Involving experts by experience in Clinical Psychology trainee research

1. Background

Experts by Experience is the term used within the Clinical and Health Psychology department at University of Edinburgh to refer to individuals who come into contact with psychological services either as a client, a patient or as a carer or advocate for another individual. While 'service users and carers', 'clients', 'patients' or 'survivors' are labels often used to refer to similar groups (Pollard et al., 2015), these have not been without criticism (e.g. British Psychology Society Division of Clinical Psychology, 2008). The term 'experts by experience' emphasises the value that individuals with experiential knowledge bring to the training programme and recognises that a meaningful contribution comes from a broader range of individuals than those seeking help for mental health difficulties.

Involvement of the public in health research has been promoted in the United Kingdom since the 1990s (e.g. Department of Health, 1999). It is also encouraged by ethics committees and is a requirement of many funding bodies, such as the National Institute of Health Research (NIHR). There is an ethical argument for engaging experts by experience in research, not least because those with experience of mental and physical health difficulties should have a say in research that is about them and has an impact on them, but also because involving those from the target population in the research design may help ensure that the study is conducted ethically and sensitively. Furthermore, research is often supported through public funding and so it can be argued that the public should have some influence over it (Thompson et al., 2009).

Engaging experts by experience within the research process also offers a range of possible practical advantages, including improved recruitment and retention in studies and better communication of findings to target groups (Domecq et al., 2014). Moreover, the experiential knowledge of living with a condition provides relevance and credibility to a research project (Lindenmeyer et al., 2007; Thompson et al., 2009). For members of the public involved, the process can be empowering and can help individuals in finding meaning in difficult experiences (Patterson et al., 2014; Simpson et al., 2014).

Nevertheless, there are challenges around engaging members of the public in research, particularly where there is greater involvement in the project. These include the potential for research to become less feasible through accommodation of multiple research questions and the consequent widening of the project's scope (Domecq et al., 2014). Project timelines, the sharing of power between researchers and experts by experience and different values about involving members of the public in research can create tensions within the research team (Gradinger et al., 2013; Thompson et al., 2009). Experts by experience may use the forum to pursue a personal agenda (e.g. Khoo et al., 2004) or involvement of the public

becomes tokenistic and lacking in meaning (Oliver et al., 2008). For experts by experience there is a significant time commitment and a need to engage in complex discussion, which may be particularly difficult for those who experience regular or prolonged periods of illness (Simpson et al., 2014). Becoming involved in research benefits from being articulate, educated and assertive to establish credibility within the team (Patterson et al., 2014) but this then raises questions about the representativeness of the members of the public who are involved in any project. There is, however, a lack of research concerning how best to recruit and engage members of the public (Domecq et al., 2014).

The Advisory Panel of Experts by Experience (APEX) was established at the end of 2011 and has been known as APEX since 2014. The panel promotes the input of experts by experience into all the main programme areas: teaching content, placements and research. This document provides specific guidance about involving experts by experience in trainee thesis projects across different stages of the project and is based on the guidelines from NIHR (2010; 2012). Note that involvement in this instance refers to the public being actively involved in the research process rather than participating in a project or engaging with it through public outreach or communication events (c.f. NIHR, 2012). This document was written by the Research Director and APEX.

2. Levels of involvement

There are various levels at which people may be involved in the research process, as defined by NIHR (2010). These are: consultation (members of the public are consulted to provide their advice and views on the project), collaboration (members of the public are involved in making decisions in the research project), user-led or controlled (the control and decisions about the project lie with the member of the public). Depth of involvement may range from making the project lay friendly to incorporating the perspective of the expert by experience at all stages of the research process (Staley et al., 2013). NIHR (2012) recognises that within projects there may be different approaches at different stages rather than one level of involvement throughout. However, they recommend that the researcher is clear about the involvement of experts by experience from the outset to avoid later confusion or tension.

3. Involvement at different stages of the project

There are different stages in which members of the public can be involved in the research process, including: identification of research priorities, design of study conditions, data collection, data analysis and informing practice (Gooberman-Hill et al., 2013). The 5 stages identified within NIHR (2010) guidelines are:

- The development of the grant application (or proposal)
- The design and management of the research

- The undertaking of the research
- The analysis of the research data
- The dissemination of research findings

Each of these stages will be looked at in turn. As with the NIHR guidance, we refer to real case examples from trainees, members of APEX and their associated networks, and staff in the clinical and health psychology department to supplement the guidance.

3.1 Development of the grant application

Involving the public at an early stage has the most value in terms of ensuring that the perspective is incorporated, however this can prove difficult due to funding for their involvement, deadlines for ethics and funding applications (Staley et al., 2013; Thompson et al., 2009). Therefore because the thesis is completed as an educational project with limited resources (e.g. time, funding, size of project team) this may be a challenge. Some ways in which people can have input into this stage are:

- Through discussion of the research idea and suggesting a particular focus to the research questions that they perceive to be of most relevance or benefit
- By reviewing the proposal and providing comments
- Identifying where experts by experience could be involved in other parts of the research project
- Being a co-applicant on the grant (NIHR, 2010).

Case example 1

Kate Randell, DClinPsychol trainee, gave a presentation of her proposed thesis project (*'Exploring the impact of psychological flexibility on the relationship between fears of cancer recurrence and adjustment in cancer survivors'*) to members of a Cancer Care group run by NHS Forth Valley, which includes patients and family members. The members provided feedback on the usefulness of the research question and its potential impact along with aspects of the study design.

'Participants gave very positive feedback about the importance of research on fear of recurrence in this population. Overall the process was very valuable in confirming the potential importance of the research topic, and providing additional ideas around fine tuning the methodology. There was a potential obstacle to making the most of this opportunity in terms of attendees taking the opportunity to share personal stories relevant to the topic. However, this group is well established with a clear focus and the Chair of the group was therefore able to appropriately manage this'.

This process would be aided by identifying a relevant pre-existing group in the trainee's local health board. APEX may also be able to help identify a particular group. Alternatively, the trainee could approach a national organisation or a group from another health board. As the programmes of research within clinical and health psychology become more established, there may be better links with particular groups of experts by experience. As with any involvement from members of the public, there is a need to ensure that the person's role is agreed in advance.

Case example 2

Amanda Larkin, DClinPsychol trainee, involved attendees of a day service at Support in Mind, Scotland in the design of her thesis (*'Exploring the role of cognitive biases in treatment decision making capacity of people who have experienced psychosis'*) project by sending a summary of the research project in advance and presenting the project at a meeting.

'The group made me aware that the wording of the materials was important and prompted me to consider the different terms that people might use for their experiences. Group members also looked at the information sheets in a different way and raised points that potential participants would want to know about, such as whether they could bring friends along to the interview, and if it was possible to meet somewhere that was comfortable for the participant for example at a café rather than at clinic. In the future, I would like to spend more time explaining the process of designing the question- when I approached the day service I had already formulated the research question and due to deadline constraints the feedback I received on the original research question was not as beneficial as it might have been at an earlier stage'.

3.2 Design and management of the research

At this stage members of the public may use expert knowledge to provide input into the practicalities of the project by:

- Improving the study materials e.g. the understandability of study information and consent forms, providing feedback on the methods of data collection
- Helping identify ways to recruit participants or provide alternative suggestions for recruitment methods where recruitment has been problematic
- Providing an alternative perspective on the ethical issues arising from the project.

Case example 3

Catriona George, DClinPsychol trainee, invited carers through the National Dementia Carers Action Network to provide comments on her thesis project proposal (looking at executive functioning in individuals with dementia, as reported by family carers) in advance of submitting it to an ethics committee.

'It made me consider the burden my research might have on carers and also the wording, which they found difficult to understand. It was quite easy to organise as I had help from a contact at Alzheimers Scotland. However, although three people had agreed to look at it, I only received comments from one. Although the input was valuable, I felt it would have been beneficial to have had the opportunity for follow up discussion with the carers. This may have provided more scope for incorporating their suggestions into the final proposal. Because my proposal was sent for review via a third party, it was not possible to do this'.

Case example 4

One of the DClinPsychol trainees involved members of the public in both a small scale research project and the thesis. For the thesis project (looking at the experiences of young people with a parent with psychosis), the trainee asked a reference group of parents with psychosis and the Young Person's Advisory Group through Scottish Children's Research Network (ScotCRN) to provide feedback about the study materials, recruitment process and interview questions.

'This was really valuable in informing the design of my study and ensuring that the recruitment process and materials, methodology and interview questions were likely to be acceptable to participants. Feedback from young people really helped inform the language and design of my recruitment materials. Advice from parents was also particularly useful in shaping how I plan to involve parents in the process.

'*With regard to my small scale project, the questionnaire I used was developed by experts by experience for use in a similar study; however I consulted those who had completed the project to develop this questionnaire in order to make it more relevant and applicable to the third sector project I was evaluating; again, this was useful in ensuring that the questions and language used were acceptable to those who took part. While the process of gaining feedback resulted in additional time planning the research, I felt this was a really worthwhile process'.*

3.3 Undertaking of the research

At this point it is possible to involve members of the public in collecting data. This may require training on their part and may therefore be a challenge for DClinPsychol thesis projects. At this point, we were unable to find any examples from our stakeholder groups of how experts by experience had been involved in research projects.

3.4 Analysis of the research data

Experts by experience can:

- Provide their own interpretations of the data to supplement the researcher's interpretations
- Highlight areas that are missing from the data that could help in the development of future research questions
- Indicate which findings are likely to be of most interest to the public (NIHR, 2010; 2012).

This process is likely to be relevant for both quantitative and qualitative research projects. However, as part of this process, lay summaries of study findings may need to be produced.

Case example 5

Charles Marley, a lecturer in the Clinical and Health Psychology department at Edinburgh, is involving an expert advisory panel, also made up of participants, in various stages of his current research project, including within the data interpretation.

'In the project I'm working on at the moment, I've included the option for participants to be involved in reviewing/clarifying interpretation of the data (observations and interviews). What I'm doing is a less formal version of having a sample group from the population the project is attempting to represent, children considered to have ADHD. It's used as a way of limiting a one sided expert approach to knowledge construction through the inclusion of participant voices at every stage of the project: the idea is that the researcher would consult the group at each research stage and include/make changes depending on the group's opinion of what was presented to them'.

3.5 Dissemination of research findings

At this point experts by experience can improve the dissemination of research findings by: advising on or developing reports that can be understood by members of the public; provide ideas on where and how findings should be disseminated; be directly involved in presenting

the findings (NIHR, 2010). We were unable to find any examples for this type of involvement of experts by experience from our stakeholder groups.

4. Other considerations

While preparing this document, other recommendations about involving experts by experienced emerged from the literature.

- There can be an advantage to having some distance between the researcher and experts by experience group so that members feel confident to provide more meaningful feedback than spelling corrections (Lindenmeyer et al., 2007).

- The researcher should keep a summary of any changes to a project as a result of involving experts by experience (Lindenmeyer et al., 2007).

- Guidance for Reporting Involvement of Patients and Public (GRIPP; Staniszewska et al., 2011) can be used to guide how members of the public have been involved in a project is reported.

- If possible, it would be fair to reimburse expenses such as travel if contact with members of the public is outside of a regular meeting.

- It may be beneficial to involve a pre-existing group because of continuity of interactions between the group and researchers (Lindenmeyer et al., 2007). This is an interesting point because it contrasts with the argument for random sample of relevant population to ensure better representation and avoidance of those with particular demographic characteristics.

- It would be useful to ask for people's feedback about being involved (especially in cases where involvement has been great) and ask if they would be interested in being asked again by you or other researchers in the department.

- Make sure that expectations of what is involved are discussed and mutually agreed.

- Location may need to be considered. A neutral location (rather than a hospital) might be more comfortable for some people and accessibility should be thought about for those who may have mobility difficulties (NIHR, 2012). However, groups may already hold meetings that you can attend, in which case location is less of an issue.

- Ask whether people would prefer to receive information by email or through the post (NIHR, 2012).

5. References

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