

# Research Overview

## Users or Losers: Does the Rhetoric of User Involvement Deliver?

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### Summary

- user involvement means different things to different people
- users can be involved both in the planning of health services and in the conduct of health services research
- not all user groups have the same opportunities for involvement
- little is yet known as to the impact that user involvement has, both on services and on the individual
- until clearer evidence is available, it remains uncertain whether users are being involved because it fits the rhetoric or because it will make a difference

### Introduction

The involvement of patients and the public at policy, management and service delivery levels of the NHS is enjoying unprecedented popularity. At the same time, the NHS Research and Development Strategy is promising to involve service users in the research that it undertakes. However, advocating user involvement is not the same thing as actually making it happen and there are still many questions left unanswered about how involving users impacts on health services and research.

Whilst undoubtedly many positive initiatives are taking place across the UK, we contend that health care professionals, researchers and service users are unlikely to embrace this agenda until they are convinced that it delivers positive outcomes. This means that until we can demonstrate that user involvement benefits services and patients then rhetoric and practice will fail to converge.

### What is user involvement?

Clarity of definition is essential when addressing user involvement. Involvement may refer to an individual participating in decisions relating to their individual care, to their participation at locality or national level in the planning and development of provision, or to them assuming a role in specific activities such as research. Within

each of these arenas, the level of participation allowed to the individual (or group) may vary, ranging from consultation or participation to user control, often reflecting differing ideological commitments.

### What are policy-makers doing to encourage user involvement?

Involving patients in health care decision-making is not a recent development. In 1972 for example, the National Association for Patient Participation (<http://www.napp.org.uk>) was set up to encourage and establish patients' groups with a view to involving the public in decisions in primary care and improve the ways that health care is delivered at local level.

More recently, patient and public involvement has become a central tenet of UK government policy (Scottish Executive, 2003; Department of Health, 1999). This has led to a number of new bodies being created to collectively support patient and public involvement at national and local levels. For example, the Commission for Patient and Public Involvement in Health (<http://www.cppi.org/>), which is funded by the Department of Health, is responsible for setting up some 571 Patient and Public Involvement Forums – one for each Primary Care Trust and NHS Trust in England. These forums are designed to give patients a direct voice in the delivery of health care and provide independent support in filing complaints. In Scotland, Partners in Change (<http://www.shstrust.org.uk/projectpinc.html>), funded by the Scottish Executive, supports approximately 90 projects that are involving patients in designing and delivering local services.

These initiatives are commendable and it is perhaps too early to say whether or not they benefit services and patients. However, even at this early stage it is doubtful that service users engaged in these initiatives are representative of multiple user views. Moreover, it is evident that the voices of particular user groups such as people with dementia are in danger of being ignored. This means that it is important to make explicit exactly which patients and members of the public are potentially

influencing the ways in which health services are planned, managed and delivered through their involvement.

Alongside encouraging patients and the public to become involved in NHS planning and development, recent policy is also promoting their involvement in health research. The Research Governance Framework for Health and Social Care (Department of Health, 2002) and the Scottish Executive (2002) for instance, advocate the involvement of users in all stages of the research process so that they become active participants as opposed to research 'subjects.' This assumes that involving users in research will lead to the development of more responsive and effective services that in turn will improve quality of care (Department of Health, 1999). However, evidence to support this assumption is relatively absent compared to the level of policy documentation promoting their involvement.

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### **Why is user involvement being encouraged?**

Patient and public involvement policy is underpinned by at least three social and political trends (Harrison et al, 2002). The growth of 'consumerism' has focused upon the ways in which service users exert 'choice' and this in turn, has led to increasing interest in matching user preferences with the types of services being designed. 'Democracy' and 'citizenship' have emphasised the involvement of citizens in a range of decision-making processes and involving patients and the public is regarded as an integral and fundamental feature of democratic society. Thirdly, the rise of 'social movements' including the emergence of 'user movements' such as, the user/survivor movement in mental health (Bertram, 2002) has turned attention to the ways in which social and political action has augmented service change. To date, however, there is limited analytical critique of how these socio-political processes drive and shape the user involvement agenda or what impact the adoption of these different models have for patients and services.

At the same time, a body of theoretical literature that informs the patient and public involvement agenda has emerged that has emphasised the epistemological significance of patient perspectives

and experiences. A 'new subjective medicine' for instance, acknowledges and even privileges the role of the patient's point of view in judging quality of care and quality of life (Sullivan, 2003) and qualitative methods for exploring how patients make sense of and experience services are now common practice in health research (Pope and Mays, 1995).

### **To what extent are users involved?**

A major criticism of the patient and public involvement agenda is that since the early 1990s the balance of status and power between patients and health care professionals has hardly changed. Patients are consulted about their views of the services that they use but they are rarely engaged as active participants in planning, developing and even running services. This means that despite the growth of practical and technical guidance for involving patients and the public (NHS Modernisation Agency) there is little evidence of user-led services that 'empower' patients (Cook, 2002). This is hardly surprising given the organisational barriers to this type of involvement including the skills and resources necessary to enable users to participate in planning and managing services and difficulties in negotiating staff and service user role boundaries (Truman and Raine, 2002).

Similarly, within health research limited progress has been made for instance, a recent survey of a random sample of completed NHS projects found that only seventeen per cent reported to involve at least one service user (Telford and Boote). This is also partly to do with the lack of resources, skills and organisational change required to effectively involve users in research (Oliver et al, 2001). 'User views research' whereby researchers seek the opinions of users is well established and the principles of 'participatory research' whereby users are engaged in the design and execution of a study are increasingly accepted. However, 'emancipatory research,' which is research that is genuinely led and controlled by service users is exceptional for the overwhelming majority of service user groups (Innes et al, 2003).

On the other hand, some service user groups, most notably disabled people, have a well-established

tradition of involvement in research and a small number of user-led organisations are taking a lead in developing capacity in participatory and emancipatory research. Psychiatry ([http://www.iop.kcl.ac.uk/iop/AdminSup/RandD/nhs\\_research.html#serv\\_users](http://www.iop.kcl.ac.uk/iop/AdminSup/RandD/nhs_research.html#serv_users)) is offering training in research to mental health service users and researchers. Moreover, a database of research that involves users is being maintained by the NHS Consumers in Research Unit (<http://www.conres.co.uk>) and this may facilitate the development of networks of researchers and service users interested in this type of research.

However, whilst practical training and guidance are to be welcomed it is clear that on its own they are insufficient. This is because health practitioners and researchers will fail to include users unless they recognise the epistemological significance of patient perspectives and experiences. Within dementia research for instance, the inclusion of people with dementia in research coincided with a growing interest in the psychological and biographical aspects of the life experiences of the person with dementia (Sabat, 2001). This development in understanding the experience of dementia challenged researchers, health practitioners and policy-makers to seek ways in which the perspectives and subjective experiences of the person with dementia could be explored (Downes, 1997). Similarly, the move towards participation in research by people with learning disability was also influenced by the development of a social as opposed to a medical model of disability (Kierman, 1999).

### Does user involvement make a difference?

Whilst the implementation of this policy agenda is gathering pace, there is a notable lack of understanding of the effect of user involvement upon patients and services. A review of papers describing the outcomes of user involvement on service development for example, shows that the impact on the quality and effectiveness of services is unknown (Crawford et al, 2002).

Similarly, there is only a small body of work that highlights the ways in which users contribute to the research process (Entwistle et al, 1998). What is largely missing from this literature is service users'

views about involvement in health research. Gathering their opinions is important since recent findings have highlighted that some users involved in research are becoming increasingly disillusioned with the process because change has failed to materialise (Innes et al, 2003). This suggests that service users involved in research and development need to know that their involvement will make a difference to, for example, clinical practice and service delivery. It also means that most research involving service users needs to be an integral part of a service planning and development process otherwise users are left wondering as to the purpose of their involvement.

### Conclusion

If patient and public involvement in NHS research and development is to advance, then increasing numbers of service users, health professionals and researchers need to possess the skills and resources to make this happen. This means that we need to utilise existing guidance, expand training and change organisations to facilitate user involvement so that capacity is developed in ways that are sustainable. However, practical guidance unaccompanied by a transformation in the ways in which patient experiences and illness is understood by health professionals and researchers is unlikely to ferment change. Finally, we need evidence that user involvement benefits services and patients because unless we can demonstrate that user involvement makes a positive contribution to NHS research and development then cynicism and disillusion are likely to emerge.

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