

Welcome to this special issue of Research, Planning and Policy, dedicated to user-led research in health and social care.

Proposed by members of the Toronto Group, (which is committed to research as empowerment) after their presentation to the Social Services Research Group annual conference in 2003, and willingly embraced by the editorial board of RPP, we hope that this issue marks the coming of age of user-led research for the readership of the journal. The papers submitted were read by members of the editorial board, and by either a user researcher or a practitioner researcher.

A Researcher Perspective

User-led research aims to differ from the more traditional health and social care research in the kind of **ownership, partnership, power relations** and **knowledge** it wishes to foster.

When successful, it constitutes an **action research** project, in so far as the active involvement of users as researchers changes the significance of the project and its product for its participants as well as for the external world. Usually it would be proposed as a way of:

- finding out what other service users really think, as user respondents can do away with layers of social desirability when talking to researchers they know to be also service users;
- looking for new angles on a difficult issue in terms of the relationships between service users and practitioners, subject marked by ambiguous knowledge, or where the main stakeholders are known to have different perspectives;
- encourage service users to be researchers because their unique knowledge has been often undervalued and invalidated by professionals and theoreticians;
- as a means to enable service users to be empowered, valued, and to gain new skills;
- as a means to enable service users to take control over yet another aspect of their lives - the knowledge base about their lives, and the impact health and social care services have had on it.

Thus the engagement of service users who have not trained before as researchers in this role has the potential to change their own self-image, that of others about them, the knowledge base, the relationships between service users and researchers, and that of service users and practitioners.

For this potential to become a reality a genuine partnership between researchers and service users has to be established, one in which each contributor offers what they have, rather than one which looks for quantitative, or formal, equality. The partnership facilitates the necessary training, the shared analysis of what are the issues to be researched and how best to do so, and the division of labour as to the best use of what each person brings to the project.

Therefore in my view (SR) the **participatory** element is central for user-led research to develop and prosper.

Working as a researcher identified by others as an academic researcher, and by myself as having a multitude of identities, including periods in which I was a service user, a carer, and a member of a minority group in more than one country) (with service users for the last six years) (Ramon, 2003) I have found the experience to be exciting, invigorating, frustrating, and demanding. Managing some such projects forced me not only to have to secure funding (from organisations which have never before funded users to be researchers) and get ethical permission (from committees which have never heard of user-led research) but also to work to deadlines, and to learn that while not every user can - or should - become a researcher, many can effectively do so to different degrees. I also have come to think that it is more important to involve the many than to focus on supporting the establishment of a small group of well trained service user researchers, while there is a place for such a group too.

Working with service users as researchers made me examine the value of what has been taken for granted in health and social care as good enough knowledge in the light of users researchers and users respondents' experiences, and to enjoy the shared discovery and giving meaning to the

experiential knowledge.

Policy makers, practitioners, researchers, service users and carers need good quality research for the improvement of health and social care which incorporates service user knowledge, user-led research can offer such research, even if it takes longer to achieve and requires more effort and self reflection by researchers.

A Practitioner Perspective

Perceptions of what is meant by user involvement in research will be influenced by our own personal biographies and whether we are service users and/or providers of services. It is also probable that the meaning attached to the term will be conditioned by the context and culture of the organisation in which service users are involved in research.

If such barriers were increasingly challenged, there would be greater opportunity for practitioners to engage in research and consequently be empowered by this process. Enhanced opportunities for practitioner involvement in research and practitioner-facilitated research can bridge evident gaps between the worlds of academic research and caring agencies. Moreover, practitioner facilitated research encourages the direct application of new knowledge, can aid understanding, contribute to practice based decision making and can contribute to improved service delivery. Building a research minded culture within statutory care organisations by challenging the barriers identified is vital if we are to advance working knowledge, increase understanding and evaluate effectiveness.

How does this relate to user involvement in research undertaken in health and social care organisations? Increasing research capacity and the empowerment of practitioners within this can enhance user involvement in research within social care organisations. Practitioners have considerable potential to build alliances given their day-to-day contact with service users. If barriers to participation in research were increasingly overcome greater opportunities for collaboration with service users in research would be possible. Partnership could complement user-led and user controlled research. Moreover, collaboration in the research and evidence gathering process would add considerably to the research culture of these organisations. From a practitioner perspective there is a need to be able to work in genuine partnership with service users with regard to experience and knowledge of services, in effect utilising alternative knowledge bases, which can usefully contribute to the knowledge and practice within social care.

From a practitioners perspective (JW), it appears important to develop wide-ranging alliances with service users and representative organisations to increase the research capacity of health and social care organisations and further develop inclusive and empowering research and practice approaches in these settings.

The benefits of increasing such capacity are to further understanding of the world in which service users live, to enable the development of more inclusive services, improve user involvement in evidence gathering processes and the evaluation of service effectiveness. However, before any of these benefits can be comprehensively attained there is a need to challenge the barriers preventing the development of such an inclusive research capacity to date.

Research needs to be theoretically relevant and accessible to individual practitioners and their organisations, in order that new knowledge has meaning for us and can therefore be effectively incorporated into practice and service delivery. Moreover, it is apparent that thus far the issues of promoting a research culture within many statutory organisations, empowering the confidence of practitioners with regard to interpreting and evaluating research, allowing time for this and enabling practitioners to undertake research studies and having these studies valued by the wider organisation are yet to be satisfactorily resolved.

There is an obvious need for statutory care organisations to become more research minded and involve practitioners in this process. With a committed and dedicated culture to support it, practitioner and user involvement in research within such organisations would produce effective and relevant findings, incorporating both knowledge bases, thus fostering more inclusive and appropriate services and ways of working.

A User Perspective

If this special issue of the Journal highlights one thing, it is the enormous diversity and heterogeneity of material that is currently being produced under the heading of user involvement in research and user-led research. This variety can be seen as both a strength and a weakness of such research. First, on the positive side, it highlights just how much work is beginning to be done in this field and the multiplicity of ways in which different individuals, groups and stakeholders are approaching it. We get the sense of a flourishing development, including both qualitative and quantitative research, research which is essentially based on traditional positivist values, as well as research which challenges them. There is international research, empirical and more 'blue skies thinking' based research.

However, there may also be a downside to this. Can the very wide range of approaches drawn together under the headings of user led research or user involvement in research really be seen to have anything in common? Might they not also reflect a lack of meaning, consensus or even rigour in this development? Aren't some of these discussions mutually exclusive and contradictory? Some readers might feel that this is true even among the contributions to this Special Issue of the Journal.

In my view (PB) the jury is still out when it comes to considering the coherence and validity of all that is now included as user involvement in research or user-led research. It really is too early to say. We are at a relatively early stage in this development. Pressures from government, research funders and service users and their organisations too, have accelerated interest in this initiative. Evaluation and critical discussion still have to catch up. There now needs to be much more taking stock and evaluation of it. Hopefully the contributions here will help in this process.

Certainly we know that there is no agreement about what user involvement in research might look like. Many different models are currently being attempted. There is not even agreement about language. In the call for papers, RPP referred to 'user-led' research. Some service user researchers would reject this term as vague and unhelpful.

Others use it interchangeably with the term 'user controlled' research. A project is currently underway, funded by Involve (formerly Consumers in NHS Research) to explore principles and definitions of user controlled research, because these are still not clear or agreed. One of the concerns of Involve has been that there should be no assumption that such research may have only one meaning and that there should be no pressure towards a narrow conformity or orthodoxy.

At the same time, some service users and service user researchers are already beginning to acknowledge and talk about the 'regressive' as well as positive potential of user involvement in research. It need not only be helpful. It has the power to tokenise, incorporate and marginalise service users, as well as enabling them to be full and equal partners and participants in research and the broader research process. There are also major concerns among some service user researchers that user involvement in research may be taken over, diluted and subverted, becoming just a tick-box exercise that doesn't significantly alter or improve research and the process of research production.

This may be one reason why disabled researchers have long framed their ideas about more empowering research in terms of *emancipatory* disability research, rather than *participatory* disability research, seeing participation as a necessary, but not sufficient, condition for research that may be empowering.

It is also important to recognise that we may all have different perspectives on user involvement in research and user controlled research, according to our own roles and viewpoints. This was one of the reasons why we thought it was important to include people as editors for this Special Issue of the Journal, who in their different ways combined perspectives as researchers, practitioners, service users and educators. I think we have all gained from this process. In our own discussions, there was considerable agreement about the papers and the subject, regardless of our different perspectives. Perhaps significantly, the paper where there was the most discussion and need for negotiation, was one written by a service user, over which we never came to a complete agreement!

Writing as someone who identifies as a long term mental health service user/survivor as well as a researcher and educator, my hope for user involvement in research is that it will flourish and lead us further along the road first taken by pioneering disabled researchers in the 1960s and 1970s. Their concern was with developing research which was concerned with:

- Changing and equalising the social relations of research productions;
- Committed to the rights and empowerments of disabled people;
- Supporting broader social change in line with the rights and needs of disabled people.

4

These still seem like a worthwhile set of core principles for user involvement in research and user-controlled research. To take them forward demands a constant process of review, monitoring and evaluation. It is crucial that service users and their perspectives are at the heart of this.

The contributors to this special issue are users, users researchers, researchers, and practitioners. We are pleased that a number of articles have been written jointly by mixtures of all four groups.

The articles offer a richness of issues, research methodologies, findings, and conceptual issues to learn from, as well as focusing on different areas of health and social care, incorporating geographical and cultural diversity.

We hope the special issue will stimulate the readers to wish to know more about user-led research and to actively seek to be involved in such a venture.

Shula Ramon, Julia Warrener and Peter Beresford

Acknowledgements

We would like to thank Zo Nicholas and Marie Diggins for the valuable reviews of most of the papers appearing in this special issue.

Shula is professor of inter-professional health and social studies at Anglia Polytechnic University, Cambridge, who has been involved in user-led research since 1998.

Contact details:

Anglia Polytechnic University,
Community Health and Social Studies,
East Road, Cambridge,
CB1 1PT
Email: s.ramon@apu.ac.uk

Julia is a Senior Social Worker in Partnership in Care and Research Associate at the Centre of Community Research in Hertfordshire University, working with people diagnosed as having personality disorder and currently researching whether those with such a diagnosis can inform and enhance the practice of mental health social workers.

Contact details:

Kneesworth House Hospital,
Bassingbourn-cum-Kneesworth,
Royston,
Hertfordshire,
SG8 5JP
Email: jwarrener@dial.pipex.com

Peter is professor of Social Policy, Director of the Centre for Citizen Participation at Brunel University, chair of Shaping Our Lives, and visiting fellow at the University of East Anglia.

Contact details:

Centre for Citizen Participation,
Brunel University,
Osterley Campus,
Borough Road, Isleworth,
Middlesex,
TW7 5DU
Email: peter.beresford3@brunel.ac.uk

Reference

Ramon, S. (ed) (2003) *Users Researching Health and Social Care: An Empowering Agenda?* Birmingham: Venture Press.