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Reflections on my role as a mental health service user co-applicant in a randomized control trial

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Reflections on my role as a mental health service user co-applicant in a randomized control trial

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Abstract

This is not a research paper but a personal and collective reflection of patient and public involvement (PPI) for the LIGHTMind 2 randomized control trial (www.isrctn.com/ISRCTN13495752). This trial compares two guided self-help psychological interventions for depression, and is delivered in the UK NHS Improving Access to Psychological Therapy services. The paper is the result of my reviewing our PPI 18 months into the trial. The PPI includes myself as a research team member and co-applicant, with lived experience of depression, mindfulness and cognitive behaviour therapy. There is a Lived Experience Advisory Panel of six people with lived experience of depression or mindfulness, who advise the researchers. Two people with lived experience of mental health difficulties and knowledge of PPI attend the Trial Steering Committee. This paper includes comments from some of the other people with lived experience and from researchers involved in the trial, included as co-authors.

I offer the Johari window (Luft, 1970) and the 4Pi National Involvement Standards (NSUN, 2018) as a way of positioning the value of PPI. Developing relationships within PPI is identified as a way of moderating the fear that some people experience as they work with researchers. I describe the importance of principles that incorporate explicit statements about the value of PPI.

Keywords: relationships, inclusive, patient and public involvement, principles, perspective

Key messages

- Members of the public can be daunted by the technicalities of research and the status and qualifications of researchers. But researchers may also feel fearful of patient and public involvement.

- Foregrounding relationships, as well as being task focused in the conduct of research, may address some of the problems associated with power differentials.

- Developing principles for involvement activities can provide a basis for ensuring the equal value of members of the public who take part as lived experience colleagues.

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Introduction

In the UK over the last two decades there has been an increasing commitment to involving members of the public in research in the form of patient and public involvement (PPI), where people with lived experience of the research subject are involved in supporting the development and delivery of the research project. INVOLVE (funded by the National Institute for Health Research (NIHR)) has a remit to support the public to be involved in identifying, prioritizing, designing, conducting and disseminating research (INVOLVE, 2020a). The NIHR defines public involvement as 'research being carried out "**with**" or "**by**" members of the public rather than "**to**", "**about**" or "**for**" them' (INVOLVE, 2020b; our bold).

It is my belief that the INVOLVE definition belies the variety and complexity in practice of PPI in research. What constitutes involvement lies, I believe, on a spectrum from projects where brief consultation informs a particular part of the project, to projects where members of the public with relevant lived experience are co-researchers and team members. Within this, having a role does not necessarily mean that the person has influence. Lived experience colleagues can in effect be 'sleeping' colleagues within the process of research. This paper makes the argument that good PPI is about relationships. These can be difficult because of power issues. Developing principles that underpin the work can enable PPI that is sensitive to people's needs.

Context

This paper was written 18 months into the LIGHTMind 2 randomized control trial (www.isrctn.com/ISRCTN13495752).This is a two-year trial funded by the UK NIHR Research for Patient Benefit (RfPB) programme. It is investigating the use of two types of clinician-supported self-help books for adults experiencing mild to moderate depression in the NHS Improving Access to Psychological Therapy (IAPT) talking therapies service: mindfulness-based cognitive therapy (MBCT) and cognitive behaviour therapy (CBT). The trial is currently taking place across eight IAPT services and intends to recruit 410 participants. The aim is to compare the effectiveness of MBCT self-help with CBT self-help with a view to determining if the choice of treatments offered to the nearly half a million people experiencing depression and using IAPT services in England each year (NHS Digital, 2018) can be increased.

I am a co-applicant with lived experience and represent the lived experience perspective in the research team. I am employed for 0.3 full-time equivalent per week for the period of the trial. I chair the Lived Experience Advisory Panel (LEAP) of six people with experience of depression or mindfulness. This is due to meet seven times during the trial, offering advice on trial materials, recruitment and eventually dissemination. In addition, I support two people with lived experience of mental health difficulties and PPI to attend the Trial Steering Committee (TSC). All of us involved in PPI have unique experiences of mental ill health: what we share in common is that this experience has profoundly affected our lives and we wish to be involved in research.

My role includes recruiting people to this PPI work, training and mentoring them and, most importantly, ensuring that the perspectives of lived experience colleagues are heard and given due consideration by the chief investigator. In this sense, I am an advocate for the PPI perspective. I attend the weekly operational meeting, where I can undertake this role. In addition, I am also a peer researcher undertaking qualitative interviews of participants in the trial.

Table 1 gives a small insight into my work. It does not include the many telephone calls checking in with PPI colleagues, the newsletters sent to PPI colleagues, and the design and delivery of training, among other things.

Table 1: Description of PPI activities

Date	Action	Outcome
2014–15	LIGHTMind Pilot	
December 2016–December 2017	Lived Experience Advisory Panel (LEAP) and Trial Steering Committee set up	Ex-participants and others recruited and trained for PPI work
January–May 2017	Ethics materials reviewed by LEAP	Application for ethics approval submitted
May 2017	Training and LEAP meeting	Training for research assistants developed
		Changes made to Patient Information Sheets
September 2017	Co-applicant with lived experience attending weekly ops meetings	Effectively linking the LEAP to weekly delivery of the research project
October 2017	LEAP members trialled Qualtrics computer program*	Adjustments made
March 2018	Review of eligibility computer package	Adjustments to delivery by research assistants made
May 2018	LEAP reviewed the possibility of recruitment via text	This did not happen
October 2018–March 2019	Review of PPI and preparation of paper	Paper submitted
March 2019	LEAP gave consideration to the secondary outcome for trial	To be reported in final paper

*__Note:__ Qualtrics and all other Qualtrics product or service names are registered trademarks or trademarks of Qualtrics, Provo, UT, USA (www.qualtrics.com).

A note on the methodology of writing

After much deliberation, I took the decision to write this paper in the first person. The paper has gone through many iterations in an attempt to satisfy team members and reviewers. In the end, it has become a paper that satisfies my need as a co-applicant with lived experience to describe what is important to me. What follows is offered in the hope that it might begin conversations and possibly plant the seeds of ideas for further research.

In preparation for writing, I held discussions with lived experience colleagues inviting them to share their experiences of involvement in LIGHTMind. In that discussion, I asked lived experience colleagues about their experiences of power and inclusion, because these are areas of which I am personally very aware.

Once the paper was drafted, it was sent to research team members, research assistants and PPI colleagues with the invitation to contribute. Some of their comments are included. Quotations are included where they have resonance with my own experiences. Colleagues who are quoted have given permission for their quotations to be used, and have signed a publicity consent form.

Some colleagues have taken the view that the paper is research without ethics approval because it includes quotations from others. Rather, my perspective is that this paper sits at a reflection point within the trial. To ignore colleagues' views would be contrary to my role of PPI co-applicant as advocate for involvement. It should not be read as a research paper.

The value of PPI

Much of the value of involvement lies in the inclusion of people who have intimate knowledge of the experience, condition, situation or community being researched. This deep connection means that their relationship to the research problem and process is different to that of the researcher. The contributions that come from this experience can be investigated by applying the Johari window (Luft, 1970), reproduced in Figure 1.

Figure 1: Johari window

	Known to self	Not known to self
Known to others	Open area	Blind spot
Not known to others	Hidden area	Unknown

We all have some knowledge about each other, but each of us is blind to aspects of ourselves and the activities with which we are involved. PPI can bring what is often hidden (the daily experiences of living with social and health challenges, and the experience of being a research participant) into the research process. One example of something we did not know until a LEAP member told us is that participants can be confused by the role of research assistants, believing them to be clinicians. Knowing this led us to developing new training for research assistants to help them explain their role and understand the participant experience. This was developed with the help of a LEAP member.

Training partly delivered by a LEAP member benefited participants in the trial because they learnt greater sensitivity. One research assistant said:

> It was really helpful, we can put our research hats on and get tunnel vision. It takes you back to why the research has been done and how you speak to people on the phone. Not in a lot of researchy jargon.

The practice of patient and public involvement

In my experience, PPI exists on a continuum from being deeply embedded in every aspect of a research project to what might be framed as minimal consultation. A number of ladders exist that might be applied to this continuum. Such a continuum was first offered by Arnstein (1969). She suggests that citizen participation exists on a ladder from manipulation at the bottom, up through therapy, informing, consultation, placation, partnership, delegated power and citizen control. This raises the question of who determines what description applies to any one activity? Indeed, one piece of consultation might be appropriate (meeting the needs of the trial), pragmatic (the best practically that we can do, given the circumstances) or tokenistic (a nod to involvement, so as to tick boxes). Even when a PPI coordinator such as I seeks to avoid tokenism, any particular aspect of the work might still be viewed by members of the public or the research team as tokenistic or, conversely, partnership or giving citizens control. Entering the world of patient and public involvement means entering a world where people may have very different perspectives about the same issue. In this respect, PPI is in many ways subjective, which in my view makes it difficult to measure and accurately report.

INVOLVE has developed standards for involvement (NIHR, 2018: 7). These are: inclusive opportunities, working together, support and learning, communications, impact, and governance. The INVOLVE guidelines have implications both for the processes of involving members of the public who could become part of the PPI group and for how PPI perspectives are received by the research team. However, it is helpful to recognize that PPI will always exist within an iterative process of development and delivery. Where this iterative process is embedded, problems in research design and delivery are passed back and forth between researchers and lived experience colleagues, morphing and changing as they go. Within LIGHTMind, where this iterative process occurred, the PPI was (and is) not tokenistic. Rather, we can say we are all working towards the same end. One example of where we experienced this was when we, as lived experience colleagues and research team members, grappled with the problem of advertising the study via text messages from GP surgeries. In the end, the complications of this in terms of confidentiality and access to information by this means meant that we did not use this approach.

The National Survivor User Network (NSUN), a mental health service user charity, has developed the 4Pi (NSUN, 2018) national standards for involvement. These involve addressing the Principles (what underpins the work?), Purpose (what is it for?), Presence (who is present – the people, and in what capacity?), Process (what skills and processes are needed to meet the aims of the work?) and Impact (what is the outcome?) of each involvement project. This framework addresses the 'how to' of PPI in general terms, and is applicable to PPI in research. I prefer this framework to the INVOLVE standards, as I find that thinking through the 4Pi has kept me on track in my role. But I have also found that using this has been something that I have largely undertaken myself. I have not shared it extensively within the research team or with lived experience colleagues.

For me, the 4Pi is particularly useful in that it suggests the development of principles that can guide the perspectives and behaviours of those involved in the research. One of my roles in LIGHTMind has been to remind researchers about how we must work inclusively with lived experience colleagues.

Recruiting to and consulting the LEAP

In my view, PPI is not just about getting a task done. It is about relationships, and fundamentally about conversations between people. When this happens, new knowledge emerges. However, working together is not always easy.

One of my primary roles has been to recruit and retain lived experience colleagues to the project. Recruiting ex-participants from the pilot was an obvious starting place. This led to knowledge about what it was like to be a participant in the pilot, which could be carried forward. However, beyond this, recruitment was not straightforward. Some people dropped out of the LEAP. We can only speculate about why, but one LEAP member said: 'I suppose I got to see how frustrating doing research can be. For example, the intricacies that researchers have to go through. Like researchers having to go back to a panel if there is a glitch.' This LEAP colleague also reflected on the difficulties of coming into this forum. They felt that PPI meetings could be frustrating:

> Also, it can be too many cooks spoil the broth. So that people have their input which is well-intentioned but it can make it quite difficult to progress the meeting. I suppose this is a potential problem with [involving people with] lived experience. It could be a reflection on me and my impatience. Some of this can be about not being listened to in wider society. We often feel we aren't listened to.

I can identify with the idea that research is frustrating, and the experience of being marginalized because of assumptions made by others about how my mental health affects me. Some of the consequences of marginalization (such as being less experienced at working together in a group or focusing on a work task) can contribute to PPI meetings becoming heated. In this situation, it is my role to offer fair and careful facilitation, enabling people to speak and be heard while attending to the task in hand. Having group agreements for meetings, role descriptions for PPI, and my own principles to work to has helped me ensure fairness to people, enabling relationships that support lived experience colleagues to be involved. In the training for lived experience colleagues, I also provide information and opportunities to talk about working together. But there is a contrasting problem: where interest has waned, perhaps because relationships between lived experience colleagues and me and the research team have not been strong enough, some people can feel disengaged. One member of the LEAP said:

> I can hardly remember, and that's the issue. We have met infrequently, so it's hard for me to recall. Having regular meetings is much better, then you remember. But is there a point in having a meeting if there is nothing to say? I think we should have virtual meetings.

Another LEAP member said:

> I can't remember much about it [the trial] and I feel bad that I can't bring it to mind. Having another meeting would have been good. It's the nature of the work that it's sporadic and nothing happens in between. It's important to make face-to-face contact early on. It might feel daunting.

A third lived experience colleague spoke about the potential impact on her of attending and taking part in LEAP work if her health deteriorated. Using a principle of addressing reasonable adjustments early on in the work has supported people to be involved. I believe that my offering a relationship between myself and lived experience

colleagues can contribute to making involvement a positive experience. It can be enjoyable, meaningful and companionable.

But there are problems. One member of the LEAP was very clear: 'We simply didn't ask for enough funding to support a full commitment to PPI in the project.' There lies a national and international problem: what price the cost of good PPI?

Experiences from a Trial Steering Committee (TSC)

The PPI plan for the trial involved two people with lived experience sitting on the TSC. A colleague in the research team identified that there was very little information to support lay people attending a TSC. As facilitators of the PPI plan, we were welcoming two members of the public onto a powerful committee that has the ability to call a halt to a trial. Training for this role is necessary. But identifying what this should look like was not straightforward. In the end, we used the Medical Research Council UK guidelines for management of global health trials (MRC, 2017) as the basis for training and for understanding the relationship of lived experience colleagues to the Trial Steering Committee. However, we had to amend them to include patient and public involvement, as there was no mention of this. We also had to amend the terms of reference for the TSC to include patient and public involvement.

One lived experience colleague said:

> I think the biggest challenge was not being afraid to open my mouth. Not being afraid to use my experiences … Challenging the researchers to rethink things in a way that doesn't put their backs up. So [they're] rethinking the process from a patient and carer's point of view.

This lived experience colleague identifies the fear that can come with involvement in health research. Faced with numerous doctors, either medical or academic, it is easy to think that the lay perspective is insignificant, not valued or even plain wrong. This lived experience colleague also highlighted how important it was for her that the chair listen. Of course, chairs do listen, but in my experience, the stresses of that task can mean that lived experience colleagues wonder if this is the case.

Being a co-applicant with lived experience

One of my ongoing battles as a co-applicant with lived experience is having enough confidence to challenge the researchers in the room. Sometimes the lived experience perspective conflicts with the researchers' perspective. Whose perspective should take precedence? Legally, we know the answer is the chief investigator, but sometimes he or she is in the position of navigating a potentially stormy sea of multiple opinions. A co-applicant with lived experience needs to be able to hold their own. I liken this to swimming in a sea inhabited by what feels like bigger (research) fish who are more adapted to the environment. Support for a co-applicant with lived experience is essential. I experience it as quite an isolated role. Support needs to be in three areas: knowledge about the research process – best provided by the chief investigator or trial manager; knowledge of PPI – best provided by someone who has this experience; and finally, someone to reflect with on the person in the professional role – what it feels like to have lived experience and undertake co-applicant tasks. It has been my experience in LIGHTMind that I have received this support, but this is not always the case. Some co-applicants may be 'sleeping' members of the team, with few responsibilities and little involvement, or they may feel poorly equipped to undertake the tasks they are

allocated. This has been my experience in other, previous research. This returns us to the importance of having conversations and building relationships, and to the question: what is tokenism and does it matter?

Issues of power

It matters if PPI is tokenistic. Tokenism suggests an undervaluing of the knowledge that comes from lived experience, and therefore by inference an undervaluing of people with lived experience. Common sense tells us that being in this position does not promote a sense of well-being. PPI could become harmful to those who are involved – for example, in the case of LIGHTMind, by adding to the sense of meaninglessness that can accompany depression.

One of the members of the LEAP said to me:

> There is definitely an issue of power from the patient perspective. You do go in thinking, how much of my knowledge is of use? Then you see the research hierarchy, talking with jargon and acronyms. You spend a lot of your time being quiet. People with a lot of letters after their name can be quite frightening.

One research team member said in response to this:

> I wonder if you touch on the fear that researchers sometimes experience as they engage with PPI? ... Problems happen with people. Full stop. So, it could be a PPI person. But it is just as likely to be a research/academic. In fact, given the power imbalance, I'd suggest it is more likely to be a senior academic.

> It tends to go wrong when the views that benefit an individual are prioritized over views that benefit the research itself.

Until I wrote this paper, I had not been told that research team members may fear the PPI process (although sometimes when taking part in PPI elsewhere, I have thought this is the case). I suppose it is inevitable that there will be stresses and power issues within a research team. Perhaps the idea of foregrounding the building of relationships needs to be extended to offset these difficulties. However, these more general comments about research should not negate the issue of how to enable people with lived experience to have the confidence to speak up and be heard.

For example, the LEAP members had strong opinions about the Qualtrics site (www.qualtrics.com) and the computer package used for assessing inclusion in the trial. We found that once we started the trial, the time given to administer the patient reported outcomes and qualitative interviews was wrong, and the computer package used for testing eligibility was, for our purposes, difficult to deliver with sensitivity. This was a matter of concern in the first months of the trial. One LEAP member said: 'I found it curious that we hadn't tested that the computer programs worked in the first place. You need to check the questionnaires and the workability of the questionnaire before use.' This refers to the suggestion that people with lived experience should have tested the patient reported outcome measures on the Qualtrics site, and the computer package used for assessing inclusion and depression, before they became part of the trial. This did not happen, despite the suggestions of lived experience colleagues, because of lack of funds to pay for the computer packages and because researchers claimed familiarity with the tools. Here, the PPI voice needed to be heard. This would have led to different information and experiences for participants.

The difficulties of managing power issues in working with people with lived experience within randomized control trials have been reported by Goldsmith *et al.* (2019), who suggest that this needs ongoing attention.

The chief investigator comments:

> Reading this paper highlights to me the power imbalance in research studies that can leave some lived experience colleagues feeling disempowered. It seems vital that we find ways to involve lived experience colleagues as equal members of research teams, bringing different but equally valuable expertise and experience to the table. The challenge is how to do this. Naming the power imbalance and how this can be experienced by lived experience colleagues feels like an important step towards finding ways to bring about a greater sense of balance and ultimately of meaningful PPI involvement.

Principles to work by

Earlier in this paper, I cited the 4Pi as the process that keeps me on track in my involvement work. As someone who has been employed in facilitating involvement in the voluntary sector, higher education and the NHS, I find I use a set of principles that keep me focused on the needs of the people who are involved. It is my experience that researchers working in the NHS have to win grants, deliver to recruitment targets and meet the other requirements of the funding body. It is stressful and, in my experience, stressed people can forget to look after themselves and others. As a result, the person, the unique human being, becomes lost, secondary to the outcomes of the trial in terms of results. The importance of the relationships and experiences is sidelined.

Here is the set of principles that have emerged through my work in LIGHTMind. They are drawn from my own experiences elsewhere and in LIGHTMind, and were shared with the research team as this paper was developed. The principles are:

- **We value lived experience**. We aim to ensure that involvement is not tokenistic. Its unique contribution to research is acknowledged.
- **The role of co-applicant with lived experience is valued**.
- **People with lived experience are colleagues with equal status to the rest of the research team**. They are there to contribute to the research, not to receive support for their health problem (although many people do experience involvement as being supportive).
- **We offer reasonable adjustments to enable someone to speak their perspective.** Training, mentoring and support are vital, and are provided. The purpose of the involvement determines how much, and what, lived experience colleagues need to know and be trained in.
- **Dialogue is fundamental to successful PPI.** Dialogue between people with lived experience (who can then identify common themes of relevance to the research), and between researchers, clinicians and lived experience colleagues is key.
- **No one should feel excluded from speaking** because of a sense of inferiority or lack of knowledge of the research process.
- **No one should feel they need to 'understand' research before they can take part**. Neither should clinicians and researchers assume that people with lived experience do not understand, or do not want to understand, the research world. Taking part in research is a learning experience for everyone.

- **People need to know what they are getting into before they get into it.** We apply the principles of good research – *informed consent* and willing participation – and timely feedback to our PPI.
- **We are compassionate** (NHS England, n.d.). We provide a supportive process for involvement, which includes clear role descriptions, payments and expenses policy, induction, training, and reviewing and feedback on the PPI. Doing this recognizes and values the whole person.

By working to these principles, I and the researchers involved do not inadvertently do harm through neglecting the presence and needs of lived experience colleagues. These principles ensure that as a research team we are sensitive in practical ways to what might be the disabling effect of living with mental ill health. However, it is my experience that principles are not enough. Where there is potential for difficult or even disruptive conversations, group agreements are helpful, and these can emerge from the principles. Having a code of conduct to work to that helps shape the way lived experience colleagues engage with each other helps me in facilitating meetings. These, together with the principles for involvement, offer a set of rights and responsibilities for PPI work.

Influencing the wider research world

It is my belief that there is still much to do in terms of enabling the voice of lived experience colleagues to truly impact the research world. For example, one LEAP member said:

> There is a bit of bafflement. I was confused that there aren't always guidelines about things. For example, the number of follow-up contacts [the team should make] when people don't respond. Research has been going on for years. It's odd that there isn't some consensus amongst researchers.

The LEAP member who made this comment raises a very important issue. Where do lay people go when they have a critique of research practices that is justifiable, and which could lead to the amendment of, for example, ethics panel practice? Where do we, the public involved in research, go to be heard?

Within social movements, particularly that of the mental health service user involvement movement, there has always been the idea that by voicing something, you can change something (Rose *et al.*, 2016). Our paper is about voicing ideas: ideas about the way researchers and co-applicants with lived experience might provide opportunities for members of the community to support research. I have felt frustration that my lived experience of health challenges has prevented me from investing the time needed to write a more conventional scholarly article. However, I would argue that there is great value in hearing about the emotional experiences of researchers and people involved in PPI, and writing in the first person is a vehicle for this. This solution has provided the opportunity to be thought-provoking, enabling readers to understand the interpersonal challenges faced by anyone involved in PPI. This paper does not have the weight of a research paper; nevertheless, I offer some recommendations to prompt readers' thinking.

Recommendations for future practice

1. Developing principles that underpin PPI in a research project is desirable. This can help deliver PPI that empowers rather than disempowers. Developing these principles into group agreements and a code of conduct for meetings makes explicit the rights and responsibilities of people within the research project. It can enable organizational responsibility in supporting members of the public, and can disarm anger and difficulty where members of the public or researchers do not feel heard.

2. We have no way of reporting the impact of PPI on lived experience colleagues, participants and team members, or the outcome of the trial. PPI has a subjective element to it and is by its very nature part of an iterative process inside the research team. This makes it difficult to describe in a coherent and methodological way. More discussion and research are needed into how to report PPI and its impact.

3. Co-applicants in health research may wish to be made aware of the Certificate of Good Clinical Practice (GCP) provided by the NIHR (n.d.). This has been of help to me in my role as co-applicant. Offering specific training with the chief investigator about the expectations of the role of co-applicant, and providing peer support from someone with lived experience and experience in research, is important. More work is needed to understand the complexities of the co-applicant role.

4. There needs to be a forum where recommendations from LEAP members for future actions in trials can be heard by the wider research community.

5. Ethics panels should ensure that patient-reported outcome measures and computer packages have been properly trialled under research conditions by people with lived experience before giving approval to protocols. Lived experience colleagues can try out the research before it is offered to participants.

6. Researchers need to be trained in the 4Pi (NSUN, 2018). Together, lived experience colleagues and researchers can develop principles to work to that can underpin the relationships necessary to enable people to work together. Training in 4Pi would ensure that everyone within the project has the same underpinning understanding of the PPI work.

7. Further funding should be available to develop the PPI evidence base.

Conclusion

Involving members of the public in research is about building relationships to enable conversations. It can be the role of a co-applicant with lived experience to facilitate this, as in this trial. Members of the public involved in research can feel distanced from, and daunted by, being involved in research. This paper suggests that principles for involvement can guide the process of PPI, enabling inclusion and valuing of lived experience perspectives. Co-applicants with lived experience can act as advocates for PPI perspectives. However, being a co-applicant with lived experience can be complicated. Co-applicants with lived experience need appropriate training and support. Tensions will arise as members of the public seek to influence a study in ways that may or may not be challenging to the authority of the research team. Researchers must be prepared to hear members of the public involved in research. The infrastructure and reporting of PPI need to be extended, as does funding to enable further in-depth study of this area.

Acknowledgements

Notes on the contributors

Laura Lea uses mental health services and first became involved in supporting the development of health research through her membership of a mental health service user peer involvement group (CAPITAL). She is a coordinator for involvement in the Research and Development Department at Sussex Partnership NHS Foundation Trust and for the clinical psychology doctorate at Salomons Institute for Applied Psychology at Canterbury Christ Church University.

Sarah Byford is Professor of Health Economics and Deputy Head of the Health Service and Population Research Department at the Institute of Psychiatry, Psychology & Neuroscience, King's College London. She specializes in the economic evaluation of mental health services, including mindfulness-based interventions for both adults and young people.

Yve Coney has been part of the LIGHTMind team since 2017, bringing to it her lived experience.

Rebecca Crane directs the Centre for Mindfulness Research and Practice at Bangor University, and has played a leading role in developing its training and research programme since 2001. She teaches and trains internationally in both mindfulness-based cognitive therapy and mindfulness-based stress reduction. Her research and publications focus on how the evidence on mindfulness-based interventions can be implemented with integrity into practice settings.

Natalia Fagabemi completed her undergraduate degree at the University of Sussex in 2016 and went on to work within adult mental health assessment and treatment services. She is passionate about the application of research within practice and increasing patient choice. This led her to join the LIGHTMind randomized control trial, where she works as a research assistant.

Tony Gurney has Crohn's disease and uses the mental health services in South London. He was offered the opportunity to assist the project via the Involvement Register at the South London and Maudsley NHS Foundation Trust (SLaM). Tony was a child carer and used to work as an operating department practitioner. He later studied entertainment technology at the University of Portsmouth, achieving a 2.1 (Hons). He now makes music.

Helen Leigh-Phippard has had mental health problems for around twenty years. She uses her lived experience of mental ill health to contribute to teaching programmes for nurses and paramedics at the University of Brighton and trainee psychologists at the University of Sussex, and to advising a scheme for trainee clinical psychologists at Canterbury Christ Church University. She has been involved for many years in the development of patient involvement in research within Sussex Partnership NHS

Foundation Trust, most recently as Chair of the Trust's Lived Experience Advisory Forum (LEAF). She has authored and co-authored articles and book chapters on her experience of mental health services. She has a degree in politics and philosophy and a PhD in international relations.

Claire Rosten is a research psychologist and methodologist. She is a senior research adviser for the NIHR Research Design Service South East and a senior research fellow at the School of Health Sciences at the University of Brighton. Her current research activity concerns the development and evaluation of mental health interventions, including the LIGHTMind study, and digital health technology to improve outcomes for NHS service users.

Kate Simms belongs to a mood and anxiety research PPI group and sits on the LIGHTMind Trial Steering Committee. She has long-term experience of receiving NHS support for her mental health disabilities. Kate is a Level 4 accredited peer support worker with experience of working on acute crisis wards. She is an art tutor for people with disabilities and dementia.

Clara Strauss is a clinical psychologist and assistant research director working for Sussex Partnership NHS Foundation Trust and also an honorary senior lecturer at the University of Sussex. She is passionate about improving mental health care through conducting research and implementing research findings so that people using mental health services can benefit from effective care and treatments.

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