Original Article

Patient and Public Involvement in Developing and Testing Mental Health-Care Interventions: Strategies and Reflections from Three Research Programs

Abstract

Patient and public involvement (PPI) is valued and widely practiced in mental health research but in different ways. We present three research programs, aiming to develop and test mental healthcare interventions and we discuss their PPI strategies and activities. In all these programs, PPI has been sought from their initial conception and design and has helped their management, intervention development processes, quantitative and qualitative evaluations, and in the assessment of PPI activities themselves. The programs focus on different groups (patients with chronic depression, patients with psychotic disorders, and carers) and develop different interventions. Comparing these programs offers the opportunity to appreciate different models of involvement. These, for example, range from training lived experience collaborators to analyze qualitative data directly to asking them to comment on findings; from involving lived experience collaborators in the design of new interventions to involving them in intervention adaptation to a particular group or circumstance; and from carrying out formal PPI evaluations to collecting informal feedback during meetings. Even in the diversity of programs and PPI activities presented, common themes could be identified in relation to: specifying (and ideally co-designing) expectations and role of contributors; making bureaucratic procedures as user-friendly as possible; appropriately choosing or blending online and offline meetings; and designing flexible and inclusive arrangements to maximize participation. Our experiences contribute to a growing evidence base that can help researchers to develop meaningful, enjoyable, and constructive collaborations with people with lived experience. These collaborations will keep clinical mental health research relevant, impactful, and tailored to patients' needs.

Keywords: *Healthcare, interventions, lived experience, mental health, patient and public involvement*

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INTRODUCTION

Major health-care innovations have been generated in recent decades with the active involvement of patients and their family members.[1-4] Mental health researchers across the world are actively collaborating with patients and their family members and friends (carers),[5-7] which is considered a central tenet of contemporary applied mental health-care research.[8,9] While the principles and value of patient and public involvement (PPI) in mental health-care research are well recognized,[5-7] there are different models to implement PPI, each with their advantages and challenges and there are concerns that PPI practices may be inconsistent or at times tokenistic.[3,4,8,9]

The authors have worked with or are lived experience research collaborators across three separate studies, all aiming to develop and test novel mental health-care interventions, in different patient (or carer) groups.[10-12] In this paper, we will describe the different models used, how lived experience collaborators were involved in different research activities, and the advantages and challenges experienced. This may help other researchers organize PPI in future research.

The description of PPI in this paper focuses on how to generally organize PPI rather than on more specific elements such as facilitation strategies, power dynamics, and personal experiences.[13,14] Describing these will require a more in-depth analysis of participant experiences. We feel a focus on organizational aspects may be

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helpful to researchers planning PPI to address mental healthcare challenges, bearing in mind that those relational and experiential elements also need to be evaluated with appropriate methodologies.[13,14]

DESCRIPTION OF PATIENT AND PUBLIC INVOLVEMENT STRATEGIES IN THREE RESEARCH PROGRAMS

The three research studies, whose PPI strategies will be presented in this paper, focused on different patient (or carer) groups. All three studies have a strong emphasis on PPI throughout the research process. Table 1 includes a summary of the activities for each project, where people with lived experience were involved. This is by no means an exhaustive list of all involvement activities undertaken and it needs to be noted that projects are at different stages in terms of completion of the research activities.

Tackling chronic depression

Tackling Chronic Depression (TACK)[10] aims to help people diagnosed with chronic depression, through adapting and testing DIALOG+, a technology-assisted and resource-oriented intervention.[16] DIALOG+ has been developed to provide structure to routine clinical meetings and make them more clinically effective through improving

outcomes. DIALOG+ constitutes an individual clinical assessment, care planning, and delivery of a therapeutic intervention, all in one procedure using the same tool. DIALOG+ was initially tested and proved to be effective for people with psychotic disorders in community care[17] and TACK has been adapted for use with people with chronic depression.[10]

TACK has seen the involvement of lived experience collaborators since the beginning of the program, with a co-investigator with lived experience of chronic depression being one of the applicants for research funding and a lived experience advisory panel (LEAP) being convened within 2 months of the program launch (chaired by the co-applicant). Lived experience collaborators were also involved in the adaptation of DIALOG+ for people with chronic depression, in the selection and development of appropriate outcome measures for use in the trial, in the management of the trial through regular meetings (4 times a year), in ensuring participant wellbeing was prioritized during and after participation, in the analysis and interpretation of qualitative data and the dissemination of program findings.

In particular, the involvement panel co-designed the "DIALOG+ Experience Questionnaire," a bespoke 7-item questionnaire (responded to on a 5-point Likert scale) plus

Table 1: Summary of patient and public involvement strategies across the three research projects

Activity	TACK	SCENE	OPAL
Establishment of LEAP	Yes, *n*=8 members, with lived experience of using services for chronic depression and/or carers	Yes, *n*=10 members with lived experience of using services for psychosis and/or carers	Yes, *n*=10 members with lived experience of caring for someone hospitalized for mental health problems and patients
Study management	Contribution during LEAP meetings (chaired by lived experience co-investigator)	Formalized "you said, we did approach"	Contribution during LEAP meetings (chaired by lived experience co-investigators)
Intervention development	Adaptation of intervention items (areas to be discussed during sessions) to the needs of people with depression. Co-produced training resources for clinical staff	Contribution to the design of intervention during LEAP meetings	Contribution during LEAP meetings and participation in the dedicated intervention development group
Evaluation design	Development of participant experience questionnaire, contribution to patient facing documents (information sheets, consent forms), feedback on selection of outcome measures for trial	Help with selecting appropriate questionnaires, contribution to patient facing documents (information sheets, consent forms)	Help with selecting appropriate questionnaires, contribution to patient-facing documents (information sheets, consent forms)
Qualitative research	Service user researchers (*n*=3) trained in qualitative research methods and subsequently involved in coding transcripts and development of themes, leading to publication[15]	LEAP commenting on themes and helping interpretation of findings	All LEAP members invited to inform the development of the codebook and shaping the themes
PPI evaluation	Discussions during LEAP meeting. Plans to publish a discursive journal article on experience of involvement	Formal PPI evaluation testing different instruments and developing a tailored evaluation strategy	Plans to carry out a formal evaluation strategy at a later stage of the project using standardized instruments

TACK: Tackling chronic depression, LEAP: Lived experience advisory panel, SCENE: Structured intervention to increase social contacts and quality of life of people with psychosis, OPAL: One-to-one peer support for family and friends of people detained under the Mental Health Act in England, PPI: Patient and public involvement

a "free text box" which researchers can use to capture participant experiences of those in receipt of DIALOG+. This instrument can be used in other studies testing or implementing DIALOG+.

In addition, three experts by experience have been trained in qualitative research methods (particularly thematic analysis) by the TACK team and were involved in the analysis of interview data on experiences and acceptability of using DIALOG+ in routine mental health care. This analysis generated a conceptual framework which informed the understanding of how DIALOG+ could be better delivered, and how staff training materials could be improved. This led to maximizing the implementation of this intervention in services across the UK.

Structured intervention to increase social contacts and quality of life of people with psychosis

Structured intervention to increase social contacts and quality of life of people with psychosis (SCENE) addresses the problem of social isolation of people with psychotic disorders.[11] Many studies[18-20] suggest that people with psychosis are often socially isolated and have small social networks, mainly featuring family members or health professionals. Social isolation is in turn, linked to poor quality of life and health outcomes.[21,22]

The SCENE research led to the development of a new intervention (social coaching), based on evidence and stakeholders' preferences, aiming to help people with psychosis to increase their social contacts and, consequently, improve their quality of life.[11]

As with TACK, SCENE also had a lived experience co-applicant and a LEAP. The SCENE LEAP members were involved in the development of the intervention and training manuals, in devising the recruitment materials and strategies to increase participation and will be involved in the interpretation and dissemination of the findings.

A particular challenge was the adaptation of intervention and study procedures necessary because of the COVID-19 pandemic and consequent physical distancing directives. LEAP members emphasized the supportive value of online activities in the absence of opportunities for in-person socializing. There were also important caveats in terms of the need to update our training and ask the coaches to consider computer access and literacy when encouraging people to engage in online social activities.

Another key co-produced activity was a formal evaluation of PPI activities. Once LEAP members and researchers were able to meet in person, a workshop was arranged. The group considered different instruments to inform the reflection and chose a practical workshop to apply the cube of involvement, as described in Gibson *et al*.[23] Members used post-it notes to position their PPI experiences on wall charts representing the four dimensions of the Cube (how many

and which activities people felt involved in, whether they felt they had a strong/weak voice, whether the study team prioritized concerns of patients and the public and whether the study team resisted to changes or made appropriate changes). This was followed by a group discussion and, the development of improvement actions. Key actions were increasing the frequency of communication between the study team and LEAP members, having more frequent and briefer meetings, and adopting different communication modalities for regular updates depending on individual preferences (i.e. via phone/post, rather than via E-mail). Following the workshop, we ensured regular space on the agenda of future LEAP meetings to review LEAP procedures and clarify consequent improvements ("you said, we did" approach).

One-to-one peer support for family and friends of people detained under the Mental Health Act in England

One-to-one peer support for family and friends of people detained under the Mental Health Act in England (OPAL) focuses on the development and testing of a "carer buddy program."[12] In this program, people who have had an experience of providing informal support to their family members or friends ("carers") when involuntarily hospitalized in the past are trained to support other carers whose family members/friends are in the hospital currently. This carer buddying program has been adapted from a similar pioneering program developed in Germany.[24] We have worked with a person with lived experience of being a carer when developing the study design and research funding application. The OPAL LEAP (10 members) meets mainly online, providing the opportunity to involve carers from across England. It includes two LEAP leads who are based at the two leading sites of the program (Coventry and Warwickshire and London). One LEAP member is a carer from Germany who contributed to the original peer support program that was to be adapted for use in England. Other LEAP members are from other areas of England, from Yorkshire to Devon.

The PPI highlight in this project is the extensive involvement of people with lived experiences in the development of the intervention. To inform the development of the characteristics of the intervention and its adaptation to England, the involvement of people with lived experience was crucial. We had a LEAP similar to TACK and SCENE but also a specific intervention development group with significant representation from LEAP members.

The LEAP provided general feedback, including the following recommendations: carefully considering the use and comfort of people participating in roleplays; providing handouts to help the provision of information; strong focus on supervision of carer buddies to maintain their wellbeing, and; encouraging carer buddies to meet with their carer in-person at least once even if both parties prefer to meet mostly online.

The intervention development group was informed by the LEAP input and worked on the specifics of the training program and its organization. This group included the German LEAP member, the two LEAP leads, the principal investigator (PI), the study research coordinator, and two academic experts in peer support, one based in the UK and one in Germany.

The training package has now been developed and will be tested in NHS Trusts across England.

LEAP members were also involved in the qualitative work leading to intervention development, which included interviews with carers, patients, clinicians, Mental Health Act Advocates, and behavioral change experts. LEAP members have been involved in developing the codebook and helping the interpretation of findings and theme development.

DISCUSSION AND REFLECTIONS

These three research programs show different ways in which people with lived experience can be involved in research and fundamentally shape the development and evaluation of mental health-care interventions.

Whilst the lived experience collaborators were involved in all stages of the research programs, the strategies used were different [Table 1].

For example, intervention development strategies ranged from involvement in the design of the intervention as a whole (i.e. peer support in OPAL) to a focus on specific aspects of an intervention (e.g. areas/items to be discussed during intervention sessions in TACK). Complex novel interventions can be developed from scratch or existing interventions adapted, all through co-production with people with lived experience.

Involvement in qualitative analysis can also vary in depth and scope.[8] Involvement can range from having lived experience collaborators directly as part of a larger multi-disciplinary analysis team, to asking feedback on the language and description of themes once developed.

PPI evaluation can be formal and based on standardized instruments and procedures or follow more informal ways of providing feedback, for example, verbally during meetings.

The three projects here also describe involvement with three different patient/carer groups (i.e. those with chronic depression, those with psychotic disorders, and carer buddies). Although most strategies can be replicated across different involvement groups, there may need to be some reflection on how variable lived experiences (and different symptomatology) may require different approaches and considerations.

It is not our intention to compare the projects and identify the most effective strategies. Rather, our experience tells us that it is important to be aware that different strategies are available, and can be implemented in different ways with different patient/carer groups. What is integral is to discuss such strategies and approaches with the lived experience contributors and develop co-produced plans which are tailored to the needs and goals of a project. This is also in accordance with current UK guidelines and PPI research reviews.[3,9]

In addition, there are factors that are important to consider when designing and organizing collaborations with lived experience contributors.

A key aspect is that recruitment processes are well organized, with clear descriptions of the role, the characteristics sought for the contributor, and that payment and support systems are well established before commencement. The best practice is to have lived experience contributors involved at the very early stages of the research design (i.e. before the project starts, e.g. during the funding application stage) and in drafting the recruitment procedures for the LEAP and for other PPI roles.

Second, the procedures for payment of public contributors should be made as smooth and user-friendly as possible. This may require both clarity of research plans and advocacy on the importance of lived experience contributors within institutions, so that appropriate mechanisms are in place.

Third, decisions on how to meet with LEAP members are also important and can influence the feedback the research team receives. Online meetings can be more convenient and, crucially, allow participation from people who live in different areas, allowing for greater geographical representation. However, in-person meetings may still make team-building easier and develop a higher level of trust and working alliance within the team. The mode of the meeting will depend on the specific needs of the project or might involve a combination of online and offline modes.

Finally, it is important to provide flexible arrangements. Examples are: offering one-to-one meetings to people who have to miss group meetings, taking into account caring or work responsibilities when arranging meetings and in general, agreeing on patterns of helpful communication, which may be different for different people (e.g. some contributors may prefer to be contacted via E-mail and others via the phone). The way study updates and progress is communicated also needs to be variable, so as to avoid "information dumps" on lived experience collaborators, and to ensure they remain engaged in the project.

CONCLUSIONS

The involvement of lived experience and public contributors in research is one of the great advances in applied health research in the last few decades. Our research programs show that lived experience contributors can be involved meaningfully in all phases of research and that as a result research outputs are improved. There are

a number of different strategies to improved involvement, but these must be relevant and appropriate for the specific groups that research teams collaborate. Our experiences contribute to an increasingly rich evidence base[3,8,9] that researchers can draw on when co-producing their studies. This will help them to develop meaningful, enjoyable, and constructive collaborations with lived experience contributors. These collaborations are a key driver to keep clinical mental health research relevant, impactful, and tailored to patients' needs.

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Conflicts of interest

There are no conflicts of interest.

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