Great expectations for participatory research: what have we achieved in the last ten years?

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Service user involvement in research used to be of the kind where individuals would be the "subjects" of research, implying a sense of exposure and even subjugation in a setting where all the power lies with the experimenter. It has now been more than ten years since P. Trivedi and I provided a guide on how to move research from individuals being passive subjects to becoming equal partners (1). It is certainly time to reflect on whether anything has changed.

The involvement of service users was thought to be beneficial in a number of different ways. In health care research, it makes the results more relevant to the community which it is aimed to benefit. Moreover, in the new world of reduced research resources, it is also likely to save money, because research involving consumers in formulating the questions, and particularly how they are asked, makes the research more valid and the science likely to proceed at a quicker pace.

In the last ten years, we have learnt one lesson: to call our subjects "participants". But is there any evidence that this has changed the power relationships? Does it mean more than learning to use the more politically correct term and one emphasized in most journals' publication style guidance? As well as examining whether naming has indeed affected research and particularly researchers, I also investigate whether there are data on how it might have affected our research outcomes.

Although the movement to more participatory research is of interest to the whole world, I have taken the UK as a central (and optimistic) example of how things can change with support and small financial investments. This is not just because of my personal research base, but also because there are few countries which have really taken the role of service user researchers and service user involvement as seriously as the UK, as judged by the number of reports in the peer reviewed literature.

TYPES OF RESEARCH PARTICIPATION

If you enter "participatory research" into a database such as Web of Knowledge, the search produces more than 1.8 million publications, but when you add the term "mental health" it reduces to less than 400. So, despite mental health disorders producing a high level of burden and being of interest to relatively large groups of researchers and policy makers, the number of papers on the topic is less than 0.02% of the total using this method. So, it is a scarce resource.

The definition of participatory research is also a problem when considering the literature. Many papers in my search called their methods participatory action research. This method was gleaned from work by Arnstein (2) on inner city regeneration, which produced a "ladder of citizen participation". This is a type of participatory research where the community suggests a research question which involves bringing about some change, and researchers provide expertise to the community on how to answer such a question. But work in mental health research is not always like this. The questions in general are set from a scientific perspective and are often about understanding a process rather than having specific change as the proximal goal. So, it is a long way from participatory action research. In fact, the methods appear to fall into the consultation variety (see below) and it is not clear that they do in fact fulfil Arnstein's expectation for community involvement.

I have drawn a new definition of participatory research from the work of an organization called INVOLVE, which is funded by the UK National Institute for Health Research (NIHR). INVOLVE supports public and patient involvement in research in the UK national health services, public health and social care (3). Three general levels of involvement were described in an early definition: consultation, collaboration and user-controlled research. But, before we even get onto this new ladder, we need to consider the least level of involvement. This is when a participant only provides data to researchers. Many people are happy to perform what may be lengthy, boring and sometimes unpleasant tasks for researchers on the understanding that these tasks will answer questions that may help others. In the UK, last year, more than 40,000 people agreed to take part in studies with a mental health component and many of these citizens presumably freely agreed to participate. This level of participation also needs to be celebrated, but several reports suggest that these individuals rarely discover what the research outcomes might be, unless they are so spectacular that they turn up in the newspaper or on television (4). This lack of dissemination might jeopardize future involvement and clearly needs to be high on the agenda of all researchers if we are to engage the next series of willing volunteers.

The INVOLVE level 1 involvement is *consultation*, and many studies carry out this task. It is clearly useful, as it may be that collaboration on the language of an information sheet, the acceptability of a particularly research design, or even the actual question asked, may aid the feasibility of study recruitment. What has also focused the minds of many UK researchers on this activity is that funders now often demand a section in the grant proposal detailing these activities. But effective consultation requires work – it can only take place when researchers provide clear information on what is planned as well as offering options and listening to feedback (more information), with the real possibility that the researchers might actually change their research. Without these ingredients, the process of consultation is, as Arnstein suggests, mere tokenism or, using terms from Trivedi and Wykes (1), just lip service.

At the next level is *collaboration*, and this is much more difficult to carry out, as it requires both consultation and the development of mutual trust, since the partnership will continue to exist after the proposal is funded. This means encouragement of some additional ideas and options and deciding together the best way forward. Again, information and support is vital and requires patience by the researchers to ensure there is ample time to gain trust and resources – even financial ones – to encourage service user involvement.

The final level is *user led research*, when the power in the relationship is reversed, with mental health service users conceiving the research ideas and carrying out the research, sometimes in consultation with academic non-service user researchers.

Since P. Trivedi and I wrote our paper on issues to consider when working with service users in research, there have been tangible changes. In the UK, support for service user involvement has grown. It has taken three components: a) investment by the NIHR to garner early support, b) clear guidance to researchers on what is expected for public and patient involvement and c) an understanding that this is a significant part of the grant review process and that lay reviewers will consider it. For instance, an NIHR grant application poses two specific questions: how have the patients and public been involved in the development of the proposal, and how will they be involved in the conduct of the research. But unfortunately not all the text provided in forms is true! An examination of ethics proposals for research across the physical and mental disorders suggests that sometimes researchers have grand plans that are not put into practice (5). The good news in mental health, however, is that the situation is different. A recent audit of mental health studies thoroughly tested the involvement plans through interviews with service users and with study teams. The data demonstrate that for at least 85% of studies involvement plans were implemented (6).

GOOD EXAMPLES OF SERVICE USER INVOLVEMENT?

Clearly, if the research questions are generated by researchers, then there is little room for involvement of service users. But there are now examples of how research priorities are set with the involvement of all potential stakeholders. Some bring together large groups of local service users and by a process of voting and suggestion produce a list of priorities (7,8). Other systems involve more collaborative approaches, such as the process adopted by the James Lind Alliance in their Database of Uncertainties about the Effects of Treatments (DUETS) (see www.duets.nhs.uk). This database contains lists of priority questions posed by stakeholders (service users, families and clinicians). The process is to identify priorities from clinical and systematic reviews and add these to ones produced by service users and clinicians. There is then a priority setting partnership steered by representatives of patient groups, clinicians and academics. In developing questions to answer in the field of schizophrenia, there were 237 priorities identified, which through discussion were reduced to 26 highly ranked (via surveys). The next step was a face-to-face meeting where the list was reduced to 10 priorities of the form "what is the best way to treat people with schizophrenia who are unresponsive to treatment?" (9,10). These priorities are now being adopted by research funders (11).

Across the UK, support for user involvement is provided by the NIHR Mental Health Research Network (MHRN). The network has focused on ensuring that high quality research studies are designed through setting up a partnership similar to DUETS. The subsequent protocols are submitted for funding and can go through a second phase of involvement in the FAST-R (Feasibility And Support to Timely Recruitment) service. FAST-R is supported by MHRN and is a free seven-day turnaround service from a group trained in research protocols who also have experience of mental health difficulties. They advise on the protocol and suggest issues that might aid recruitment. So, for instance, as a minimum they might suggest some slightly different wording on the information sheet or a change in design to make it more acceptable to service users. MHRN also provides information on good practice for working with service users and carers through its website (www.mhrn.info).

In addition to this national support, there are also islands of good practice and innovation, and one such unit is the Service User Research Enterprise (SURE) at the Institute of Psychiatry, King's College London. This unit pioneered service users as researchers. It was founded by this author, who was its first director, but now (showing its maturity) is co-led with a service user researcher, D. Rose. Research in SURE is different from participatory action research, where the researcher is not part of the community but acts on behalf of the community in the research. In our model, service users have the skills of a researcher but, in addition, are considered part of the community under investigation, due to their status as someone who has used or is using mental health services. In addition to our general approach of employing service user researchers, SURE has also developed a number of different participatory methodologies. We understood the need for evidence of treatment outcomes, so we have a method for producing systematic reviews which includes service users with experience of the problem under investigation and the treatment being considered. Our first systematic review (12) on the outcomes of electroconvulsive therapy (ECT) used peer reviewed literature, historical evidence from media libraries as well as Internet forums. It was steered by a group of individuals who had received ECT, and two of the researchers had also had this experience. Our conclusions had a large impact, because of novel findings which helped the understanding of the memory effects following treatment. It also changed clinical guidance across the UK.

What became clear in our examination of the ECT evidence was that some side effects had been missed or misinterpreted because of the lack of evidence from service user valued outcome measures. The outcomes of trials will be compromised if assessments are unappealing or misunderstood by service users or do not capture the essence of their experience. We approached this problem in two ways. First, service user panels reviewed and prioritized outcomes used in current clinical trials to ensure we could advise researchers on which of the popular ones were thought to be appealing and valued (13). Then we began to develop methods of user involvement to create novel measures (14,15).

Less than one third of clinical trials recruit to target (16) and one potential for service user involvement is to improve recruitment success. This potential tangible effect might motivate researchers (and funders) to make greater efforts with user involvement. We investigated the portfolio of clinical research studies kept on the MHRN database. We discovered that there had been an increase in service user involvement over the time that the database operated (about 8 years), with more collaborative studies and recently service user led studies. Some diagnostic areas clearly found involvement challenging, but this was limited to just one or two areas. But the most surprising result was that service user involvement did contribute to successful recruitment to the study. This occurred after taking into account the funder, the clinical study group under investigation, study design complexity, whether it was randomized, whether it had planned follow-up and whether it was interventional (17). This really is tangible evidence that researchers (and funders) would benefit from more involvement.

ARE THEIR LIMITATIONS OF SERVICE USER INVOLVEMENT?

There is a tendency to assume that service users need to be involved only when the research has a clear tangible clinical outcome such as a therapy or a service – effectively at the end of the translational pipeline. Some funders in the Ennis and Wykes (17) study did not encourage user involvement, such as the Medical Research Council. Their portfolio consists of earlier stage studies, often at proof of concept, and they might argue, as others have, that service user involvement is less necessary at this early stage. However, colleagues and I have suggested that involvement must start at an early stage even in the consideration of biomarkers and is one key to successful early translation (18). It is our contention that putting service users at the heart of translation will mean that less resource is lost through poor decisions made at this early phase. Currently only involvement at later stages of drug development is thought necessary. As Woolf (19) puts it, "bringing a drug to market without knowing how to bring it to patients undermines its larger purpose and can only diminish its profitability for investors". But we argue that the efficient use of resources and scientific direction can only be enhanced through service user involvement even at the stage of biomarker development (18). If we had input on which side effects are considered important and use this to determine the subsequent phases of drug development, then compounds might be more acceptable after reaching the final stages.

WHERE DOES THE FUTURE LIE WITH SERVICE USER PARTICIPATORY RESEARCH?

Clearly participatory methodologies will continue to develop into trials and epidemiology. With citizen research we might also reach out to the wider community to collate data to inform our science. For instance, the website PatientsLikeMe (www.patientslikeme.com) already harnesses the views of service users to increase our understanding of side effects and current use and acceptability of treatments. These data might be not only used for research and treatment development, but also for the important "back translation" to the initial phases to treatment. An extension of this is our new eMPOWERMENT study, which allows service users to have access to their electronic care records. The programme has been implemented with the full collaboration of service users. The final system collates information from hospital, community and general practitioners' records and provides useful links to important information on disability benefits and medication. But it also allows service users to input their own data into the mental health care record.

We are currently using participatory methods to develop measures of side effects and recovery to add to our measures of wellbeing, and will soon be embarking on further service user requested assessments. The hope is that the data produced by such a system will help to identify good (and poor) clinical outcomes of both treatment and services. Furthermore, it will provide large scale data which has great research potential for more subtle process measures and moderating factors important in defining the stratified medicine we aspire to.

CONCLUSIONS

In the past ten years there has been a qualitative advance (at least in the UK) not only in service user involvement but also in the available participatory methodologies. There is research support for involvement and I know that there are researchers in the USA, Canada and Australia who are interested in these advances. We would like to see many more people move from interest to implementation, because we have found tangible benefits for researchers. We hope, however, that any adoption of the approaches outlined here will be because there is a genuine belief that there is value in user involvement (20) and not merely a response to requirements of funding bodies – although at least this would be a start.

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