opinion & debate

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Collaborative research between users and professionals: peaks and pitfalls

In this article, I shall give an overview of the emerging field of collaborative research between clinical academics and service users in the field of mental health, along with some examples of different kinds of collaborative research and the value they can bring to more mainstream studies. I shall also discuss some of the obstacles to collaborative research in mental health and suggest directions for the future.

Collaborative research is beginning to be established in some clinical specialities, notably, cancer, HIV, AIDS and Alzheimer's disease (Dunbar, 1991; Hanley *et al*, 2001; Thornton, 2002; *Quality Research in Dementia*, http://www.qrd.ion.ucl.ac.uk/consumers.htm). In mental health, user-led research preceded collaborative research in time and has been carried out in the UK for nearly a decade. There has been a myriad of small projects and at least two large programmes of work, both of them based in charities (Faulkner & Layzell, 2001; Rose, 2001). Much of this work takes the form of evaluation of services from the user's perspective, although Faulkner & Layzell (2001) investigated people's own strategies for living with mental distress.

Until recently, user-led research was not accepted by the academic mainstream. Nearly all of its publications are part of what is known as the 'grey' literature. It does not appear in peer-reviewed journals. However, there is now a sea-change in the status of user-led and collaborative research. Funding bodies such as National Health Service Executive Research and Development and Wellcome require evidence of user involvement in research proposals and sometimes require that users be involved centrally in the research itself.

What is user-led research?

User-led research involves service users controlling all stages of the research process; design, recruitment, ethics, data collection, data analysis, writing up and dissemination. The two programmes cited above involve service users who are also researchers sharing their skills with service users who are not primarily researchers. However, they have much to contribute because they have experienced the same problems and services as the participants in the research. They are increasingly being called 'experts by experience' (Faulkner & Thomas, 2002). For example, the user-focused monitoring programme at the Sainsbury Centre for Mental Health (Rose, 2001) devised a community care questionnaire for interviewing participants. This took four 4-hour meetings of brainstorming, the coordinator fashioning a questionnaire, the group amending it, re-fashioning and close attention to the language used. The result was different from professional questionnaires commonly used because it derived from a service user perspective.

The group who produced the questionnaire then interviewed other users on their experiences in the community. One notable result was that 'ordinary' users, sampled randomly from enhanced care programme approach, voiced similar concerns to those that have been expressed by 'activists' for 20 years. This belies the criticism that the concerns of activists are unrepresentative.

What is collaborative research?

The Consumers in NHS Support Unit (2001) proposes that there are three levels of user involvement in research: consultative, collaborative and user-led. The latter has been discussed already and consultation is often of minimal form (perhaps an informal request to look over a questionnaire). However, within collaborative research there are different levels of involvement. Collaborative research tries to weave features of user-focused research into more mainstream work. For example, in trials, user-researchers may have an influence on the outcome measures used (Perkins, 2001). To explain this further, I shall use some examples from the Service User Research Enterprise (SURE) at the Institute of Psychiatry in London. This is a collaborative unit that I coordinate and is staffed by service users. Its Director is a professor of psychology.

In one trial involving SURE, the service user-researcher pointed out that the outcome measure – medication compliance – was inconsistent with the intervention – motivational interviewing. Although

compliance remained an outcome, user empowerment was also included (Trivedi & Wykes, 2002).

User-led components of collaborative projects

Another way in which collaborative research can be conducted is that the service user research team may be part of a larger project and their role is to carry out the user-led component of that project. An example comes from a project being conducted by SURE on continuity of care for people with long-term needs. The funders specified that part of each project should look at how users and carers experience continuity of care. There is a large managerial and professional literature on continuity of care (Freeman *et al*, 2000) but little on the user experience. Our hypothesis is that users' and carers' perceptions might be different from those of managers and professionals.

Finally, the empirical part of a project may be conducted by people who have themselves received the treatment under consideration. An example is SURE's recent review of consumers' perspectives on electroconvulsive therapy, which, without compromising scientific rigour, shed a different light on this topic to clinical research (Rose *et al*, 2003).

Involving service users in local R&D structures

User involvement has now been achieved in the R&D Steering Group of the Trust local to the Institute of Psychiatry. The intention was to avoid tokenism: the haphazard selection of one or two service users to sit on the Committee completely unsupported.

Thus, it was agreed that a group of service users be convened that would delegate two members to attend the Steering Group meetings supported by a SURE employee. The group was initially convened at an Open Meeting and has been running for a year. It meets monthly, receives all the committee papers and decides which are the most important points for the two delegates to raise. The two delegates and the SURE employee then attend the full Committee meeting, taking an active part. They then feed back to the wider group the following month.

Obstacles

Frank scepticism

Some writers are openly sceptical about the value of user involvement in research. Tyrer (2002: 406) argues that it may 'drive mental health research into the sand'. Only a demonstration that user-focused research provides a valuable counterpoint to professional research can counter such a stance. I return to this point below.

Ticking the user involvement box

As the requirement of funders for user involvement in research proposals develops, it is important that this involvement is meaningful. It is here that minimal consultation may be used in order to 'tick the user involvement box'. This is clearly to be avoided. SURE now runs a 'clinic' one afternoon a week where clinical academics can have an initial discussion about what our involvement in a research proposal might be.

Power differentials

The question of power differentials in research applies to the relation of junior to senior research staff generally. However, the issues may become compounded in collaborative research in mental health.

First, even if a user-researcher has all the requisite degrees, they are unlikely to have the same career track record. Mental health problems themselves can interrupt careers, but there is still discrimination and stigma that prevent people from seeking or getting research posts. Second, and linked to this, there are salary and status differentials so that even experienced user researchers in a collaborative project will be perceived as 'junior'. Some user-researchers acting as consultants to research projects do not get a salary at all, they receive therapeutic earnings, despite substantial input. Finally, and most corrosive, is when the user−professional research relationship is overlaid by an implicit patient−doctor *clinical* relationship. It is as if some collaborators are regarding user-researchers through a double lens − once as a researcher and secondly as somebody's patient. This point is probably most significant in mental health because the knowledge of psychiatric patients may be downgraded due to their diagnosis.

The future

The main problem faced in doing user-focused or collaborative research is that it is sought after now but may soon become a passing fashion. We need strategies to avoid this so that such research has credibility and can be seen as beneficial to the research community.

First, we have to deliver. There is no point in getting large grants if one cannot deliver on them. This is not simple, because work may be judged by different criteria according to whether the assessors are users, professionals or funders. The first acid test will be whether the outputs of the now well-funded collaborative research projects are accepted by peer-reviewed journals.

Research capacity should be built up among the service users who are interested. The difficulties in education and careers that may beset people with mental health problems have been discussed already. One strategy is just to give people the confidence that they can do this if they want to. Qualified service users can be employed in research posts and their careers advanced by registering them for PhDs; local service users can be

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trained and users may act as co-facilitators in focus groups or as interviewers.

Academics need their capacity built up too. They need to learn what user involvement in research can and should amount to, and be persuaded that collaborative research will increase quality and provide a *necessary* complement to mainstream research. For example, user-focused research can give detailed information about responses to treatment. In clinical research this is usually measured only by drop-out rates but more qualitative methods can tell us much more about why people continue treatment or not.

Conclusion

If user-focused and collaborative research do become part of the mainstream, this will likely provide some new forms of evidence upon which to base practice. Users come to the research endeavour with a different perspective to professionals and are able to elucidate how services and treatments feel to service users 'from the inside'. They can provide fresh insights, and so research done from this perspective should lead to services that are more acceptable to consumers than many find them today.

References

CONSUMERS IN NHS RESEARCH SUPPORT UNIT (2001) *Involving Consumers in Research and Development in the NHS: Briefing Notes for Researchers*. London: Consumers in NHS Support Unit.

DUNBAR, M. M. (1991) Shaking up the status quo: how AIDS activists have challenged drug development and approval procedures. *Food, Drug and Cosmetic Law Journal*, **46**, 673–706.

FAULKNER, A. & LAYZELL, A. (2001) *Strategies for Living*. London: The Mental Health Foundation.

— & THOMAS, P. (2002) User-led research and evidence-based medicine. *British Journal of Psychiatry*, **180**, 1–3.

FREEMAN, G., SHEPPERD, S., ROBINSON, I., *et al* (2000) *Continuity of Care: Report of a Scoping Exercise for the SDO Programme of NHS R&D*. London: NHS Service Delivery and Organization.

HANLEY, B., TRUESDALE, A., KING, A., *et al* (2001) Involving consumers in designing, conducting and interpreting randomised controlled trials: questionnaire survey. *BMJ*, **322**, 519–523.

PERKINS, R. (2001) What constitutes success?: the relative priority of service users' and clinicians' views of mental health services. *British Journal of Psychiatry*, **179**, 9–10.

ROSE, D. (2001) *Users' Voices: the Perspectives of Mental Health Service Users on Community and Hospital Care*. London: Sainsbury Centre for Mental Health.

—, WYKES, T., LEESE, M., *et al* (2003) Patients' perspectives on electroconvulsive therapy: a systematic review. *BMJ*, **326**, 1363–1366.

THORNTON, H. (2002) Patient perspectives on involvement in cancer research in the UK. *European Journal of Cancer Care*, **11**, 205–209.

TRIVEDI, P. & WYKES, T. (2002) From passive subjects to equal partners: qualitative review of user involvement in research. *British Journal of Psychiatry*, **181**, 468–472.

TYRER, P. (2002) Commentary: research into mental health services needs a new approach. *Psychiatric Bulletin*, **26**, 406–407.

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