It takes persistence to make a reality of the
rhetoric of user-led research

User researchers in control

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The last ten years have seen growing acceptance of the notion of user-led research in mental health services. This is partly a result of the growing influence of the survivor movement and the emergence of increasingly vocal local user groups, and partly due to the advent of a consumerist culture within UK health policy, which is reflected in recent documents on patient and public involvement and patient choice,[1,2] and, crucially for people with mental health problems, in the national service framework for mental health.[3]

Within the fields of health and medicine, lay or user involvement has come to be regarded as a necessary condition of sound research. This development has been encouraged and promoted by bodies such as INVOLVE (formerly Consumers in NHS Research) and the Cochrane Collaboration, and most funding bodies now require applicants to show that service users have at least been consulted about the aims, methods and outcomes of any proposed study, even if they are not expected to play an active role in conducting it.

Opportunities for service user involvement in research vary.[4,5] Most research teams are still dominated by academic researchers, with service users playing supportive or consultative roles. At the opposite end of the spectrum are user-led or user-controlled research projects. This, as Hanley and colleagues point out, 'does not mean that service users undertake every stage of the research, or that "professional" researchers are necessarily excluded from the process altogether'.[4] It does mean that service users initiate the research, direct its course, and ultimately 'own' the findings. The Mental Health Foundation's Strategies for Living project is widely regarded as having pioneered user-led research in the mental health field.[6] Another influential model is user-focused monitoring, developed at the Sainsbury Centre for Mental Health.[7]

Rhetoric abounds about the need for and potential benefits of user involvement in research.[8-10] The reality, both for service users and academic researchers, of developing successful working partnerships has received far less attention. In this article we report the experiences of a user-led group in undertaking a modest piece of mental health service research, to highlight the real benefits of and barriers to user leadership in this sphere.

Getting started
We represent an ad hoc research team comprising two mental health service users, an independent user involvement worker, an academic researcher and three clinicians, who came together during the planning stages of this particular study. Other members have come and gone as they found it difficult to sustain the commitment to the study or had too many competing demands on their time.

The study was initiated by service users but was a long time in the making. Unlike academic researchers, who are under constant pressure to generate new research activity and win grants, service users have no research remit and no system of rewards for engaging in research. This study grew out of a very different activity. The users, with the user involvement worker, were initially engaged in listening to the views of individuals receiving mental health care and supporting them in getting those views heard within the local service context. During the course of that work, it became clear that a single service issue was emerging repeatedly as problematic for users: namely, 'care planning'. However, it took several years, a number of false starts, and lengthy discussions with a range of professionals for this to turn into a research project. Without the guidance and support of clinical staff, an NHS librarian and an academic research department, it is unlikely that we would ever have set out on the research path. ➔

→ Formulating a 'research question' was the first step and was far from straightforward. At first we were totally focused on addressing negative experiences of care planning. We had been receiving a large number of reports from both users and carers that they were not as involved as they wanted to be in the individual care planning process that is central to modern mental health service delivery under the Care Programme Approach.[11] On the basis of these complaints, we made an assumption that the care planning process was not working as it should, that users and carers were being excluded from decision making, and that this was a situation that needed to be put right. We also thought we knew what was needed to put it right, and plunged straight in with an intervention designed to help users and carers play a more central role in identifying their own health and social care needs and devising strategies to meet them. This, perhaps not surprisingly, proved ineffective, but we were able to learn from our failure: that you can't arrive at a solution without first investigating the nature, origins and extent of the problem. This gave rise to a properly formulated research question, namely: 'What are the bridges and barriers to user and carer involvement in care planning?' This provided scope to explore good as well as bad professional practice.

Next steps

The next steps were searching the literature, designing the study and writing the proposal. These involved drawing on the skills of both NHS staff and academics. We realised that it would be impossible to carry out research on the work of a community mental health team (CMHT) without the advice and support of its managers and front-line clinical staff. Capitalising on existing relationships and forging new ones were essential in gaining access to library resources and information about CMHT procedures, and in seeking help with the study design and methodology. In this way a research team emerged that brought together a range of knowledge and expertise but was still emphatically user-led. We were undoubtedly helped in this by the current political climate, with its strong endorsement of public involvement in health service planning and research and the resulting pressure on both academic departments and NHS trusts to demonstrate willingness to work with service users.

Gaining ethical approval for the study was a daunting prospect. We had been led to believe that the sole raison d'etre of Local Research Ethics Committees (LRECs) is to make life difficult for prospective researchers, and that many a research project had fallen at this hurdle. To our astonishment, however, our application sailed through in record time.

This is one area where close collaboration between service users, clinicians and academics can really pay off. LRECs exist to protect NHS patients, service users and other members of the public from those who wish to perform risky or invasive experimental procedures on them in the interests of science. By initiating and designing the study themselves, it is likely that service users will already have identified and eliminated many potential ethical hazards. They will know if particular procedures or questions are likely to cause distress,

because they possess what Williams and Popay call 'the privilege of experience'.[12] In our team, the service users played a crucial role in early discussions about how people would react to video/audio-recording care planning meetings. They also ensured that questions were worded in a sensitive and accessible form, and tried out draft interview schedules on other service users. The mental health professionals on the team were able to comment on clinical issues, while the academic member took responsibility for completing the forms and managing the ethics and research governance processes.

The funding barrier

Funding was and remains the biggest barrier. Ours was a small-scale, home-grown study born out of the experiences of NHS users and carers and their desire to make tangible improvements to the services on which they rely. This is the type of research in which service users are most likely to want to get involved, and that they are most qualified to lead on, because it is relevant and meaningful at local level, as well as being generalisable nationally. However, since the withdrawal of NHS regional funding in England, there is no longer any mechanism for financing such research. The current competitive funding environment in the UK, in which the Department of Health, the NHS and, increasingly, the research charities identify the topics they want researched and then put projects out to competitive tender, can only favour high-ranking academic research departments and relegate service users to the sidelines. Genuine user-led groups cannot, and most probably have no desire to, compete at that level. As Thornicroft and colleagues point out, service users' priorities for research are not the same as those of professionals and funding bodies.[13] They have their own questions to answer, and their own reasons for wishing to undertake research.

We eventually secured a small grant from Folk.us, a local organisation set up with funding from the Department of Health to facilitate and promote user and carer involvement in health and social care research in north and east Devon. This was enough to carry out a pilot study, and we are now hoping to obtain further funding from local sources to enable the main study to go ahead.

Collecting and analysing data

Much user-led research consists of very small-scale studies that are accomplished 'on the cheap' because users carry out the work themselves, very often in their own time, and without remuneration. However, like academics and clinicians, user researchers may not have the time to undertake all the day-to-day work of a project themselves, and it may not always be advantageous for them to do so. Our study was conducted on home ground, within the very service that the user researchers themselves were using. The clinical staff and clients were known personally to them, and serious questions about bias and confidentiality would have arisen had the users tried to do the recruitment and data collection themselves, particularly as the study involved observing and recording personal care planning sessions in which individuals' lives, their illnesses and their service requirements would be discussed in detail. It was therefore agreed from the outset that a research

worker would be employed for that purpose. Hence the pressure to secure adequate funding.

Once the data had been collected and the tapes transcribed and anonymised, the user researchers were free to play a full part in the analysis. Users bring unique insights, particularly to the analysis of qualitative observational and interview data, as they can identify with participants and know what it is like to be in their place. However, this is likely to be emotionally challenging and may bring personal issues to the surface. It is therefore important that support is in place for users at this stage in the research process.

Disseminating findings

Townend and Braithwaite argue that providing service users with the opportunity, through research, to bring about changes in mental health services 'may serve as a panacea for some of the negative consequences of their experiences of mental health service usage'.[10] Our user researchers found the experience of reporting preliminary results to members of the CMHT the most satisfying and empowering aspect of the research process, reversing usual roles and redressing the power imbalance between professionals and clients.

Here again, the 'privilege of experience'[12] works to their advantage. Not only are they able to present user perspectives in a sensitive and persuasive manner; they have a facility and a freedom to talk about mental health issues in a way that academics and clinicians cannot. Our user researchers often draw on their own experiences of being unwell, and a brief personal anecdote, spontaneously and amusingly told, can often illustrate or reinforce a point in a way that no weight of statistical evidence or academic status can.

Control and ownership

Issues of ownership arose throughout the study, in relation both to the process and the findings, as long-established ways of thinking and working were challenged. Keeping focused on the original research question required a considerable amount of determination in the face of pressure from NHS staff and academics to pursue avenues that they perceived to be more clinically relevant or more likely to bring external recognition. Long delays, and possibly loss of some eligible participants, were caused by the fact that many members of the CMHT wanted to discuss the project with their clients before allowing them to be contacted by the research team. Then the completed pilot study generated so much interest locally that the team has struggled to retain control of its findings and prevent premature conclusions being drawn.

Within the research team itself there have been a number of competing agendas, with different members of the group under pressure to deliver in different ways. The pressures on academics to meet assessment-driven targets, which depend on winning large grants and publishing in high-ranking medical journals, make it particularly difficult for them to contribute time and energy to small-scale, user-led projects such as this.

Our study set out to explore bridges and barriers to user and carer participation in care planning. The process also revealed bridges and barriers to user and carer leadership in research. One of the most ➔

Bridges and barriers

The care programme approach for people with a mental illness (CPA) was designed to encourage users, carers and professionals to work together to draw up individual care packages, identifying the user's health and social care needs and devising strategies to meet them. Evidence suggests, however, that users and their carers still feel excluded from the process of care planning and that professionals lack clear guidance as to how to facilitate greater involvement.

Our study, 'Bridges and barriers to user and carer involvement in care planning', aimed to explore how the care planning process operates in practice and to identify factors that help and hinder the involvement of users and carers. Care plan review meetings were observed and audio-taped and semi-structured interviews were conducted afterwards with the service user and the care co-ordinator. Plans to interview informal carers had to be abandoned because none were present during review meetings. Tapes of meetings and interviews were transcribed and analysed using qualitative methods.

Four service users and their care co-ordinators were recruited for the pilot study. When we sought to identify carers for inclusion in the study three of the users told us they had a relative who played a significant role in their life, but this person was not identified as a 'carer' in the client record and was not invited to their CPA review.

From the data collected we identified a number of factors that could operate as barriers and bridges to user involvement:

- time – arranging meetings to suit consultants and allowing too little time resulted in participants feeling rushed and in service users feeling they had not been listened to
- venue – holding meetings in the user's home, as opposed to an institutional setting, appeared to give users a greater sense of control
- numbers – large meetings with several workers present tended to generate 'inter-professional talk' that excluded the service user. One-to-one or small meetings produced more effective professional–user dialogue
- structure – lack of structure in meetings was associated with lack of clear decision making. Systematic reviewing of the existing care plan resulted in more effective decision making
- relationships – mutual trust between professional and client was a key factor in user-centred reviews. Lack of trust and conflict between workers were seen to be damaging to the care process
- communication style – closed questions requiring 'yes/no' answers restricted user participation in the decision making process; open questions enabled the user to explore options and reach their own decisions
- service user's state of mind and engagement with services – insight, mental stability, relative wellness and a positive attitude towards services in general were clearly associated with engagement in the review process
- professional roles and responsibilities (eg. risk management) may limit the extent to which users can be involved in decision making.

important bridges was the dedicated user involvement worker, who was able to co-ordinate meetings and provide administrative back up. A political climate that, at least in theory, promotes users' and carers' rights, and the eagerness of NHS staff and academics to get involved also smoothed the progress of this piece of research. On the other hand, while the study was intended to be both user-led and carer-led, the demands of the informal caring role made it impossible for carers to stay involved in the project. Furthermore, the absence of funding, issues around confidentiality and access to client information, and competing claims by those both in and outside the research team have all presented considerable challenges. This has led us to conclude that the rhetoric of user-led research conceals a complex and difficult reality, and it is likely to be some time before user leadership becomes an established and uncontested feature of research practice.

The study was carried out by Jenny Hounsell and Billy Kitson, who are Exeter mental health service users, Charlotte Hubbard of Exeter Mental Health Service User Project, Stephen Downs, Adam Morgan and Terri Warr from Devon Partnership NHS Trust, and Christabel Owens of the Peninsula Medical School. We intend to use these preliminary findings as a foundation for a longer-term study for which we are currently seeking funding.

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