How Lived Experience can help Neuroscience Become More Relevant to Mental Health

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Methodology

Keywords: Lived Experience Advisory Panel, Psychotherapy, translational neuroimaging, remote group meeting, research design, real-world relevance, ecological validity.

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Abstract

Background: Translational neuroscience aims to make discoveries about the brain that will benefit health, especially mental health. Up to now, however, translational neuroscience studies have been designed with very little input from stakeholders who have lived experience of mental health problems. To address this serious gap, stakeholder participation needs to take place at many levels, as it does in service-oriented studies.

Methods: We convened a ‘Lived Experience Advisory Panel’ (LEAP) in order to improve the design of a new study about people’s decision to trust in and continue with, or to stop, psychotherapy treatments.

Results: The LEAP productively challenged the ecological validity and relevance of the study design, increasing its potential to improve mental health and to attract research funding. It helped determine the place of lived experience experts in multiple roles within the study throughout its duration. It also helped improve relevance by refining the framing of the therapy-like tasks within the study, and by improving the specification of the study population. LEAP discussions informed the pathways to impact first the consultation process itself, and then the new study. The LEAP convened during the COVID-19 lockdown and its remote work process, described here, demonstrates both the potential for greater involvement of stakeholders in research design, but also some difficulties which future collaborations should address.

Conclusion: Involvement of relevant stakeholders very early in the process of designing this research study has improved the study design and its potential to bring positive impacts to those stakeholders. This should be considered broadly across research fields and particularly within translational neuroscience, where limited input by stakeholders with lived experience of mental health problems have been sought to date.

Plain English Summary

Much research about how the brain functions aims to benefit health, but traditionally such studies - so-called ‘translational neuroscience’ - have been designed with very little input from people who have lived experience of mental health problems. Better methods to involve relevant individuals are urgently needed. Hence, we brought together a ‘Lived Experience Advisory Panel’ (LEAP) to improve the design of a new study. The study itself aims to better understand why people seeking help sometimes trust and continue with psychological therapy, but sometimes withdraw from it. With a strong focus on help-seekers, the study offered an excellent opportunity to benefit from the contributions of experts-by-experience.

The LEAP constructively challenged the real-world relevance of the study, increasing its potential to improve mental health and to attract research funding. It helped define who the study participants should be, and exactly how people with lived-experience of mental health conditions should be involved in the study. It also helped design therapy-like experiments for the study. The LEAP met remotely during the COVID-19 lockdown. This demonstrated the method’s potential for more involvement of relevant people in
designing research, especially people with accessibility needs, but also highlighted some difficulties associated with remote meetings.

Overall, involving relevant people early in the process of this research improved the design of the study and its potential to bring positive impacts to stakeholders. Such early involvement should be further developed within ‘translational neuroscience’, where people with lived experience of mental health problems have previously had limited opportunities to contribute.

Introduction

The importance of the voice of patients and other key stakeholders in neuroscience research aiming to advance mental health is not, as yet, widely recognised. It remains relatively untested and under-developed. On the other hand, clinical research has long since recognised the importance of stakeholder opinion (Moutoussis et al., 2000) and there is ever-growing recognition from funders, researchers and practitioners alike as to the benefits and importance of involving patients and the public in all research fields generally. Indeed, clinical research has finally started to move away from a ‘professionals know best’ model, where front-line stakeholders are assumed to lack the expertise to seriously contribute, towards collaborative work (McPin Foundation, 2020; Simpson et al., 2013), some of which is highly sophisticated (The James Lind Alliance, 2020). Thankfully, contemporary sciences of the mind and brain no longer see people seeking mental-health help as passive victims of a brain disease, but as active agents of their own recovery. Hence science urgently needs to find and address the research practices that may disempower such agents. Nowhere is this more evident than in social neuroscience aiming to improve psychological therapies (Moutoussis et al., 2018).

The present work was motivated by the need to involve stakeholders in decision-making research on why people stop psychotherapy. Throughout this article, ‘unilaterally stopping’ psychotherapy will be a shorthand for ‘the user of a psychological therapy stops participating in this therapy before the end of the course expected by the professional delivering the service on the basis of their agreement with the user’. For example, a cognitive-behavioural therapist and a user agree on a course of 10 weekly sessions; however, after session three, the user disagrees with the therapist that further sessions would be of benefit, and stops attending. There is no implication that this was a good decision or not, nor do we refer to other types of therapy ending, such as the patient and therapist agreeing that further sessions, even if originally planned, would not benefit the patient. Stopping unilaterally is a major concern which has attracted decades of research, with 20%-50% of patients still stopping therapy unilaterally and many suffering adverse outcomes (Hans & Hiller, 2013; Swift & Greenberg, 2014).

The neuroscience research team at UCL started from the hypothesis that stopping unilaterally is essentially a rational but difficult decision, based on a prediction of whether subsequent sessions could be entrusted to deliver useful learnings and empower the user. We planned to study how the brain forms such predictions and makes decisions. To do this, in a proposed study, we planned to recruit pairs of participants, one in the role of ‘therapist’ and one in the role of ‘patient’, with the latter participating from
within a state-of-the-art brain scanner (Fig. 1). However for strong technical reasons, the 'therapist'-
'patient' interaction must be significantly simplified, and focus only on a few of the most essential
elements of such an interaction, rather than include the complexities involved in a real-world example of
therapy. We therefore needed the input of stakeholders not just because of the general principles outlined
above ('nothing about us without us'), but in order to select the most essential aspects of trusting-in-
therapy to focus on.

We hypothesised that lived experience could improve the design of the proposed study, as the decision to
stop or further trust in therapy is a very important issue for both seekers, as well as providers, of help.

The Leap Process: Method And Experience

Method

In order to improve the design of the proposed study, we invited expressions of interest amongst the
Service User and Carer Group Advising on Research (SUGAR) at City University of London (Simpson et al.,
2013) to join a Lived Expert Advisory Panel (LEAP). The SUGAR group is a well-established group of
service users and carers who have been advising on research for over ten years. The SUGAR group
facilitator (SB) convened the meetings, first in City University and then via City University 'Zoom' platform.
The LEAP meetings ran between May and July 2020. Continuity of LEAP membership was emphasised,
and LEAP members were provided with technical support by the coordinator.

Two preparatory meetings were held, where a public engagement specialist (JT, SP) and the principal
investigator (MM) presented the study, described the purpose and importance of the panel, and explained
what involvement in the LEAP would look like. Information sheets were circulated in parallel to potential
panel members. This resulted in eight people with lived experience of mental health services taking up the
invitation to form a panel (the LEAP), which met a further three times. It was agreed that meetings would
take 45 min to 1 hour in duration, and take place at two-week intervals via the online platform Zoom
because of the COVID-19 pandemic. LEAP members would be paid for their work out of a small grant
awarded by the Wellcome Centre for Human Neuroimaging Public Engagement team and that the present
article would be one of the outputs of the collaboration.

Each LEAP meeting started with a short presentation by the researcher, summarising relevant aspects of
the proposed study and progress thus far, and focusing each session on obtaining input around a
specific theme, for example relevance of the study as a whole, relevance of the therapy-like tasks or who
to involve throughout the study. However, discussions were left open and as undirected as possible, as
overly-prepared questions would be restrictive and not do justice to completely fresh ideas that lived
experience was likely to bring. Before each meeting, JT and MM thought about the possible
implementation of ideas from the previous session and prepared materials to aid discussions. In parallel,
before working meetings, the LEAP met with SB for preparation and support.
Results: How The Leap Informed Study Design

The LEAP elaborated why the incorporation of lived experience both in the process of conducting the research itself, and in the process of designing and submitting funding applications for the proposed research, must be central to the study design. Key learnings that may be useful to neuroscience and related research, however, are about what enabled this LEAP to prove productive, even in the difficult time of COVID-19 lockdown.

Desirable features of LEAP sessions

The LEAP was productive thanks to a number of features. The use of language immediately emerged as important both for the communication of information but also for crucial clarification of working relationships. Key terms that required clarification were 'service user', 'person seeking help' and 'co-production', so that the role of this LEAP could be put in black and white. Efforts were made to ensure that LEAP members knew the purpose of their inputs and how discussions would be taken forward, but also how sessions would run, what was expected of each member and key dates. Next, presenting and explaining the constraints imposed by technical limitations involved in brain-scanning research (such as the statistical difficulties) was an important challenge to engage with. It was demanding, and benefitted from the contribution of a PE expert as well as a clinician-researcher. While challenging, it was essential in terms of setting expectations of which elements of the study design had room to be shaped and improved by the LEAP, and which elements might be harder to adapt to feedback without making the data impossible to analyse.

The clinical background of both the researcher (MM) and SUGAR facilitator (SB) were also important in bridging the research - lived experience communication gap. Often, it is difficult for researchers to put lived experience into practical use in the form that it is directly expressed. When this happened in our case, the professionals with clinical experience could more easily imagine the expert experience described in its clinical setting, and check back whether this or that translation of the point made into research practice would be faithful to the original experience. In addition, having two different professionals experienced in facilitating groups helped ensure that all voices, expert and professional, were heard in a supportive environment. Overall, as has long proved the case with clinical research, the absence of highly technical expertise in LEAP members in no way impeded their ability to contribute creative ideas and critique the proposed research. Their questions, comments and ideas were thoughtful, meaningful and challenging to the research design. Notably, this group was established to feed into research, so members were already familiar and experienced in many aspects of the research process. Practically, the Zoom-based meetings were a convenient and economical way of conducting the LEAP, but required technical support and coordination, suffered from technical 'glitches' and did not offer the same quality of a real life working group ('bring your own biscuits').

Increasing research impact beyond the academic community
The LEAP focused on increasing the relevance of the proposed research for stakeholders not only because it is desirable in itself, but also to help attract research funding. As an example of funder requirements, the Economic and Social Research Council requires ‘a clear demonstration of ‘real world relevance’ and ‘impact beyond academic community’, especially ‘impact for service users’. The LEAP process helped us better understand these ‘impacts’. First, what persons seeking help want and need may not be confined to the classical intervention model. The latter is about making discoveries that can inform how professionals intervene to directly target symptoms and disabilities. However, useful impact also includes steering research towards what help-seekers want - especially, what issues they prioritise to research, and what they would like to learn about these issues. The LEAP process thus clarified that stakeholders seek research that challenges pathologizing experience, and promotes stakeholder understanding. In our project, the LEAP consultation suggested that researchers should communicate what we know already, but also share what our key questions are about the role of the brain in trusting in psychological treatments. More specifically, how the brain learns is very important for therapy, and it important for stakeholders to have access to the key questions about such learning. Finally, the LEAP challenged the research as it was proposed, because of its lack of people with lived experience as full participants (see below). Addressing these gaps can improve the relevance of research beyond academia, and hence make it more attractive to funders and more impactful to stakeholders.

Roles of experts by experience within the proposed study

The LEAP thus suggested roles for people with lived experience not only as study participants, but also to aid the delivery of proposed research. Experts by Experience can provide important direct input throughout the study by shaping and overseeing the experience of study participants and providing support where necessary, especially if the latter have vulnerabilities. Those with lived experience who can act as ‘bridge people’ between a target research population and the research study would be invaluable as a source of support, advice, participant recruitment and as a point of contact. LEAP members recognised that this has worked effectively in other relevant projects.

Rendering the proposed research more relevant to mental health

The LEAP helped address the issue that the setting of real-life therapy, which our research aims to improve, is very different from what happens in a laboratory. The LEAP discussed how to use laboratory experiments to investigate trusting and engaging with psychological therapy.

First, it was pointed out that both the experience of, and decision-making within therapy may be quite different in people with lived experience, or people potentially seeking help, compared to largely indifferent volunteers. There were also concerns that including only volunteers with no lived experience would lack authenticity, as these individuals may not be able to “get into the shoes” of someone seeking help. This is hugely important for the relevance of the study. The study should aim to transition safely and efficiently from initial ‘low stake’ participant groups (eg those without lived experience) to ‘high stake’ groups (subclinical or help-seeking participants). Implementing this transition within the study would benefit from LEAP involvement. This would help both in identifying differences in the perception of the
experiment itself, important for the analysis of the study, but also, crucially, in providing optimal support for sub-clinical participants during the study.

The LEAP then addressed ecological validity. For task studies to be relevant to stakeholders, task content needs to be ecologically valid, i.e. representing real concerns. In our case, it is crucial to represent the issue of patient-therapist trust as closely as possible. This brings important difficulties which are poorly addressed by current paradigms, which largely rely on monetary exchange. LEAP members stressed that the internal motivation of the participants, as opposed to extrinsic motivation induced by money or punishments, is important to increase study relevance. According to the LEAP, external motivation (doing it for money) and/or acting (in the sense of going through the motions) greatly reduce relevance. The recruitment, task content and conduct of the study should aim to maximise genuine participation in the endeavour.

In therapy, trust can break down when help-seekers feel ‘let down’ by professionals, but this is difficult to study in the laboratory (Fig. 2). Some key determinants of trust for help-seekers were already thought about in the study, but others were not. The LEAP pointed out the importance for trust of first impressions and of previous experience, of pre-therapy information shaping expectations, and of the communication of emotion between therapist and patient (both verbal and non-verbal). The LEAP also suggested that greater relevance would be achieved if timing factors such as length and number of appointments could be framed within the study, as they are crucial determinants of the readiness to trust.

Finally, the LEAP made some useful, straightforward suggestions to improve the research design, such as the inclusion of questionnaires asking about psychological attachment patterns. These might help further understand how the central issues studied, such as the role of learning, might differ in those with different relationship experiences while growing up. The LEAP thus improved research design beyond lived experience as might be narrowly understood.

Discussion

We describe how a Lived Experience Advisory Panel (LEAP) advanced the research design of a neuroscience study aiming to advance mental health. The LEAP improved the real-world relevance of the research in terms of its ecological validity, its value for stakeholders and potential appeal to funders. It was conducted electronically, under COVID-19 lockdown conditions. The process was feasible, economical and practical, and provides a useful prototype, a learning tool and acts as a proof of concept for more public engagement activities to be conducted remotely. However, the online nature of the engagement did impair the flow of conversations and at times injured continuity of membership, which is very important in such discussions.

A number of lessons were gained from this process from a public engagement perspective. These included first, the need for an introduction at the start of the project which was longer and more substantial than face-to-face formats and less technical research. Second, project teams need to consider how to build a sense of community and team-work of a group when engaging online. This may be
particularly the case where members are previously not known to each other. It is useful to plan time for informal activities at the start of sessions, to allow time for people to connect online. The need for skillful facilitation, needed to ensure that all members have an equal voice, became even more apparent online. The number of discussion points possible to cover in an online meeting were found to be fewer than in in-person meetings. These lessons should all inform future digital engagement projects, both within translational neuroscience and beyond.

Factors contributing to the success of this LEAP are likely to include its basis in a well-functioning existing structure (i.e. the City University SUGAR group) and its members’ previous experience in feeding into research. As expected, lack of technical expertise in the LEAP was not an impediment. The multidisciplinary composition of the professional team involved (Psychosocial Nursing, Public Engagement, Medical Psychotherapy) also helped the process.

Much neuroscience research purporting to subserve mental health employs over-abstracted tasks of dubious ecological validity (Moutoussis et al., 2016; Nord et al., 2017), an issue of central concern for us. Key suggestions of the LEAP here included the importance of internal motivation of participants to engage with the issue of trusting in therapy, a requirement that participants with a real stake in the issue be recruited into the research, and especially the need for the laboratory paradigm to capture as appropriately as possible the potential of being ‘let down’ by one’s therapist. These were valuable suggestions while at the same time posing a serious challenge to the research design. It may only be possible to adequately address them if the proposed research itself allows enough space for qualitative review and trying-out of ideas, including substantial piloting.

In terms of increasing the relevance of the research, an issue which is also very important to research funders, the LEAP suggested that providing good information about the scientific basis of treatment to people seeking help is an important aspect of research. We can go further and say that the information which is (or is not) made available can normalise and empower, or on the contrary pathologize and disempower, stakeholders. Therefore, it is important for experts by experience to help scientists focus on those questions whose answers can potentially empower stakeholders. In our case, where the study involved an interaction between ‘patient’ and ‘therapist’, LEAP members emphasized that the workings of the therapist's mind and brain should be given much attention, rather than unilateral stopping being cast as a one-sided ‘patient problem’. Next, the way that neuroscience findings are presented may be empowering or disempowering. For example, neuroscience may cast its findings as if people are ‘slaves to their evolutionary brain’, or it may emphasise the brain's potential for development and change. However, communication of sophisticated neuroscience, including its limitations, in our case benefitted from involvement of a multidisciplinary team including experts by experience but also public engagement experts and a chartered Psychologist/neuroscientist and medical psychotherapist. All these processes were deemed important both for the research proposal which was the focus of this study, but also for the unfolding of the research study itself.

Future stakeholder involvement
The process described here was productive, but had important limitations that present opportunities for further work. The LEAP was useful, but it fell short of co-production, which would involve longer-term, better-funded participation of stakeholders in research planning. Also, the current LEAP was richly diverse with respect to many aspects of identity, but was highly knowledgeable of mental health services. In that sense, it was not representative of many people seeking psychological treatment, who have no knowledge even of basic aspects of mental health care (e.g. the difference between appointments with a psychiatrist vs. a counsellor). Future stakeholder participation should also involve inexperienced people interested in therapy. Relevance and ecological validity were addressed, but not fully resolved. Further development is needed for laboratory studies to examine service factors that affect engagement, such as the knowledge of the amount of time one will have for therapy. These are important for persons seeking help. In addition, LEAP members would have preferred more realistic laboratory tasks, such as including unfolding therapy scenarios. Further work will be required here, as unfolding scenarios are as yet unsuitable for brain-scanning studies, which require a lot of repetition to yield results. This may be addressed in future both through further work involving stakeholders, but also through advances in technology such as wearable devices. Finally, once the pandemic is over, accessible and low-cost on-line meetings should complement (where possible) rather than replace real-life group work.

**Conclusions**

This study demonstrated the importance of involving mental-health stakeholders, and in particular experts-by-experience, early in the design of studies of brain function aspiring to be of translational relevance to mental health. The particular methodology used was a ‘Lived Experience Advisory Panel’ which met with a three-member multidisciplinary professional team for on-line discussions. The outcomes of the process constructively challenged and greatly enriched the research design, including the nature of its participants, the role of experts-by-experience in the conduct of the study, the dimensions or features of the research paradigm, and the importance of information dissemination for real-world impact.

**Declarations**

**Ethics approval and consent to participate**

This research did not involve qualitative or quantitative experimental participants, but only experts-by-experience who co-authored this work and took place within the existing framework of the SUGAR group. Therefore no separate Research Ethics approval was necessary. Nevertheless, all LEAP members were informed in writing and verbally in detail about the nature of the advisory discussions sought, and gave informed consent to participate in the advisory discussions.

**Consent for publication**

LEAP members were invited to co-author the present output, or retained the right to be acknowledged or to abstain., participated and consented in the current publication. All LEAP members chose to be co-authors.
and are listed in Table 1 below.

**Availability of data and materials**

All data is incorporated into the body of the main article text. All materials including information for LEAP members, consent forms, and slide presentations are freely available from authors MM and SB on demand.

**Competing interests**

None of the authors have competing interests to declare.

**Authors' contributions**

SB convened the SUGAR group, facilitated discussions, gave support to LEAP members, advised the UCL team and edited this article. The LEAP performed the bulk of the discussions, came up with the ideas outlined in the Results section, edited and endorsed this article. SP and JT coordinated meetings, managed the production of materials, participated in chairing discussions, edited and endorsed this article. MM initiated the consultation process, conceived and drafted the index study proposal, made session presentations, and drafted this article.

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**Tables**

| Table 1 | Authors belonging to the Lived Experience Advisory Panel for this study |
|---------|--------------------------------------------------------------------------|
| Richard Humm |
| June Hanshaw |
| Isaac Samuels |
| Rosemary Amuda |
| Claudette Brandon |
| Ted Oliver |
| Syeda Tahir |
| Zhenreenah Muhxinga |

| Table 2 | Authors affiliated to the WCHN public Engagement Team |
|---------|------------------------------------------------------|
| **Joanne Thomas** *(project Public Engagement specialist)* |
| Sophie Perry *(Public Engagement officer)* |
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Figures

A. Real therapy is a very complex, sensitive conversation between two people. B. In our research, a participant in the role of therapy user (in the brain scanner) interacts with one in the role of therapist (using a computer). The setup necessary for brain research only permits us to study a few essentials about how the brain makes decisions to trust, to participate or not in the interaction, etc.

Figure 1

A. 'help seeking person' 'therapist'

B. 'help seeking person' 'therapist'
A. Real therapy is a very complex, sensitive conversation between two people. B. In our research, a participant in the role of therapy user (in the brain scanner) interacts with one in the role of therapist (using a computer). The setup necessary for brain research only permits us to study a few essentials about how the brain makes decisions to trust, to participate or not in the interaction, etc.

Figure 1
Figure 2

Discussion surrounding how to represent ‘being let down’ in the laboratory. In the laboratory task, the participant in the ‘patient’ role sees the black square screen, where they are represented by the green bald man (on the left). In this example, they have entrusted the ‘therapist’, but the therapist has ‘let them down’, which is represented by the ‘patient’ suffering a large loss of ‘points’, whereas the ‘therapist’ only a small one. The LEAP debated whether such a representation of ‘being let down’ could evoke feelings and decisions resembling those resulting from being let down in real therapy.
Figure 2

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