptive phenomenological method in psychology as a human science that would challenge the approach taken by the natural sciences to understand experiential phenomena. Moreover, Giorgi (1997; 2009) based his methodology and method on the universal scientific principles of generality, systematic, critical, and methodical. True to the nature of phenomenological philosophy and the contemporary research methodologies that have been cited throughout, the four principles have been applied in a way that positions the epistemological and ontological claims firmly with the participants' consciousness, which were then constituted by myself. Indeed, the study has been eidetically generalised and discussed to reveal the psychological essence (i.e. rigidity and openness) and the explicit constituents of the psychological structure. However, at no point have the academic claims from the study transcended the context and subjectivity in which it was found to make a statement of true universal causality.

The method that was used was systematic, critical, methodical in ways that enabled me to make an eidetic generalisation about the psychological meaning of recreation in the natural environment for those living with and beyond cancer. Throughout, I have offered an understanding and comprehension of how the findings also relate to the backdrop and contexts of the wider scholarly literature. Yet, I have performed and presented this in a manner that is critical and aware of the potential claims of universality that could have emerged in this study had I not stated otherwise. Simply put, I have been fully aware that by comparing the findings of this study to the findings of other studies that have been cited (i.e. green and blue models of care), I expose myself to engaging in what considered to be the *modus operandi* of the natural sciences (i.e. universal generalisation). I have, on the other hand, simply

proposed that some of the essential psychological meanings may be similar to what is found in other contexts without claiming for it be to absolute or true.

Overall, the rigour of the study has been based upon gaining access to a subjectively grounded lifeworld and phenomenon through the participants' consciousness, which was then constituted by me through Giorgi's (2009) transparent and critical method in phenomenological psychology.

## **6.6 Recommendations for future research**

### **6.6.1 Introduction**

It is at this point of the thesis whereby recommendations for future research are proposed to contribute toward the enhancement of this specific area of interest. The reader may choose to make their assessment of what areas of interest in this study need to be explored further. However, what follows are three recommendations that have been produced that relate to the implications were discussed in the original contribution to knowledge. Specifically, the recommendations relate to both theoretical and practical directions that warrant further study.

### **6.6.2 Explore the constituents in greater phenomenological depth**

Upon reflection, a combination of the constituents that were presented in the findings of this study could be examined in greater depth to ascertain a finer phenomenological account of the experiential ranges that are within. For example, a carefully considered study may now want to explore in more detail how the subtle changes from constituent one to constituent two occurs through a lifeworldly perspective. Though this sense of openness may not occur for some individuals, the lifeworldly perspective could, for example, illuminate the regions of time, space, sociality, and self in much more phenomenological detail for those who do experience this initial sense of psychological shift from rigidity to openness.

Such a recommendation could also be extended to focus purely on a phenomenological study of men and their experiences of unstructured programmes. Whether is it through an idiographic or descriptive account, considerably more phenomenological studies of male experiences can assist in the understanding and subsequent design of services for men of all age groups who are living with or



beyond cancer. Not only would this expansion of research interest allow a greater understanding of why men choose to engage with such services, but it would also enable such services to be carefully designed in ways that are meaningful and tailored. Further study of this topic of interest could allow more civil society organisations to be unearthed and drawn into the current cancer strategies and ambitions as a way of offering a greater variety of services which may include the natural environment in their service design.

### **6.6.3 Economic evaluation of implementing a nature-based solutions model of rehabilitation and survivorship for those living with and beyond cancer.**

Throughout both the previous and current chapter, the proposition of implementing a nature-based model of care (i.e. green and blue care) for those living with and beyond cancer has been sensitively offered. If this is to become a possibility for healthcare services, an economic evaluation of this type of specific model for cancer rehabilitation and survivorship should be considered. An economic evaluation of this sort could be compared and considered against the existing approaches that have been developed in the healthcare setting for cancer rehabilitation and survivorship initiatives. To achieve a greater degree of clarity and understanding, an economic evaluation could be broken down into various forms. For example, this could include a cost-benefit analysis, a cost-effectiveness analysis, a cost-utility analysis, and a cost-consequence analysis, all of which could identify whether a community or civil society approach could be included in the NHS' wider rehabilitation and survivorship pathway.

At present, one of the practical outputs from this body of work has been based on establishing a collaboration between the 4 Cancer Group and Macmillan Cancer Support. Despite being in the early phases of development, it is anticipated that a collaboration of this type can fulfil the policy reforms cited throughout this thesis, introduce the possibility of a nature-based model of care on a wider scale, and indeed increase the likelihood of an economic evaluation being conducted to test for feasibility. Consequently, a collaboration of this nature can carefully integrate both the 4 Cancer Group's and Macmillan's respective agendas together and attempt to make collaborative plans for both the short and long term future. As such, potential cancer strategies and ambitions can be managed carefully, whereby

theoretical guidance can be implemented almost immediately without the associated challenges of civil society collaborations.

#### **6.6.4 Questionnaire-based study of living with and beyond cancer.**

Lastly, it would be of interest to follow the recommendations of designing and conducting a study that seeks to use a questionnaire with the inclusion of qualitative free-text to simultaneously measure and thematise the experience of living with and beyond cancer. Similar to the economic evaluation cited above, this recommendation and approach could be beneficial for the sake of comparing the questionnaires that have been cited in this study against an improved QoL questionnaire that has incorporated qualitative free-text.

In another sense, the study that was conducted by Corner et al. (2013, p.8) simply introduced free-text sections of the various questionnaires in which the researchers were studying. The findings identified the significance of why those living with and beyond cancer feel “cut adrift” from the health services after they enter the rehabilitation and survivorship phase of the trajectory. Therefore, both the EQ-5D and EORTC QLQ-C30 that have been cited in this study could be modified to include a greater degree of qualitative characterisation that could help inform the way strategies and ambitions are designed in the future.

### **6.7 Conclusion**

The penultimate chapter of this thesis has offered a comprehensive account of the significance and limitations of the entirety of this body of work. Indeed the conclusive chapter has elaborated on the findings concerning the guiding methodology and literature that has been used throughout, as well as addressing how this study can be extended by addressing recommendations for future research. The following chapter, *Personal reflections on the research process*, has been written in a style that adheres to the reflexivity that is required of qualitative and phenomenological projects. At several times throughout the thesis, I have signposted the reader to refer to the reflections chapter and it is within this section that communicates how I managed each step of the process. Whilst the chapter has been written in a personal manner, I have used Finlay’s (2008) methodological guidance for reflective practice as the guiding framework. Consequently, what has been produced combines how I approached the study “in-action and on-action”. However, considerably more will be

explained in the following text that relates to this type of reflection and how I engaged with it.

## **7.0 Personal reflections on the research process**

### **Introduction**

This chapter aims to communicate how I have endeavoured to fulfil the qualitative and phenomenological objective of being as reflective as entirely possible throughout the process of this research study. I have chosen to do so because there exist certain assumptions, and sometimes accusations, that qualitative and phenomenological research is without scientific rigour because of its interpersonal design and methods (Finlay, 2008; Applebaum, 2012; Giorgi, 2009). A researcher pursuing a qualitative question, therefore, has a responsibility to self-disclose and self-reflect upon their influence on the project and its handling, providing details of their approach throughout each phase (Finlay, 2008). More specifically, then, chapter seven has been designed to present and communicate how I engaged in theoretical and practical reflections throughout each chapter of the thesis. Methodologically, this chapter has been informed by Finlay's (2008) reflection-in-action and reflection-on-action, which, simply expressed, is a process of reflection during and after the study that informs the reader of the decisions that were made throughout.

Before engaging in a reflective exercise of each chapter, it is necessary to address my how a degree of bias may have impacted on my role throughout this entire process despite trying to adhere to both phenomenological and personal standards. These standards can be compromised due to what can be considered as biased positions within the study. Such positions include (i) my role as the student representative and collaborator between the 4 Cancer Group and the University of Brighton, (ii) my ongoing and previous background of health and exercise science, psychology, and policy, and (iii) personal experiences of cancer.

Firstly, my role at the 4 Cancer Group did not extend further than boundaries of my role as the PhD student researcher. My practical involvements with the charity throughout the project was solely dedicated toward providing a phenomenological analysis rather than assist the charity with matters concerning their internal development. I scheduled and participated in monthly or weekly meetings with the 4 Cancer Group management team and staff to exchange strategic ideas for participant recruitment and the overall management of this study. Therefore, it could be considered that I kept and maintained a professional distance from the charity to purposely avoid being drawn into a position that would leave me vulnerable to bias by extending my role beyond student collaborator.

Secondly, as a personal and professional supporter for recreational activity and exercise, I was keenly aware of what could be an influential position in this research project. Staying close to the phenomenological attitude, I was committed to exploring the experiential and psychological implications of recreational programmes in the specific context of living with and beyond cancer. Instead of accepting how rehabilitation and survivorship services are currently being enframed by the NHS and Macmillan, I was keen to further understand how alternative approaches can facilitate a meaningful and humanistic way of living with and beyond cancer.

Thirdly, and lastly, I have had personal experiences of cancer. Whilst I have not experienced cancer directly, I have experienced cancer through immediate family members, understanding some of the social, physical and psychological repercussions attached to this chronic health condition. What could be construed as a tightly informed opinion or set of beliefs regarding the meaning of cancer, and what it means to live with it, was, in fact, another opportunity to reflect on its presence in this study and my life.

To summarise, I am a novice phenomenological researcher with personal and professional understandings of the phenomenon of interest. Using Finlay's (2008) guidance, as well as the philosophical work of others (Zahavi, 2018; Spiegelberg and Schuhmann, 1994; Giorgi, 2009), I have tried to adhere and follow reflective and phenomenological principles to mediate and set aside my personal and professional orientated attitude, and in turn, learn of the subjective experience of the

participants in this study. What follows is a comprehensive account of what I did in order to facilitate a continuous reflective attitude throughout the entirety of the research study, with details of each chapter to show the full rigour and scope that was undertaken.

## **Chapter one - Introduction**

My initial reflections of the introductory and foundational aspects of the study were consumed by thoughts and feelings that were questioning my ability to critique past and present strategy for those living with and beyond cancer by using phenomenologically informed psychology. Moreover, this process felt like I was challenging something much greater than my capabilities in that the research would not serve a worthy purpose for those who could benefit from it.

However, relying on my research experience and educational background, I believed that a number of the elements found in the current NHS strategies and ambitions that were cited in the introduction were not the one and true way of managing rehabilitation and survivorship for those living with and beyond cancer who require post-treatment support. This level of reflection involved recalling past experiences of my time spent working as a research assistant on public health interventions across the East Riding of Yorkshire during 2015-2016. I could, as a result of this experience, understand why this approach would not be the most suitable strategy for those living with and beyond cancer. The current emphasis placed on lifestyle interventions across public health is heavy, with short and long term effectiveness being modest at best. Recognising how this approach would not suit everybody who has had experiences of cancer, and the wider services that are under pressure, I thereby sought to position this critique as one of the features that would inform a large part of the study. Yet, the ways in which this positioning informed the study were handled with care and attention to reduce the chance of distorting the phenomenological nature of the methodology and analysis.

Therefore, the opportunity to critique some elements of the current strategy was a timely remedy for my initial concerns about the direction and depth of the study. What was initially an opportunity to collaborate with relatively small, grassroots charity to evaluate their recreational services suddenly transformed into a much broader research focus that could exhibit the suitability of the civil society as a

supporting sector for the NHS, Macmillan, and, importantly, those living with and beyond cancer.

## **Chapter two – Narrative literature review**

Generally, my experiences of undertaking a narrative literature review that had phenomenological influences was a very positive experience. This sense of positivity occurred for two reasons.

Firstly, my previous experience of conducting and writing literature reviews had been a process of assembling them in a systematic manner that left little or no room for the writing of the historical development of the phenomenon of interest. However, the opportunity to use a narrative approach, in many ways, was a freeing experience in that I could explore the qualitative depths of the subject whilst maintaining a rigorous stance through the use of the CASP checklists. And secondly, the incorporation of the phenomenological attitude was an opportunity to see and conduct the narrative literature review from a whole different perspective. After much contemplation and days spent working with the thesis, I began to fully appreciate the important role that the attitude could bring to the narrative literature review. Largely condensed in this reflection, I eventually saw the attitude as a means of placing the study against a context of scholarship without automatically having to accept it as something that I would need to carry with me throughout the entirety of the study. Previously, and in my naivety, I may have interpreted the literature review process as something that would have to inform the fullness of the research project. Of course, there were elements of this review that did serve as parts of the backbone of this study, but there were numerous other topics of literature that were held at a distance to maintain a full engagement with the phenomenological attitude.

Indeed, it is also worthwhile to reflect upon the specific research phenomenon of interest that was at the heart of this study. As discussed, I chose to perform a descriptive phenomenological analysis on unstructured recreational programmes for those living with and beyond cancer in the natural environment. However, this phenomenon of interest could have been considerably more specific. For example, Giorgi and Gallegos (2005) study of how they both researched 'living through positive experiences of psychotherapy' was a very specific phenomenon that was within a much wider context. I, on the other hand, chose to study the entirety of the

experience of the recreational programme to determine the essential psychological features of the experience. I could have engaged the phenomenon from many different phenomenological angles, but I deemed it wise to remain as broad as possible as this was one of the first studies to approach this phenomenon from a descriptive phenomenological perspective.

## **Chapter three – Methodology and methods**

### **Overview**

Chapter three, *Methodology and methods* was split into three parts that had a specific purpose for the study. The first two parts of the chapter could be considered to be a textbook and broadly pedagogic analysis of the historical and contemporary use of qualitative research and phenomenological philosophy. Yet, I chose to engage both subjects in this manner out of respect for the depth that is contained within. Too often are phenomenological and qualitative essays lacking in communicating the basic and most rudimentary philosophical underpinnings, reiterating Applebaum's (2012) concerns about being aware of your philosophic praxis as a researcher. I, therefore, chose to respect the subject by communicating the underpinning logic and history in a way that would allow the reader to understand how and why this area has evolved throughout time. Once I had communicated this level of foundational philosophy and science, I could begin to express why Giorgi's (2009) methodology and method was the most suitable approach for this study, as opposed to IPA, for example. My study did not, then, take centre stage in the initial writings of the chapter. I was satisfied to commit to this decision as I wanted to present the range of philosophical and methodological possibilities to the reader rather than arrive at an immediate presentation of this study.

Reflecting upon this decision now, I am confident and aware that I made the correct choice by communicating the origins of the philosophical and research-based movements. I am aware that it is easy to become embroiled in such methodological discussions that have and are likely to continue for some time. Yet, without some form of acknowledgement and recognition, it would mean to portray phenomenology from only one perspective, which would not illuminate its contested complexities.

### **The phenomenological attitude**

The critical and reflective stance of myself as a part of the research process also calls for reflection of the phenomenological attitude that has been discussed previously in the thesis. It is an approach to manage the reductionist plea for 'value-free' research, something of which is not possible given that we all share intersubjective dimensions in a natural world (Finlay, 2008; Zahavi, 2018). However, it is important to reflect and observe how I attempted to use the phenomenological attitude when using Amedeo Giorgi's descriptive phenomenological method in psychology (Finlay, 2008).

My earliest reflections of the phenomenological attitude comprised of an initial confusion of how to implement the 'attitude' in a practical way that would fulfil descriptive phenomenological criteria (Giorgi, 2009). The phenomenological attitude's importance in the phenomenological literature, especially Amadeo Giorgi's descriptive phenomenological method in psychology, made this confusion transform into anxiety and feelings of being overwhelmed of how to manage a philosophical concept that is complex and tied up with various of other philosophic expressions (i.e. bracketing, epoche, bridling). As a consequence, my initial encounters and attempts to harness the phenomenological attitude were a considerable challenge that produced feelings of incompetency.

However, as my knowledge of phenomenology, both as a philosophy and research methodology slowly started to grow, I began to feel at ease with how I could start to implement practical ways in which I could engage in the phenomenological attitude. I initially had to accept that my initial reasoning was completely missing the essence of what the phenomenological attitude stands for. To begin with, I had approached the concept with the determination that I could reject all of my comprehension of the subject matter to fulfil the requirements of 'bracketing' or 'suspending' my knowledge and experiences. However, upon engaging with key scholarship and literature (Giorgi, 2009; Zahavi, 2018; Spiegelberg & Schuhmann, 1994) and academic workshops (Zahavi, 2019), my understanding and original approach of rejection transformed into a state of being open to my knowledge and experiences in a way that would help me fully disclose what I believed to be essentially true of the phenomenon being studied. I could then start to be open to my dogmatic beliefs that had informed much of my academic experiences to date.



As discussed in chapter three, the phenomenological attitude had very close connections with what I have experienced in my role as a health advisor working with clinically obese individuals who have disordered eating patterns of behaviour. Therefore, the shift in my appreciation and understanding of the phenomenological attitude was confirmed after coming to terms with (i) my initial but misguided awareness of the concept, (ii) a greater understanding of the philosophical literature and key scholars in this field, and (iii) how the concept had similarly been a part of my clinical approach by allowing patients to express their subjective experience without imposing my own beliefs or psychological interventions on their perspective.

As a consequence of developing more confidence in my theoretical and philosophical understanding of the phenomenological attitude, I moved onto developing a way of demonstrating how I could practically implement its use throughout the thesis. What follows is two comprehensive examples of how I used the phenomenological attitude to inform the research process.

### **Pre-understanding sub-chapters within the introduction and literature review**

Firstly, by including considerations of my pre-understandings in both my introduction and narrative literature review, I was able to reflect carefully on what knowledge and experiences I was bringing to the study. For example, my initial considerations of “who am I coming into this study?” was and still is a deliberate attempt to locate how my educational, professional, and personal groundings are going to be present throughout the entirety of the research project. This, too, applies to the conclusionary sub-chapters that are located within both the introduction and the narrative literature review. Both examples, therefore, aimed to evoke and demonstrate how I was able to engage with the phenomenological attitude without overcomplicating or simplifying the task.

### **Phenomenologically informed interviews**

Second of all, my attempts to use the phenomenological attitude throughout the data collection phase of the study was a rewarding way in which I engaged with its purpose. Specifically, my attempts to use the attitude within my phenomenologically informed interviews was an interesting experience insofar that I could feel Linda

Finlay's (2011) call for disciplined naivete to be present as I listened and responded to the participants' recollections of their experiences of their recreational programme. As an example, when one participant talked of how his "world was flipped upside down" after his diagnosis of cancer, I did not assume to know how this was experienced despite possibly understanding how this may have happened in own experiences or my advisory role in clinical settings. Rather, I questioned the participant to further explain how this felt and what it meant to him, which then informed a deeper and more meaningful understanding of his subjective world.

The use of the phenomenological attitude was also reinforced by an academic workshop I attended at the University of Oxford. The workshop was hosted by Dan Zahavi and aimed to explore some of the key tenets of phenomenology in applied sciences, with the phenomenological attitude, or the 'epoche', being one of them. Zahavi, who is critical of the simplified and overused phenomenological attitude in health sciences, discussed how it is possible to explore its use and possibilities for when one is engaging in research whereby one cannot assume to know the reality of another. Therefore, in the case of this study, my attempts to use the attitude seemed credible and reasonable given that I have not had a personal and direct experience of living with and beyond cancer.

## **Data Analysis**

Reflecting upon Amadeo Giorgi's methodology and method was a difficult process in that it has caused me to feel a range of conflicting views throughout the entirety of the PhD process. Clearly, Giorgi's methodology and method is an incredible resource to make comprehensive psychological claims that closely adhere to the original tenets found in the phenomenology that was espoused by Husserl. Moreover, Giorgi's method offers a structured process that helps and assists one to feel like they can execute phenomenologically orientated psychology without feeling like the whole process is insurmountable. For example, step three of Giorgi's (2009) method is a critical process that I believe is missing in most qualitative methodologies, whereby the original transcripts are reduced to a description that manages to contain much of the subjective detail that was discussed by the participant. The methodology is then further reinforced by Giorgi's insistence of staying close to the phenomenon of interest as opposed to moving beyond the data to make broad and possibly unrealistic ontological claims of reality. This is

something, I believe, is innocently, and perhaps naively, encouraged in qualitative research that is done without knowing the full philosophical ramifications for doing so (Applebaum, 2012).

Yet, it can be a significant challenge for a novice researcher to undertake Giorgi's methodology and method. Whilst I do appreciate the difficulties Giorgi has faced in trying to forge a comprehensive and qualitatively oriented psychology against the criticisms of the natural sciences, the methodology and method did at times feel like I was too focussed on methodological procedure rather than the meaning that I was attempting to evoke. This did, however, change and ease with time and independent reading but the entirety of the of analytical phases of the study did feel like a constant balance between fulfilling the scientific mandate that Giorgi has established and respecting the subjective details that phenomenology demands. As a consequence, there were times when I believed that I was apprehensive about satisfying the methodology and method rather than evoking the essential psychological description and structure that was within the numerous transcripts I had amassed.

#### **Chapter four - Findings**

Although I did harbour reservations about my ability to fulfil Giorgi's methodology and method, the process of crafting the findings chapter was the most fluid and straightforward of any throughout the entire experience. My previous experience of writing findings chapters in previous qualitative work has often been consumed by a concern for displaying a thematic analysis that does not capture the entirety of the phenomenon being studied (Giorgi, 2009; Applebaum, 2011). However, what became apparent during this process was that using Giorgi's method would allow the entirety of the participants' experiences to be encapsulated within the description and the essential constituents that supported the psychological structure.

This level of comfort does not, however, suggest that the process of writing the findings was an easy and simple task. The task of analysing the transcripts was rigorous and included many attempts of going back and forth through Giorgi's steps to ensure that I was honouring my fidelity towards the phenomenon of interest (Applebaum, 2012; Halling, 2020). But in doing so, Giorgi's (2009) approach enabled me to fully disclose all of the explicit and implicit meanings that were expressed by the participants without feeling like the study was missing key

information. Essentially, the rigorous and systematic nature of Giorgi's analytical framework provided me with an opportunity to prepare and write a comprehensive findings chapter that detailed the entirety of the phenomenon that was expressed by the participants and constituted by myself.

## **Chapter five - Discussion**

Upon adhering to Finlay's (2008) methodological guidance for reflection I will reflect on my experience of writing the discussion as it happened in the moment and retrospectively. To begin with, my overall impression was one of apprehension. I had never previously written a discussion that had not started with an immediate engagement with the scholarly literature that is closely associated with the discipline and phenomenon of study. Attempting, therefore, to discuss the findings in greater depth without moving too quickly from the findings was something that required a lot of reflection and consideration, as I did not want to simply reproduce what I had already written during the findings chapter. However, after my initial concerns had been managed through my reflections, I realised that the study and its findings needed to be elevated in a disciplinary and philosophical manner to fully explore the essence of what I was communicating. Not only did this lead to the findings being deepened through the psychological discussion of rigidity and openness, but my academic ability was, I believe, aligned with what is expected at the level of doctoral study.

The first two sub-chapters consequently transformed the study in ways that I did not envisage as I was preparing to engage with it. The writing of the two sub-chapters subsequently encouraged me to continue to work closely with the findings in ways that would allow me to satisfy the psychological and phenomenological depth that was pregnant within them. This approach also allowed me to access a greater appreciation for the phenomenological attitude that has been employed throughout the study.

## **Chapter six - Conclusion**

The final chapter presented the clear and obvious opportunity to collect and communicate fragments of the thesis to finally consolidate the essential message of the thesis. My observation of the many conclusive contributions and recommendations that have been drawn from the body of work presented highlights

the value and importance of the study. For example, both the theoretical and practical contributions and recommendations were an opportunity to fully examine the impression that this thesis has left on the wider academic and scholarly context. Upon reflecting on this impression now, the study could be considered to be a success in that it delivered beyond the original expectations that were placed upon by myself and possibly the wider research team.

What's more, the conclusion also allowed me to briefly acknowledge the depth of my comprehension of philosophy and science. More specifically, the conclusion was an opportunity to showcase the importance of evaluating the study by phenomenological standards, as opposed to the standards of the natural sciences. Too often does it occur whereby qualitative studies offer a host of limitations that reflect critical awareness of the philosophy of empiricism, especially experimentation. Whilst I tried to acknowledge how empirical limitations could be applied to this thesis, I engaged with the limitations of the phenomenological method to demonstrate my awareness and critical understanding of the differences.

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## Appendix A – Ethical application and approval

CRECLHPS-18-01

9 April 2018

Dear Oliver

Thank you for your resubmission to the Cross-School Research Ethics Committee for Life, Health and Physical Sciences at the University of Brighton.

The committee feel you have now addressed all the issues raised and are happy to offer a favourable ethical opinion for this study. However, the committee have one final comment relating to the section 'What if I am unhappy during my participation in the study?' The committee have suggested that as you are now saying that you will automatically destroy all the data relating to a participant if they withdraw from a study, you could instead ask them if you could retain this data for your research. You would only have to destroy this data if a participant stated that you could not retain it for use in your research. The committee are happy for you to make this change with the agreement of your supervisor in order for the favourable ethical opinion to apply to your submission.

Favourable ethical opinion is given on the basis of a project end date of 1/10/2020. If you need to request an extension, please contact the CREC secretary. Please note that the decisions of the committee are made on the basis of the information provided in your application. The CREC must be informed of any changes to the research process after a favourable ethical opinion has been given. Tier 2 research that is conducted without having been reviewed by the committee is not covered by the University research insurance cover. If you need to make changes to your proposal please complete and submit a change notification form in order that the CREC can determine whether the changes will necessitate any further ethical review. The form is available at:

<https://staff.brighton.ac.uk/ease/ro/Pages/ethics%20and%20governance/CREC-SS.aspx>

Once your research has been completed, please could you fill in a brief 'end of project report form' that can be found on the same website. Finally please could I ask that you flag up any unexpected ethical issues, and report immediately any serious adverse events that arise during the conduct of this study.

We wish you all the best with your research and hope that your research study is successful. If the CREC can be of further assistance with your study, please contact us again.

Best wishes



Lucy Redhead  
Chair, Cross-School Research Ethics Committee (Tier  
2) Life, Health and Physical Sciences

Copy: Professor Kathleen Galvin by email

# Research Ethics Review Tier 1 Checklist

This Tier 1 checklist should be completed for every research project that involves human participants. It is used to identify whether a Tier 2 application for ethics approval needs to be submitted. If a Tier 2 application is required, please use the Tier 2 Ethics Approval Application Form.

Before completing this form, please refer to the *Ethical Research Guidelines for Staff and Students* and the University's *Guidance on Good Practice in Research Ethics and Governance*; both are available at: [http://staffcentral.brighton.ac.uk/ro/ethics\\_govern.shtm](http://staffcentral.brighton.ac.uk/ro/ethics_govern.shtm). The principal investigator or, where the principal investigator is a student, the supervisor, is responsible for exercising appropriate professional judgement in this review. This checklist must be completed before potential participants are approached to take part in any research.

The principal investigator/student has read and understood the *Ethical Research Guidelines for Staff and Students* and referred to the *University Guidance on Good Practice in Research Ethics and Governance*.

## Section A: Applicant Details

1	Project title	
2	Name of researcher (applicant)	Oliver Thurlow
3	Status ( <i>please select</i> )	Postgraduate Student - PhD
4	Email address	ojt18@brighton.ac.uk
5a	Contact address	
5b	Telephone number	

## Section B: For Students Only

6	Module or Unit name and number – or	PhD – School of Health Sciences
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	<b>MA/MPhil/PhD course &amp; School</b>	
<b>7</b>	<b>Supervisor / tutor's name</b>	<b>Professor Kathleen Galvin</b>
<b>8</b>	<b>Email address</b>	<b>K.Galvin@brighton.ac.uk</b>
<b>9</b>	<b>Contact address</b>	<b>School of Health Sciences Westlain House Falmer Brighton BN1 9PH  01273 644028</b>

**Supervisor / tutor: Please answer Yes / No to the statements below (or N/A where not applicable). The study should not begin until 'Yes' is applied to all statements where relevant**

The topic and ethical implications of the research have been addressed with the student.	<b>YES</b>	<b>NO</b>	
The topic merits further research of the kind being proposed, and this is appropriate to their level of study	<b>YES</b>	<b>NO</b>	
The student has confirmed they understand the Ethical Research Guidelines for Staff and Students	<b>YES</b>	<b>NO</b>	
The student has the skills to carry out the research	<b>YES</b>	<b>NO</b>	
The participant information sheet or leaflet and consent form are appropriate	<b>YES</b>	<b>NO</b>	<b>N/A</b>
The procedures for recruitment and obtaining informed consent are appropriate	<b>YES</b>	<b>NO</b>	<b>N/A</b>

The procedures for ensuring confidentiality/anonymity of respondent data are appropriate	<b>YES</b>	<b>NO</b>	<b>N/A</b>
Risk assessment has been carried out and the form completed where necessary	<b>YES</b>	<b>NO</b>	<b>N/A</b>

### Comments from supervisor / tutor

N/A

### Section C: Project Details

Please see Tier Two application

### Section D: Research Checklist

Please answer each question by indicating the appropriate answer: **YES / NO**

<b>1</b>	Does the study involve participants who are particularly vulnerable or unable to give informed consent? (For example, children, people with learning disabilities, your own students)* <i>See below for more details.</i>	<b>YES</b>	<b>NO</b>
<b>2</b>	Will the study require the co-operation of a gatekeeper for initial access to the groups or individuals to be recruited? (e.g. students at school, members of self-help group, residents of nursing home)	<b>YES</b>	<b>NO</b>
<b>3</b>	Will it be necessary for participants to take part in the study without their knowledge and consent at the time? (e.g. covert observation of people in non-public places)	<b>YES</b>	<b>NO</b>
<b>4</b>	Will the study involve discussion of sensitive topics (e.g. sexual activity, drug use)?	<b>YES</b> <b>Discussion of health condition</b>	<b>NO</b>

5	Will the study involve invasive, intrusive or potentially harmful procedures of any kind?	YES	NO
6	Is pain or more than mild discomfort likely to result from the study?	YES	NO
7	Is the study likely to induce psychological stress or anxiety or cause harm or negative consequences beyond the risks encountered in normal life?	YES Mild stress	NO
8	Will the study involve prolonged or repetitive testing?	YES	NO
9	Will financial inducements (other than reasonable expenses and compensation for time) be offered to participants?	YES	NO

#### Comments from supervisor/tutor

N/A
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\* Children are defined as those under the age of 16 years. Any research activities involving children or vulnerable adults must be referred to the Arts & Humanities Research Ethics and Governance Committee for Tier 2 approval prior to the start of the research. Vulnerable participants are those who are vulnerable by reason of temporary or permanent mental or physical disability or incapacity, age or illness. They could also include people who are vulnerable for reasons such as social inequality or marginalisation, or their status as homeless people, drug users, sex workers, victims of crime, bullying or domestic violence, as well as those who may be vulnerable due to their sexual orientation. People who have undergone traumatic or adverse emotional events may also be vulnerable, especially with regard to research relating to that event.

In cases where researchers are working with children, Disclosure and Barring Service (DBS) checks may be required, notably if researchers are working unsupervised. Researchers should liaise in advance with the organisation(s) in which they plan to work to discuss this and clarify those details on the *Tier 2 Ethics Approval Application Form*.

If you have answered '**NO**' to **all** questions:

- Submit the completed and signed form to the supervisor/tutor for approval

- Attach copies of any relevant documentation, i.e. questionnaires/interviews and/or focus group questions; participant information sheets; consent forms; risk assessment forms; feedback forms; and procedures for ensuring confidentiality/anonymity in the storage and use of data.

If you have answered 'YES' to **any** of the questions in Section D:

- You will need to describe more fully how you plan to deal with the ethical issues raised by your research. **This does not mean that you cannot do the research, only that your proposal will require further review, and possibly referral to the Arts & Humanities Research Ethics and Governance Committee.** You will need to submit your plans for addressing the ethical issues raised by your proposal using the Tier 2 Ethics Approval Application Form and in the first instance submit this to your supervisor/tutor. He/she will decide the level of approval required.

If you answered 'YES' to **question 1**:

- You will need to consult the *Ethical Research Guidelines for Staff and Students* and *the University Guidance on Good Practice in Research Ethics and Governance*. If you or anyone connected with the research will be working directly with young people you may also need to conduct a DBS in order to carry out this work. It is advisable to initiate this process well in advance of your project start date. Please consult your supervisor/tutor for further advice as to whether a check is required. If it is advised, you should liaise in advance with the organisation(s) in which you are planning to work to discuss this.

Please note that it is your responsibility to follow the College's and University's *Guidance on Good Practice in Research Ethics and Governance* including providing appropriate information sheets and consent forms and ensuring confidentiality in the storage and use of data. Any significant change in the question, design or conduct over the course of the research should be notified to your supervisor/tutor and may require a new application for ethics approval.

**28/11/2017**

Signed: **Oliver Thurlow** Date: \_\_\_\_\_

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Principal Investigator:

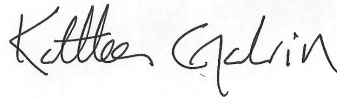
**17/01/2018**

Signed: **Kathleen Galvin** Date: \_\_\_\_\_

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**Supervisor / tutor (where appropriate):**

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Emailed version with names in the signature boxes is acceptable.

In the case of students, supervisors/tutors should retain the completed forms.

In the case of staff they should be submitted to the Secretary of the Arts & Humanities Research Ethics and Governance Committee. Secretary to A&HREGC:  
[j.embleton@brighton.ac.uk](mailto:j.embleton@brighton.ac.uk)

Updated March 15<sup>th</sup> 2018



## Tier 2 Cross-School Research Ethics Committee (CREC) Application Form

Please note that review by a Tier 2 CREC is only required for proposals that present more than minimal ethical risk. For lower risk proposals, please complete the Tier 1 form and submit it to your School Research Ethics Panel. The Tier 1 form includes a checklist to help determine the level of review required. If it is unclear whether your proposal requires Tier 1 or Tier 2 review, please complete the Tier 1 form and checklist in the first instance. If your proposal has been referred up to the CREC by your Tier 1 School Research Ethics Panel, please attach a copy of the completed Tier 1 form to this application. Please do not include any other forms or documents with your application, other than those listed in the checklist in section 11.

Please adhere to the indicated word counts on this form. Any application that exceeds the word counts will not be considered by the CREC.

### 1 Applicant details

Project title	
Proposed start and end date of project	<b>2/10/2017 – 01/10/2020</b>
Name of researcher	<b>Oliver James Thurlow</b>
School	<b>School of Health Sciences</b>
Level (UG/Taught PG/PGR/Staff)	<b>PGR - PhD</b>
Address	
Phone	
Email (please use University email address)	<b>ojt18@brighton.ac.uk</b>

Funder (if applicable)	<b>University-funded studentship</b>
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## 2 Student details

Course/Module/Unit name/number	<b>PhD</b>
Name of supervisor/tutor	<b>Professor Kathleen Galvin</b>
Supervisor contact details	<b>School of Health Sciences Westlain House Falmer Brighton BN1 9PH  01273 644028  K.Galvin@brighton.ac.uk</b>

## 3 Introduction (Maximum 500 words)

Please provide a brief background to the research, including context and rationale and the purpose of the research and aims of the study/hypothesis to be tested.

Current national statistics identify that more than half of England's population will be diagnosed with some form of cancer in their lifetime (WHO, 2017). The Office for National Statistics and Public Health England published findings that reveal there was close to 300,000 cancer diagnoses in England registered in 2015, equating to nearly 822 diagnoses per day. The most common forms of cancer occurred in the anatomical region of the breast (15.4%), prostate (13.3%), lung (12.5%), and colorectal (11.6%), with males (153, 061) accounting for more diagnoses than females (146,862). Because of such high frequencies of cancer occurrence, the phenomenon of experiencing cancer has become a paramount research topic. Previous research in this area has highlighted that the natural environment (in-situ) is highly advantageous for the rehabilitation for cancer sufferers and can have a significantly positive impact on the physical, psychological, social, environmental, and spiritual of their overall experience (Burke et al., 2017; Midtgaard et al., 2015). Moreover, a considerable amount of emphasis in this academic area has focussed on structured interventions, concentrating on casual effects of behaviour change, especially with women (Burke et al., 2017; Midtgaard et al., 2015). Though this has proved to be useful, considerably more research is needed in an effort to understand the implications of unstructured recreational programmes and how they affect those living with and beyond cancer. Caddick, Smith, and Phoenix (2015) provide

an appropriate example of unstructured programmes, whereby war veterans who suffered from Post-Traumatic-Stress-Disorder (PTSD) employed surfing as an active and natural remedy for the enhancement of their overall health and wellbeing. Outcomes proposed that surfing represented a vehicle or haven from the trauma of their previous wartime experiences, enabling the veterans to facilitate their own physical and psychological wellbeing outside of a clinical environment (Caddick et al., 2015).

This doctoral research, therefore, aims to surface the deep issues relating to unstructured recreational programmes within the context of cancer. It is significantly important to understand the implications of this unique form of rehabilitation and survivorship that the 4Cancer Group provides for their beneficiaries. The intended research plan will cut through the taken for granted assumptions of the lived experience of cancer by directly interviewing with those who have been affected by the condition. The research will also be used to define the benefits for future generations who will live with cancer, providing tangible evidence to enhance the ongoing progression of unstructured recreation on a regional and national level. A further outcome of the research will be focussed on building a methodological framework from which subsequent research can be conducted.

#### **4 Research approach and methods (Maximum 1,000 words)**

Please outline the research approach and methods to be used including:

- How is the research to be conducted – what is the design?
- How, where and when will data be collected (please include copies of any questionnaires to be used, or sample interview questions)?
- What research methods (statistical or qualitative) will be used? Please demonstrate an understanding of procedures to be used and/or training undertaking in research methods.
- How will the results be analysed and by whom?
- How will the analysis achieve the purpose of the study?
- What facilities/resources will be required and who will provide them?

The methodology and methods that have shaped the design of this doctoral study have been influenced by phenomenological and qualitative approaches. The rationale behind this decision was formed by the understanding that the study has been designed to form a subjective and experiential understanding of how those living with and beyond meaningfully engage with unstructured recreation in the natural environment (Burke et al., 2017). As a result, the primary researcher is going to employ the method of repeated one-to-one, phenomenological interviews to understand the participants' experiences of unstructured recreational programmes in the natural environment.

Moreover, Phenomenology is, first and foremost, understood to be a philosophy, involving the study of consciousness and phenomena (Moran, 2000; Giorgi, 2009). Indeed, one of the main tenets of phenomenology as an academic researcher is to

“bracket” or put aside their natural attitude regarding what is being studied. Moreover, phenomenology attempts to encounter everyday experiences in the search for a descriptive essence of what we experience through subjectivity. By employing this methodology and method, the researcher not only allows the participants to express their understanding of their experiences but also enables the opportunity to extend the current limited knowledge in this area of research (Burke et al., 2017).

Before the commencement of the interviews, the principal researcher is going to practice phenomenological interviewing with both the primary and secondary supervisors. The purpose of doing so will be to refine the skills necessary to conduct an authentic phenomenological interview, reducing the possibility of feeling unprepared when it comes to the formal interviews with the potential participants. Once the trial phase of the study has been completed, the primary researcher will then engage with the proposed audio recorded, one-to-one interviews in a neutral, safe, and quiet location. This location has been agreed upon by both charity officials and academic supervisors to be a private room based at the University of Brighton, Falmer campus and the participants private home or workplace office. This will permit the participants to feel at ease throughout the interview process, whilst reducing the chance of noise or any other interferences. As well, the principle researcher has opted to include repeated interviews in this research design. Therefore, the principle researcher can schedule a second or third interview with each participant to ascertain more data, if necessary. The participants will be asked if they would like to participate in another interview, which will then be arranged to suit the participants’ schedule.

Furthermore, once the interviews have taken place, they will then be transcribed verbatim and then analysed in accordance with Giorgi’s (2009) descriptive analysis, which was based on Husserl’s phenomenological philosophy. This follows as:

“1) The first step is to read through the written descriptions provided by the participants all the way to the end. In order to do a proper analysis, one must know how the described lived experience ends.

2) While the normal natural attitude is sufficient for the first step, the rest of the analysis requires that the researcher assumes the attitude of the phenomenological (or scientific) reduction. This means that the objects that emerge within the description are taken to be phenomena or simply objects that present themselves to the consciousness of the experiencer but the notion that such objects really exist in the way that they present themselves is not acknowledged.

3) Now, since descriptions can be lengthy they have to be broken into parts so that proper analyses of the descriptions can be done. Since phenomenological analyses are concerned with the discrimination of meanings, the separation of the parts of a unified description is based upon meanings, and each part is called a meaning unit and it is determined by a careful rereading of the description with the intention to distinguish parts from a phenomenological perspective.

4) Once the meaning units are determined, the task of the next step is to transform the meanings contained in the description in phenomenologically sensitive ways. Thus, the

attitude to achieve this task requires one to not only be in the attitude of the phenomenological (scientific) reduction but also that one be sensitive to the meaning of what is being expressed.

5) The last step is to get the general structure of the experience. This is done by reviewing all of the transformations in order to determine the essential experience.” (Giorgi, Giorgi, and Morley, 2017).

### **5a Participants and recruitment: general information (Maximum 500 words)**

What sort of participants (age range, ethnicity, number, gender) are to be recruited? Will any vulnerable groups of people or individuals be involved? Consider the concept of ‘vulnerability’ in its broadest sense.

What inclusion/exclusion criteria will be used? Is exclusion from the research likely to deny an individual access from services that would otherwise have been provided?

How will initial contact be made? Include details of gatekeepers and others who are to be approached? Please supply a copy of any means of advertising, such as posters, leaflets, emails, web pages or letters.

A minimum of five and a maximum of twelve individuals will be interviewed during the data collection process. In compliance with the studies purpose, it is anticipated that the ages of the potential participants will vary from adolescents to adults. Maximum variation sampling will be employed through the ‘4 Cancer Group’ (gatekeeper) to recruit participants. The sampling will be conducted by administrative staff from the 4 Cancer Group by emailing or sending physical letters to beneficiaries who have been previously involved in the charity’s activities. In order to make the process less coercive and more systematically rigorous, the 4 Cancer Group’s administrative staff will email beneficiaries who have indicated that they would be willing to receive updates and charity information in the future via their post-respite survey response. Subsequently, the 4 Cancer Group will still be maintaining their position as the gatekeeper or intermediary during the initial phases of participant recruitment. As well, all personal information of the potential participants will remain with the 4 Cancer Group during this period.

For those potential participants who are under-sixteen, it will be clearly stated that both the child and the parent(s) or legal guardian must understand and independently consent to their involvement in the study (Please see attached forms) (Groundwater-Smith, Dockett, Bottrell, 2014). Interested participants will be provided with a formal letter/email of invitation, as well as a participant information sheet, by the 4 Cancer Group and informed that they have as much time as possible to reflect and decide on whether they would like to participate in the study. Participants will also be required to complete and

sign the informed consent documentation on the days of which they are due to be interviewed. Participants will be informed and reminded of all the ethical considerations that have helped form this study and will also be reminded that they can withdraw on the day of the interview if they do not feel comfortable.

For inclusion in the study, participants: (1) must have had an experience with the 4Cancer Group's respite trips, (2) have been indirectly affected by/or directly suffered from cancer, (3) be from any ethnic background but able to communicate their experiences through the English language, (4) be in a physically and mentally comfortable disposition to discuss their experiences at length, and (5) will be no younger than 12-years-old.

However, potential participants will be politely excluded from the study if they are unable to provide informed consent due to the severity of their condition. This includes physical or cognitive distress and impairment. The participants care team (i.e family and health care professionals) will be responsible for assessing whether potential participants will be able to proceed with throughout the data collection process (Groundwater-Smith et al., 2014). However, it is severely unlikely that a participant will be contacted for recruitment if the 4 Cancer Group know or discover that a potential participant's current condition is too debilitating to participate in the study. Additionally, if a participant's condition worsens during the research period, they will be excluded from further interviews to prioritise their health and wellbeing (Groundwater-Smith et al., 2014). In the event of this occurring, the participant's care team will be fully briefed and informed, so they are aware of why the participant has been excluded. However, participants will not be completely excluded from the study; they will be informed that they can still participate providing they are comfortable to do so at a later date.

*copy of any relevant materials used to recruit participants should be attached to this application*

**5b Participants and recruitment: payments to participants (Maximum 500 words)**

Will participants be reimbursed or paid for their expenses and/or time? If so, please provide details of any payments or vouchers to be offered, or other incentives such as being entered a prize draw (you should ensure that any payment does not constitute an inappropriate inducement to take part).

Participants will be made aware that they are entitled to claim back travel expenses. If potential participants do decide to take part, the travel expense form will be emailed or physically mailed to them alongside relevant information on how to complete the form. Participants will also be made aware that their contributions will be a part of a contribution to new knowledge within an educational based context.



<ul style="list-style-type: none"> <li>• Discussion of sensitive and personal topics.</li> <li>• Researcher distress and concern for the participants.</li> <li>• Child/adolescent assent.</li> </ul>	<ul style="list-style-type: none"> <li>• The investigator will handle any sensitive situations with caution and care and will also acknowledge any emotional response throughout the entire research process.</li> <li>• If at any point, the primary researcher conducting the interviews feels any kind of emotional or psychological distress, they will seek advice or guidance from both supervisory figures and an impartial university wellbeing team. Please see the flowchart diagram attached for the planned protocol in the event of such an occurrence (Finlay and Evans, 2009).</li> <li>• Children or adolescent participants will have the freedom to decide whether they want to participate in the study. However, if they do not want to participate, they will not be pressured into changing their mind. Also, parents must independently consent for their child to participate in the research process.</li> </ul>
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## 7 Participant information and consent (Maximum 500 words)

Please outline how participants will be informed (both orally and in writing) about the research and their participation in the study. How will you ensure that information is provided in a format/language suitable for the target audience? Please describe how written consent will be obtained, or if you are working with participants who cannot give written consent, an explanation of the reason for seeking oral consent and details of the procedure to be adopted.

If consent is not being sought or will not be sought until after data has been collected (e.g. if it involves covert observation), please say why consent will not be sought or why the delay is necessary, and what steps will be taken (if any) to debrief participants and obtain consent afterwards.



An initial recruitment letter and participant information sheet will be emailed or physically mailed to the participants who have indicated that they may want to take part in the study by the administrative staff of the 4 Cancer Group (Please see each of the attached forms). This form will identify benefits, risks, and overall information of the study, thus allowing the participants to know what is going to happen and why this is so. Participants are entitled to have as much time as necessary to decide if they would like to participate in the study. All of the written content will be user-friendly in an effort to make sure potential participants understand the research procedures and their own rights. This strategy coincides with the data protection act of 1998, stating that these steps must be taken for the study to be ethically responsible. As well, this strategy ensures that the participants' rights have been considered.

Moreover, if potential participants have any questions that they need addressing directly, contact details of the primary researcher will be made available to them through the 4 Cancer Group. Upon providing such details, the researcher can further explain or clarify any of the information that was originally provided. Participants will still be reminded at this point that it is completely their choice if they would like to take part in the study and they should not feel pressured into participating. In addition, the participants will also be reminded that they can withdraw from the study at any stage before data analysis without having to give any specific reasons. Once all of the relevant information and forms have been read and understood, the principal researcher will then start to schedule a suitable date for the research interviews, providing participants still feel comfortable enough to take part in the interview.

Furthermore, participant consent will be taken in writing on the day of the first interview. The participant will be reminded of the study's purpose and the relevant information that was cited in the participant information sheet. The participants will therefore have another opportunity to ask any questions before giving consent and participating in the interview.

*Copies of consent forms, participant information sheets and any other information for participants should be attached to this application*

## **8 Confidentiality and data storage (Maximum 500 words)**

Please describe measures that will be taken to ensure anonymity, privacy, confidentiality, and data protection. This should include:

- How participants will be identified without breach of the data protection act and to guard against invasion of privacy (e.g. if you plan to access personal information to identify potential participants)?
- What steps will be taken to anonymise data (this may include removing identifying information in addition to names)
- How data (both physical and digital) will be collected, handled, transferred, and stored

- Who will have access to the data other than the researcher (eg supervisors, transcribers etc)?
- How long data will be retained, and how it will eventually be destroyed
- Where the research data will be published (eg essay, dissertation, academic paper, exhibition, online) and who will have access to the results

In the event of a serious disclosure that may have a direct or indirect effect on the health, safety, and wellbeing of those or others during the interview process, confidentiality will be broken with or without consent. This is necessary as I will be obliged to protect the health, safety, and wellbeing of those who might be at risk. However, if all data that is collected does not pose a risk or threat, all of the audio recorded interviews that will have been gathered will be transcribed, analysed, and stored away confidentially. The participants' data will be allocated as pseudonyms and the data will be presented in an anonymous coding system that will not divulge any names, identities, and the personal details of those that are involved in the study.

The participants' consent forms and any other personal forms will be secured separately from the interview data to avoid revealing the names and personal details of participants. All paper data will be filed and locked in a filing cabinet which can only be accessed by the principle researcher or research supervisors. All electronic forms of data will be stored within an electronic device that will require a specific access code, which only the researcher will know. All data that will be gathered and shared will be conducted in accordance to the data protection act of 1998, and will be destroyed ten years after the data has been collected via a paper shredder and permanent electronic deletion. During the ten years following data collection, no other persons will have access to this data which could reveal any personal information. Lastly, the data that will be collected will be used for thesis publication (online publications & physical thesis document), and will not reveal the personal information of those who decide to participate in the study.

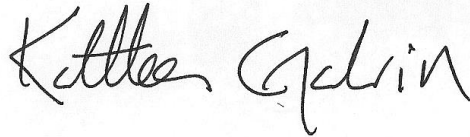
## 9 Other ethical issues

Please outline any other ethical issues that have not already been discussed in the sections above and describe how these will be addressed.

As well as being advised and consulted by both of my supervisors, I have also sought the advice of the 4 Cancer Group, who are acting as my gatekeeper and PPI group. The charity's input and engagement has had an impact on some elements of the design, structure, and overall integrity of the study, but not all. Also, please see the risk assessment form attached for further elaboration of potential risks and hazards.

## 10 Supervisor sign-off (for student research only)

I confirm that I have checked the application and that the student has addressed the relevant ethical issues, has received training in ethics as part of their module or programme and has the necessary skills and experience to carry out the proposed research.



Supervisor:

Date: 17/01/2018

## 11 Checklist for accompanying documents

Please ensure you have attached copies of any of the following documents where relevant, and please do not include any other forms with your application.

- Tier 1 form (where proposal has been referred up from School Research Ethics Panel)
- Information sheets
- Consent forms
- Advertising or recruitment materials?
- Sample questionnaires or interview questions
- Risk assessment forms
- Letters of support from external organisations involved in the research
- List of references cited in the application

Please also note that the application must be complete and please ensure that it has been checked for accuracy, grammar, and spelling.

Please return this form and all accompanying documentation to the Secretary of the Cross-School Research Ethics Committees (Kate Connolly, [k.connolly2@brighton.ac.uk](mailto:k.connolly2@brighton.ac.uk)).

University of Brighton  
Village way  
Falmer Campus  
Brighton  
BN1 9PH

Hello,

My name is Oliver Thurlow. I am a PhD student at the University of Brighton, working with the 4 Cancer Group for an educational based study. I am writing to you to let you know about an opportunity to participate in an interview-based study that is aimed at learning about your experiences of the 4Cancer Group's recreational services that you have participated in.

To give you a brief insight, I am planning to arrange between one to three recorded interviews that will explore your experiences of cancer and the 4 Cancer Group's recreational services. Your involvement in this study is completely your choice as your wellbeing is important to us. If you would like to participate in the interviews, we can organise your inclusion as soon as possible. Firstly, for more information on the study, you are encouraged to read the attached participant information sheet that includes all the relevant information.

If after reading the participant information sheet you believe you would like to participate, you should contact a member of the 4 Cancer Group, who will then place you in contact with myself. From that point onwards, I will give you more information about what will happen next. If you do not feel comfortable and confident enough to take part in the study, you do not have to respond to this letter. Your decision not to respond will be respected and will indicate your decision not to participate. You should not feel pressured into participating in this study.

If you would like to know more information about the study, you are free to contact the 4 Cancer Group or myself via email or phone call. The appropriate contact details are enclosed within the participant information sheet.

Yours sincerely,

Oliver Thurlow

## Participation Information Sheet - Adults

### What is the purpose of this study?

The purpose of the study is to get a better understanding of the experiences of those that have been affected by cancer and recreation by using one-to-one interviews. At present, there is still a lot more to learn about this topic and we would like to understand your thoughts, feelings, opinions of the 4 Cancer Group's recreational services and how it's impacted your experience of cancer.

### Why have I been chosen?

You have been invited to participate in this study as you have been affected by cancer. You will have also been involved in one of the 4 Cancer Group's recreational programmes that they offer through one of their services.

### What happens if I volunteer to take part in this study?

Firstly, it is up to you to decide if you want to take part. You can have as much time as possible to decide if you would like to participate. You are more than welcome to discuss this with your family and friends if you are not sure. If you would like to participate, you should contact the 4 Cancer Group to let them know you want to take part.

### What will I have to do?

#### First stage:

You will be given a date to come and take part in an interview. On the day of the interview, I will ask you to sign a consent form, talk to you about the interview to make you feel at ease, and then begin the interview. Once this has finished, you will have the opportunity to ask any questions about what will be done with your interview. The interview is likely to last for a maximum of two hours and is designed to make you comfortable.



**Potential second and third stage:**

If I feel like it would be a good idea to do a second and third interview to gain a better understanding of your experiences, I will ask you if this is ok to do so. A second or possibly third interview will then be arranged with you to suit your schedule.

**Will I receive any financial reward for taking part?**

You will have the option to decide whether you would like the interviews to be conducted in your home or elsewhere. If you decide to take the latter of the two options, you are more than welcome to visit the University of Brighton for your interview. If this choice is made, you will be able to claim back travel costs. I will make sure you receive either a physical or digital version of the travel expenses form.

**Are there any benefits of taking part?**

There are no direct health benefits for taking part in this study, but this is an opportunity to share your opinions which may offer you a better understanding of your experiences, thoughts, and feelings.

**Will participation involve any physical discomfort or harm?**

As you are only going to be participating in one, two, or three interviews, it is unlikely that your participation will involve any physical discomfort or harm. However, on the day of an interview, the location will be risk assessed to reduce any potential risks to the point whereby you and myself feel comfortable and ready to begin the interview.

**Will participation involve any embarrassment or stressful situations?**

The interview will at times focus on sensitive experiences. This could therefore provoke an emotional response during the interview. Whilst this cannot always be stopped from happening, you can take a break from the interview at any time if you feel like it is becoming too distressing for any reason. If you feel that the interview is too upsetting after a short break, the interview will be stopped immediately. If this does happen, you will be asked about whether you would like your existing interview recording to be deleted or saved.

### **What will happen once I have completed all that is asked of me?**

You will be made aware that the interview has finished and asked if there is anything you wish to add that you may have forgotten to say during the interview. I will then talk with you about what is going to be done with the interview recording. To give you an idea now, the interview recording will be typed on a computer word-for-word, anonymised, studied, and then presented within a written essay on the topic of recreational services for people with an experience of cancer.

### **In what event will confidentiality have to be broken? How will my taking part in this study be kept private?**

It is important for you to know that all the things you say are completely private. The conversations that we have during the interview will be stored on a password protected recorder so no-one else can listen to them. We will only use a research code to identify you and all the personal details that you give us will be kept in secure and safe rooms at the University of Brighton. We may use some of the things you say when we write about the study, but we will take your name and any other personal information from the documents, so no one will know who was speaking. We will check you are happy for us to use the things you say in this way. If you tell us something that makes us worried about your safety and welfare, we may have to discuss this with you. We may recommend other sources of support or help, including your GP. We will always inform you if we must seek help on your behalf as we need to be sure you are safe. This means we always inform you, but we might not necessarily need your active permission. This means, what you say would not be kept completely private if it is a serious disclosure.

### **How will my interview recording be used?**

The outcomes of this study will be written up as part of an essay on cancer and recreation. This will involve using some of the things you say from your recorded interviews. Also, I am planning on using the information you provide for the study for presentations and journals for people to read. This will again involve using some of the things you said from your recorded interview.

### **Who has made sure that this study is safe?**

This study has undergone full ethical clearance and all risks have been assessed and approved by an ethics committee at the University of Brighton. Also, the research study has been approved by the chair of trustees from the 4 Cancer Group.



### **What if I am unhappy about my participation throughout the study?**

It is important for you to know that you are free to withdraw your interviews for any reason. If you decide that you do not wish to take any further part, then please tell me and the 4 Cancer Group and we will make sure you are withdrawn. You do not need to give a reason for your withdrawal and any personal information or recordings that you have provided (both paper and electronic) will be safely removed or deleted as soon as possible after you have left the study.

However, the only circumstance whereby we would not be able to delete your interview information would be because it may have already been written up, anonymised, and included in the study's wider analysis alongside other anonymised information. It would therefore be difficult to identify and remove what you have said. However, prior to the anonymisation of the interview information, we would be able to delete or remove anything you provide if you would like us to do so.

Also, if you are unhappy about anything during your participation you are entitled to make a complaint. The contact details of the operations manager from the 4 Cancer group have been provided below for you. You are free to email him directly if you would like to report or discuss something. If he is unavailable, you should contact one of the two administrative staff who will assist you. You should be made aware that nobody from the research team (myself and supervisors) will have access to your complaint and we will be made aware of any complaints independently.

### **What should I do now?**

Firstly, I'd like to thank you for reading the participant information sheet. You should now take your time to reflect on whether you would like to take part in the study. You are encouraged to talk about this decision with family and friends so that you are fully confident about your decision. If you do decide that you would like to take part, you should contact the 4 Cancer Group as soon as possible. However, if you do decide that you would not feel comfortable participating in this study, you can either tell the administrative staff or you can ignore this invitation. It is important for you to know that your decision will be completely respected.

### **Primary researcher and charity contact details**

**Name:** Oliver Thurlow

**Email:** [o.thurlow@4cancer.org](mailto:o.thurlow@4cancer.org)

**Administrative Staff:** Cathy Jenkins (cjenkins@4cancer.org) or Pippa Ashton (pashton@4cancer.org)

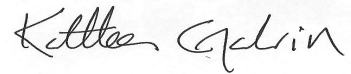
**Operations Manager:** Dave Smith – Dsmith@4cancer.org

**Admin Tel:** 01635 297222

## **Principal Researcher Signature:**

**Date:** 25/11/2017

## **Primary Supervisor Signature:**

A handwritten signature in black ink that reads "Kaitlin Quinn". The signature is written in a cursive style and is positioned to the right of the "Primary Supervisor Signature:" label.

**Date:** 17/01/2018

University of Brighton  
Village way  
Falmer Campus  
Brighton  
BN1 9PH

Hello,

My name is Oliver Thurlow. I am a PhD student at the University of Brighton, working with the 4 Cancer Group for an educational based study. I am writing to you to let you know about an opportunity to participate in an interview-based study that is aimed at learning about your experiences of the 4Cancer Group's recreational services that you have participated in.

To give you a brief insight, I am planning to arrange between one to three recorded interviews that will explore your experiences of cancer and the 4 Cancer Group's recreational services. Your involvement in this study is completely your choice as your wellbeing is important to us. If you would like to participate in the interviews, we can organise your inclusion as soon as possible. Firstly, for more information on the study, you are encouraged to read the attached participant information sheet that includes all the relevant information.

If after reading the participant information sheet you believe you would like your child to participate, you should contact a member of the 4 Cancer Group, who will then place you in contact with myself. From that point onwards, I will give you more information about what will happen next. If you do not feel comfortable and confident enough for your child to take part in the study, you do not have to respond to this letter. Your decision not to respond will be respected and will indicate your decision not to participate. You should not feel pressured into participating in this study.

If you would like to know more information about the study, you are free to contact the 4 Cancer Group via email or phone call. The appropriate contact details are enclosed within the participant information sheet.

Yours sincerely,

Oliver Thurlow

## Participation Information Sheet – Parents

### What is the purpose of this study?

The purpose of the study is to get a better understanding of the experiences of those that have been affected by cancer and recreation by using one-to-one interviews. At present, there is still a lot more to learn about this topic and we would like to understand your child's thoughts, feelings, opinions of the 4 Cancer Group's recreational services and how it's impacted your experience of cancer.

### Why has my child been chosen?

Your child has been invited to participate in this study as they are a young person who has been affected by cancer. Your child and possibly you will have also been involved in one of the 4Cancer Group's recreational programmes that they offer through one of their services.

### What happens if my child volunteers to take part in this study?

First, it is up to you to decide if you want your child to take part. You can have as much time as possible to decide if you would like for them to participate. You are more than welcome to discuss this with family and friends if you are not sure. We encourage you and your child to talk about this also, so you can both come to an agreement about your decision. If you would like them to participate, you should contact the 4 Cancer Group to let them know you want to take part.

### What will your child have to do?

Firstly, it is simply wished that you and your child continue reading this participant information sheet and reflect on whether you think you would like your child to participate in the study.

#### **First stage:**

You and your child will be given a date to take part in the interview. On the day of the interview, I will ask you and your child to sign a consent form, talk to you both about the interview to make you both feel at ease, and then begin the interview. Once this finished, you will have the opportunity to ask any questions about what will be done with your interview. The interview is likely to last for a maximum of two hours and is designed to make your child comfortable always.



**Potential second and third stage:**

If I feel like it would be a good idea to do a second and third interview to gain a better understanding of your child's experiences, I will ask you and your child if this is ok to do so. A second or possibly third interview will then be arranged with you and your child.

**Notes**

You are welcome to join your child during the interview, but it is better for them that they complete this by themselves without the presence of somebody else in the room. This is only advised because we want your child to fully express themselves without the judgement of others.

**Will my child and I receive any financial rewards for taking part?**

You and your child will have the option to decide whether you both would like the interviews to be conducted in your home or elsewhere. If you decide to take the latter of the two options, both of you are more than welcome to visit the University of Brighton for your interview. If this choice is made, you will be able to claim back travel costs. I will make sure you receive either a physical or digital version of the travel expenses form.

**Are there any benefits of taking part?**

There are no direct health benefits for taking part in this study, but this is an opportunity for your child to share their opinion which may offer them a better understanding of their experiences, thoughts, and feelings.

**Will participation involve any physical discomfort or harm for your child?**

As we are only going to be participating in one, two, or three interviews, it is unlikely that your child's participation will involve any physical discomfort or harm. However, on the day of the interview, the location will be risk assessed to reduce any potential

risks to the point whereby you, your child, and myself feel comfortable and ready to begin the interview.

### **Will my child's participation involve any embarrassment or other psychological stress?**

The interview will at times focus on sensitive experiences. This could therefore provoke an emotional response during the interview. Whilst this cannot always be stopped from happening, your child will be allowed to take a break from the interview at any time if they feel like it is becoming too upsetting for any reason. If you or they believe that the interview is too upsetting after a short break, the interview will be stopped immediately. If this does happen, you and your child will be asked whether you would like your existing interview recording to be deleted or saved.

### **What will happen once my child has completed all that is asked of them?**

You and your child will be made aware that the interview has finished and asked if there is anything they wish to add that they may have forgotten to say during the interview. I will then talk with you and your child about what is going to be done with the interview recording. To give you an idea now, the interview recording will be typed on a computer word-for-word, anonymised, studied, and then presented within a written essay on the topic of recreation for people with experiences of cancer.

### **How will my child's participation in this study be kept confidential?**

It is very important for you to know that all the things your child says are completely private. The conversations that we have during the interview will be stored on a password protected recorder so no-one else can listen to them. We will only use a research code to identify your child and all other personal details that you and your child give us will be kept in secure and safe rooms at the University of Brighton. We may use some of the things you say when we write about the study, but we will take your child's name and any other information from the documents, so no one will know who was speaking. We will check you and your child are happy for us to use the things your child says in this way. If your child tells us something that makes us worried about their safety and welfare, we may have to discuss this with you. We may recommend other sources of support or help, including your GP. We will always inform you if we must seek help on your child's behalf as we need to be sure they are safe. This means we will always inform you, but we might not

necessarily need your active permission. This means, what your child says would not be kept completely private if it is very serious.

### **How will my child's interview recording be used?**

Results from this specific study will be written up as part of a written essay on the subject of cancer and recreation. This will involve using direct quotations from your child's recorded interviews. Also, I am planning on presenting the research findings through presentations and journals, which again will involve using some of the things your child said from their recorded interview.

### **Who has made sure this study is safe?**

This project has undergone full ethical clearance and all risks have been assessed and approved by an ethics committee at the University of Brighton. Also, the research project has been approved by the 4 Cancer group.

### **What should I do if I and my child are unhappy about the study?**

It is important for you to know that your child is free to withdraw their interview. If you decide that you do not wish for your child to take any further part, then please tell me and the 4 Cancer group and we will make sure your child is withdrawn. You do not need to give a reason for your child's withdrawal and any personal information or recordings that you have provided (both paper and electronic) will be deleted as soon as possible after your child has left the study.

However, the only circumstance whereby we would not be able to delete your child's interview information would be because it may have already been written up, anonymised, and included in the study's wider analysis alongside other anonymised information. It would therefore be difficult to identify and remove what your child has said. However, prior to the anonymisation of the interview information, we would be able to delete or remove anything your child provides if you would like us to do so.

Also, if you are unhappy about anything during your child's participation you are entitled to make a complaint. The contact details of the operations manager from the 4 Cancer group has been provided below for you. You are free to email him directly if you would like to report or discuss something. If he is unavailable, you should contact one of the two administrative staff, who will assist you. You should be made aware that nobody from the research team (myself and supervisors) will have access to your complaint and we will be made aware of any complaints independently.



### What should I do now?

Firstly, I'd like to thank you for reading the participant information sheet. You should now take your time to reflect on whether you would like your child to take part in the study. You are encouraged to talk about this decision with family, friends, and your child so that you are fully confident about your decision. If you do decide that you would like your child to take part, you should tell the administrative staff at the 4 Cancer group. However, if you do decide that you would not feel comfortable for your child to participate in this study, you can either tell the administrative staff or you can ignore this invitation. It is important for you to know that your decision will be completely respected.

### Primary researcher and charity contact details

**Name:** Oliver Thurlow

**Email:** [o.thurlow@4cancer.org](mailto:o.thurlow@4cancer.org)

**Administrative Staff:** Cathy Jenkins (cjenkins@4cancer.org) or Pippa Ashton (pashton@4cancer.org)

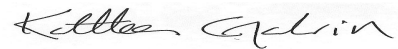
**Operations Manager:** Dave Smith – dsmith@4cancer.org

**Admin Tel:** 01635 297222

### Principal Researcher Signature:

**Date:** 25/11/2017

### Primary Supervisor Signature:



**Date:** 17/01/2018

University of Brighton  
Village way  
Falmer Campus  
Brighton  
BN1 9PH

Hello,

My name is Oliver Thurlow. I am a PhD student at the University of Brighton, working with the 4 Cancer Group for an educational based study. I am writing to you to let you know about an opportunity to participate in an interview-based study that is aimed at learning about your experiences of the 4Cancer Group's recreational services that you have participated in.

To give you a brief insight, I am planning to arrange between one to three recorded interviews that will explore your experiences of cancer and the 4 Cancer Group's recreational services. Your involvement in this study is completely your choice as your wellbeing is important to us. If you would like to participate in the interviews, we can organise your inclusion as soon as possible. Firstly, for more information on the study, you are encouraged to read the attached participant information sheet that includes all the relevant information.

If after reading the participant information sheet you believe you would like to participate, your parents or legal guardians should contact the 4 Cancer Group as soon as possible. The 4 Cancer Group will then direct your interest toward myself, the primary researcher. From that point onwards, I will give you more information as to what will happen next. If you do not feel comfortable and confident enough to take part in the study, you do not have to respond to this letter. Your decision not to respond will be respected and will indicate your intention not to participate. You should not feel pressured into participating in this study.

If you would like to know more information about the study, you are free to contact the 4 Cancer Group via email or phone call. The appropriate contact details are enclosed within the participant information sheet.

Yours sincerely,

Oliver Thurlow

## Participation Information Sheet – Young Person (Aged 12-17)

### What is the purpose of this study?

The purpose of the study is to get a better understanding of the experiences of those that have been affected by cancer and recreation by using one-to-one interviews. At present, there is still a lot more to learn about this topic and we would like to understand your thoughts, feelings, opinions.

### Why have I been chosen?

You have been invited to participate in this study as you are a young person who has been affected by cancer. You will have also been involved in one of the 4Cancer Group's respite trips that they offer through one of their services.

**Who, Me?  
Yes, You!**

### What happens if I volunteer to take part in this study?

First, it is up to you to decide if you want to take part. You can have as much time as possible to decide if you would like to participate. You are more than welcome to discuss this with your parents/legal guardians, brothers or sisters, and friends if you are not sure. If you would like to participate, you should tell your parents/legal guardians and they will contact the 4 Cancer Group to let them know you want to take part.

### What will I have to do?

#### First stage:

You will be given a date to come and take part in the interview. On the day of the interview, I will ask you to sign a form that explains that you understand the study, talk to about the interview to make you feel at ease, and then begin the interview. Once this has finished, you will have the opportunity to ask any questions about what will be done with your interview. The interview is likely to last for a maximum of two hours and is designed to make you feel comfortable always.



### **Potential second and third stage:**

If I feel like it would be a good idea to do a second and third interview to gain a better understanding of your experiences, I will ask you and your parents/legal guardians if this is ok to do so. A second or possibly third interview will then be arranged with you and your parents/legal guardians.

### **Will I receive any financial reward for taking part?**

You will have the option to decide whether you would like the interviews to be conducted in your home or elsewhere. If you decide to take the latter of the two options, you are more than welcome to visit the University of Brighton for your interview. If this choice is made, you and the parent who will be travelling with you will be able to claim back travel costs. I will make sure you or your parents/legal guardians receive either a physical or digital version of the travel expenses form.

### **Are there any benefits of taking part?**

There are no direct health benefits for taking part in this study, but this is an opportunity to share your opinion which may offer you a better understanding of your experiences, thoughts, and feelings.

### **Will participation involve any physical discomfort or harm?**

As we are only going to be participating in one, two, or three interviews, it is unlikely that your participation will involve any physical discomfort or harm. On the day of the interview though, the location will be checked to make sure that there are no serious risks to the point whereby you, your parents/legal guardians, and myself feel comfortable and ready to begin the interview.

### **Will participation involve any embarrassment or stressful situations?**

The interview will at times focus on some sensitive experiences, which might make you feel upset. While this cannot always be stopped from happening, you can take a break from the interview at any time if you feel like it is becoming too upsetting for any reason. If you think that the interview is too upsetting after a short break, the interview will be stopped straight away. If this does happen, you will be asked whether you would like your existing interview recording to be deleted or saved. However, the interview has been planned to be an enjoyable experience.

### **What will happen once I have completed all that is asked of me?**

When the interview is finished I will ask you if you want to add anything that you may have forgotten to say during the interview. I will then talk with you about what is going to be done with the interview recording. To give you an idea now, the interview recording will be typed on a computer word-for-word, studied, and then presented within a written essay on the topic of recreational programmes for people who have experienced the condition of cancer. In this essay, your personal information, such as your name, will not be identifiable at any point.

### **How will my taking part in this study be kept private?**

It is very important for you to know that all the things you say are completely private. The conversations that we have during the interview will be stored on a password protected recorder so no-one else can listen to them. We will only use a research number to know who you are and all the personal details that you give us will be kept in safe rooms at the University of Brighton. We may use some of the things you say when we write about the study, but we will take your name and any other information from the documents, so no one will know who was speaking. We will check you are happy for us to use the things you say in this way. If you tell us something that makes us worried about your safety and welfare, we may have to discuss this with or without your permission with somebody else as we need to be sure you are safe. This means, what you say would not be kept between me and you if it is a very serious disclosure.

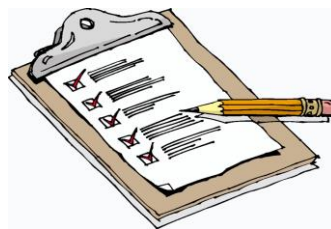


### How will my interview recording be used?

The outcomes of this study will be written up as part of an essay on cancer and recreation. This will involve using some of the things you say from your recorded interviews. Also, I am planning on using the information you provide for the study for presentations and journals for people to read. This will involve using some of the things you said from your recorded interview. Throughout these presentations and journals, you will not be identifiable at any point as we will use a different name or number when we talk or write about your interview.

### Who has made sure that this study is safe?

This study has undergone full clearance and all risks have been assessed and approved by an ethics team at the University of Brighton. Also, the research study has been accepted and approved by the 4Cancer group.



### What if I am unhappy about my participation throughout the study?

You are free to withdraw the interviews you provide at any time without having to give a reason. If you decide that you do not wish to take any further part of the study, then please tell me and your parents/legal guardians. Any personal

information or recordings that you have provided (both paper and electronic) will be safely removed or deleted as soon as possible after you have left the study. Only in situations whereby your interview has already been used and is not identifiable as your information would we be unable to delete or remove your interview information.

Also, if you are unhappy or upset about anything during your participation you are free to make a complaint. If this does happen, you should tell your parents/legal guardians about this and they will contact the right person outside of the research team to talk to. Your parents/legal guardians will be given the contact details of the person to talk to on their participant information sheet.

### What should I do now?

Firstly, I'd like to thank you for reading the participant information sheet. You should take your time to reflect on whether you would like to take part in the study. You are encouraged to talk about this decision with family and friends so that you are fully confident about your decision. If you do decide that you would like to take part, you should tell your parents/legal guardians and they will inform the 4 Cancer Group on your behalf.

### Primary researcher and charity contact details

**Name:** Oliver Thurlow

**Email:** [o.thurlow@4cancer.org](mailto:o.thurlow@4cancer.org)

**Charity Administrative Staff:** Cathy Jenkins ([cjenkins@4cancer.org](mailto:cjenkins@4cancer.org)) or Pippa Ashton ([pashton@4cancer.org](mailto:pashton@4cancer.org))

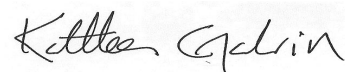
**Charity Operations Manager:** Dave Smith – [Dsmith@4cancer.org](mailto:Dsmith@4cancer.org)

**Tel:** 01635 297222

**Primary Researcher Signature:**

**Date:** 25/11/2017

**Primary Supervisor Signature:**





**Date:** 17/01/2018



## Risk Assessment Form

This risk assessment form ensures that the level of risk has been appropriately assigned, that the associated hazards are acceptable, and that all appropriate control measures have been put in place before, during, and after the methodological procedure to **minimise each specific risk** associated with the procedure. I have also considered 'The Health and Safety Code of Practice – Safe Lone Working Policy (2007)' when designing this specific risk assessment form.

1. Procedure covered	<b>Phenomenological one-to-one interviews</b>
2. Location covered	<b>University of Brighton, Falmer Campus and Participants homes or private offices.</b>
3. Those at risk	<b>Principal researcher and participants.</b>
4. Student Supervisors	<b>Primary: Professor Kathleen Galvin Secondary: Dr. Pirjo Vuoskoski</b>

<b>1-4</b>	<b>Low Risk</b>
<b>5-9</b>	<b>Moderate Risk</b>
<b>10</b>	<b>High Risk</b>

5. Hazards	6. Specific control measures	7. Risk (S x L = RR) S = Severity L = Likelihood RR = Risk Rating
<b>The participants may become rude, impatient, and/or abusive</b>	<b>Explain Hazard:</b> The participants may take offence to some of the questions, possibly resulting in them to become agitated during the research process.  <b>Control measure:</b> They will be reminded that responses will remain between themselves and the principal researcher and have no reason to feel at risk in any way. The interview	<b>1x2 = 2</b>

	will be terminated immediately if this proves unsuccessful.	
<b>The participant may become frustrated at the length of the interview.</b>	<p><b>Explain Hazard:</b> Because the interview is likely to be a time-consuming process, the participant may become frustrated and may not want to carry on with the remainder of the interview.</p> <p><b>Control measure:</b> The participant will be briefed prior to the interview as to the amount of time that might be used to conduct the interview. An option for a break during the interview will also be available.</p>	1x2 = 2
<b>Discussion of sensitive and personal topics.</b>	<p><b>Explain Hazard:</b> A question that will be posed may uncover some upsetting experiences for the participant.</p> <p><b>Control measure:</b> The principal researcher will handle any sensitive situations with caution and care and will also acknowledge any emotions that may cause any sort of psychological distress.</p>	1x2 = 2
<b>The possibility of coercion</b>	<p><b>Explain Hazard:</b> The participants may feel pressured or expected to take part in the study.</p> <p><b>Control measure:</b> It is the participant's choice as to whether they do or do not want to take part in the study. During the consent process, participants will be advised and reminded that they can withdraw from the study at any time prior to data analysis without any reason. It will also be stressed to participants both orally and within the informed consent documents that participation in this study and/or withdrawal will not be detrimental to them and their relationship with the 4 Cancer Group. Also, it is expected that potential participants will not feel coerced into participating because of the strategies that are going to be employed. The 4 Cancer Group will contact potential participants for recruitment if previous beneficiaries have indicated that they would like to be contacted about future charity events or communications.</p>	1x2 = 2
<b>Field Work</b>	<b>Explain Hazard:</b> Interviews will be conducted within a safe and secure environment for both the principal researcher and participant.	1x1 = 1

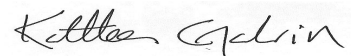
	<p><b>Control measure:</b> Data will only be collected in an environment that is deemed safe and secure. During the recruitment process, for example, the principal researcher will stress that the location of the interview will only be confirmed once the participant feels comfortable and secure.</p>	
<p><b>Anonymity and Confidentiality</b></p>	<p><b>Explain Hazard:</b> The participants involved may worry that their identity and interview data may be revealed to unwanted persons.</p> <p><b>Control measure:</b> Collected research data will conform and comply with legislation regarding the data protection act of 1988. Identifiable information (i.e names, personal information, recordings) will not be published or made available to anybody not involved in the research. Access toward the data will be limited toward the research team only. All research that refers to one's identity will be presented in a coded format, whilst written data will be filed within a secure filing cabinet and electronic data will be saved within a device that will require a secure access code only. The material will be kept safely stored for ten years before it will be destroyed appropriately. However, confidentiality will be broken if a participant reveals something that poses a serious risk or threat to the health, safety, and wellbeing of themselves or others. Please see the flowchart diagram attached for the planned protocol in the event of such an occurrence (Finlay and Evans, 2009).</p>	<p>1x2 = 2</p>
<p><b>Data Handling</b></p>	<p><b>Explain Hazard:</b> Inappropriate handling of the data that will be collected.</p> <p><b>Control measure:</b> The obtained data will be analysed by a qualified and trained team of academics. The data will also be stored away in a safe location that will not be accessible to others outside of the research team.</p>	<p>1x1 = 1</p>
<p><b>Informed Consent</b></p>	<p><b>Explain Hazard:</b> Provision of procedural participant information sheet and informed consent form.</p> <p><b>Control measure:</b> Each participant will be provided with a participant information sheet to decide whether they would or would not like to</p>	<p>1x1 = 1</p>

	<p>take part in the research study. Participants will be informed about the aims, interview method, anticipated benefits, and potential hazards of the research. The participants are entitled to as much time as they need to consider whether they would like to participate and there will be an opportunity for participants to raise any issues or concerns regarding the study. Subsequently, the potential participants will have a sufficient timeframe to decide if they do or do not want to participate in the study. If they do, they can complete all the relevant and necessary forms to comply with the study's procedures.</p>	
<p><b>Travel Procedure</b></p>	<p><b>Explain Hazard:</b> The principal researcher may have potential travel issues getting to an arranged location.</p> <p><b>Control measure:</b> The principal researcher will drive with due care and attention when travelling to the location of the interview.</p>	<p>1x2 = 2</p>

**Principal Researcher Signature:**

**Date:** 25/11/2017

**Primary Supervisor Signature:**

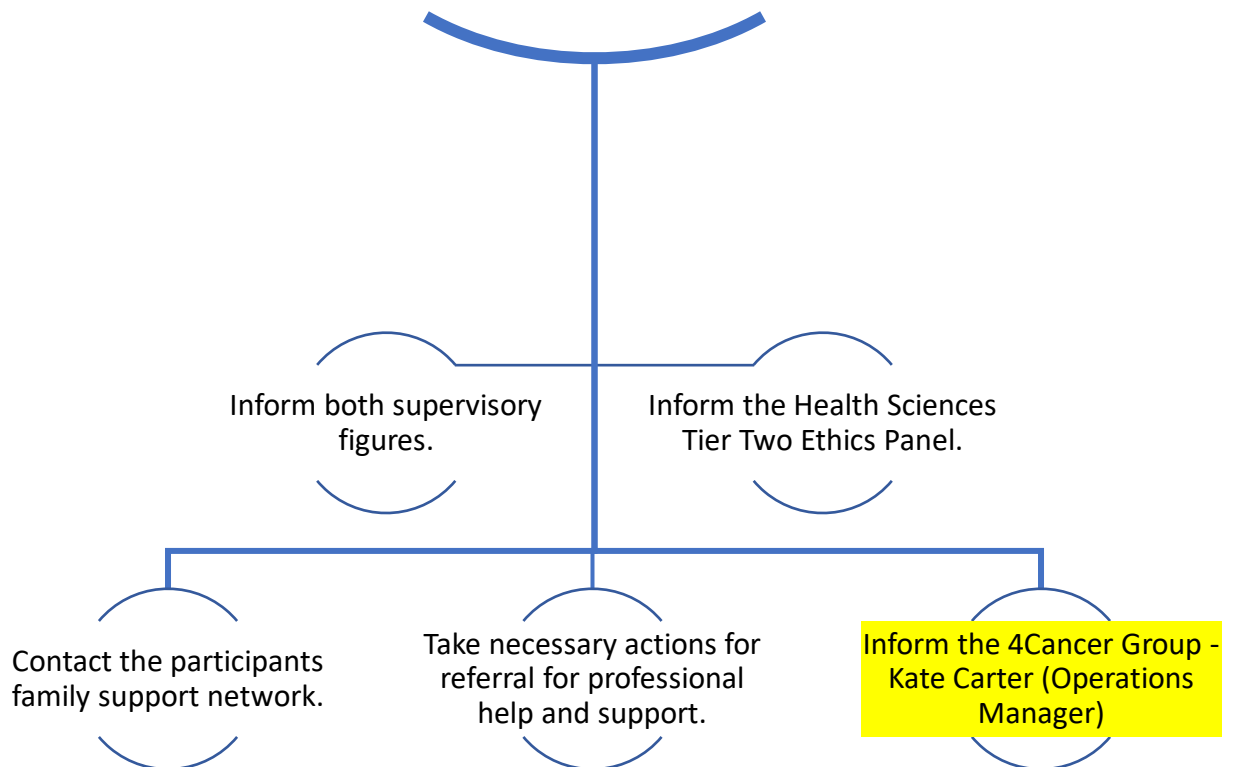


**Date:** 17/01/2018

## Flowchart Diagram

### Crisis Management and Safeguarding Participant Distress and Protection from Harm During an Interview

Participant disclosure that poses a threat to their or others welfare (i.e thoughts of self-harm or intentions to harm others) - Termination of interview if considered too serious. If terminated, offer personal support to participant through talking about their problems. Necessary actions will then be taken with or without consent if the disclosure poses a very serious risk to themselves or others. Please see below.



# University of Brighton - Qualified First Aiders

## Name and Details

### **Paul Vallis – Restaurant Supervisor**

University of Brighton

Falmer Campus

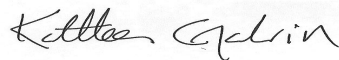
Westlain House

Westlain Restaurant

### **Principal Researcher Signature:**

**Date:** 25/11/2017

### **Primary Supervisor Signature:**



**Date:** 17/01/2018



## **Appendix B – Participant one to twelve – psychological descriptions**

### **Psychological Description – Participant Number One**

Participant number one (P1) experienced changes to herself and in her life when she discussed how she was judged and bullied by other people her age for having cancer. A consequence of such experiences caused P1 to feel physically and mentally exhausted all of the time, as well as the struggle to make new friends when she changed schools. However, P1 identified that the recreational sailing programmes were a way of finding security in her sense of reality as she could express herself. This manifested in a way whereby she was not being judged by others, could have fun with her family and other people, and could participate in a new exercise that is easier for her to manage. P1 stated that she enjoyed being able to participate in the programme's as she is often too tired to do normal exercises that normal people do.

P1 says that she felt involved in the programme as everybody had to work together, such as when they were expected to join in with the technical manoeuvres of tacking and raising the sails, as opposed to being sat down for the entirety of the day. P1 states that it was also an opportunity for her to test her balance due to the variety of weather conditions she has sailed in. P1's sense of being involved in the programme was facilitated by the friendly sailing instructors, made her feel welcome, and generally helped her gain a better understanding of recreational sailing. This sense of security was also shared in the presence of her family. P1 stated that if her family were not there to support her, she would feel less confident, and shy in that she wouldn't want to talk to people she wouldn't take part in the programme.

This sense of personal engagement was extended to those who also attended the programme. P1 states that the other people who attended were all like her in that they've all had cancer and been in similar situations to her. P1 is aware that she has made friends and trusted these people insofar that they can talk about their lives (i.e. school and college), but not to the point where they keep in touch. P1 says that these are normal conversations with normal people, emphasising the point that there is no awkward silences and no judgement. P1 states that this positive experience caused her to feel calm and happy.

## **Psychological Description – Participant Number Two**

Participant number two (P2) reflected upon a sense of change in herself and her life when she attended her cancer support group. P2 states that a cancer specialist attended the group and presented numerous graphs and figures about her particular endocrine cancer. P2 says that the life expectancy rates had a span of five years before simply dropping off, which caused P2 to feel deflated as she didn't want to just drop off the graph. P2 states that the thought of dropping off the graph concentrated her mind as she didn't know whether it could be weeks or months for her to live. P2 states that she and her husband subsequently make a policy of doing something every weekend to feel inspired to leave her comfort zone.

P2 says that the recreational programmes offered by the 4 Cancer Group were a part of the policy because it would help her leave her comfort zone and make her say yes to new opportunities. P2 described the recreational sailing programme as more than she expected it to be, as both she and her husband felt uplifted and boosted by the end of the day. P2 says that she observed her husband gazing off into the distance as they sailed throughout the day. P2 states that she did not expect to be as physically involved in the sailing as she was. P2 states that the instructors, who lived locally and had a lot of local knowledge, invested a lot of confidence in the participants to operate the vessel, which she thought she would've needed weeks of training to do so. P2 says that she feels inspired to do this again if the opportunity was presented.

P2 states that there was an easy and natural interaction between those who attended the recreational sailing programme, comparing it with her other cancer support group that she regularly attends. Though it was just one day, P2 states that with the help of the instructors, those who attended managed to share some of their story about their experiences. For example, P2 states that a mother and her young daughter opened up about their struggles with cancer. P2 is, however, aware that the whole day is not focussed on talking about cancer, but it is an opportunity to be bold and talk about sensitive things. P2 stated that she is now passionate and bolder than ever before, citing her experiences of writing magazine articles and speaking at public lectures about her life. P2 states that the sailing programme was an

opportunity to not care about the small things anymore as everyone was together, joining in, having fun, and laughing.

### **Psychological Description – Participant Number Three**

P3 was aware that she understood the changes in her life and herself to be associated with the challenges of receiving a cancer diagnosis and the subsequent medical treatment. P3 states that she didn't know what was going on and she didn't understand everything, citing her family and friends being there to support her through this time. As well, P3 started to do her research on her illness when she was over the initial feeling of being unwell. P3 says that despite being around nice and funny medical professionals, the atmosphere would change when she would have an injection, describing how the feelings of being in pain remind her of the hard times. P3 states that the recreational sailing programme was an opportunity to help her get back to a sense of normality, subsequently making her feel good because it was outside the atmosphere of the hospital.

Stating how it was her first time on a boat with her family, P3 elaborated on how the programme helped her feel free as the views of nature were beautiful and the entire experience was much more natural than being in a hospital bed, describing an example of the wind rushing through her hair. P3 reflected on how she now looks at the pictures that she had taken on the day with her mum and sister, explaining that she now uses them to decorate her house. P3 recognises that she felt comfortable as she got to know the other participants who were on the programme. P3 states that it was fun as they got to know each other, with P3 stating that her mother primarily talked about their cultural and ethnic backgrounds.

P3 states that her initial expectations about the sailing programme were based on watching the crew perform all the manoeuvres. However, P3 described it as exciting for her and her family to be involved, explaining that the instructors taught her a lot and made her feel safe. P3 states that she was learning how to control the boat, identifying the easy and challenging parts of the manoeuvres that she had to engage with while sailing the vessel. While P3 said the programme's meaning was about being with family, P3 explained that the physical nature of the sailing helped align with her post-treatment guidelines of getting back to normal life, whereby she could participate in activities to increase her energy levels.

## **Psychological Description – Participant Number Four**

Participant number four (P4) acknowledges that there was a change in himself and his life due to the many side-effects of undetected cancer, such as extreme headaches and sickness, that would leave him screaming in pain. P4 recognised his subsequent diagnosis of a brain tumour caused him to react in a way that he knew he had to fight and survive. P4 describes this process as something that flipped his world upside down in two ways. Firstly, P4 that realising he was close to death had a negative effect on his routine, before, secondly, understanding the positive implications. P4 reflected upon how the experience was helpful for him to develop an open and confident mindset. P4 is aware that his mindset chooses who he will be, reflecting on how he since applied to be head boy at his school and achieved better grades when he considers how shy he used to be before his diagnosis.

Despite not knowing anybody other than his friend on the recreational sailing programme, P4 saw it as an opportunity as he could learn life skills, make friends, and learn the principles of sea sailing. This was reinforced by P4's belief that the programme would help him release and express everything he has been through. P4 acknowledged that the environment enabled him to see a new side to him that he hasn't seen before, such as cooking for the entire crew with his friend. P4 states that the instructors were kind and helpful in that they encouraged him to be involved through step-by-step guidance. This included how to do the figure-eight knot, tacking through the sea, raising the sails, and operating the helm of the boat. P4 recognises that he expressed himself in a manner that involved being the motivator of the team, which resulted in the team working well together as they were always in sync with their specific jobs.

P4 recognised that as the group progressed into the programme, they began to have a good time together, which involved having a laugh as a group. P4 reflected on how well he got to know these people in short amount time, explaining how he opened up and made friends with them. P4 is aware that he also tried to listen politely and respectfully to the people who opened up about their cancer experience. P4 states that he, too, told the group about what he had been through. P4 expressed that the group were shocked to learn about the size of his tumour. P4 stated that

since the programme, he has arranged to meet with the group, saying that they share in something very powerful, like a family with a strong bond.

### **Psychological Description – Participant Number Five**

Participant number five (P5) is aware that her mind demands a lot of time from her as she has lived with anxiety before and after her diagnosis of cancer. P5 states that her world is tightly controlled to the point whereby she doesn't do much or drive very far. As an example, P5 says that she would spend hours thinking about how vast the sea and sky is, causing her to have panic attacks. P5 says the thought of going on water, which is out of her control, was a massive anxiety. However, P5 stated that a change in herself and her life was established when she began to acknowledge her mortality. P5 described this as a way of having her eyes open and seeing things differently, which is what happened when she had cancer. While P5 did not go sailing during the previous year, P5 is aware that cancer has now changed her perspective in that she wants to take on new challenges, which is how she felt in her twenties before the fear and anxiety came along. P5 accepted that the sailing caused her to panic but she also accepts these opportunities to help her stop being scared of things and to, in turn, harness her energy and positivity. P5 states that the atmosphere and environment were nice because nothing was expected of her, in that she only had to be herself as opposed to when she is back in society, where, she feels, she is expected to be productive and achieve materialistic things.

P5 says that the outdoor and physical environment of the sailing programme provides a useful opportunity, in that it is comparable to a fun social event. P5 states the opposite of this could be like an AA support group which can result in negative interactions. P5 reflected upon how the recreational sailing programme allows her to grow and stretch beyond her original capabilities, describing how she was sat in the corner of the boat experiencing a sense of silence and pure calm. This sense of experience is also attributed to the wider group P5 sailed with, whereby they could be together as a team to help each other. P5 recognises that the interactions and diversity amongst the group are important for finding security in the experience. P5 elaborated by saying that being around those living with and beyond cancer is important as it helps expand the identity of the group, as opposed to the defining characteristics that people see on TV adverts. P5 states that the instructors were an

important part of the group and the entire experience. P5 says that the instructors not only helped her sail without making her feel stupid or inadequate but were very much amongst the group. P5 says that one of the men opened up about his wife's experience with breast cancer, confirming that this interaction was about being in collaboration rather than simply sailing together.

### **Psychological Description – Participant Number Six**

Participant number six (P6) described herself as being stuck in a rut, explaining that most of the time she goes to the park by herself. P6 also identified that she does not go to many places or do very much other than her work routine of driving to and from work. P6 is aware that the recreational programme posed a challenge to this routine, but it was an opportunity to challenge her comfort zone as it's something she has never done before. P6 described the day as being very well organised but she was aware that she was scared to sail the boat. P6 explains that she had only just finished treatment and was subsequently worried about the physical nature of the sailing. P6 describes how she was worried about positioning her legs and making a fool out of herself, but she managed to stand up and do it eventually, stating that she felt different by the end of the sailing. While cancer is what brought them together as a group, P6 acknowledges the group is more than that and it isn't always a deeply layered experience. P6 recognises that she may have asked someone what stage they are at in their treatment, but it moves on from this to understand the person as the person while they participate in the activities of the event. P6 states that she would go sailing again as she's glad she put her name down.

### **Psychological Description – Participant Number Seven**

Participant number seven (P7) expressed that she has come to understand a sense of herself and her life through two separate experiences of cancer. P7 states that she kept working during her first diagnosis of cancer to keep herself sane, emphasising how a cancer support group gave her strength at the time because the women who attended were many years into the post-treatment phase. P7 states that her second diagnosis of cancer brought about a change in her attitude, describing how she works differently as a consequence. P7 states that she now pushes herself to do things that are out of her comfort zone, such as the recreational

programme, which is something she has never done before. P7 recognises that her attitude has also changed in that her second diagnosis opened her eyes, describing how her sense of normality has now changed. P7 states that some people, other than family and close friends, think her cancer experience is over but P7 states that it'll never be over.

P7 states that coming to these types of groups is an opportunity to see people getting on with normal life despite never getting over it. P7 recognises that this type of group environment can help her through peer support, yet she recognises that she doesn't need to talk about it most of the time. P7 does, however, realise that others may need to talk about it to feel safe, whereby they will tell her everything. P7 states that the strength of such a group is based on this balance. P7 states that the two sailing instructors were very kind and encouraging in that they looked after her and never once made her feel stupid or inadequate throughout the programme. While the weather and the appropriate sailing attire made it hard to move freely around the boat, P7 states that they were able to pull the ropes and do some tacking before coming in to avoid a storm, recalling comical moments that occurred while they were doing their respective jobs on-board. In this respect, P7 recognised that she didn't have to look too deeply at the experience as they could chat, giggle, and enjoy it together. P7 states that she is aware that the deeper things are going on around them without having to clarify them too explicitly, highlighting the point that the sailing program made her feel like life is comfortable, which she described as lovely and a nice feeling.

### **Psychological Description – Participant Number Eight**

Participant number eight (P8) is aware that she did not know anybody who had been through cancer. P8 did not understand, therefore, what lay ahead of her when she was diagnosed with breast cancer. P8 is aware that not much impinged on her insular life as she had lived with depression prior to her cancer diagnosis, explaining that she doesn't show joy and a love of life. P8 states that the opportunity to be a part of the recreational sailing programme was a chance to do something that was out of her comfort zone, describing these new opportunities as eye-openers as it is a situation that she cannot fully control. P8 states that she faced her fear and did it, citing how she didn't realise how much she enjoyed the programme until her daughter pointed out her smile on one of the pictures that were taken on the day.

P8 states that it's nice for someone to acknowledge this due to her depression and how cancer suddenly became her defining characteristic, stating that there is more to her than that. P8 states that breaching out of her comfort zone allows her to see herself and others differently, describing her sailing programme as a huge achievement. P8 is aware that she does question coming to these type of events as she is ten years on from her diagnosis and treatment. While P8 states that it can suddenly bring up everything that she has left behind, she recognises the importance of showing people what it looks like after the chemotherapy suite, which, she describes, as uninspiring as it does not show other sides of the story. P8 states that the recreational sailing programme and the nice manner of the instructors was a huge morale boost as P8 doesn't participate in exercise or do anything physical on a day-to-day basis other than her work routine. However, whilst sailing was a challenge in that it was unfamiliar, P8 states that it's hard to find the same moments in her everyday life because her work is very demanding. P8 says she would attend the programme again as she didn't have to prove her level of productivity and was not constantly called upon because everyone was taking turns, explaining that she has to be 130% productive when she is working.

### **Psychological Description – Participant Number Nine**

Participant number nine (P9) stated that she noticed changes and symptoms in herself that were associated with breast cancer. P9 remembered that an oncologist confirmed the diagnosis after an emergency mammogram and biopsy, explaining that the news was hugely shocking and devastating, with P9 describing how her whole world turned upside down. P9 stated that although she had heard terrible stories of chemotherapy due to working at a hospice, she did not know what lay ahead of her. P9 recognised that she began to reflect on the situation by asking herself a thousand questions about the future, work, money, and her children. P9 acknowledges that this was worsened by extended periods of treatment, which resulted in having a mastectomy, and discussions of having a will in place with an oncologist. P9 reflected upon how this caused her to worry and having sleepless nights, emphasising how she had to have difficult conversations with close friends about the guardianship of her daughters if she were to die, explaining that they were conversations she didn't ever want to have to contemplate.



Yet, P9 stated that the recreational sailing programme she attended was simple in that it helped remove her from a state of being stressed and worried, with P9 describing the program as therapeutic as any other formal event she attended in the past. P9 also says that the program was a change of scenery as hospital appointments usually dominate her calendar. For example, P9 acknowledged that it would be nice for her and her youngest daughter because the event was held on Mother's Day, which meant they could do something completely different together. Understanding that she didn't worry about a thing on the day of the programme, P9 said that she met two other ladies with whom she shared personal conversations about body image, relationships, and other scary topics. P9 also stated that she and the two ladies talked about things that they cannot say to other people, labelling this as black humour as it relates to questions they receive from people that drives them mad.

P9 is aware that she and her daughter, who is slightly autistic, were fully involved in the sailing of the boat, describing how the instructors helped her daughter to steer the vessel. Discussing how her daughter still talks about it, P9 says that she was happy that the instructors showed that level of confidence in her daughter, reflecting on how the instructors were good with children who are quiet and reticent. P9 acknowledges that though events like the recreational sailing programme help her remould herself from her previous sense of life, she is aware that cancer has changed her forever. P9 explained how she is going to be taking medication for the next ten years for treatment-related side-effects that are similar to osteoporosis. P9 recognises that family and friends try to be supportive, but they do not know how much cancer controls her, stating that there is a fear that never goes away.

### **Psychological Description – Participant Number Ten**

Participant number ten's (P10) life and sense of self changed due to two diagnoses of cancer. P10 described this as a nightmare, whereby he is in a dream-like state as he is aware that there is no cure for his cancer. Although his family are still hoping for a good outcome, P10 stated that he's got no control over the situation. P10 acknowledged that he tries to balance the positives with the negatives, but he cannot avoid the dark thoughts of what is going on. P10 stated that he cries and sobs until he can start to live with it again, which is where he waits until the next

round of thoughts begins. P10 described these moments as natural occurrences that he cannot fight, explaining that he doesn't want to feel sorry for himself, but he has to be respectful to what is going on in his mind. While P10 stated that did not respond to counselling, as he has his way of dealing with his situation, such as connecting with old work colleagues, P10 is aware that he chose to attend to recreational sailing programme for two reasons. P10 stated that he chose to be a part of the programme as it gives him a way of having some degree of control of his life in that it allows him to make targets for himself. P10 also reflected upon the fact that sailing takes his mind off of cancer because it is something he enjoys, emphasising the point that he has always been physically active through his work and personal life. P10 recognised that he gets an immediate benefit from being active to the point where he can feel the endorphins giving him a tremendous feeling.

P10 reflected upon how the sailing was hands-on, describing how he was winching and helming the vessel under the guidance of the skipper throughout the day. P10 stated that although he didn't want to talk about his condition too much as he was there to lose in himself in the sailing programme with his son, P10 was aware that he was trying to read the signals and be careful about what he and the other participants talked about. For example, P10 stated that he spent some of his time talking to a woman in her thirties about how cancer had left him with vision in one eye, ongoing cancer in his liver, and how he didn't know what his next steps would be in the process. P10 states that the recreational sailing programme has no sense of pressure as one can be fully involved in the sailing manoeuvres as possible or one can sit back, talk, and relax, explaining that this encapsulated his experience.

### **Psychological Description – Participant Number Eleven**

Participant number eleven (P11) understood changes in himself and his life were related to the diagnosis of Hodgkin's Lymphoma, which occurred two weeks after he married his wife. P11 described this process as a shock and expressed that everything in his life was destroyed by that moment. P11 states that this manifested in a way where he couldn't eat or sleep properly as he was always thinking about what was going on and what type of future lies ahead of him. As opposed to talking to his wife, who was under a lot of pressure, P11 explained that he kept a journal

from 2017 to 2019 to try and make peace with cancer and deal with his emotions by processing the little details. The chapters within the journal, P11 stated, were split into two. This involved P11 writing a philosophical introduction that captured his current dilemma before moving onto a humoristic part that focussed on the good days and the bad days, such as when he had a severe sense of depression. P11 explained that this subsequently gave him perspective, helping him to not care about the superficial things anymore. P11 identified the recreational sailing programme as an opportunity to break up the time that he spends battling his thoughts, describing the process as unnecessary suffering that can be made a lot worse in his head. In this respect, P11 stated that the program helped him as he didn't think about any of the real difficulties that he was at that time facing.

The programme was described by P11 as refreshing, peaceful, and without mental effort, with P11 understanding that he is normally chasing away negative thoughts about his current health. P11's reasoning for attending the program was also extended to include being immersed amongst British people to practice his English language skills, as P11 is a legal immigrant from Europe. P11 is aware that it surprised himself on the day of the programme because he didn't realise he had the physical strength, describing how his mind had not adjusted to his energy levels. Though he felt tender afterwards, P11 states that he was pulling on ropes for much of the day and was eager to learn every manoeuvre. P11 stated that it was essential for him to work with his hands as most people are very digital these days, describing this as a good feeling. P11 stated that despite being reluctant to talk about this experience during treatment, he found that he spoke with a young boy on the day of the programme, explaining that this was the first time he had properly spoken about it. P11 described this communication as good because the young boy had been through the same process as him, resulting in P11 acknowledging that it is easier to talk about it now.

### **Psychological Description – Participant Number Twelve**

Participant number twelve (P12) is aware that his life and sense of self had changed due to physical and psychological issues that made him go for an appointment with his doctor. P12 states that he was diagnosed with bladder cancer after a long time of waiting, understanding that he had taken the diagnosis in his stride and did not fully absorb it at first. P12 was aware that he had the energy for it due to his busy

work schedule and described the process as an amazing, yet tough, thing to take on-board as he didn't know what to expect or whether he was going to live. P12 recognises that it was during the process of his treatment when he began to notice a transition in his mindset, describing how he was balancing being on auto-pilot and losing his mind while waiting to know if the initial treatment had been successful. P12 stated that he was struggling emotionally and had to be prescribed anti-depressants to help him function as he was aware that he could lose everything. P12 understands that both the recreational sailing and skiing programme's he attended resonated with him as he had been through an awful lot with cancer. P12 states that it is nice to have a sense of support and recognition from a charity which helps reduce the time spent thinking about his fears, describing them as dark places.

### **1<sup>st</sup> Programme – Recreational Skiing Programme**

P12 stated that this programme was the one that hit home for him, describing it as an opportunity for him to escape the doom and gloom of the past few years by having a bit of "me time". P12 is aware that this was enhanced through being physically involved in an activity with someone (professional skier) that he has looked up to since he was young, understanding that there was no negative in any situation. P12 stated that while he understands that he was the only one out of nine who had experienced cancer, he tried creating awareness of his situation all the while being aware that some may feel comfortable or uncomfortable in those situations.

### **2<sup>nd</sup> Programme – Recreational Sailing Programme**

P12 stated that the recreational sailing programme was not something that he naturally gravitated towards, but he understood it to be an occasion to be with his family in a different environment for the day. P12 stated he found this to be an experience whereby he could sit back and relax, watching the world go by. P12 is aware that he consciously decided not to share anything about his experience of cancer as he didn't want to share any of those moments of hardship with anybody. P12 described this as an opportunity to put all of it behind oneself.

P12 is aware that now he is three years post-diagnosis his sense of support, which he describes as scaffolding, is starting to fade away. Though P12 acknowledges that this is a natural process, P12 states that his fear of cancer recurring makes him

feel vulnerable and insecure, leaving him feeling like he wants to reach out to someone despite knowing that he will continue to have regular check-ups. For example, P12 states how using the toilet has become a concern for him as he finds himself checking for blood in his urine.

## Appendix C – Participant examples of descriptive phenomenological analysis

### Participant Number Nine: Step Three – Transformation of a participant’s natural attitude expressions into phenomenologically sensitive expressions.

Original description of the lifeworldly expression	Third-person description of lifeworldly expression.	Psychological sense of the expression	Transformation of the expression.
<b>P9: Ok, so... in June 2017, I noticed some changes in how I felt physically and I went to go see my GP to get it investigated but I already had some degree of knowledge that some of these changes were associated with breast cancer</b>	P9 states ok, so... in June 2017, she noticed some changes in how she felt physically and she went to go see my GP to get it investigated but she already had some degree of knowledge that some of these changes were associated with breast cancer	With reference to her experience of being diagnosed with cancer, P9 recognises that she noticed changes in how she felt in June 2017. P9 states that she already had some degree of knowledge that the changes were associated with breast cancer while going to get it investigated by the GP.	P9 is aware that her experience of being diagnosed with cancer was realised after she noticed changes in how she felt in June 2017. P9 states that she already had some knowledge that the changes were associated with breast cancer while going to get it investigated by the GP.
<b>P9: I saw a doctor and was referred under the two-week rule to Frimley Park Hospital. That was on a Thursday and by Monday I was having an emergency mammogram and, erm, a biopsy</b>	P9 states that she saw a doctor and was referred under the two-week rule to Frimley Park Hospital. P9 says that was on a Thursday and by Monday she was having an emergency mammogram and, erm, a biopsy.	P9 is aware that she was referred by a doctor under the two-week rule to a hospital on a Thursday. P9 says that the following Monday she was having an emergency mammogram and biopsy.	P9 is aware that she was referred by a doctor under the two-week rule to a hospital on a Thursday and by Monday P9 had an emergency mammogram and biopsy.
<b>P9: I was told, the exact words, “this might be something sinister”. Those words then played on my head for the next week and a bit whilst I was waiting for the biopsy results to come back</b>	P9 states she was told, the exact words, “this might be something sinister”. P9 says those words then played on my head for the next week and a bit whilst she was waiting for	P9 was told that “it might be something sinister”, saying that those words played on her mind while she waited for the biopsy results to come back.	P9 is aware that “it might be something sinister” played on her mind while she waited for the biopsy results to come back.

	the biopsy results to come back		
<b>P9: Erm, at that point, I was and am a single mum. I've been a single mum for my children since they were small. At that point, I had two teenagers of 14 and 16. The eldest was going through exams at that time, so I was trying to, sort of, not let on to them that anything was going on until I knew for sure</b>	P9 states that at that point, she was and is a single mum. P9 says she has been a single mum for her children since they were small. P9 says at that point (the diagnosis), she had two teenagers of 14 and 16. P9 says the eldest was going through exams at that time, so she was trying to, sort of, not let on to them that anything was going on until she knew for sure	P9 states she is and has been a single mum for her children since they were small. During the diagnosis, her children were both 14 and 16, with P9 saying that she was trying to not let them onto to anything as one of them was going through exams.	P9 states she is and has been a single mum for her children since they were small. During the diagnosis, her children were both 14 and 16, with P9 saying that she was trying to not let them onto to anything as one of them was going through exams.
<b>P9: I then had an appointment with an oncologist to discuss the results. They confirmed that I had quite an aggressive and invasive lobular carcinoma of my left breast...</b>	P9 states that she then had an appointment with an oncologist to discuss the results. P9 says that they confirmed that she had quite an aggressive and invasive lobular carcinoma of her left breast...	P9 recognises that an oncologist confirmed that she had an aggressive invasive lobular carcinoma of her left breast.	P9 says that an oncologist confirmed that she had an aggressive invasive lobular carcinoma of her left breast.
<b>P9: I had a feeling the news was coming but, erm, it was delivered by an oncologist in quite a matter of fact way.</b>	P9 states that she had a feeling the news was coming but, erm, it was delivered by an oncologist in quite a matter of fact way.	Although she had a feeling it was coming, P9 says that it was delivered by the oncologist in a matter of fact way.	Although she had a feeling it was coming, P9 says that it was delivered by the oncologist in a matter of fact way.
<b>P9: Luckily, I saw a breast cancer specialist nurse straight after, who was lovely. So, although I had feared the worst and thought I was prepared for it, having those words said to me was hugely shocking and devastating... my</b>	P9 says luckily, she saw a breast cancer specialist nurse straight after, who was lovely. P9 states so, although she had feared the worst and thought she was prepared for it, having those words said to her (by the oncologist) was hugely shocking and devastating... her	P9 recognises that although she saw a lovely cancer specialist nurse afterwards and that she was prepared for it, those words by the oncologist were hugely shocking and devastating, saying that her whole world rocked underneath her.	Although she saw a lovely cancer specialist nurse afterwards and that she was prepared for it, P9 says those words by the oncologist were hugely shocking and devastating, saying that her whole world rocked underneath her.

<b>whole world rocked underneath me.</b>	whole world rocked underneath me.		
<b>P9: Erm, I've always been quite a strong independent person, bringing up my girls by myself. My youngest doesn't see her father, so she has only got me. I've also got an elderly mother who I look after... no brothers or sisters, so I've always been quite healthy up until then</b>	P9 says she's always been quite a strong independent person, bringing up my girls by herself. P9 states that her youngest (daughter) doesn't see her father, so she has only got her. P9 says she's also got an elderly mother who she looks after... no brothers or sisters, so she's always been quite healthy up until then.	Up until her diagnosis, P9 says she has always been a healthy and independent person, bringing up her girls and looking after her elderly mother by herself.	Up until her diagnosis, P9 says she has always been a healthy and independent person, bringing up her girls and looking after her elderly mother by herself.
<b>P9: Quite a strong person and I've always worked</b>	P9 states that she is quite a strong person and she's always worked	P9 states that she is quite a strong person and she's always worked	P9 is aware that she is a strong person and she has always worked.
<b>P9: And suddenly, it was like, oh right... (laughs)... I've got to look after myself here but what is ahead? What about my children? What about my mother? What about my job? How am I going to pay the bills? Clearly, a thousand questions went through my head</b>	P9 states and suddenly, it was like, oh right... (laughs)... she's got to look after herself here but what is ahead? What about her children? What about her mother? What about her job? How is she going to pay the bills? P9 states clearly, a thousand questions went through her head	P9 is aware that she had to look after herself but she was asking herself a thousand questions, such as what is ahead? What about her children? What about her mother? What about her job? How is she going to pay the bills?	P9 states that she had to look after herself but she was asking herself a thousand questions, such as what is ahead? What about her children? What about her mother? What about her job? How is she going to pay the bills?
<b>P9: literally my whole world turned upside down</b>	P9 states that literally her whole world turned upside down	P9 recognises that her whole world turned upside down.	P9 recognises that her whole world turned upside down.
<b>R: Of course, ok... so that was the initial reaction. What happened during the phases of treatment? P9: So, initially, I had a lumpectomy and I thought I would get away with that... but it turned out that the cancer had spread to</b>	P9 states so, initially, she had a lumpectomy and she thought she would get away with that... but it turned out that the cancer had spread to her lymph nodes and was quite a big tumour.	P9 states that she initially had a lumpectomy, but she is aware that the cancer had spread to her lymph nodes and was quite a big tumour.	P9 states that she initially had a lumpectomy, but she is aware that the cancer had spread to her lymph nodes and was quite a big tumour.



<p>my lymph nodes and was quite a big tumour</p>			
<p><b>P9: I then had to have a mastectomy, followed by chemotherapy and radiotherapy - was a thing that scared me... it really, really scared me. Erm, I didn't know how ill I would get</b></p>	<p>P9 states that she then had to have a mastectomy, followed by chemotherapy and radiotherapy - was a thing that scared her... it really, really scared me. P9 says erm, she didn't know how ill she would get</p>	<p>P9 recognises that she had to have a mastectomy, followed by chemotherapy and radiotherapy, saying that's what scared her as she didn't know how ill she would get.</p>	<p>P9 states that she had a mastectomy, followed by chemotherapy and radiotherapy, saying that's what scared her as she didn't know how ill she would get.</p>
<p><b>P9: I was worried about my health insurance because I didn't have any. I was worried about my mortgage insurance because I had a big mortgage to pay... Noise disruption... yeah, it was... I just didn't know what was ahead.</b></p>	<p>P9 says she was worried about her health insurance because she didn't have any. P9 says she was worried about her mortgage insurance because she had a big mortgage to pay... Noise disruption... yeah, it was... she just didn't know what was ahead.</p>	<p>Saying she didn't know what was ahead, P9 says she was worried because she didn't have health insurance and because she had a big mortgage to pay.</p>	<p>Saying she didn't know what was ahead, P9 says she was worried because she didn't have health insurance and because she had a big mortgage to pay.</p>
<p><b>P9: I had heard terrible stories about chemotherapy. Luckily and unluckily, whichever way you see it, I work for a hospice with nurses and they are incredibly caring, but at the same time, I also have a where I see people in the inpatient unit who are in their final days because of cancer. You know, ladies who are a similar age to me.</b></p>	<p>P9 says she had heard terrible stories about chemotherapy. P9 states that luckily and unluckily, whichever way you see it, she works for a hospice with nurses and they are incredibly caring, but at the same time, she also have a where she see's people in the inpatient unit who are in their final days because of cancer. You know, ladies who are a similar age to herself.</p>	<p>P9 recognises that she had heard terrible stories about chemotherapy. P9 says she is both lucky and unlucky as she works for a hospice whereby the nurses are incredibly caring but she sees ladies who are a similar age to herself in their final days because of cancer.</p>	<p>P9 recognises that she had heard terrible stories about chemotherapy. P9 says she is both lucky and unlucky as she works for a hospice whereby the nurses are incredibly caring but she sees ladies who are a similar age to herself in their final days because of cancer.</p>
<p><b>P9: So, although people were saying "this is treatable", I also knew that it</b></p>	<p>P9 states so, although people were saying "this is treatable", she also knew that it</p>	<p>P9 states that she was aware that the cancer was both treatable and sometimes unsuccessful.</p>	<p>P9 states that she was aware that the cancer was both treatable and sometimes unsuccessful.</p>

wasn't always successful	wasn't always successful		
<b>P9: So, yes, I was very scared... apprehensive about the treatment and how or if I was going to be able to work to bring in money. Yeah, I was terrified about a lot of things...</b>	P9 states so, yes, she was very scared... apprehensive about the treatment and how or if she was going to be able to work to bring in money. P9 says yeah, she was terrified about a lot of things...	P9 says she was scared, apprehensive and terrified about lots of things, including the treatment, work and money.	P9 says she was scared, apprehensive and terrified about lots of things, including the treatment, work and money.
<b>R: Yeah... I can appreciate those points you have made. What did you find was the best way to cope with this period of your life?</b> <b>P9: Erm, well, I don't have a partner, but I do have some very, very close friends. The sort of friends you could ring up in the middle of the night if you needed to. They are very good friends. There is three of them that have been my rock... really, my rock</b>	P9 states erm, well, she doesn't have a partner, but she does have some very, very close friends. The sort of friends you could ring up in the middle of the night if you needed to. P9 says they are very good friends. There is three of them that have been her rock... really, my rock	P9 is aware that she doesn't have a partner but she has very close friends, describing them as her rock. P9 says they are friends she could ring up in the middle of the night if she needed them.	P9 is aware that she doesn't have a partner but she has very close friends, describing them as her rock. P9 says they are friends she can ring up in the middle of the night.
<b>I would not have gotten through it without them. They, you know, bought shopping for me, they have come and cheered me up. When I started to lose my hair and didn't want to go out, they always were always boosting me up and getting me through it.</b>	P9 states she would not have gotten through it without them. P9 says they, you know, bought shopping for her, they have come and cheered her up. P9 says when she started to lose her hair and didn't want to go out, they always were always boosting her up and getting her through it.	P9 is aware that her friends cheered her up, saying she would not have gotten through it without them. P9 says they bought shopping for her and boosted her up when she lost her hair.	P9 is aware that her friends cheered her up, saying she would not have gotten through it without them. P9 says they bought shopping for her and boosted her up when she lost her hair.
<b>P9: So, yeah, my friends got me through it</b>	P9 states so, yeah, her friends got her through it (the treatment)	P9 recognises that her friends got her through the treatment	P9 recognises that her friends got her through the treatment

<p><b>P9: My colleagues at work. As I say, I work in a very caring environment with nurses in a hospice. It was quite hard at times though because you want to focus on your job and not have people keep coming up to you and asking how you are... it was a bit of a mixture at work</b></p>	<p>P9 states that her colleagues at work. P9 says she works in a very caring environment with nurses in a hospice. P9 says it was quite hard at times though because she wants to focus on her job and not have people keep coming up to her and asking how she was... it was a bit of a mixture at work</p>	<p>Although she acknowledges that she works in a caring environment, P9 describes work as being a bit of mixture, saying it was hard as she didn't want people asking how she was.</p>	<p>Although P9 acknowledges that she works in a caring environment, P9 describes work as being a bit of mixture, saying it was hard as she didn't want people asking how she was.</p>
<p><b>R: So there was a lot of social support? P9: Yes, absolutely</b></p>	<p>P9 states yes, absolutely</p>	<p>P9 states yes absolutely regarding receiving a lot of social support.</p>	<p>P9 states that she received a lot of social support.</p>
<p><b>R: Ok. So, to build upon that specific area of social support then, how did you become involved or aware of the 4 Cancer Group's activity? The sailing experience... P9: Ok, so, when I was going through my treatment, I was referred to the foundation centre at the Royal Surrey Hospital, which gave me things like a 'look good, feel good' session with makeup, massage therapy, and reiki. They recommended a company called 'something to look forward to'...</b></p>	<p>P9 states ok, so, when she was going through her treatment, she was referred to the foundation centre at the Royal Surrey Hospital, which gave her things like a 'look good, feel good' session with makeup, massage therapy, and reiki. P9 states that they recommended a company called 'something to look forward to'...</p>	<p>With reference to how she became aware of the 4 Cancer Group, P9 states that the foundation centre at the hospital recommended a company called 'something to look forward to', as well as giving her a health and beauty therapy.</p>	<p>With reference to how she became aware of the 4 Cancer Group, P9 states that the foundation centre at the hospital recommended a company called 'something to look forward to'.</p>
<p><b>R: Ok. I know they work closely with the 4 Cancer Group... P9: Ok. Erm, I was told that they give people, sort of, donations, gifts, days out and experiences. I</b></p>	<p>P9 says ok. P9 says erm, she was told that they (something to look forward to) give people, sort of, donations, gifts, days out and experiences. P4 says she registered</p>	<p>P9 recognises that she registered with something to look forward to, who then contacted her to make her aware of their association with the 4 Cancer Group.</p>	<p>P9 recognises that she registered with 'something to look forward to', who then contacted her to make her aware of their association with the 4 Cancer Group.</p>

<b>registered with them and it was them who contacted me to say they had an association with the 4 Cancer Group...</b>	with them and it was them who contacted her to say they had an association with the 4 Cancer Group...		
<b>P9: I don't know how it worked but they informed her that they had a sailing experience for those living with cancer and cancer patients</b>	P9 says that she didn't know how it worked but they (something to look forward to) informed they had a sailing experience for those living with cancer and cancer patients	P9 states that something to look forward to informed her that the 4 Cancer Group had a sailing experience for those living with cancer.	P9 states that 'something to look forward to' informed her that the 4 Cancer Group had a sailing experience for those living with cancer.
<b>P9: They told me they had an event on Mother's Day coming up and I thought it would be good because it isn't always about me... it was about the impact it has had on my daughters too. It had been a really scary time for them</b>	P9 states that they told her they had an event on Mother's Day coming up and she thought it would be good because it isn't always about her... P9 says it was about the impact it has had on her daughters too. P9 states it had been a really scary time for them	Stating that the cancer had a scary impact on her daughters, P9 is aware that that sailing trip would be good as it was on Mother's day.	Aware that cancer had a scary impact on her daughters, P9 is aware that sailing trip would be good as it was on Mother's day.
<b>P9: So the thought of being offered this and on Mother's Day was fantastic. My eldest daughter was at university at the time, so I took my youngest daughter, who is 16, and, erm, it was just the knowledge of having a day out on a sailing experience was completely different</b>	P9 states so the thought of being offered this and on Mother's Day was fantastic. P9 says her eldest daughter was at university at the time, so she took her youngest daughter, who is 16, and, erm, it was just the knowledge of having a day out on a sailing experience was completely different	P9 states that she took her youngest daughter, as her eldest was at university at the time. P9 states that having the sailing experience on Mother's day was fantastic, describing it as being completely different.	P9 states that she took her youngest daughter, as her eldest was at university at the time. P9 states that having the sailing experience on Mother's day was fantastic, describing it as being completely different.
<b>P9: My daughter and I could do it together... yes, we were both really happy to be offered it.</b>	P9 states that she and her daughter could do it together... P9 says yes, we were both really happy to be offered it.	P9 recognises that she and her daughter were both happy to go sailing as they could do it together.	P9 states that she and her daughter were both happy to go sailing as they could do it together.

<p><b>R: Ok, I understand. Can I ask what you got from the sailing experience? You know, you've just talked about time with your daughter. Where was the meaning in this for you?</b></p> <p><b>P9: Well... it was completely different for me. My mind tends to ruminate on things a lot. I'm a definite worrier (laughs). Erm, I often need something to occupy my mind and something to stop me worrying</b></p>	<p>P9 states well it (the sailing) was completely different for her. P9 says her mind tends to ruminate on things a lot. P9 says she's a definite worrier (laughs). P9 states she often needs something to occupy her mind and something to stop her worrying</p>	<p>Acknowledging that her mind tends to ruminate and that she is a worrier if her mind is not occupied, P9 states that the sailing was completely different for her.</p>	<p>Acknowledging that her mind tends to ruminate and that she is a worrier if her mind is not occupied, P9 states that the sailing was completely different for her.</p>
<p><b>P9: It was just perfect because there was two other ladies on the day with their families who were a similar age to me. One of them had teenage children as well, which was nice for my daughter.</b></p>	<p>P9 states that it was just perfect because there was two other ladies on the day with their families who were a similar age to her. P9 states that one of them had teenage children as well, which was nice for her daughter.</p>	<p>P9 recognises that it was perfect for her because there were two other ladies there who were a similar age. P9 is aware that one of them had a daughter too, saying it was nice for her daughter.</p>	<p>P9 recognises that it was perfect for her because there were two other ladies there who were a similar age, stating that one had a daughter too.</p>
<p><b>P9: It was, just, a complete change of everyday scenery. Something positive. Something to look at the calendar and look forward to, rather than hospital visits and check-ups, which usually dominate my calendar</b></p>	<p>P9 states that it was, just, a complete change of everyday scenery. Something positive. Something to look at the calendar and look forward to, rather than hospital visits and check-ups, which usually dominate her calendar</p>	<p>P9 is aware that the sailing trip was a change of scenery and something to look forward to, as hospital appointments usually dominate her calendar.</p>	<p>P9 states that the sailing trip was a change of scenery and something to look forward to, as hospital appointments usually dominate her calendar.</p>
<p><b>P9: It was lovely on the day because the ladies had gone through something similar to me as well</b></p>	<p>P9 states that it was lovely on the day because the ladies had gone through something similar to her as well</p>	<p>Describing the day as lovely, P9 states that the two ladies had been through something similar.</p>	<p>Describing the day as lovely, P9 states that the two ladies had been through something similar.</p>

<p><b>P9: The staff and the crew were so lovely, funny and cheerful. They really welcomed my daughter too.</b></p>	<p>The staff and the crew were so lovely, funny and cheerful. They really welcomed my daughter too.</p>	<p>P9 states that the crew were lovely, funny and cheerful, stating that they welcomed her daughter.</p>	<p>P9 states that the crew were lovely, funny and cheerful, stating that they welcomed her daughter.</p>
<p><b>P9: Throughout the day, I started to chat to these two other ladies, and we shared a lot of our experiences</b></p>	<p>P9 states that throughout the day, she started to chat to these two other ladies, and they shared a lot of our experiences</p>	<p>P9 states that she and two other ladies talked and shared their experiences throughout the day.</p>	<p>P9 states that she and two other ladies talked and shared their experiences throughout the day.</p>
<p><b>P9: We occasionally had a laugh about some of the things we have been through. A bit of black humour about some things</b></p>	<p>P9 states that they (the two other ladies) occasionally had a laugh about some of the things they have been through. P9 describes this as a bit of black humour about some things</p>	<p>P9 is aware that she and the two other ladies had a laugh about things they have been through, describing it as black humour.</p>	<p>P9 says that she and the two other ladies had a laugh about things they have been through, describing it as black humour.</p>
<p><b>P9: Erm, we also talked about how our children had coped with things. It was good because we were able to share things in a very relaxed and different environment. It really picked me up at times.</b></p>	<p>P9 states that they also talked about how their children had coped with things. P9 says it was good because they were able to share things in a very relaxed and different environment. P9 states that it really picked me up at times.</p>	<p>With reference to how it picked her up, P9 says that they talked about how their children coped, describing it as a relaxed and different environment.</p>	<p>With reference to how it picked her up, P9 says that they talked about how their children coped, describing it as a relaxed and different environment.</p>
<p>R: Yes... that's something that has become very apparent to me throughout these interviews... some people didn't expect these, sort of, encounters and conversations... was this the same for you? <b>P9: I mean, it's difficult sometimes because with my close friends I can tell</b></p>	<p>P9 says it's difficult sometimes because with her close friends she can tell them anything but with a complete stranger... to open up and talk about cancer, the treatment and the things she has been through, erm, it is quite difficult...</p>	<p>As opposed to her close friends, who she can tell anything, P9 states that it was difficult to open up about cancer and the things she has been through to strangers.</p>	<p>As opposed to her close friends, P9 states that it was difficult to open up about cancer and the things she has been through to strangers.</p>

<p>them anything but with a complete stranger... to open up and talk about cancer, the treatment and the things you have been through, erm, it is quite difficult...</p>			
<p><b>P9: But, you know, one of the ladies, came up to me and introduced herself and we just got talking. We were sitting on the deck of the boat, watching the world go by. We shared one conversation after another... before we knew it, there was three of us ladies sat there chatting away about all our experiences. It was a long day out, so we just sat there and started to get to know each other. I began to feel very, very comfortable with them.</b></p>	<p>P9 states one of the ladies, came up to her and introduced herself and they just got talking. P9 states they were sitting on the deck of the boat, watching the world go by. P9 states that they shared one conversation after another... before they knew it, there was three of them ladies sat there chatting away about all their experiences. P9 states it was a long day out, so they just sat there and started to get to know each other. P9 states she began to feel very, very comfortable with them.</p>	<p>P9 recognises that one of the ladies introduced herself and they began talking. P9 is aware that they had a long day ahead, saying that she began to feel very comfortable with the two women. P9 states they sat on the boat, watching the world go by, sharing one conversation after another about their experiences.</p>	<p>P9 recognises that one of the ladies introduced herself and they began talking. P9 is aware that they had a long day ahead, saying that she began to feel very comfortable with the two women. P9 states they sat on the boat, watching the world go by, sharing one conversation after another about their experiences.</p>
<p><b>P9: Because we'd been through very similar experiences, I think we felt quite open to talk about treatment and, erm, you know, the things we found scary, you know, the things like our body image following cancer. We were talking about relationships (laughs)... I found myself having quite personal conversations with</b></p>	<p>P9 states because they'd been through very similar experiences, she thinks they felt quite open to talk about treatment and, erm, you know, the things they found scary, you know, the things like their body image following cancer. P9 says they were talking about relationships (laughs)... P9 says she found herself having quite personal</p>	<p>Stating that she felt ok about it, P9 acknowledges that they were having personal conversations about body image, relationships, and the things they found scary, as they had shared experiences.</p>	<p>Stating that she felt ok about it, P9 acknowledges that they were having personal conversations about body image, relationships, and the things they found scary.</p>

<p><b>them. But I felt very ok about it...</b></p>	<p>conversations with them. P9 says but she felt very ok about it...</p>		
<p><b>R: Was this quite a unique experience to you? Given that you say you were having very personal conversations with these strangers...</b>  <b>P9: I do go to a monthly group with other ladies that have been through cancer and I have started to get to know them a bit. I'm also a member of a few online forums... but you just make the odd comment, but here, on that sailing experience, it was more relaxed... Do that make sense?</b></p>	<p>P9 states that she does go to a monthly group with other ladies that have been through cancer and she has started to get to know them a bit. P9 states that she is also a member of a few online forums... but she just makes the odd comment, but here, on that sailing experience, it was more relaxed... Do that make sense?</p>	<p>P9 recognises that she is a member of both an online forum and in-person group for those that have been through cancer, whereby she makes the odd comment, but she describes the sailing experience as being more relaxed.</p>	<p>P9 recognises that she is a member of both an online forum and in-person group, whereby she makes the odd comment, but she describes the sailing experience as being more relaxed.</p>
<p><b>R: Yes...</b>  <b>P9: It just felt very relaxed and it didn't feel like we were having, like, a counselling session. We were just chatting about things.</b></p>	<p>P9 states that it just felt very relaxed and it didn't feel like they were having, like, a counselling session. P9 says we were just chatting about things.</p>	<p>Stating they chatted about things, P9 is aware that she felt very relaxed and it didn't feel like counselling.</p>	<p>Stating they chatted about things, P9 is aware that she felt very relaxed and it didn't feel like counselling.</p>
<p><b>R: Yes... this is something I'm becoming more aware of... Am I right in thinking that it doesn't feel as forced and it is about peer support in a way?</b>  <b>P9: Yes... we were talking about cancer, but we also talked about other things in our life. Erm, where we worked, how we found working through cancer, was our bosses</b></p>	<p>P9 states yes... they were talking about cancer, but they also talked about other things in their life. P9 says erm, where they worked, how they found working through cancer, was their bosses supportive, have they tried this for X, Y and Z. Little tips for how they coped with certain things...</p>	<p>With reference to the things they talked about, P9 is aware that they talked about cancer. P9 states that they also talked about work, such as the support from their bosses, and tips for how they cope with things.</p>	<p>With reference to the things they talked about, P9 is aware that they talked about cancer. P9 states that they also talked about work, such as the support from their bosses, and tips for how they cope with things.</p>



<p>supportive, have you tried this for X, Y and Z. Little tips for how they coped with certain things...</p>			
<p><b>P9: I mentioned the company ‘something to look forward to’ and they had also used them too. I’d been offered certain things which I told them about... you know, the little things that you can share with others. They mentioned some other things that they tried.</b></p>	<p>P9 states that she mentioned the company ‘something to look forward to’ and they (the two women) had also used them too. P9 states she had been offered certain things which she told them about... you know, the little things that she can share with others. P9 states that the two other women mentioned some other things that they tried.</p>	<p>As well as sharing information on other things, P9 states that the two other women had used ‘something to look forward to’, as well as other things they had tried.</p>	<p>As well as sharing information on other things, P9 states that the two other women had used ‘something to look forward to’.</p>
<p><b>P9: It just had such a relaxed nature to it...</b></p>	<p>P9 states that it (the sailing) just had such a relaxed nature to it...</p>	<p>P9 states that the sailing trip had a relaxing nature.</p>	<p>P9 states that the sailing trip had a relaxing nature.</p>
<p><b>R: Ok, sure. How did this help you specifically? Has this changed who you are now?</b>  <b>P9: Erm, it’s just... it didn’t feel like a counselling session at all. The environment and the people on board had similar experiences just made me automatically feel relaxed...</b></p>	<p>P9 states that erm, it’s just... it didn’t feel like a counselling session at all. P9 says that the environment and the people on board had similar experiences just made her automatically feel relaxed...</p>	<p>P9 is aware that it didn’t feel like a counselling session, stating that their shared experiences made her feel automatically relaxed.</p>	<p>P9 is aware that it didn’t feel like a counselling session, stating that their shared experiences made her feel automatically relaxed.</p>
<p><b>R: Yes...</b>  <b>P9: Before I had even started having a conversation about anything, you know, we just bonded without having to say too much... by our experiences...</b></p>	<p>P9 states that before she had even started having a conversation about anything, you know, they just bonded without having to say too much... by their experiences...</p>	<p>With reference to their shared experiences, P9 states that they bonded without having to say too much or have a conversation.</p>	<p>With reference to their shared experiences, P9 states that they bonded without having to say too much.</p>

<p>R: Ok, thank you. Earlier in the interview, you described yourself as quite a worrier...</p> <p>P9: Yes, I'm a terrible worrier (laughs)</p>	<p>P9 states yes, I'm a terrible worrier (laughs)</p>	<p>P9 states that she is a terrible worrier</p>	<p>P9 states that she is a terrible worrier</p>
<p>R: How did your experiences with cancer impact this?</p> <p>P9: At one point, the oncologist said to me "have you got a will in place?" and that freaked me out terribly.</p>	<p>P9 states at one point, the oncologist said to her "have you got a will in place?" and that freaked her out terribly.</p>	<p>P9 recognises that she was freaked out by the oncologist asking if she had a will in place.</p>	<p>P9 recognises that she was freaked out by the oncologist asking if she had a will in place.</p>
<p>P9: I seriously began to contemplate "what if I didn't make it?". I had so many sleepless nights and nightmares about it</p>	<p>P9 states that she seriously began to contemplate "what if she didn't make it?". P9 says she had so many sleepless nights and nightmares about it</p>	<p>P9 states that she nightmares and sleepless nights about the thought of not making it.</p>	<p>P9 states that she nightmares and sleepless nights about the thought of not making it.</p>
<p>P9: To me, it was more about what would happen to my children if I wasn't around. It really, really worried me. I struggled a lot with it</p>	<p>P9 states that to her, it was more about what would happen to her children if I wasn't around. P9 says It really, really worried me. P9 says I struggled a lot with it</p>	<p>P9 says she struggled and worried about what would happen to her children if she wasn't around.</p>	<p>P9 says she struggled and worried about what would happen to her children if she wasn't around.</p>
<p>P9: I had to have some very difficult conversations with friends about, you know, "if something happens to me, will you do this and that for me? Will you look after them for me?". Erm, conversations that you don't ever want to have and things you don't ever want to contemplate went through my mind. Yeah, I did struggle.</p>	<p>P9 states that she had to have some very difficult conversations with friends about, you know, "if something happens to her, will you do this and that for her? Will you look after them for her?". P9 states erm, conversations that she doesn't ever want to have and things you don't ever want to contemplate went through her mind. P9 states yeah, she did struggle.</p>	<p>With reference to how she struggled, P9 states that she had to have conversations with friends about if they could look after her daughters if she wasn't around. P9 says that these are conversations she didn't ever want to contemplate.</p>	<p>P9 states that she had to have conversations with friends about if they could look after her daughters if she wasn't around. P9 says that these are conversations she didn't ever want to contemplate.</p>

<p>R: With all of those considerations and being able to reflect on those experiences with other people on the sailing experience, has this changed much for you?</p> <p><b>P9: Yes, quite a lot. Before the cancer, I wouldn't go out and do things in the evenings and on the weekends as much</b></p>	<p>P9 states yes, quite a lot. P9 says before the cancer, she wouldn't go out and do things in the evenings and on the weekends as much.</p>	<p>With reference to what changed her, P9 states that before the cancer, she wouldn't go out and do things in the evenings and weekends.</p>	<p>With reference to what changed her, P9 states that before the cancer, she wouldn't go out and do things in the evenings and weekends.</p>
<p><b>P9: I would see lots of friends, but although I am chatting to you now, I can be quite shy and reserved with, erm, people I don't know</b></p>	<p>P9 states that she would see lots of friends, but although she is chatting to R now, she can be quite shy and reserved with, erm, people she doesn't know</p>	<p>P9 states that while she has friends, she is shy and reserved with people she doesn't know.</p>	<p>P9 states that while she has friends, she is shy and reserved with people she doesn't know.</p>
<p>P9: I have joined a social group for single people. I now go out on lots of different trips, including the sailing event. I've also joined a book club (laughs). I've joined all these different things</p>	<p>P9 states that she has joined a social group for single people. P9 says she now go out on lots of different trips, including the sailing event. P9 I've also joined a book club (laughs). I've joined all these different things</p>	<p>P9 states that she is more social now, whereby she has joined a singles group, a book club, and attends different trips, such as the sailing.</p>	<p>P9 states that she is more social now, whereby she has joined a singles group, a book club, and attends different trips, such as the sailing.</p>
<p><b>P9: I'm much more... you know the expression 'don't sweat the small stuff'... I'm much more, you know, less worried about the little things and, erm, whereas before I wouldn't be bothered to go out after work, and I would make every excuse to not do something. I now think no; I've had a scare... I'll now go out. I might not stay</b></p>	<p>P9 states she's much more... you know the expression 'don't sweat the small stuff'... P9 says she's much more, you know, less worried about the little things and, erm, whereas before she wouldn't be bothered to go out after work, and she would make every excuse to not do something. P9 says she thinks now think no; she's had a scare... she'll now go</p>	<p>P9 recognises that she is less worried about the little things now, stating she doesn't sweat the small stuff. P9 states that before the cancer, she would make an excuse not to do something, whereas now, she'll go out, stating that the cancer gave her a scare.</p>	<p>P9 says that she is less worried about the little things now, stating she doesn't sweat the small stuff. P9 states that before the cancer, she would make an excuse not to do something, whereas now, she'll go out, explaining that the cancer gave her a scare.</p>

really late, but I'll go out	out. P9 says she might not stay really late, but she'll go out		
<b>P9: I've now moulded myself to start doing more things. My calendar is now full of things as opposed to when I was pre-cancer</b>	P9 states that she's now moulded herself to start doing more things. P9 states that her calendar is now full of things as opposed to when she was pre-cancer	P9 is aware that her calendar is now full as opposed to when she was pre-cancer, stating that she has moulded herself.	P9 is aware that she has moulded herself, whereby her calendar is now full of things to do.
<b>P9: It is full of things with people who I know and the clubs that I have joined. Other things have sprung off of that and I've met some new people... even through this monthly cancer group that I go to, I've met a lot of ladies there. You know, I've met people that I would never have met</b>	P9 states that it is full of things with people who she knows and the clubs that she has joined. P9 says other things have sprung off of that and she's met some new people... even through this monthly cancer group that she goes to, she's met a lot of ladies there. P9 says you know, she's met people that she would never have met	P9 states that through the groups she's joined, things have sprung up and she's met people she would never have met before.	P9 states that through the groups she's joined, things have sprung up and she's met people she would never have met before.
<b>P9: So, yes, it has made me think... you know what, this could all change tomorrow...</b>	P9 states so, yes, it (the cancer) has made her think... you know what, this could all change tomorrow...	P9 states that the cancer has made her think that it could all change tomorrow.	P9 states that the cancer has made her think that it could all change tomorrow.
<b>R: Sure, absolutely. Staying on that subject of meeting people... you say that you met two other ladies on your sailing experience?</b> <b>P9: Yes</b>	P9 states yes	P9 states yes, she did meet two other ladies on the sailing trip.	P9 states that she did meet two other ladies on the sailing trip.
<b>R: You said that you had quite personal conversations with them?</b> <b>P9: Yes</b>	P9 states yes	P9 states yes, she did have personal conversations with the two ladies	P9 states yes, she did have personal conversations with the two ladies

<p><b>R: I believe you used the topic of body image as something that you talked about?</b></p> <p><b>P9: Yes</b></p>	<p>P9 states yes</p>	<p>P9 states yes, she did talk about body image with the two ladies</p>	<p>P9 states yes, she did talk about body image with the two ladies</p>
<p><b>R: Can you elaborate on that a little bit more, please?</b></p> <p><b>P9: Yes... I mean, one of the other ladies had a mastectomy, which is obviously a huge thing for a lady to go through</b></p>	<p>P9 states yes... she mean, one of the other ladies had a mastectomy, which is obviously a huge thing for a lady to go through</p>	<p>With reference to talking about body image, P9 states that one of the ladies had a mastectomy, stating that it is a huge thing for a lady to through.</p>	<p>P9 states that one of the ladies had a mastectomy, stating that it is a huge thing for a lady to through.</p>
<p><b>P9: We were talking about how your body image might reflect on your new relationships. And how you dress, the clothes you wear.</b></p>	<p>P9 states that they were talking about how their body image might reflect on your new relationships. P9 states and how they dress, the clothes they wear.</p>	<p>P9 states that they talked about how their body image may impact relationships and what clothes they wear.</p>	<p>P9 states that they talked about how their body image may impact relationships and what clothes they wear.</p>
<p><b>P9: I'm having some reconstructive surgery at the end of the year and one of the ladies works in the hospital where I am going to have it done. She knows the consultant and she was very reassuring as I'm very nervous about it</b></p>	<p>P9 states she is having some reconstructive surgery at the end of the year and one of the ladies works in the hospital where she is going to have it done. P9 states that she knows the consultant and she was very reassuring as P9 is very nervous about it</p>	<p>With reference to being nervous about having reconstructive surgery, P9 says that one of the ladies on the trip was reassuring as she works at the hospital and knows the consultant.</p>	<p>Although P9 feels nervous about having reconstructive surgery, P9 says that one of the ladies on the trip was reassuring as she works at the hospital and knows the consultant.</p>
<p><b>P9: One thing that was important that we talked about was that some people don't really understand if you haven't been through cancer, is that they're great (people) when you're going through chemotherapy and radiotherapy and you've lost your hair... but when</b></p>	<p>P9 states that one thing that was important that they talked about was that some people don't really understand if they haven't been through cancer, is that they're great (people) when she was going through chemotherapy and radiotherapy and she had lost her hair... but</p>	<p>Recognising that the cancer has changed her forever, P9 states that some people were great while she was going through treatment, such as when she lost her hair, but P9 states that when she went back to work and her hair had grown back, people said I bet "you're glad that is all</p>	<p>P9 states that some people were great while she was going through treatment, such as when she lost her hair, but P9 states that when she went back to work and her hair had grown back, people said I bet "you're glad that is all over, you can get back on with your life". P9 states that</p>

<p><b>you've finished that treatment and you've gone back to work and your hair has grown back, people will talk to you as if "I bet you're glad that is all over, you can get back on with your life". But you are forever changed by this...</b></p>	<p>when she finished that treatment and she had gone back to work and her hair has grown back, people will talk to her as if "I bet you're glad that is all over, you can get back on with your life". P9 says but you are forever changed by this...</p>	<p>over, you can get back on with your life".</p>	<p>this has changed her forever.</p>
<p><b>R: Can you tell me what you mean by that?</b>  <b>P9: Yes... obviously the mastectomy has hugely affected my body confidence, erm, and I'm still a single lady and the thought of having a relationship with somebody scares me witless because of how my body looks now</b></p>	<p>P9 states yes... obviously the mastectomy has hugely affected her body confidence, erm, and she's still a single lady and the thought of having a relationship with somebody scares her witless because of how her body looks now</p>	<p>P9 recognises that the mastectomy has affected her body confidence, stating that she is scared witless of having a relationship because of how her body looks.</p>	<p>P9 recognises that the mastectomy has affected her body confidence, stating that she is scared witless of having a relationship because of how her body looks.</p>
<p><b>P9: Erm, I just find it hard because even people at work, who are nurses, talk to me as if I am all good now. I mean, I'm on medication for the next ten years, which gives me a lot of joint pain and stiffness. I have to have fusions every six months to try and combat the effects of this medication. I've got similar problems to what people with osteoporosis suffer with</b></p>	<p>P9 states erm, she just finds it hard because even people at work, who are nurses, talk to her as if she is all good now. P9 states she's on medication for the next ten years, which gives her a lot of joint pain and stiffness. P9 states she has to have fusions every six months to try and combat the effects of this medication. P9 states that she's got similar problems to what people with osteoporosis suffer with</p>	<p>Although nurses talk to her as though she is all good, P9 states that she's on medication for the next 10 years which give her pain and stiffness. P9 has to have a fusion to combat the medication, which gives her similar problems as to those who suffer from osteoporosis.</p>	<p>Although nurses talk to her as though she is all good, P9 states that she's on medication for the next 10 years which give her pain and stiffness. P9 has to have a fusion to combat the medication, which gives her similar problems as to those who suffer from osteoporosis.</p>

<p><b>P9: Erm, I still get tired. There's still a tiredness from the treatment that hasn't gone away</b></p>	<p>P9 states erm, she still gets tired. P9 says there's still a tiredness from the treatment that hasn't gone away</p>	<p>P9 is aware that she is still tired from the treatment.</p>	<p>P9 is aware that she is still tired from the treatment.</p>
<p><b>P9: Every day I have to live with the knowledge that if I get a twinge or a pain I start thinking "has it come back". You have to live it and that fear never, ever goes away. You worry about it and you try not to. You're not over it when the chemotherapy and radiotherapy stops</b></p>	<p>P9 states that every day she has to live with the knowledge that if she gets a twinge or a pain she starts thinking "has it come back". P9 states that she has to live it and that fear never, ever goes away. P9 says that she worries about it and she tries not to. P9 says she's not over it when the chemotherapy and radiotherapy stops</p>	<p>P9 states that even when the chemotherapy and radiotherapy stops, there is a fear that never goes away. P9 states that even if she feels a twinge, she worries about if it has come back, but tries not to.</p>	<p>P9 states that even when the chemotherapy and radiotherapy stops, there is a fear that never goes away. P9 states that if she feels a twinge, she worries about if the cancer has come back, but tries not to.</p>
<p><b>P9: Even when somebody says there is evidence or an indication that there is no cancer in your body, you are still controlled by it. I found that however caring people are in your life, whether that is a friend or family, only someone who has been through it can really understand that...</b></p>	<p>P9 states that even when somebody says there is evidence or an indication that there is no cancer in your body, she is still controlled by it. P9 states that she found that however caring people are in your life, whether that is a friend or family, only someone who has been through it can really understand that...</p>	<p>Although people, be they family or friends, can be caring, and if you've been no sign of any cancer in your body P9 states that only someone who has had cancer will understand how much it controls you.</p>	<p>Although people, be they family or friends, can be caring, and if you've had no sign of any cancer in your body, P9 states that only someone who has had cancer will understand how much it controls you.</p>
<p><b>R: Yes, ok... So, I'm right in thinking that these were the topics you covered on the day?</b> <b>P9: Yes, exactly. We all talked of how the mastectomy damaged our body confidence</b></p>	<p>P9 states yes, exactly. P9 says they all talked of how the mastectomy damaged their body confidence</p>	<p>P9 states that they talked of how the mastectomy damaged their body confidence.</p>	<p>P9 states that they talked of how the mastectomy damaged their body confidence.</p>
<p><b>P9: We also had a bit of laugh about the things people say to</b></p>	<p>P9 states that they also had a bit of laugh about the things</p>	<p>P9 states that they laughed about what people say when they</p>	<p>P9 states that they laughed about what people say when they</p>



<b>you, were they mean well but sometimes you think “Oh god, please don’t say that to me”.</b>	people say to them, were they mean well but sometimes you think “Oh god, please don’t say that to me”.	mean well but you don’t want them to say it.	mean well but you don’t want them to say it.
<b>P9: You know, when people say, “I bet you’re glad it’s all over” and “oh, how are you now?”. You know, we sort of laughed about it because we can’t bear it when someone says this or that to me</b>	P9 states you know, when people say, “I bet you’re glad it’s all over” and “oh, how are you now?”. P9 says you know, they sort of laughed about it because they can’t bear it when someone says this or that to them	P9 states that she and the other ladies laughed about when people say, “I bet you’re glad it’s all over” and “oh, how are you now?”, as they can’t bear it.	P9 states that she and the other ladies laughed about when people say, “I bet you’re glad it’s all over” and “oh, how are you now?”, as they can’t bear it.
<b>P9: Erm, it was good because those are the types of things you cannot say to other people. You know, we were having a bond and a connection about things that drive us mad or things that people say because they don’t know what to say or they don’t understand</b>	P9 states erm, it was good because those are the types of things you cannot say to other people. P9 states you know, they were having a bond and a connection about things that drive them mad or things that people say because they don’t know what to say or they don’t understand	P9 is aware that they had a bond and connection about the things they cannot say to other people, such as those questions that drive them mad.	P9 is aware that they had a bond and connection about the things they cannot say to other people, such as those questions that drive them mad.
<b>P9: What was good about it was that they felt all of the same things that I felt</b>	P9 states that what was good about it was that they (the women) felt all of the same things that she felt	P9 states that it was good because the women felt the same things she felt.	P9 states that it was good because the women felt the same things she felt.
<b>R: Yes, ok. Staying on that subject, you said your children also attended the sailing experience with you? P9: Yes... and there was some other children there too</b>	P9 states yes, and there was some other children there too	With reference to having her child with her on the sailing trip, P9 states yes, and there was some other children there too	P9 states that her child and other children were on the sailing trip too.
<b>P9: My daughter, who came with me, wouldn’t normally talk at first because she is slightly autistic. She finds it</b>	P9 states that her daughter, who came with her, wouldn’t normally talk at first because she is slightly autistic. P9 says she	P9 recognises that the daughter who came with her is slightly autistic, whereby she finds it hard to talk to people.	P9 recognises that the daughter who came with her is slightly autistic, whereby she finds it



<b>really hard to talk to people.</b>	finds it really hard to talk to people.		hard to talk to people.
<b>P9: My children didn't really talk a lot about the cancer when I was going through it. I mean, they talk more about it now as opposed to when I was in the middle of it all. But, yeah, it had a huge impact on them</b>	P9 states that her children didn't really talk a lot about the cancer when she was going through it. P9 says they talk more about it now as opposed to when she was in the middle of it all. P9 says but, yeah, it had a huge impact on them	P9 recognises that although they will talk about it now, her children didn't talk about cancer when she going through it, saying that it had a huge impact on them.	P9 recognises that although they will talk about it now, her children didn't talk about cancer when she going through it, saying that it had a huge impact on them.
<b>P9: As I said, my youngest doesn't see her dad. She's only really got me and my mum, who is very elderly, so, erm, she had worries about what would happen to me. She went quite into herself and didn't talk about it when I was going through the treatment</b>	P9 states as she said, her youngest (daughter) doesn't see her dad. P9 states that she's (her daughter) only really got her and P9's mum, who is very elderly, so, erm, she had worries about what would happen to her. P9 states that she went quite into herself and didn't talk about it when she was going through the treatment	P9 recognises that her youngest daughter went into herself during P9's treatment, stating that her daughter had worries. P9 is aware that her daughter has only got her and her mum, as she doesn't see her dad.	P9 recognises that her youngest daughter went into herself during P9's treatment, stating that her daughter had worries. P9 is aware that her daughter has only got her and her mum, as she doesn't see her dad.
<b>P9: But I do just want to say this at this point, the crew on the sailing experience were obviously very, very use to children or teenagers who are quite reticent and quiet. They were so brilliant.</b>	P9 states that the crew on the sailing experience were obviously very, very use to children or teenagers who are quite reticent and quiet. P9 states that they (the crew) were so brilliant.	P9 says that the crew were brilliant and were very familiar with children who are quiet and reticent.	P9 says that the crew were brilliant and were very familiar with children who are quiet and reticent.
<b>P9: They asked my daughter if she wanted to steer the boat, go into the lock, everything associated with what we had to do.</b>	P9 states that they (the crew) asked her daughter if she wanted to steer the boat, go into the lock, everything associated with what they had to do.	P9 acknowledges that the crew involved her daughter in everything associated with sailing, such as steering and going into the lock.	P9 says that the crew involved her daughter in everything associated with sailing, such as steering and going into the lock.

<p><b>P9: She was very quiet at first but, obviously, they've had such good experience at being with children and teenagers in this situation. They got her on the boat</b></p>	<p>P9 states that she (her daughter) was very quiet at first but, obviously, they've had such good experience at being with children and teenagers in this situation. P9 says they got her on the boat</p>	<p>P9 is aware that the crew had good experience of being with children and teenagers, saying that she was very quiet at first.</p>	<p>P9 is aware that the crew had good experience of being with children and teenagers, saying that she was very quiet at first.</p>
<p><b>P9: I've got pictures of her steering, looking very happy. That was nice for me as well because, you know, when you're going through all of this (cancer), you worry about your children as well. You worry about how they're feeling and coping</b></p>	<p>P9 states that she's got pictures of her steering, looking very happy. P9 says that was nice for her as well because, you know, when she was going through all of this (cancer), she worried about her children as well. P9 says you worry about how they're feeling and coping</p>	<p>Stating that she got pictures of her daughter looking happy, P9 says it was nice for her as she was worried about how her children we're coping and feeling while P9 was going through cancer.</p>	<p>Stating that she got pictures of her daughter looking happy, P9 says it was nice for her as she was worried about how her children we're coping and feeling while P9 was going through cancer.</p>
<p><b>P9: It was nice for me to see her having a good time. The crew were just so caring and lovely with her.</b></p>	<p>P9 states that it was nice for her to see her (daughter) having a good time. P9 states that the crew were just so caring and lovely with her (daughter).</p>	<p>With reference to how caring and lovely the crew were with her daughter, P9 says it was good to see her daughter having a good time.</p>	<p>P9 recognises that the crew were caring and lovely with her daughter, stating that it was good to see her have a good time.</p>
<p><b>R: Did you join her in taking part in any of the onboard activities?</b> <b>P9: Yeah, I had a go (laughs)... there was 12 of us but we all managed to have a go</b></p>	<p>P9 states yeah, she had a go (laughs)... there was 12 of them but they all managed to have a go (at the sailing)</p>	<p>P9 states that she and the 12 other participants managed to have a go at the sailing.</p>	<p>P9 states that she and the 12 other participants managed to have a go at the sailing.</p>
<p><b>R: Sure. That's something else that's become apparent to me. Even if you're not a keen sailor, as such, people who have participated in these events have learnt some very basic skills</b></p>	<p>P9 states yeah, she means, the skipper talked about the locks and how they work. P9 states that she and her daughter were very interested in all these types of things. You know, how they</p>	<p>P9 recognises that both she and her daughter were interested in how the locks work and the history of the river they sailed on.</p>	<p>P9 recognises that both she and her daughter were interested in how the locks work and the history of the river they sailed on.</p>

<p>associated with the sailing. Is this applicable to you?</p> <p><b>P9: Yeah, I mean, the skipper talked about the locks and how they work. My daughter and I were very interested in all these types of things. You know, how they work, how old this part of the river was, you know</b></p>	<p>work, how old this part of the river was, you know</p>		
<p><b>P9: They also pointed out things along the way. They were so knowledgeable, the crew</b></p>	<p>P9 states that they (the crew) also pointed out things along the way. They (the crew) were so knowledgeable, the crew</p>	<p>P9 states that the crew were knowledgeable as they pointed things out along the way.</p>	<p>P9 states that the crew were knowledgeable as they pointed things out along the way.</p>
<p><b>P9: My daughter still talks about it now, you know, steering the boat and going through the lock. The skipper, at one point, left her steering to herself and she had that funny panic-stricken look on her face (laughs) but she did incredibly well to remain in charge.</b></p>	<p>P9 states that her daughter still talks about it now, you know, steering the boat and going through the lock. P9 states that the skipper, at one point, left her steering to herself and she had that funny panic-stricken look on her face (laughs) but she did incredibly well to remain in charge.</p>	<p>P9 states that her daughter still talks about operating the boat, with P9 saying that at one point on the trip, the skipper left her to steer by herself, which caused her to panic but she did incredibly well to remain in charge.</p>	<p>P9 states that her daughter still talks about operating the boat, with P9 saying that at one point on the trip, the skipper left her to steer by herself, which caused her to panic but she did incredibly well to remain in charge.</p>
<p><b>P9: I felt that she did well with the responsibility. In all seriousness, though, I think seeing someone show confidence in her really boosted her confidence which, in turn, then makes me feel incredibly happy.</b></p>	<p>P9 states that she felt that she (her daughter) did well with the responsibility. P9 says in all seriousness, though, she thinks seeing someone show confidence in her really boosted her (daughters) confidence which, in turn, then makes P9 feel incredibly happy.</p>	<p>With reference to doing well with the responsibility, P9 states that she feels incredibly happy because somebody showed confidence in her daughter.</p>	<p>P9 states that her daughter did well with the responsibility. P9 says that she feels incredibly happy because somebody showed confidence in her daughter.</p>

<p><b>R: And she continues to talk about this now?</b>  <b>P9: Yes, quite a lot of the time actually...</b></p>	<p>P9 states yes (her daughter does talk about the sailing), quite a lot of the time actually...</p>	<p>P9 states that her daughter talks about the sailing quite a lot.</p>	<p>P9 states that her daughter talks about the sailing quite a lot.</p>
<p><b>R: Oh, ok. Great. OK, to take a step back, was there anything else about this particular sailing event that meant something to you?</b>  <b>P9: It's difficult... because it is a complete change of scenery, erm, the focus isn't or wasn't about cancer, which is sometimes the dominating theme of these things. It just so happened that as we were sat there, we started naturally chatting about things.</b></p>	<p>P9 states that it's difficult... because it is a complete change of scenery, erm, the focus isn't or wasn't about cancer, which is sometimes the dominating theme of these things. P9 says it just so happened that as they were sat there, they started naturally chatting about things.</p>	<p>With reference to what the sailing trip meant to her, P9 states that it was a change of scenery whereby they just sat and chatted naturally, and cancer wasn't the dominating theme.</p>	<p>With reference to what the sailing trip meant to her, P9 states that it was a change of scenery whereby they just sat and chatted naturally, and cancer wasn't the dominating theme.</p>
<p><b>P9: As I said, it wasn't like we were going to meeting or group about cancer survival. There was no pressure to talk or tell anybody</b></p>	<p>P9 states as she said, it wasn't like they were going to meeting or group about cancer survival. P9 states there was no pressure to talk or tell anybody</p>	<p>P9 states that it wasn't a group meeting about cancer survival and there was no pressure to tell anybody.</p>	<p>P9 states that it wasn't a group meeting about cancer survival and there was no pressure to tell anybody.</p>
<p><b>P9: If you wanted to talk, you could but if you didn't then you didn't have to. The ironic thing is that cancer wasn't the focus. Yes, it was an experience for people who have been through it... Does that make any sense?</b></p>	<p>P9 states if you wanted to talk, you could but if you didn't then you didn't have to. P9 states that the ironic thing is that cancer wasn't the focus. P9 states yes, it was an experience for people who have been through it... Does that make any sense?</p>	<p>While it was for people had been through cancer, P9 states that you could talk about cancer if you wanted to but the irony was that it wasn't the focus.</p>	<p>While it was for people had been through cancer, P9 states that you could talk about cancer if you wanted to but the irony was that it wasn't the focus.</p>
<p><b>R: Absolutely. Listening to others talk of this event, I'm</b></p>	<p>P9 states that's how she felt... if you wanted to start a</p>	<p>P9 says that during the day there was no pre-requirement to</p>	<p>P9 says that during the day there was no pre-requirement to</p>

<p>aware that it is a fine balance between what you have mentioned... there is a deliberate focus for the people using these events, but it doesn't feel forced? Please correct me if I am wrong...</p> <p><b>P9: That's how I felt... if you wanted to start a conversation about anything you had experienced, then that was fine within our group. But there was no pre-requirement of 'during this day we will be having a discussion about X, Y or Z of your cancer experience'</b></p>	<p>conversation about anything you had experienced, then that was fine within the group. P9 says but there was no pre-requirement of 'during this day we will be having a discussion about X, Y or Z of your cancer experience'</p>	<p>talk about their cancer experience but you could start a conversation about what you had experienced within the group if you wanted to.</p>	<p>talk about their cancer experience but you could start a conversation about what you had experienced within the group if you wanted to.</p>
<p><b>P9: You could've just sat there and soaked in the day without talking to anybody. It was nice that the focus was on different things... and it was completely new</b></p>	<p>P9 states that you could've just sat there and soaked in the day without talking to anybody. P9 says it was nice that the focus was on different things... and it was completely new</p>	<p>P9 states that the sailing was completely new, whereby they could focus on different things, such as soaking in the day without talking to anybody if you wanted to.</p>	<p>P9 states that the sailing was completely new, whereby they could focus on different things, such as soaking in the day without talking to anybody if you wanted to.</p>
<p><b>P9: For me, I have to be able to switch off worrying and busy doing something else. When I'm just sat by myself doing something quietly, my mind starts to wander off and go through things</b></p>	<p>P9 states that for her, she has to be able to switch off worrying and busy doing something else. P9 says when she's just sat by herself doing something quietly, her mind starts to wander off and go through things</p>	<p>P9 is aware that if she is sat by herself, her mind starts to wander and worry. P9 recognises that she has to be busy doing something else.</p>	<p>P9 is aware that if she is sat by herself, her mind starts to wander and worry. P9 recognises that she has to be busy doing something else.</p>
<p><b>P9: But if I am focussing on something else, you know, like, the sailing event, you begin to reflect on it and think</b></p>	<p>P9 states but if she is focussing on something else, you know, like, the sailing event, she begins to reflect on it and think</p>	<p>P9 states that she reflected upon the sailing trip, thinking how about she felt uplifted and noticed that she didn't worry</p>	<p>P9 states that she reflected upon the sailing trip, thinking how about she felt uplifted and noticed that she didn't worry</p>

<p><b>“I haven’t worried about a thing today, I’ve just had a really good time”. You know, on the way home I felt really uplifted...</b></p>	<p>“she hasn’t worried about a thing today, she’s just had a really good time”. P9 says you know, on the way home she felt really uplifted...</p>	<p>about a thing on the day.</p>	<p>about a thing on the day.</p>
<p><b>P9: Yeah, I was sat there thinking “what a lovely day. My daughter and I enjoyed ourselves. I met some lovely people who shared a lot about themselves. The crew were brilliant. They made me laugh and were very humorous.</b></p>	<p>P9 states yeah, she was sat there thinking “what a lovely day”. P9 states my daughter and herself enjoyed ourselves. she met some lovely people who shared a lot about themselves. The crew were brilliant. They made her laugh and were very humorous.</p>	<p>P9 states that she had a lovely day, whereby she and her daughter met some lovely people who shared a lot about themselves, including the crew who were brilliant and very humorous.</p>	<p>P9 states that she had a lovely day, whereby she and her daughter met some lovely people who shared a lot about themselves, including the crew who were brilliant and very humorous.</p>
<p><b>P9: I just came away reflecting on how such a simple sailing event can be such an uplifting thing for us. And for someone like me, who gets stressed a lot and worries a lot, to come away and think “wow, I’m really happy” ...</b></p>	<p>P9 states that she just came away reflecting on how such a simple sailing event can be such an uplifting thing for them. P9 says and for someone like her, who gets stressed a lot and worries a lot, to come away and think “wow, I’m really happy”...</p>	<p>Acknowledging that she felt happy after the sailing, P9 recognises that a simple event like sailing was uplifting for her, someone who gets stressed and worries a lot.</p>	<p>Acknowledging that she felt happy after the sailing, P9 recognises that a simple event like sailing was uplifting for her, someone who gets stressed and worries a lot.</p>
<p><b>P9: Sorry, but I’m a little pushed for time at the moment... I’ve got a couple more minutes but then I have to pop out to get my daughter...</b></p>	<p><b>P9: Sorry, but I’m a little pushed for time at the moment... I’ve got a couple more minutes but then I have to pop out to get my daughter...</b></p>	<p><b>P9: Sorry, but I’m a little pushed for time at the moment... I’ve got a couple more minutes but then I have to pop out to get my daughter...</b></p>	<p><b>P9: Sorry, but I’m a little pushed for time at the moment... I’ve got a couple more minutes but then I have to pop out to get my daughter...</b></p>
<p><b>R: That’s fine... so, to summarise, there is a nature to these events that is not forced, in an environment that allows your mind to switch off?</b></p>	<p>P9 states yes, absolutely... and the other people who were there. P9 states and, again, for someone like her, she’s been to a lot of talks about cancer and many things to</p>	<p>To summarise her experience, P9 states that the sailing benefitted her as she wasn’t just sat there talking about cancer, which has happened at other formal events to help her</p>	<p>To summarise her experience, P9 states that the sailing benefitted her as she wasn’t just sat there talking about cancer, which has happened at other formal events to help her</p>

<p><b>P9: Yes, absolutely... and the other people who were there. And, again, for someone like me, I've been to a lot of talks about cancer and many things to try and help me, erm, move on from cancer. You know, a lot of formal events. But this was just different. It was just an event that benefitted me in so many different ways and it wasn't about just being there, talking about cancer. That in itself as about as therapeutic as any formal thing I have experienced in the past. That's how I would try and summarise it...</b></p>	<p>try and help her, erm, move on from cancer. You know, a lot of formal events. P9 says but this was just different. It was just an event that benefitted her in so many different ways and it wasn't about just being there, talking about cancer. P9 says That in itself as about as therapeutic as any formal thing she has experienced in the past. P9 says that's how she would try and summarise it...</p>	<p>move on. P9 states that the sailing in itself is as therapeutic as those formal events that she's attended in the past.</p>	<p>move on. P9 states that the sailing in itself is as therapeutic as those formal events that she's attended in the past.</p>
<p>R: Ok. That makes sense to me. As I know you're pressed for time, I'd like to thank you for taking the time to talk to me today, it is very much appreciated</p>	<p>R: Ok. That makes sense to me. As I know you're pressed for time, I'd like to thank you for taking the time to talk to me today, it is very much appreciated</p>	<p>R: Ok. That makes sense to me. As I know you're pressed for time, I'd like to thank you for taking the time to talk to me today, it is very much appreciated</p>	<p>R: Ok. That makes sense to me. As I know you're pressed for time, I'd like to thank you for taking the time to talk to me today, it is very much appreciated</p>
<p><b>P9: That's fine. I'd like to thank yourself for taking the time to listen to me also.</b></p>	<p><b>P9: That's fine. I'd like to thank yourself for taking the time to listen to me also.</b></p>	<p><b>P9: That's fine. I'd like to thank yourself for taking the time to listen to me also.</b></p>	<p><b>P9: That's fine. I'd like to thank yourself for taking the time to listen to me also.</b></p>
<p><b>END OF INTERVIEW</b></p>	<p><b>END OF INTERVIEW</b></p>	<p><b>END OF INTERVIEW</b></p>	<p><b>END OF INTERVIEW</b></p>

**Step Four**  
**Participant**  
**No. 9**  
**Description of**  
**Lived**  
**Experience**



P9 is aware that her experience of being diagnosed with cancer was realised after she noticed changes in how she felt in June 2017. P9 states that she already had some knowledge that the changes were associated with breast cancer while going to get it investigated by the GP. P9 is aware that she was referred by a doctor under the two-week rule to a hospital on a Thursday and by Monday P9 had an emergency mammogram and biopsy. P9 is aware that the words "it might be something sinister" played on her mind while she waited for the biopsy results to come back.

P9 states she is and has been a single mum for her children since they were small. During the diagnosis, her children were both 14 and 16, with P9 saying that she was trying to not let them onto to anything as one of them was going through exams.

P9 says that an oncologist confirmed that she had an aggressive invasive lobular carcinoma of her left breast. Although she had a feeling it was coming, P9 says that it was delivered by the oncologist in a matter of fact way. Although she saw a lovely cancer specialist nurse afterwards, and that she was prepared for the diagnosis, P9 says those words by the oncologist were hugely shocking and devastating, saying that her whole world rocked underneath her.

Up until her diagnosis, P9 says she has always been a healthy and independent person, bringing up her girls and looking after her elderly mother by herself. P9 is aware that she is a strong person and she has always worked. P9 states that she had to look after herself, but she was asking herself a thousand questions, such as what is ahead? What about her children? What about her mother? What about her job? How is she going to pay the bills? P9 recognises that her whole world turned upside down.

P9 states that she initially had a lumpectomy, but she is aware that the cancer had spread to her lymph nodes and it was quite a big tumour. P9 states that she had a mastectomy, followed by chemotherapy and radiotherapy, saying that's what scared her as she didn't know how ill she would get. Saying she didn't know what was ahead, P9 also states she was worried because she didn't have health insurance and because she had a big mortgage to pay. P9 recognises that she had heard terrible stories about chemotherapy. P9 says she is both lucky and unlucky as she works for a hospice whereby the nurses are incredibly caring, but she sees ladies who are a similar age to herself in their final days because of cancer.

P9 states that she is a terrible worrier. P9 recognises that she was freaked out by the oncologist asking if she had a will in place. P9 states that she has nightmares and sleepless nights about the thought of not making it. P9 says she struggled and worried about what would happen to her children if she wasn't around. P9 is aware that she doesn't have a partner, but she has very close friends, describing them as her rock. P9 says they are friends she can ring up in the middle of the night. P9 is aware that her friends cheered her up, saying she would not have gotten through it without them. P9 says they bought shopping for her and boosted her up when she lost her hair. P9 recognises that her friends got her through the treatment. P9 states that she had to have conversations with friends about if they could look after her daughters if she weren't around. P9 says that these are conversations she didn't ever want to contemplate. Overall, P9 says she was scared, apprehensive and terrified about lots of things, including the treatment, work, and money.

With reference to how she became aware of the 4 Cancer Group, P9 states that the foundation centre at the hospital recommended a company called 'something to look forward to'. P9 recognises that she registered with 'something to look forward to', who then contacted her to make her aware of their association with the 4 Cancer Group. P9 states that 'something to look forward to' informed her that the 4 Cancer Group had a sailing experience for those living with cancer. Aware that the cancer had a scary impact on her daughters, P9 states that a sailing trip would be good as it was on Mother's Day. P9 states that she took her youngest daughter, as her eldest was at university at the time. P9 states that having the sailing experience on Mother's Day was fantastic, describing it as being completely different as they could do it together. P9 also states that the sailing trip was a change of scenery and something to look forward to, as hospital appointments usually dominate her calendar.

P9 recognises that it was perfect for her because there were two other ladies there on the sailing trip who was a similar age, stating that one had a daughter too. P9 states that she and the two other ladies talked and shared their experiences throughout the day. P9 says that she and the two other ladies had a laugh about things they have been through, describing it as black humour. With reference to how it picked her up, P9 says that they talked about how their children coped, describing it as a relaxed and different environment.

As opposed to her close friends, P9 states that it was difficult to open up about cancer and the things she has to through to strangers. Yet, P9 recognises that one of the ladies introduced herself and they began talking. P9 is aware that they had a long day ahead, saying that she began to feel very comfortable with the two women. P9 states they sat on the boat, watching the world go by, sharing one conversation after another about their experiences. Stating that she felt ok about it, P9 acknowledges that they were having personal conversations about body image, relationships, and the things they found scary. P9 recognises that she is a member of both an online forum and in-person group, whereby she makes the odd comment, but she describes the sailing experience as being more relaxed as is it didn't feel like counselling. P9 states that they also talked about work, such as the support from their bosses, and tips for how they cope with things. With reference to their shared experiences, P9 states that they bonded without having to say too much.

P9 states that she did talk about body image with the two ladies. P9 states that one of the ladies had a mastectomy, stating that it is a huge thing for a lady to through. P9 states that they talked about how their body image may impact relationships and what clothes they wear. P9 recognises that the mastectomy has affected her body confidence, stating that she is scared witless of having a relationship because of how her body looks. Although P9 feels nervous about having reconstructive surgery, P9 says that one of the ladies on the trip was reassuring as she works at the hospital and knows the consultant.

P9 states that they laughed about what people say when they mean well but you don't want them to say it. P9 states that she and the other ladies laughed about when people say, "I bet you're glad it's all over" and "oh, how are you now?", as they can't bear it. P9 is aware that they had a bond and connection about the things they cannot say to other people, such as those questions that drive them mad. P9 states that it was good because the women felt the same things she felt.

P9 recognises that the daughter who came with her is slightly autistic, whereby she finds it hard to talk to people. P9 recognises that although they will talk about it now, her children didn't talk about cancer when she going through it, saying that it had a huge impact on them. P9 recognises that her youngest daughter went into herself during P9's treatment, stating that her daughter had worries. P9 is aware that her

daughter has only got her and her mum, as she doesn't see her dad. P9 says that the crew were brilliant and were very familiar with children who are quiet and reticent. P9 says that the crew involved her daughter in everything associated with sailing, such as steering and going into the lock. P9 states that her daughter still talks about operating the boat, with P9 saying that at one point on the trip, the skipper left her to steer by herself, which caused her to panic but she did incredibly well to remain in charge. P9 states that her daughter did well with the responsibility. P9 says that she feels incredibly happy because somebody showed confidence in her daughter. P9 states that her daughter talks about the sailing quite a lot. Stating that she got pictures of her daughter looking happy, P9 says it was nice for her as she was worried about how her children were coping and feeling while P9 was going through cancer. P9 states that she and the 12 other participants managed to have a go at the sailing. P9 recognises that both she and her daughter were interested in how the locks work and the history of the river they sailed on. P9 states that the crew were knowledgeable as they pointed things out along the way.

With reference to what the sailing trip meant to her, P9 states that it was a change of scenery whereby they just sat and chatted naturally, and cancer wasn't the dominating theme. P9 states that it wasn't a group meeting about cancer survival and there was no pressure to tell anybody. While it was for people who had been through cancer, P9 states that you could talk about cancer if you wanted to but the irony was that it wasn't the focus. P9 says that during the day there was no pre-requirement to talk about their cancer experience but you could start a conversation about what you had experienced within the group if you wanted to. P9 states that the sailing was completely new, whereby they could focus on different things, such as soaking in the day without talking to anybody if you wanted to. P9 is aware that if she is sat by herself, her mind starts to wonder and worry. P9 recognises that she has to be busy doing something else. P9 states that she reflected upon the sailing trip, thinking how about she felt uplifted and noticed that she didn't worry about a thing on the day.

P9 states that before the cancer, she wouldn't go out and do things in the evenings and weekends. P9 states that while she has friends, she was shy and reserved with people she doesn't know. P9 states that she is more social now, whereby she has joined a singles group, a book club, and attends different trips, such as the sailing

trip. P9 says that she is less worried about the little things now, stating she doesn't sweat the small stuff. P9 states that before the cancer, she would make an excuse not to do something, whereas now, she'll go out, explaining that the cancer gave her a scare. P9 is aware that she has moulded herself, whereby her calendar is now full of things to do. P9 states that through the groups she's joined, things have sprung up and she's met people she would never have met before. P9 states that cancer has made her think that it could all change tomorrow.

P9 states that some people were great while she was going through treatment, such as when she lost her hair, but P9 states that when she went back to work and her hair had grown back, people said I bet "you're glad that is all over, you can get back on with your life". P9 states that the cancer has changed her forever. Although nurses talk to her as though she is all good, P9 states that she's on medication for the next 10 years which give her pain and stiffness. P9 has to have a fusion to combat the medication, which gives her similar problems as to those who suffer from osteoporosis. P9 is aware that she is still tired from the treatment. P9 also states that even when the chemotherapy and radiotherapy stops, there is a fear that never goes away. P9 states that if she feels a twinge, she worries about if the cancer has come back, but she tries not to. Although people, be they family or friends, can be caring, P9 states that only someone who has had cancer will understand how much it controls you.

To summarise her experience P9 states that she had a lovely day, whereby she and her daughter met some lovely people who shared a lot about themselves, including the crew who were brilliant and very humorous. Acknowledging that she felt happy after the sailing, P9 recognises that a simple event like sailing was uplifting for her, someone who gets stressed and worries a lot. P9 states that the sailing benefitted her as she wasn't just sat there talking about cancer, which has happened at other formal events to help her move on. P9 states that the sailing in itself is as therapeutic as those formal events that she's attended in the past.

### **Psychological Description – Participant Number Nine**

Participant number nine (P9) stated that she noticed changes and symptoms in herself that were associated with breast cancer. P9 remembered that an oncologist confirmed the diagnosis after an emergency mammogram and biopsy, explaining

that the news was hugely shocking and devastating, with P9 describing how her whole world turned upside down. P9 stated that although she had heard terrible stories of chemotherapy due to working at a hospice, she did not know what lay ahead of her. P9 recognised that she began to reflect on the situation by asking herself a thousand questions about the future, work, money, and her children. P9 acknowledges that this was worsened by extended periods of treatment, which resulted in having a mastectomy, and discussions of having a will in place with an oncologist. P9 reflected upon how this caused her to worry and having sleepless nights, emphasising how she had to have difficult conversations with close friends about the guardianship of her daughters if she were to die, explaining that they were conversations she didn't ever want to have to contemplate.

Yet, P9 stated that the recreational sailing programme she attended was simple in that it helped remove her from a state of being stressed and worried, with P9 describing the program as therapeutic as any other formal event she attended in the past. P9 also says that the program was a change of scenery as hospital appointments usually dominate her calendar. For example, P9 acknowledged that it would be nice for her and her youngest daughter because the event was held on Mother's Day, which meant they could do something completely different together. Understanding that she didn't worry about a thing on the day of the programme, P9 said that she met two other ladies with whom she shared personal conversations about body image, relationships, and other scary topics. P9 also stated that she and the two ladies talked about things that they cannot say to other people, labelling this as black humour as it relates to questions they receive from people that drives them mad.

P9 is aware that she and her daughter, who is slightly autistic, were fully involved in the sailing of the boat, describing how the instructors helped her daughter to steer the vessel. Discussing how her daughter still talks about it, P9 says that she was happy that the instructors showed that level of confidence in her daughter, reflecting on how the instructors were good with children who are quiet and reticent. P9 acknowledges that though events like the recreational sailing programme help her remould herself from her previous sense of life, she is aware that cancer has changed her forever. P9 explained how she is going to be taking medication for the next ten years for treatment-related side-effects that are similar to osteoporosis. P9

recognises that family and friends try to be supportive, but they do not know how much cancer controls her, stating that there is a fear that never goes away.

**Participant Number Four: Step Three – Transformation of the participant’s natural attitude expressions into phenomenologically sensitive expressions.**

Original description of the lifeworldly expression.	Third-person description of lifeworldly expression.	Psychological sense of the expression.	Transformation of the expression.
<p><b>I think the, erm, basis of these types of charities like these is the... well, especially the trip I went on, is to build up the confidence of every patient... and it definitely built up my confidence... hard to describe... kind of</b></p>	<p>P4 states that he thinks the, erm, basis of these types of charities like these is the... well, especially the trip he went on, is to build up the confidence of every patient... P4 says that it definitely built up my confidence... hard to describe... kind of</p>	<p>With reference to the meaning of the trip, P4 states that these types of charities and trips like the sailing is to build confidence, saying that it definitely built up his confidence.</p>	<p>P4 states that the meaning of the charity and the trip is to build confidence, saying that it built up his confidence.</p>
<p><b>R: Ok, so when you say your confidence... So, like, if you’re shy, like I am, and closed and do not want to express their feelings about what you’ve been through, these kinds of trips can help you to express what you have been feeling and build up your confidence throughout the trip</b></p>	<p>P4 says so, like, if you’re shy, like he is, and closed and do not want to express your feelings about what you’ve been through, these kinds of trips can help you to express what you have been feeling and build up your confidence throughout the trip.</p>	<p>P4 states that he is shy, closed and does not want to express his feelings about what he has been through, proposing that these trips can help express what you have been through and build up confidence.</p>	<p>P4 states that he is shy, closed and does not want to express his feelings about what he has been through, proposing that these trips can help express what you have been through and build up confidence.</p>

<p><b>And the staff were so friendly. They can just, well, not force it out of you but encourage it out of you... they're not forcing you to do anything but they are so helpful, and these trips have definitely boosted my confidence a lot...</b></p>	<p>P4 states that the staff were so friendly. P4 says that they (the staff) can just, well, not force it out of you but encourage it out of you... they're not forcing you to do anything but they are so helpful, and these trips have definitely boosted his confidence a lot...</p>	<p>With reference to boosting his confidence, P4 is aware that the staff on the sailing trip were friendly, describing them as encouraging but not forceful.</p>	<p>With reference to boosting his confidence, P4 is aware that the staff on the sailing trip were friendly, describing them as encouraging but not forceful.</p>
<p><b>R: Ok, sure... before you went on the trip, did you feel like you couldn't express yourself?</b>  <b>Erm... a little but not really... I was always open to my mum and, well, both parents but there was a time when I would always keep it to myself, but these trips have just helped me release everything.</b></p>	<p>P4 states erm... a little but not really... P4 says he was always open to his mum and, well, both parents but there was a time when he would always keep it to himself, but these trips have just helped him release everything.</p>	<p>With reference to feeling like he could and couldn't express himself before he went on the sailing trips, P4 acknowledges that he was open with both parents and there were times when he would keep it to himself, but the sailing helped release everything.</p>	<p>P4 acknowledges that the sailings trips helped him release everything, despite being open with both of his parents and keeping it to himself.</p>
<p><b>R: Yes... ok... so, when you say release everything... can you tell me more about that?</b>  <b>Well, I express everything to everybody now... my confidence was always just ok. I was always quite shy but this has boosted my confidence so much. Like every time I am out, I talk to people, saying, "Hi, how are you?"</b></p>	<p>P4 states that he expresses everything to everybody now... saying that his confidence was always just ok. P4 says that he was always quite shy but this has boosted his confidence so much. P4 says like every time he is out, he talks to people, saying, "Hi, how are you?"</p>	<p>P4 states that he now expresses everything, describing that his confidence in the past was just ok and he had always been quite shy. P4 states that he now talks to people when he is out, asking how they are.</p>	<p>P4 states that he now expresses everything, describing that his confidence in the past was just ok and he had always been quite shy. P4 states that he now talks to people when he is out, asking how they are.</p>
<p><b>These trips... it's definitely helped so much. I wasn't too closed off but yeah, it was a great weekend.</b></p>	<p>P4 states that these trips... it's definitely helped so much. P4 says he wasn't too closed off but yeah, it was a great weekend.</p>	<p>Stating that the trips have helped so much, P4 acknowledges that he wasn't too closed off and that it was a great weekend.</p>	<p>Stating that the trips have helped so much, P4 acknowledges that he wasn't too closed off and that it was a great weekend.</p>



<p><b>R: Can you describe the weekend and what happened?</b></p> <p><b>Well, first off, we sailed out of the river Hamble in the harbour. We were being taught the basics of the boat, you know, to get the sail up, how to do it. We tacked and tacked our way through the sea. We had some lunch and docked in for the night at the Isle of Wight. We then sailed all the way back to the mainland the following day. On the way back, we were learning some of the knots as well. I remember doing the figure eight.</b></p>	<p>P4 states that they sailed out of the river Hamble in the harbour. P4 says they were being taught the basics of the boat, you know, to get the sail up, how to do it. P4 says that they tacked and tacked their way through the sea, had some lunch, and docked in for the night at the Isle of Wight. P4 says they then sailed all the way back to the mainland the following day. P4 states that on the way back, they were learning some of the knots as well. P4 says he remembers doing the figure eight.</p>	<p>With reference to what happened on the weekend of sailing, P4 describes sailing out of the river Hamble. P4 says that they were taught the basics of sailing, stating he learned how to raise the sail. P4 says that they tacked their way through the sea before docking in for the night at the Isle of Wight. P4 states that they sailed back to the river Hamble the following morning, and he can remember learning how to do the figure-eight knot.</p>	<p>P4 states that the weekend consisted of sailing from the River Hamble to the Isle of Wight. P4 states he was taught the basics of sailing such as raising the sail, tacking through the sea and learning the figure-eight knot.</p>
<p><b>But yeah, they are great life skills to have.</b></p>	<p>P4 states yeah, they are great life skills (sailing) to have.</p>	<p>P4 states that sailing skills are great life skills to have.</p>	<p>P4 states that sailing skills are great life skills to have.</p>
<p><b>R: Ok... when you say we, who else was there?</b></p> <p><b>Well, obviously, when you start off, you don't really talk to each other... but when you progress into the trip, you get to know them a bit more, you start to become friends and I made friends with pretty much everyone on that trip that weekend. Yeah, we all had a blast on the boat.</b></p>	<p>P4 states that well, obviously, when you (he and the other teenagers) start off, you don't really talk to each other... but when you progress into the trip, you get to know them a bit more, you start to become friends and he made friends with pretty much everyone on that trip that weekend. P4 states yeah, they all had a blast on the boat.</p>	<p>P4 states that at the start of the sailing weekend, he and the other teenagers didn't talk to each other. P4 says that as they progressed into the trip, he got to know them a bit more, acknowledging that he made friends with everyone, realising that they all had a blast on the boat.</p>	<p>P4 states that at the start of the sailing weekend, he and the other teenagers didn't talk to each other. P4 says that as they progressed into the trip, he got to know them a bit more, acknowledging that he made friends with everyone and they all had a blast on the boat.</p>
<p><b>R: In what way did you have a blast?</b></p> <p><b>All having such a good time. Having a</b></p>	<p>P4 states that they all were having such a good time. P4 states they were having a</p>	<p>With reference to how they had a blast together, P4 states that they were having</p>	<p>P4 states that they were having a good time together, whereby they had a</p>

<p><b>laugh. Learning more things about the boat and learning more about what the charity does.</b></p>	<p>laugh. P4 says that they were learning more things about the boat and learning more about what the charity does.</p>	<p>a good time whereby they had a laugh together. P4 states that they were learning more about the boat and what the 4 Cancer Group does.</p>	<p>laugh as a group. P4 states that they were learning more about the boat and what the 4 Cancer Group does.</p>
<p><b>R: And you talked about the staff as well?</b>  <b>Yeah, the staff were so helpful. They were really kind. They would understand if you didn't get it the first time around, but they would guide you step-by-step on how to do the process of tacking and putting the sail up... They were very kind when we arrived.</b></p>	<p>P4 states that yeah, the staff were so helpful. P4 says that they were really kind. P4 says that they (the staff) would understand if you didn't get it the first time around, but they would guide you step-by-step on how to do the process of tacking and putting the sail up... P4 says that they were very kind when we arrived.</p>	<p>With reference to the staff, P4 states they were kind and helpful, especially when he arrived. P4 acknowledges that they would help you step-by-step on how to do the tacking or putting up the sail, even if he didn't get it the first time around.</p>	<p>P4 states the staff were kind and helpful, especially when he arrived. P4 acknowledges that they would help you step-by-step on how to do the tacking or putting up the sail, even if he didn't get it the first time around.</p>
<p><b>R: What were your initial thoughts when you arrived?</b>  <b>I was thinking before this trip that it would be fun to go sailing for a while but there was a feeling of other people, not too much of shy way but not knowing them. But my target was to get to know them and be their friend, and luckily, I did.</b></p>	<p>P4 states that he was thinking before this trip that it would be fun to go sailing for a while but there was a feeling of other people, not too much of shy way but not knowing them. P4 says but his target was to get to know them and be their friend, and luckily, he did.</p>	<p>With reference to his initial thoughts when he arrived, P4 is aware that he thought it would be fun to go sailing. P4 was aware of the feeling of other people, stating that it wasn't too much in a shy way but in a way of not knowing them. P4 says that he wanted to get to know them, and luckily, he did.</p>	<p>P4 recognises that his initial thoughts were that it would be fun to go sailing, but he was aware that he didn't know the other people that would be there, but it wasn't in a shy way. P4 recognises that he wanted to be their friend and, luckily, he did that.</p>
<p><b>But when you arrive somewhere, like, new when you don't know anyone, your main target is to make friends and learn something...</b></p>	<p>P4 states but when you arrive somewhere, like, new when you don't know anyone, your main target is to make friends and learn something...</p>	<p>P4 is aware that when he arrives in a new place, his main target is to make friends and learn something.</p>	<p>P4 is aware that when he arrives in a new place, his main target is to make friends and learn something.</p>
<p><b>R: Do you think you did that on this trip we are talking about?</b>  <b>Yeah...</b></p>	<p>P4 states yeah (he did make friends and learn something new). P4 says that as a team, all as a team. P4</p>	<p>With reference to if and how he made friends and learnt something new, P4 states that they were</p>	<p>P4 states that he is aware that the sailing helped each other work as a team and</p>

<p><b>R: Ok... so how did you do this?</b></p> <p><b>As a team... all as a team. It really helped our teamwork and our communication skills with each other.</b></p>	<p>says it really helped our teamwork and communication skills with each other (how they did this).</p>	<p>a team, which helped their teamwork and communication skills with each other.</p>	<p>communicate with each other.</p>
<p><b>R: What role did you take on in the team?</b></p> <p><b>Well, in the midst of the sailing, I was encouraging everyone but not telling them what to do. But, like, to compare, whenever I am playing rugby, I always try to motivate my teammates. So, when we were on the boat and we were putting up the sail, I was trying to inspire the guys by saying “come on guys, we can do this”. So, I would be that motivating figure.</b></p>	<p>P4 states that well, in the midst of the sailing, he was encouraging everyone but not telling them what to do. P4 says that but, like, to compare, whenever he is playing rugby, he always tries to motivate his teammates. P4 says so, when we were on the boat and we were putting up the sail, he was trying to inspire the guys by saying “come on guys, we can do this”. P4 states so, he would be that motivating figure.</p>	<p>With reference to his role in the team when sailing, P4 describes himself as motivating figure, encouraging everyone but not telling them what to do. P4 uses the example of putting up the sail as a way of describing how he inspired the team to do it.</p>	<p>With reference to his role in the team when sailing, P4 describes himself as motivating figure, encouraging everyone but not telling them what to do. P4 uses the example of putting up the sail as a way of describing how he inspired the team to do it.</p>
<p><b>R: How did everyone react to this on the boat?</b></p> <p><b>Well, they laughed along with me, but I do think I motivated them a lot. We worked as a team really well. We were always in sync when we were doing our jobs, like putting up the sail.</b></p>	<p>P4 states that well, they laughed along with him, but he does think he motivated them a lot. P4 says that they worked as a team really well. P4 says that they were always in sync when we were doing their jobs, like putting up the sail.</p>	<p>P4 recognises that although everyone was laughing with him, he motivated them a lot, stating that they worked well as a team and were always in sync when they were doing their jobs.</p>	<p>P4 recognises that although everyone was laughing with him, he motivated the team a lot, stating that they worked well together and were always in sync when they were doing their jobs.</p>
<p><b>R: Did you expect this to happen on your trip? In terms of your involvements?</b></p> <p><b>Erm, no. I didn't expect myself to be so involved. And normally, I step back a bit, but I do</b></p>	<p>P4 states erm, no. P4 says he didn't expect himself to be so involved. P4 acknowledges that normally, he steps back a bit, but he does sometimes lead from the front.</p>	<p>P4 is aware that he didn't expect to be so involved. P4 states that normally we will step back but he will sometimes lead from the front in situations.</p>	<p>Though he acknowledges that normally he does step back in these situations and that he wasn't expecting to be so involved in the sailing, P4 is aware that he does</p>

sometimes lead from the front.			sometimes lead from the front.
<b>R: And did this happen on the trip? I wouldn't say I was taking charge because of the staff but I always there to be the motivator.</b>	P4 states that he wouldn't say he was taking charge because of the staff but he was always there to be the motivator.	P4 recognises that his position was of the motivator rather than taking charge and responsibility.	P4 recognises that his position was of the motivator rather than taking charge and responsibility.
<b>R: Ok... so upon reflecting upon that part of the trip, what did all of that mean to you? Making new friends and the life skill of sailing and cooking, too.</b>	P4 states that making new friends and the life skill of sailing and cooking, too (was the meaning of trip).	P4 states that the meaning of the trip for him was making new friends and developing life skills such as sailing and cooking.	P4 states that the meaning of the trip for him was making new friends and developing life skills such as sailing and cooking.
<b>On the boat, we cooked some meals. On the first night, we cooked spaghetti (laughs) and it went fairly well. I and my friend both did really well and we both enjoyed the cooking. It's funny because I didn't see this side to me a few years ago.</b>	P4 states that on the boat he cooked some meals. P4 says on the first night we cooked spaghetti (laughs) and it went fairly well. P4 says that he and his friend both did really well and they both enjoyed the cooking. P4 says that it's funny because he didn't see this side to himself a few years ago.	P4 recognises that the sailing weekend helped see a new side to him that he didn't see a few years ago. P4 reflects on the experience of cooking with his friend on the trip, stating that they both cooked spaghetti, which went well.	P4 recognises that the sailing weekend helped see a new side to him that he didn't see a few years ago. P4 reflects on the experience of cooking with his friend on the trip, stating that they both cooked spaghetti, which went well.
<b>R: How do you mean? Well, with the cancer, you know, I had a brain tumour in my head that was the size of a lemon. It was giving me extreme headaches and making me vomit because it was pushing on my nerves. But yeah, I would've never had done any of this if it hadn't been for the cancer.</b>	P4 states that well, with the cancer, you know, he had a brain tumour in his head that was the size of a lemon. P4 says that it was giving him extreme headaches and making him vomit because it was pushing on his nerves. P4 says but yeah, he would've never had done any of this if it hadn't been for the cancer.	P4 is aware that had it not been for the cancer, which he states was the size of a lemon, he would never have done any this (sailing weekends)	P4 is aware that had it not been for the cancer, which he states was the size of a lemon that caused him to vomit and produced extreme headaches, he would never have done these teenage sailing weekends.
<b>But yeah, the symptoms were terrible. I was getting</b>	P4 states but yeah, the symptoms were terrible. P4 says he	P4 recognises that the symptoms of cancer were terrible. P4	P4 recognises that the symptoms of cancer were terrible. P4

<p>lots of headaches and the paracetamol just wasn't working. Through the summer holidays, I was still getting bad headaches and my vision started to go, so we went to the optician and I got some glasses. They still weren't helping because I was still getting headaches. I then got a stronger prescription and it improved a little but not entirely because I was getting double vision.</p>	<p>was getting lots of headaches and the paracetamol just wasn't working. Through the summer holidays, he was still getting bad headaches and his vision started to go, so he went to the optician and he got some glasses. P4 says they still weren't helping because he was still getting headaches. P4 says he then got a stronger prescription and it improved a little but not entirely because he was getting double vision.</p>	<p>states that he twice got a glasses prescription to help but he was still getting the headaches and double vision.</p>	<p>states that he twice got a glasses prescription to help but he was still getting the headaches and double vision.</p>
<p>After that, around the November time, the headaches were shorter but they were really, really painful and I was vomiting too. Mum and dad thought it was a migraine and I thought that too, maybe, you know, because of the teenage hormones kicking in. Going into Christmas, December time, I was properly vomiting all of the time and the headaches were there every morning. I was sometimes screaming in pain.</p>	<p>P4 states that after that, around the November time, the headaches were shorter but they were really, really painful and he was vomiting too. P4 says that his mum and dad thought it was a migraine and he thought that too, maybe, you know, because of the teenage hormones kicking in. P4 states that going into Christmas, December time, he was properly vomiting all of the time and the headaches were there every morning. P4 states that he was sometimes screaming in pain.</p>	<p>P4 recognises that in November, the headaches were shorter but significantly more painful and he was still vomiting, which he and his parents' thought was due to adolescent hormones. P4 states that around December, he was vomiting all the time and he was having headaches every morning, whereby he was sometimes screaming in pain.</p>	<p>P4 states that during both November and December, his symptoms were getting significantly worse. Although he and his parents thought it was adolescent hormones, P4 was sometimes screaming in pain due to the daily headaches and vomiting.</p>
<p>And then after Christmas, once I got back to my grandparents, I went</p>	<p>P4 states then after Christmas, once he got back to his grandparents, he</p>	<p>P4 recognises that after arriving at his grandparents after Christmas, he went to</p>	<p>P4 states that after Christmas he went to the hospital on the 4<sup>th</sup> January as he just</p>

<p>to the hospital because I just wasn't right. We went down to the optician in the hospital and she believed she saw something on a scan. So we went down for a CT scan and that day, 4<sup>th</sup> January, I was diagnosed with big lemon, brain tumour. It just flipped my world upside down.</p>	<p>went to the hospital because he just wasn't right. P4 states that we (he and his family) went down to the optician in the hospital and she believed she saw something on a scan. P4 says so we (he and his family) went down for a CT scan and that day, 4<sup>th</sup> January, he was diagnosed with big lemon, brain tumour. P4 says that it just flipped his world upside down.</p>	<p>the hospital as he just wasn't right. P4 and his family first went to see the optician, who then referred P4 for a CT scan after seeing something on a scan. P4 says that it was then on the 4<sup>th</sup> January when he was diagnosed with a brain tumour, describing it as something that flipped his world upside down.</p>	<p>wasn't right. P4 states that an optician referred him for a CT scan at the hospital, which revealed that he a brain tumour, describing it as something that flipped his world upside down.</p>
<p>R: Ok... thank you for sharing that. When you say "flipped your world upside down"... how did this happen for you? I was this big sportsman and I loved my sport. I enjoyed going out with my friends. I enjoyed playing video games with my friends. I enjoyed not being in pain (laughs). But when I found out I was diagnosed, it made me realise that I had a huge journey ahead and that I was very close to death. And knowing that I could not play rugby or be with my friends, my mum started crying and so did I really, but I knew I was going to fight it and try to survive. Luckily, I did.</p>	<p><b>P4 states that he was this big sportsman and he loved his sport. P4 says that he enjoyed going out with his friends. P4 states that he enjoyed playing video games with his friends. P4 states that he enjoyed not being in pain (laughs). P4 states but when he found out he was diagnosed, it made him realise that he had a huge journey ahead and that he was very close to death. P4 states that and knowing that he could not play rugby or be with his friends, his mum started crying and so did he really, but he knew he was going to fight it and try to survive. P4 sates luckily, he did.</b></p>	<p>P4 is aware that he enjoyed sport, going out with friends, playing video games with friends, and not being in pain before he was diagnosed. P4 states that when he was diagnosed, he acknowledged that he had a huge journey ahead of him, realising that he was close to death. P4 states that he and his mum cried, but he knew he had to try to fight it and survive, saying that he was lucky that he did.</p>	<p>P4 is aware that he enjoyed sport, going out with friends, playing video games with friends, and not being in pain before he was diagnosed. P4 states that when he was diagnosed, he acknowledged that he had a huge journey ahead of him, realising that he was close to death. P4 states that he and his mum cried, but he knew he had to try to fight it and survive, saying that he was lucky that he did.</p>
<p>It just flipped my world upside down because it changed</p>	<p>P4 states that it just flipped his world upside down because</p>	<p>P4 is aware that the diagnosis flipped his world upside in two</p>	<p>P4 is aware that the diagnosis flipped his world upside in two</p>



<p>my routine completely. I mean, before then, I was never going to go for head boy at my school. Like, in year 9 or 10, I was, like, no I am not going to go for it whatsoever and my grades weren't the best either. But then, after going through the treatment, it made me realise how close to you are to death. Your life is short and you've got to live it, you only live once. So, in a way, it boosted my confidence tremendously. At the end of that very year, year 10, I did go for head boy and I managed to get it. It's improved my grades tremendously too. When it flipped my world upside down, it had, like, a positive impact on me, if that makes sense.</p>	<p>it changed his routine completely. P4 means, before then, he was never going to go for head boy at his school. P4 states that like, in year 9 or 10, he was, like, no he is not going to go for it whatsoever and his grades weren't the best either. P4 states that but then, after going through the treatment, it made him realise how close to you are to death. P4 says that your life is short and you've got to live it, you only live once. P4 says that so, in a way, it boosted his confidence tremendously. P4 says that at the end of that very year, year 10, he did go for head boy and he managed to get it. P4 notes that it's improved his grades tremendously too. P4 states that when it flipped my world upside down, it had, like, a positive impact on him, if that makes sense.</p>	<p>ways. P4 states that the diagnosis firstly changed his routine before having a positive impact on him. P4 is aware that being close to death boosted his confidence as he realised he only has one life. P4 reflected on the fact that after the treatment he applied for head boy at his school, something of which he never thought of doing, and that his grades improved tremendously too.</p>	<p>ways. P4 states that the diagnosis firstly changed his routine before having a positive impact on him. P4 is aware that being close to death boosted his confidence as he realised he only has one life. P4 reflected on the fact that after the treatment he applied for head boy at his school, something of which he never thought of doing, and that his grades improved tremendously too.</p>
<p><b>R: Yes...</b> Like it had a positive and negative impact. It made me more confident. It made me more, like, listen in lessons now. But negatively, I could've died.</p>	<p>P4 states that like it (cancer diagnosis) had a positive and negative impact. P4 says that it made him more confident. P4 says that it made him more, like, listen in lessons now. P4 says but negatively, he could've died.</p>	<p>P4 is aware that the cancer diagnosis had both a positive and negative impact on him. P4 is aware that it helped him academically, but he also acknowledged that he could've died.</p>	<p>P4 is aware that the cancer diagnosis had both a positive and negative impact on him. P4 is aware that it helped him academically, but he also acknowledged that he could've died.</p>
<p><b>R: Ok. With reference to the positive and</b></p>	<p>P4 states that he saw a positive opportunity</p>	<p>P4 recognises that he saw the sailing trip as</p>	<p>P4 recognises that he saw the sailing trip as</p>

<p>negative, in which way did you see the sailing trip with the 4 Cancer Group?</p> <p>I saw a positive opportunity because sometimes you don't have the money to do it and it isn't an everyday hobby. I saw it as a once in a lifetime opportunity. So yeah, I said, let's go sailing. Good opportunity for life skills, make friends and learn a thing or two about the sea and the principles you need to understand.</p>	<p>(to go sailing) because sometimes you don't have the money to do it and it isn't an everyday hobby. P4 states that he saw it as a once in a lifetime opportunity. P4 states so yeah, he said, let's go sailing. P4 says that it was a good opportunity for life skills, make friends and learn a thing or two about the sea and the principles you need to understand.</p>	<p>a positive opportunity as it isn't an everyday hobby and can be quite expensive. P4 states that it was a once in a lifetime opportunity to go sailing, whereby he could learn life skills, make friends and learn the principles about sea sailing.</p>	<p>a positive opportunity as it isn't an everyday hobby and can be quite expensive. P4 states that it was a once in a lifetime opportunity to go sailing, whereby he could learn life skills, make friends and learn the principles about sea sailing.</p>
<p>R: What was it like when you went out to sea?</p> <p>Being out on the water, I was a bit nervous because I didn't really know what I was doing. I mean, when I first went out on the helm, we were in a gale wind and I've never been so frightened, in a funny way. The skipper told me to make "slow movements" and the first thing I did was a huge movement on the helm.</p>	<p>P4 states that being out on the water, he was a bit nervous because he didn't really know what he was doing. P4 states he means, when he first went out on the helm, we were in a gale wind and he's never been so frightened, in a funny way. P4 says that the skipper told him to make "slow movements" and the first thing he did was a huge movement on the helm (laughs).</p>	<p>With reference to what it was like sailing in the sea, P4 states that he was nervous. While laughing, P4 states that he didn't know what he was doing, as he made a big movement when steering the boat at the helm when the skipper told him to make slow movements.</p>	<p>With reference to what it was like sailing in the sea, P4 states that he was nervous. While laughing, P4 states that he didn't know what he was doing, as he made a big movement when steering the boat at the helm when the skipper told him to make slow movements.</p>
<p>But yeah, after a while, my knowledge of the boat was a lot better because of the time we spent doing the jobs we had to do. But yeah, it comes back to my mindset of seeing things</p>	<p>P4 states but yeah, after a while, his knowledge of the boat was a lot better because of the time they spent doing the jobs they had to do. P4 states but yeah, it comes back to his mindset of seeing</p>	<p>With reference to his mindset seeing things positively and negatively, P4 is aware that his knowledge of the boat was a lot better after spending time doing different jobs.</p>	<p>With reference to his mindset seeing things positively and negatively, P4 is aware that his knowledge of the boat was a lot better after spending time doing different jobs.</p>



<p><b>positively and negatively.</b></p>	<p>things positively and negatively.</p>		
<p><b>R: Sure... Can you talk some more about that mindset?</b>  <b>I approach things with an open mind. Always an open mind, a smile on my face, and be positive. I just feel like everything should be approached with an open mind, and that is how the sailing has helped me.</b></p>	<p>P4 states that he approaches things with an open mind. P4 says always an open mind, a smile on his face, and be positive. P4 states that he just feels like everything should be approached with an open mind, and that is how the sailing has helped him.</p>	<p>With reference to his mindset, P4 states he approaches things with an open mind, a smile on his face and positivity, stating that is how the sailing helped him.</p>	<p>P4 states he approaches things with an open mind, a smile on his face, and positivity, stating that is how the sailing helped him.</p>
<p><b>It may be losing a rugby match against the hardest team in the county or going through a tough time with school but you've always got to go in with an open mind of you can do it or you can win. Even though you might be the second-best at something, you've always got to have that mindset because it'll get you far in life, and that is what I believe now. That you have to go into everything with that mindset now. Like, knowing how to sail, it might get me somewhere in life now.</b></p>	<p>P4 states that it may be losing a rugby match against the hardest team in the county or going through a tough time with school but you've always got to go in with an open mind of you can do it or you can win. P4 says that even though you might be the second-best at something, you've always got to have that mindset because it'll get you far in life, and that is what he believes now. P4 says that you have to go into everything with that mindset now. P4 notes it is like, knowing how to sail, it might get him somewhere in life now.</p>	<p>P4 is aware that his open mindset applies to his participation in rugby matches and school, stating that he always go in with an open mindset now. P4 states that he believes that this will get him far in life, saying that learning and knowing how to sail is a part of that.</p>	<p>P4 is aware that his open mindset applies to his participation in rugby matches and school, stating that he always go in with an open mindset now. P4 states that he believes that this will get him far in life, saying that learning and knowing how to sail is a part of that.</p>
<p><b>If you see what I mean. Everyone looks at open-mindedness differently.</b></p>	<p>P4 states ff you see what I mean. P4 says everyone looks at open-mindedness differently.</p>	<p>P4 is aware that everyone looks at open-mindedness differently.</p>	<p>P4 is aware that everyone looks at open-mindedness differently.</p>

<p><b>R: And you see it in the way that you just described?</b></p> <p><b>Yeah, so if you've never tried something before and it does seem interesting, then why not? I just like to think of it as, like, an opportunity to learn new things. The amount of things I've done now because of it is just ridiculous when I think back to how shy I was. The mindset chooses who you will be.</b></p>	<p>P4 states yeah, so if you've never tried something before and it does seem interesting, then why not? P4 says he just likes to think of it as, like, an opportunity to learn new things. P4 states that the amount of things he's done now because of it is just ridiculous when he thinks back to how shy he was. P4 says the mindset chooses who you will be.</p>	<p>With reference to how he sees open-mindedness, P4 states that he thinks of it as opportunities to do new things that seem interesting if you've never tried them before. P4 states that mindset chooses who you will be, saying that it's ridiculous how much he has done now when he thinks back to how shy he was.</p>	<p>P4 states that he thinks of open-mindedness as opportunities to do new things that seem interesting if you've never tried them before. P4 states that mindset chooses who you will be, saying that it's ridiculous how much he has done now when he thinks back to how shy he was.</p>
<p><b>But yeah, to keep it on track, the sailing helped so much. It just helps you to get to know people you don't know in such a short period of time. They get to learn so much about you and you get to learn so much about them, that's what these trips do. They help the patient open up and make new friends who have gone through a similar situation. And, as I said, the staff are there to help and be really kind.</b></p>	<p>P4 states but yeah, to keep it on track, the sailing helped so much. P4 says it just helps you to get to know people you don't know in such a short period of time. P4 says they get to learn so much about you and you get to learn so much about them, that's what these trips do. P4 states that they help the patient open up and make new friends who have gone through a similar situation. And, as he said, the staff are there to help and be really kind.</p>	<p>P4 recognises that the sailing helped so much, as it helps you get to know and learn about other people in a short space of time. P4 is aware that these trips helped him open up and make friends with people who have been through a similar situation, saying that the staff were helpful and kind too.</p>	<p>P4 recognises that the sailing helped so much, as it helps you get to know and learn about other people in a short space of time. P4 is aware that these trips helped him open up and make friends with people who have been through a similar situation, saying that the staff were helpful and kind too.</p>
<p><b>R: To use your words, how did everyone open up?</b></p> <p><b>Well, not too far but ask them in a polite way. So I said to someone, "if you don't mind me asking, what kind of</b></p>	<p>P4 states well, not too far but you had to ask them in a polite way. P4 says so he said to someone, "if you don't mind me asking, what kind of cancer did you have?". P4 says that he meant no</p>	<p>With reference to opening up, P4 states that he would ask people in a polite and respectful way about what kind of cancer they had. P4 states it was fine if they didn't want to tell him, but if</p>	<p>With reference to opening up, P4 states that he would ask people in a polite and respectful way about what kind of cancer they had. P4 states it was fine if they didn't want to tell him, but if</p>

<p>cancer did you have?”. I meant no disrespect by it and if they didn’t want to tell me, it was absolutely fine. But if they did, I would listen and try and help them.</p>	<p>disrespect by it and if they didn’t want to tell him, it was absolutely fine. P4 states but if they did, he would listen and try and help them.</p>	<p>they did he would listen and try and help them.</p>	<p>they did he would listen and try and help them.</p>
<p><b>R: Did that happen on the day? Some people open up and some didn’t?</b>  <b>Yeah, well, because this trip is to help people’s confidence, I didn’t find anyone not willing to open up about what they have been through. These trips really do help in that sense.</b></p>	<p>P4 states yeah, well, because this trip is to help people’s confidence, he didn’t find anyone not willing to open up about what they have been through. P4 states that these trips really do help in that sense.</p>	<p>P4 recognises that the sailing trips help in these that it helps people’s confidence, whereby people can open up about what they have been through.</p>	<p>P4 recognises that the sailing trips help in these that it helps people’s confidence, whereby people can open up about what they have been through.</p>
<p><b>R: Did you share anything with your group?</b>  <b>Yeah, I was quite open and I did tell them about what I had been through...</b></p>	<p>P4 states that yeah, he was quite open and he did tell them about what he had been through...</p>	<p>With reference to sharing anything with his group, P4 is aware that he was quite open in the sense that he did tell them what he had been through.</p>	<p>With reference to sharing anything with his group, P4 is aware that he was quite open in the sense that he did tell them what he had been through.</p>
<p><b>R: How did the others respond to this?</b>  <b>Blimey, was the tumour that big (laughs). Yeah, the shock of never expecting someone to have a tumour that big. A large, lemon-like tumour inside of your brain.</b></p>	<p>Blimey, was the tumour that big (laughs). Yeah, the shock of never expecting someone to have a tumour that big. A large, lemon-like tumour inside of your brain.</p>	<p>P4 is aware that the others who attended the sailing weekend were shocked to learn of how big his brain tumour was.</p>	<p>P4 is aware that the others who attended the sailing weekend were shocked to learn of how big his brain tumour was.</p>
<p><b>Again, you never expect someone to have leukaemia at my age, you never expect it. They did and didn’t understand it, if you get what I mean.</b></p>	<p>Again, you never expect someone to have leukaemia at my age, you never expect it. They (the others on the trip) did and didn’t understand it, if you get what I mean.</p>	<p>P4 recognises that you don’t expect someone his age to have leukaemia, stating that some of the others on the trip could understand while others could not.</p>	<p>P4 recognises that you don’t expect someone his age to have leukaemia, stating that some of the others on the trip could understand while others could not.</p>
<p><b>With cancer, it’s such a common thing but</b></p>	<p>P4 states that with cancer, it’s such a</p>	<p>P4 recognises that you don’t expect</p>	<p>P4 recognises that you don’t expect</p>

<p><b>then you don't expect it to be so close to you. Even the friends who hadn't suffered, they did try to help and talk about the situation. On and off the trip, my friends were definitely there and were talking to me, always being nice to me, but, without being mean, never understood what it was like.</b></p>	<p>common thing but then you don't expect it to be so close to you. P4 states that even the friends (on the trip) who hadn't suffered, they did try to help and talk about the situation. P4 says that on and off the trip, his friends were definitely there and were talking to him, always being nice to him, but, without being mean, they never understood what it was like.</p>	<p>cancer to be close you despite it being common. P4 states that both on and off the trip, his friends were there to talk to him, be nice to him, and talk about the situation. P4 is aware that they never fully understood what it was like.</p>	<p>cancer to be close you despite it being common. P4 states that both on and off the trip, his friends were there to talk to him, be nice to him, and talk about the situation. P4 is aware that they never fully understood what it was like.</p>
<p><b>But I was told that it was worse being a friend of the patient rather than being the patient themselves because you may or may not lose someone close to you.</b></p>	<p>But I was told that it was worse being a friend of the patient rather than being the patient themselves because you may or may not lose someone close to you.</p>	<p>P4 acknowledges that he was told that it was worse being a friend of a cancer patient as you may or may not lose someone close to you.</p>	<p>P4 acknowledges that he was told that it was worse being a friend of a cancer patient as you may or may not lose someone close to you.</p>
<p><b>R: Did your friends talk about that with you? Well, my mum, for example, it's been harder for her than it has been for me. But the sailing trips, although she was worried, have shown her that I am better now. She's happy that I am at the stage I am now.</b></p>	<p>P4 states well, my mum, for example, it's been harder for her than it has been for me. But the sailing trips, although she was worried, have shown her that I am better now. She's happy that I am at the stage I am now.</p>	<p>P4 recognises that it's been harder for his mum than it has for him. P4 states that she was initially worried about the sailing trips but they have shown her that he is better now, making her happy with his progress.</p>	<p>Although P4 recognises that it's been harder for his mum than it has been for him, P4 does recognise that the sailing trips have shown her that he is better now.</p>
<p><b>That's the funny thing about these trips. My mum was scared for me and so was I, a little. But you're happy at the same time. It was like a rollercoaster really. You are petrified but it's actually quite fun,</b></p>	<p>P4 states that's the funny thing about these trips. P4 says that his mum was scared for him and so was he, a little. P4 states but you're happy at the same time. P4 says that it was like a</p>	<p>P4 recognises that the sailing trips were scary for him and his mum, but P4 suggests that you're happy at the same time. P4 compares the sailing to a rollercoaster, describing it as fun, petrifying and a mixed</p>	<p>P4 acknowledges that the trips were scary for him and his mum, stating that he wasn't sure how he was going to react. P4 says that he was happy and compares the sailing to a rollercoaster,</p>

<p><b>it's a mixed bag but in a good way. You are not sure how you are going to react.</b></p>	<p>rollercoaster really. P4 says that you are petrified but it's actually quite fun, it's a mixed bag but in a good way. P4 says that you are not sure how you are going to react.</p>	<p>bag. P4 wasn't sure how he was going to react in this setting.</p>	<p>describing it as a mixed bag of being fun and petrifying.</p>
<p><b>R: Thank you for sharing that. I know we are pressed for time today, but is there anything else you would like to add? I would just like to talk quickly about the legacy effect. We're meeting in Exeter soon and we're just going to hang out for the day. It's funny because I don't think we all would've been friends if it wasn't for the cancer. We're all very different people and we all come from different walks of life, but we share in something that is very powerful and it becomes, like, a family feeling. We all have such a strong bond together.</b></p>	<p>P4 states that he would just like to talk quickly about the legacy effect. P4 says that we're (him and the others on the sailing trip) are meeting in Exeter soon and they're just going to hang out for the day. P4 says that It's funny because he doesn't think they all would be friends if it wasn't for the cancer. P4 states that they're all very different people and they all come from different walks of life, but they share in something that is very powerful and it becomes, like, a family feeling. P4 states that they all have such a strong bond together.</p>	<p>P4 recognises that there has been a legacy effect between him and the others on the sailing trip. P4 states that they're meeting up to hang out soon while acknowledging that had it not been for the cancer they probably would not be friends. P4 says that they're all very different people but they share in something very powerful, stating that they are like a family with a strong bond.</p>	<p>P4 recognises that there has been a legacy effect between him and the others on the sailing trip. P4 states that they're meeting up to hang out soon, while acknowledging that had it not been for the cancer they probably would not be friends. P4 says that they're all very different people but they share in something very powerful, stating that they are like a family with a strong bond.</p>

# **Step Four**

# **Participant**

# **No.4**

# Description of Lived Experience

P4 is aware that he enjoyed sport, going out, playing video games with friends, and not being in pain before he was diagnosed with cancer. P4 is aware that had it not been for the cancer, which he describes as the size of a lemon that caused him to vomit and produce extreme headaches, he would never have done the teenage sailing programme with the 4 Cancer Group.

P4 recognises that the symptoms of cancer were terrible. P4 states that he twice got a glasses prescription to help but he was still getting headaches and double vision. P4 states that during both November and December his symptoms were getting significantly worse. Although he and his parents thought it was adolescent hormones, P4 was sometimes screaming in pain due to the daily headaches and vomiting. P4 states that after Christmas he went to the hospital on the 4<sup>th</sup> January as he just wasn't right. P4 states that an optician referred him for a CT scan at the hospital, which revealed that he a brain tumour, describing it as something that flipped his world upside down. P4 states that when he was diagnosed, he

acknowledged that he had a huge journey ahead of him, realising that he was close to death. P4 states that he and his mum cried, but he knew he had to try to fight it and survive, saying that he was lucky that he did.

P4 is aware that the diagnosis flipped his world upside in two ways. P4 states that the diagnosis negatively changed his routine before having a positive impact on him. P4 is aware that being close to death boosted his confidence as he realised he only has one life. P4 reflected on the fact that after the treatment he applied for head boy at his school, something of which he never thought of doing, and that his grades improved tremendously too.

P4 recognises that his initial thoughts were that it would be fun to go sailing, but he was aware that he didn't know the other people that would be there. P4 recognises that he saw the sailing trip as a positive opportunity, as it isn't an everyday hobby and can be quite expensive. P4 states that it was a once in a lifetime opportunity to go sailing, whereby he could learn life skills, make friends, and learn the principles about sea sailing. P4 is aware that when he arrives at a new place, his main target is to make friends and learn something.

P4 states that the meaning of the 4 Cancer Group's sailing trips is to build confidence. P4 states that he is shy, closed and does not want to express his feelings about what he has been through, emphasising that the teenage sailing programme helped him express what he has been through and build up his confidence. P4 acknowledges that the programme helped him release everything, despite being open with both of his parents. P4 states that he expresses everything now, explaining that his confidence in the past was just ok as he had always been quite shy. P4 states that he is now more sociable.

P4 states that the weekend consisted of sailing from the River Hamble to the Isle of Wight. P4 states the staff were kind and helpful, especially when he arrived. With reference to boosting his confidence, P4 is aware that the staff on the sailing trip were friendly, describing them as encouraging but not forceful. P4 acknowledges that they would help you step-by-step on how to do the figure-eight knot, tacking through the sea, and putting up the sail, even if he didn't get it the first time around. With reference to what it was like sailing in the sea, P4 states that he was nervous about it. While laughing, P4 states that he didn't know what he was doing. P4 says



he made a big movement when steering the boat at the helm despite the skipper telling him to make slow movements.

P4 states that at the start of the recreational programme, he and the other teenagers didn't talk to each other. P4 says that as they progressed into the trip, he got to know them a bit more, acknowledging that he made friends with everyone. P4 states that they were learning more about the boat and what the 4 Cancer Group does. P4 states that he is aware that the sailing helped each other work as a team and communicate with each other. With reference to his role in the team when sailing, P4 describes himself as motivating figure, encouraging everyone but not telling them what to do. P4 uses the example of putting up the mainsail as a way of describing how he inspired the team to do it. P4 recognises that although everyone was laughing with him, he motivated the team a lot, stating that they worked well together and were always in sync when they were doing their jobs. Though he acknowledges that normally he does step back in these situations and that he wasn't expecting to be so involved in the sailing, P4 is aware that he does sometimes lead from the front. P4 recognises that his position was of the motivator rather than taking charge.

P4 recognises that the sailing helped him get to know and learn about other people in a short space of time. P4 is aware that these trips helped him open up and make friends with people who have been through a similar situation. With reference to opening up, P4 states that he would ask people in a polite and respectful way about what kind of cancer they had. P4 states it was fine if they didn't want to tell him, but if they did he would listen and try and help them. With reference to sharing anything with his group, P4 is aware that he was quite open in the sense that he did tell them what he had been through. P4 is aware that the others who attended the sailing weekend were shocked to learn of how big his brain tumour was. P4 recognises that you don't expect someone his age to have leukaemia, explaining that some of the others on the trip could understand, while others could not.

P4 states that the meaning of the trip for him was making new friends and developing life skills such as sailing and cooking, explaining that these are great life skills to have. P4 recognises that the sailing programme helped see a new side to him that he didn't see a few years ago. P4 reflects on the experience of cooking with his friend on the trip, stating that they both cooked spaghetti, which went well.

With reference to his mindset of seeing things positively and negatively, P4 is aware that his knowledge of the boat was a lot better after spending time doing different jobs. P4 states he approaches things with an open mind, a smile on his face, and positivity, stating that is how the programme helped him. P4 is aware that his open mindset applies to his participation in rugby matches and school, stating that he always goes in with an open mindset now. P4 states that he believes that this will get him far in life, saying that learning and knowing how to sail is a part of that. P4 is aware that everyone looks at open-mindedness differently. P4 states that he thinks of open-mindedness as opportunities to do new things that seem interesting if you've never tried them before. P4 states that mindset chooses who you will be, saying that it's ridiculous how much he has done now when he thinks back to how shy he was.

P4 states that both on and off the trip, his friends were there to talk to him, be nice to him, and talk about the situation. Although, P4 is aware that they never fully understood what it was like. P4 acknowledges that he was told that it was worse being a friend of a cancer patient as you may or may not lose someone close to you. Although P4 recognises that it's been harder for his mum than it has been for him, P4 does recognise that the sailing programme has shown her that he is better now. P4 acknowledges that the programme was scary for him and his mum, stating that he wasn't sure how he was going to react. P4 says that he was happy and compares the sailing to a rollercoaster, describing it as a mixed bag of being fun and petrifying.

P4 recognises that there has been a legacy effect between him and the others on the teenage sailing programme. P4 states that they're meeting up to hang out soon, acknowledging that had it not been for the cancer they probably would not be friends. P4 says that they're all very different people but they share in something very powerful, stating that they are like a family with a strong bond.

## **Psychological Description – Participant Number Four**

Participant number four (P4) acknowledges that there was a change in himself and his life due to the many side-effects of undetected cancer, such as extreme headaches and sickness, that would leave him screaming in pain. P4 recognised his subsequent diagnosis of a brain tumour caused him to react in a way that he knew he had to fight and survive. P4 describes this process as something that

flipped his world upside down in two ways. Firstly, P4 that realising he was close to death had a negative effect on his routine, before, secondly, understanding the positive implications. P4 reflected upon how the experience was helpful for him to develop an open and confident mindset. P4 is aware that his mindset chooses who he will be, reflecting on how he since applied to be head boy at his school and achieved better grades when he considers how shy he used to be before his diagnosis.

Despite not knowing anybody other than his friend on the recreational sailing programme, P4 saw it as an opportunity as he could learn life skills, make friends, and learn the principles of sea sailing. This was reinforced by P4's belief that the programme would help him release and express everything he has been through. P4 acknowledged that the environment enabled him to see a new side to him that he hasn't seen before, such as cooking for the entire crew with his friend. P4 states that the instructors were kind and helpful in that they encouraged him to be involved through step-by-step guidance. This included how to do the figure-eight knot, tacking through the sea, raising the sails, and operating the helm of the boat. P4 recognises that he expressed himself in a manner that involved being the motivator of the team, which resulted in the team working well together as they were always in sync with their specific jobs.

P4 recognised that as the group progressed into the programme, they began to have a good time together, which involved having a laugh as a group. P4 reflected on how well he got to know these people in short amount time, explaining how he opened up and made friends with them. P4 is aware that he also tried to listen in a polite and respectful way to the people who opened up about their cancer experience. P4 states that he, too, told the group about what he had been through. P4 expressed that the group were shocked to learn about the size of his tumour. P4 stated that since the programme, he has arranged to meet with the group, saying that they share in something very powerful, like a family with a strong bond