



**Assessment & Learning
in Practice Settings**

**ALPS Research Capacity Final Report
(3 of 3)**

**Service User Involvement in Mental
Health Training, Education and
Research in West Yorkshire**

Dr Virginia Minogue and Sarah Hardy

West Yorkshire Mental Health Research and Development
Consortium

In 2007 ALPS awarded funding to three projects which were designed to advance the goals of the ALPS programme and build additional research capacity within the partnership, to further the cross-institutional goals of ALPS

Service User Involvement in Mental Health Training, Education and Research in West Yorkshire

This report was prepared by Dr Virginia Minogue and Sarah Hardy and the service user and carer research working group whose members were:

- Lesley Dale
- Sara Firth
- Dr Simon Gelsthorpe
 - Kate Karban
- Prof Mike Lucock
- Stephen Winter
- Trevor Ramsey

Acknowledgements

Thanks also go to Barrie Holt, Peter Relton, Colin Perry, David Woodcock, John Girdlestone for their input.

Abbreviations used in the report

CCF – Central Commissioning Facility (of the NIHR)

HEI – Higher Education Institute

NIHR – National Institute for Health Research

PALS - Patient Advice and Liaison Service

PPI – Patient and Public Involvement

R & D – Research and Development

UKCRC – United Kingdom Clinical Research Collaboration

UKCRN – United kingdom Clinical Research Network

Contents

| | |
|---|----|
| Executive summary..... | 4 |
| Introduction..... | 6 |
| Background..... | 7 |
| • Policy context | 7 |
| • Service user involvement in mental health research, training and education..... | 8 |
| • The impact and effectiveness of service user involvement in research, training and education..... | 11 |
| • Funding service user involvement..... | 12 |
| The Research Project..... | 14 |
| • Aims | |
| • Research questions | |
| • Methodological framework | |
| Results..... | 17 |
| Discussion..... | 24 |
| Conclusion..... | 26 |
| References..... | 28 |
| Appendix 1: Service user and carer involvement in research & development.... | 31 |

Figures and Tables

| | |
|--|----|
| Figure 1 – The Research Cycle..... | 10 |
| Table 1 - Training opportunities offered by NHS and Universities..... | 19 |
| Table 2 - Support offered by NHS and Universities..... | 20 |
| Table 3 - Provision of feedback by NHS and Universities..... | 21 |
| Table 4 - How service user involvement has added value..... (from the NHS and University perspective) | 22 |

Executive Summary

1. A collaborative study, lead by service users and carers, of service user and carers involvement in mental health education, training, and research was undertaken. This comprised of a literature review and a scoping study across the 3 specialist mental health NHS Trusts and 4 Universities in West Yorkshire in 2008. The latter involved a survey of senior managers in all the organisations, interviews and focus groups with service users and carers involved in teaching and research.
2. The study examined the effectiveness of service user and carer involvement from the service user and carer, professional and policy perspective. It aimed to determine whether it was possible to define and measure effective and meaningful service user and carer involvement. It also sought to discover which processes and strategies were most effective in achieving meaningful involvement.
3. The literature review identified a raft of policy and guidance, emanating from the Department of Health, advocating involvement but a lack of consistency in its application.
4. Service user and carer involvement is taking place across a number of areas within mental health education, training and research. However, it is still ad hoc and there is no clear methodology within teaching and training. Service user and carer involvement in research is also varied but there are clear methodologies identified, although they are not implemented with any consistency. Benefits of involvement in education and training, which were identified primarily related to the addition of the user perspective and the impact on student practice. Benefits of involvement in the research process similarly included the user perspective and, in addition, increased relevance of research questions and research methodology, and improved staff recruitment. Benefits to the service user and carer were also recognised. Despite the high level of involvement activity barriers still exist and included: funding, lack of opportunities, lack of support and training, and failure to value the user perspective.
5. The study found that all the NHS organisations included had service user involvement policies in place but this was less clear for the Universities. Many service users and carers thought that the main reason for involving them in activities was because it was a mandatory requirement. Definitions of involvement covered a broad range of activity. Involvement for service users and carers covered a range of teaching, training and research activity but also included peer support and other support groups. NHS and University staff had a more instrumental view of what comprised involvement and described it as active, meaningful, partnership work which had value and impact. Service user and carer motivation for involvement could be categorised as altruism or personal gains.
6. Organisations used a range of methods to recruit service users and carers. Despite this, all the service user and carer participants in the study had been recruited through personal approaches and were critical of access to opportunities. This invariably led to involvement in further activities further restricting the inclusiveness of the projects. Processes for recruitment tended to be informal and did not involve matching the skills of the user to the activity or vice versa.
7. There was a broad range of involvement activity amongst the service user and carer respondents in the study. Only a very small number had any formal training or qualifications and primarily brought experience of mental health and services to their involvement. NHS and University respondents pointed to a range of resources including dedicated staff, support and training opportunities they had to support service user and carer involvement. Service users and carers were clear that support and training needs

should be assessed on an individual basis. Although they identified few support and training needs, they were critical of the opportunities available and whether they met their needs.

8. Payment for involvement was welcomed by service users and carers as it reinforced their value and expertise. However, although all organisations had funding available, payment was inconsistent.
9. Service user and carer involvement was highly valued by NHS and University staff. Evidence of the impact of involvement in terms of achieving changes in practice or service delivery was largely anecdotal. Impacts were identified in the following areas: strategic direction, service delivery, improving the learning experience, and staff recruitment.
10. There is a clear need to address the issue of how to measure the impact and effectiveness of service user engagement in education and research. There is, in published and grey literature, a lot of evidence of involvement using different methodologies.
11. Feedback was not provided to service user and carer participants frequently enough by the NHS and University staff. Few service users and carers were able to identify the outcomes of their involvement that were cited by the staff. This suggests a lack of communication and continuity in terms of maintaining communication to ensure the longer term impacts of involvement were disseminated.
12. Recommendations include:
 - NHS, University organisations and service users and carers should build on the good practice and positive experiences identified in this study.
 - The NHS and Higher Education sector and service users and carers need to work towards a shared understanding of service user and carer involvement activity.
 - Access to involvement activities needs to be more inclusive and transparent.
 - Support and training needs to reflect the needs of the individual and the particular involvement activity or project. Accessibility of training opportunities should be reviewed.
 - Further reviews of the existing literature on the involvement of service users and carers in health and social care education, training and research need to take place.
 - Further work to identify relevant outcome measures to determine the impact and effectiveness of service user and carer involvement in health and social care education, training and research needs to take place.

Introduction

This report outlines the findings from phase one of a study, undertaken in 2008, of service user and carer involvement in mental health training, education and research. The study examined the policy and practice of service user involvement from the perspective of the service user and carer. It aimed to define and measure effective and meaningful service user involvement, and identify the processes and strategies for service user involvement which are most effective in achieving meaningful involvement.

The study was lead by a multi disciplinary group of health care professionals, researchers, and service users and carers from across the area covered by the West Yorkshire Mental Health Research and Development Consortium¹. It was supported by research managers from the Consortium and academics from the University of Huddersfield, Leeds Metropolitan University, and the University of Bradford. The study was funded by the Assessment and Learning in Practice Settings (ALPS) research programme.

Rationale for undertaking this research

From the literature it appears that:

- There is a lack of routine evaluation of service user and carer involvement in research, training and education.
- Although there is a great deal of service user involvement in those areas, there is no systematic attempt to understand which model(s) of involvement is the most effective and in what situations. A programme of research around the area would therefore be of great importance.
- There are different types of evaluation taking place for different purposes thereby making it difficult to determine which types of evaluation are most appropriate.
- There is a lack of methodology and theory underpinning this area and a lack of connectivity between policy, education and research.

¹ The West Yorkshire Mental Health Research and Development Consortium was made up of the 3 specialist mental health and learning disability NHS Trusts in West Yorkshire and the 4 Universities in the region (Bradford, Huddersfield, Leeds and Leeds Metropolitan).

Background

An extensive literature search was undertaken across the key areas of:

- Policy.
- Service user and carer involvement in health services research, training and education.
- The processes of service user and carer involvement in health services research, training and education.
- The effectiveness and impact of service user and carer involvement in health services research, training and education.
- Cost implications of service user and carer involvement.

In conducting a literature search, a distinction was made in the use of terminology between public and patient involvement and service user involvement in mental health services. Public and patient involvement was used to refer to structures set up under the direction of the Government or Department of Health e.g. Patient and Public Involvement Forums, Local Involvement Networks or LINKs. Service user and carer involvement, in the context of this study, refers to the type of activities service users and carers may engage in at a local level e.g. involvement in research, teaching, training, recruitment, committee membership. For the purposes of this project, activity was described as service user and carer involvement.

Policy context

A raft of health and social care literature, and policy guidance, has, over the last ten years, advocated patient and public involvement (PPI) in their care and decisions about their treatment (Department of Health 2000a, 2001a, 2004, 2005, Bowers et al 2005). Two earlier guidance documents espoused the view that the public should participate in decisions and policies that affect their health and shape health services (Department of Health 1998, 1999). The NHS Plan (Department of Health 2000a) and Involving Patients and the Public in Healthcare (Department of Health 2001a) developed this further by giving patients and the public a greater say in the NHS and setting out proposals for implementing patient-centred care. Patient Advice and Liaison Services (PALS) and Patient Forums were also introduced in every NHS Trust. The emphasis on patient-centred and patient-led services and public involvement remained central to Government policy in subsequent moves to modernise services (NHS Improvement Plan, 2004, and Creating a Patient Led NHS, 2005). Similarly, public involvement in NHS research became more prevalent (Department of Health 2000b, 2001, 2005). Foundation Trusts and the introduction of Local Involvement Networks will further increase public scrutiny of NHS business and the accountability of service providers.

Overview of key policy and guidance:

- In the Public Interest: Developing a Strategy for Public Participation in the NHS (1998) – people who use NHS services have a right to participate in decisions and policies that affect their health and shape health services.
- Patient and Public Involvement in the New NHS (1999) – participation should be a core part of achieving health and health service objectives and NHS organisations should develop ways of strategically and systematically building in patient and public involvement.
- NHS Plan (2000) – patients and public get a greater say in the NHS.
- Research and Development for a First Class Service (2000) – as part of their funding agreements, Research and Development (R & D) departments in NHS Trusts were required to identify service user involvement in their work.
- Health and Social Care Act 2001 – section 11 placed a legal duty on the NHS to involve and consult with patients and the public in planning and delivering health services.

- Involving Patients and the Public in Healthcare (2001) – sets out proposals for implementing patient centred NHS outlined in NHS Plan. It also set out the intention to introduce PALS and a Patient Forum in every Trust
- A Research and Development Strategy for Public Health (2001)
- Research Governance Framework for Health and Social Care (2001 and 2005) – indicated that patients and the public should be involved in research wherever possible.
- NHS Improvement Plan (2004) – puts people at the heart of public services.

Despite the wealth of policy and guidance, PPI still lacked consistency. The Health Committee's Report on Patient and Public Involvement in the NHS (2007) stated that the purpose of PPI was not clear in relation to improving the design and provision of services and increasing accountability. The report went on to say that PPI should be part of the core business of the NHS.

Service user involvement in mental health research, training and education

A review of the literature demonstrates that user involvement is taking place in a number of areas including: research, service planning and evaluation, education and training. The majority of the research to date has focused on the processes involved in service user and carer involvement and assessing the possible differences across the NHS. Key findings suggested that, at present, user involvement is very much used on an ad hoc basis with different levels of service user involvement occurring across the UK. Different approaches to involvement have been identified including managerial, consumerist, political activist and self-help management models (Beresford 2005, Simpson et al 2002). This underlines the complexity of this area which is underpinned by issues of power, culture, and politicisation.

Training and Education

In terms of mental health training and education, a literature search found material relating to:

- The involvement of service users and carers in mental health education and training;
- Approaches to service user involvement;
- Inclusion of service users and carers in assessment of learning;
- The perceived advantages to organisations of service user and carer involvement;
- The perceived advantages to the service user and carers on their involvement;
- Recommendations for best practice;
- Concerns about including service users and carers in teaching;

The search identified more than 70 articles, written between 1995 and 2007, relating to involvement in general mental health training, training for nurses and for social workers. A further 30 related to training for psychologists and psychiatrists. Many more articles were found which dealt with involvement in health education and training more generally but were not included in this review.

It is clear from the articles that service users and carers have been engaged in mental health education and training in a range of ways. These include: consultation, joint training with professionals, user lead training, curriculum development, the production of learning materials, and assessment. (For examples of the different approaches see: Forrest 2000, Happell et al, 2003; Bailey, 2005; Khoo et al, 2004; Simons et al, 2006; Bennett et al, 2003; Repper et al, 2004). As with other areas of PPI, involvement requires a fundamental shift in culture within Higher Education in order to incorporate the service user view. A review of the literature undertaken by Repper et al (2004) found that most reports of involvement activities focused on the process rather than the outcome. For the most part, service user involvement has been seen as a very positive step by HEI educators, students and service users but support systems and remuneration were important issues for service users. Involvement was generally

initiated by staff members although service users chose to get involved for altruistic or personal reasons.

The principal benefit of service user involvement in mental health education, identified in a number of papers, was the insight provided by the experience of the service user or carer to the student (Bennett et al 2003, Happell et al 2003, Repper et al 2004, Khoo et al 2004). Repper et al, however, questions whether students should not also learn important lessons by listening more to their patients/service users' accounts when working in practice situations. Happell et al and Khoo et al found that there was an impact on practice with several of the postgraduates in their evaluation having introduced user focused initiatives in practice. Others, such as Simons et al (2006), draw attention to the work that still has to be done to achieve a socially inclusive approach to service user involvement in higher education. Organisational factors and unintentional discrimination may introduce barriers to participation e.g. lack of support, lack of training, complex systems for remuneration, lack of value placed on the user voice. Forrest et al (2000), Bennett et al (2003), and Bailey (2005) draw attention to the challenges and conflicts that can arise through involvement in curriculum development, recruitment and assessment processes when service user and professional views of what constitutes 'good' may differ. Two surveys of service user involvement in psychiatrists training illustrate this (Babu et al 2008; Narula et al, 2008). Trainees were happy to have service users and carers sharing their experience and views but less keen to have them involved in curriculum development or selection processes. Appropriate training and support for service users was seen as a key issue.

Research

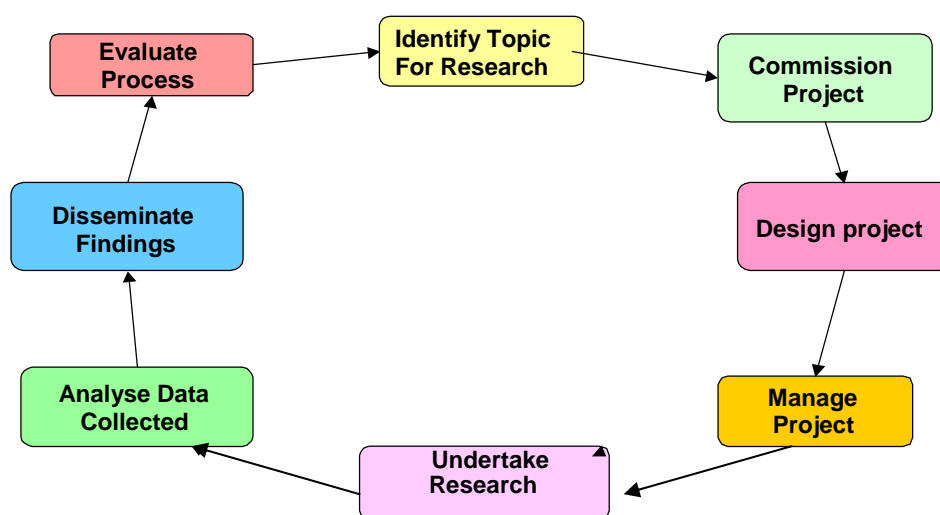
Service user involvement in mental health research is not a new phenomenon, indeed participatory research has been in common use in developing countries for several decades. In the UK, involvement really began to evolve in the 1990s and, despite some initial cynicism, has been accepted and embraced by the research community. The setting up of Involve (formerly Consumers in NHS Research), in the 1990s, to support and facilitate public involvement is testament to the NHS commitment. In tandem, many NHS Research and Development (R & D) departments have expended a great many resources on developing capacity amongst service users and carers and ensuring their involvement in R & D activity.

The National Institute for Health Research (NIHR) is the umbrella organisation for all aspects of the research process including infrastructure, systems for governance and information, and research funding. The NIHR places the patient and public at the centre of its purpose and its activities (Department of Health 2006a). For example, all the Clinical Research Networks within the NIHR have some mechanism to support user involvement; similarly, research centres and facilities are expected to develop and support PPI. The research element of the NIHR, comprising of the streams of funding for programmes and projects, also has patient and public involvement at its core as illustrated by the Programme Grants for Applied Research and the Research for Patient Benefit. Public involvement is currently supported in a number of ways including through the Central Commissioning Facility (CCF), Involve, and, by contracting with other organisations. Service user involvement in research is vital if research is to be meaningful and effective and deliver service user derived outcomes. The research community also has to be publicly accountable and service user involvement is a clear conduit to wider dissemination of research findings in the community. Mental health research is lead by the Mental Health Research Network (<http://www.mhrn.info/index.html>) and a series of regional hubs.

There are two tiers at which the patient and public engage in the research agenda: strategic development and the actual research process. Within those two tiers there are different levels of involvement: consultation, collaboration, and service user led research (Involve 2004). A great deal has already been achieved in terms of PPI and research as evidenced by the development of public involvement groups within the UK Clinical Research Collaboration and

UK Clinical Research Network. Involve is clearly a well established group and other support is provided by the NHS Centre for Involvement and the James Lind Alliance. In addition, there are many examples of public involvement in research in the NHS, Higher Education Institutes (HEIs), and social care organisations across the UK. Many have achieved a significant degree of success and have demonstrated the potential for involvement at all stages of the research process. Examples of service user involvement in research include involvement in the peer review of research applications, the preparation of bids, consultation over research design and methodology, collaboration including taking part in interviews, service user led research, and dissemination (see www.invo.org.uk; Trivedi and Wykes 2002; Faulkner and Morris 2003; Joseph Rowntree Foundation 2004; Rose 2004; Tait and Lester 2005). The research cycle (see Figure 1) describes the process in which there may be many opportunities for service user involvement. Involvement can take place at a number of points, each of them bringing a different level of engagement and empowerment. However, involvement remains fragmented and expertise in involving service users is still developing and tends to be lodged with specific individuals in NHS R & D departments or within research networks.

Figure 1 – The research cycle



A recent survey of NHS R & D managers by the RD Forum Service User and Carer working group (RD Forum 2008: www.rdforum.nhs.uk) found that there was a great deal of public involvement in NHS research but that few NHS R & D departments had dedicated resources to support this activity. Furthermore, despite the many opportunities identified in that study, there are still barriers to patient and public involvement. These include:

- Funding/resources to adequately support patient and public involvement at both strategic and research programme level.
- Funding for patient led research.
- Capacity building – lack of opportunities for training for involvement activity and the inconsistency and quality of the training available.
- The lack of patient/service user derived outcomes.
- Focus on Randomised Control Trials rather than quality of life and qualitative research preferred by many patient/service user groups.
- The focus on large multi centre projects rather than the local concerns expressed by patients and the public.
- The lack of cross fertilisation with HEIs.
- The perception many patient and public involvement groups have of collaborations with HEIs, industry and other partners.

- Staff resistance – research suggests that service users and carers feel staff resistance is one of the biggest barriers to involvement, possibly caused by a fear that involvement would increase user expectations and add to the pressures of already overworked teams (Poulton, 1999), or due to its challenge to traditional researcher led ideologies and processes, (Telford, 2004).
- Lack of information.
- Motivation – in a few cases service user and carer motivation has been identified as a possible barrier to involvement but a deeper search of the literature identified a gap in the evidence as to the motivations and reasons as to why service users and carers choose to be involved in research or other involvement activities.

Although well established, service user led research is not without its critics and occasionally there may be differences of opinion when service user's priorities for research topics do not match those of organisations, are particularly sensitive, or, perceived as critical to the organisation. But, it is highly unlikely that service users would choose to focus on a service area they did not think was a priority given their own experiences of receiving services. A major concern is that the service user perspective and the unique skills base they bring to research will be lost if not adequately funded. New streams of funding for NHS research, which are allocated on a competitive basis, may make it difficult for locally based or service user lead research, to continue to be supported and the fear is that a valuable resource will be lost.

The impact and effectiveness of service user involvement in research, training and education

Currently, the evidence base evaluating the effectiveness of service user involvement in service planning, delivery and research is limited. A Cochrane Review (Nilsen et al 2008), which examined methods of consumer involvement in developing healthcare policy and research, concluded that there was little evaluation in this area and little evidence of the best methodology to employ. The current evidence suggested that involving service users in developing patient information material improved its clarity and readability. Using service user interviewers in surveys showed small differences in the data collected but there was no evidence of any subsequent influence on service development.

However, there is a growing body of research, and a great deal of anecdotal evidence, which suggests there are real benefits and positive outcomes, for the individual and the NHS, arising from service user involvement (e.g. Telford et al 2004, Lowes and Hulatt 2005, Staley and Minogue 2006). Much of this is based on small scale local projects rather than large scale programmes of research or systematic reviews of the available evidence (e.g. Minogue et al, 2005). There may also be particular features of participatory or user led research that are fundamentally different to other mainstream research experiences. For example, the goals may be different. Service users are generally drawn to involvement through their experience of health services and can be seeking empowerment through the research process. It is also the case that service users may gain a great deal of personal reward from their involvement, for example through increased self esteem and confidence as well as development of new skills. Involve also identifies a range of benefits that service users can accrue from the research process (Involve 2004).

A review of the literature suggested that there may be a gap in health and social care research looking at the impact and effectiveness of service user and carer involvement. Nilsen et al (2008), Involve (2007), and SCIE (March 2004) support this view highlighting that there is a lot of information about how to involve people but little monitoring of whether service user involvement makes a difference i.e. improves or changes services. Simpson et al (2002) suggested that the changes that are sought by including service users in the research process are 'not expressed clearly' and proposed introducing involvement as a 'health technology' to aid clarity.

Possible impacts of service user and carer involvement in the research process that were identified in the literature included:

- Empowerment of service users and carers – improving self identity;
- Innovation;
- Services redefined and therefore becoming more effective;
- Positive and negative impacts for service users and carers;
- Involvement in staff training and development improving staff ability to form relationships with service users and carers;
- Involvement in recruitment leading to more appropriate staff employed.

Taking this debate further, Involve have facilitated the development of a network of people interested in public involvement in research (InvoNET) and have attempted to define different types of impact i.e.

- Impact on funding/commissioning;
- Impact on research;
- Impact on research ethics;
- Impact on service users;
- Impact on researchers;
- Impact on implementation and change.

However, this still does not address the issue of how to measure the impact and effectiveness of service user engagement in education and research. At present the majority of the literature is focused on the processes of involvement and evaluation of the effectiveness of such involvement seems to have been neglected. In the social care setting, the Social Care Institute for Excellence (SCIE 2007) identified a gap between service user participation and evaluation and undertook a study to develop measures to evaluate the impact of service user and carer evaluation. They found that service user and carer participation is not routinely evaluated, meaning that the difference it makes to the services people use is largely unknown. They were unable to clearly determine which methods of evaluation and measures were most suitable for different types of participation.

Many, if not most, NHS Trusts and Higher Education Institutions have a clear commitment to involving service users in their business. For the majority, this will mostly consist of consultation about key developments or inclusion on committees such as Clinical Governance Councils. Others have gone further and created posts such as Service User Development Workers, active groups of volunteers and befrienders who link directly with service users and service user groups. Foundation Trust status, of course, places the community, and therefore users of services, at the heart of the decision making process. However, despite the increase and the level of service user involvement in NHS services, the value and effectiveness of involvement in research has not been systematically evaluated and this is a gap in research evidence. It is clear from the existing literature that more evaluation needs to take place to understand the most effective methods of engagement, the long term impact on practice and service development, and the positive and negative impacts of involvement on the service user.

Funding service user involvement

Effective involvement of service users in mental health education and training, and at all stages of the research process, particularly at planning, priority setting and pre-protocol stage, cannot be cost neutral. Indeed it should reflect the good practice on payments for public involvement activity espoused in Reward and Recognition (Department of Health 2006b) and by Involve (www.invo.org.uk).

A search of the literature identified that there is little or no research looking at the costs of service user involvement suggesting that this is an area that needs further work and investigation. The lack of research in the area implies that costing has not been identified as an important area to consider despite the concerns expressed by service user and carer support organisations such as Involve. With new Government guidelines promoting service user and carer involvement in all areas of health care, and HEIs and NHS Trusts having to find the funds to allow such processes to occur, finance must consequently be considered a big area of concern.

The Research Project

Aims

The aim of the research project was to examine service user and carer involvement as a technology, within two areas of mental health:

- Learning and teaching
- Research and evaluation

to determine the effectiveness of service user involvement from the service user, professional and policy perspective.

Research questions

The primary research questions are:

1. Is it possible to define and measure effective and meaningful service user involvement?
2. What processes and strategies for service user involvement are most effective in achieving meaningful involvement?

This phase of the research programme also attempted to address a number of secondary research questions:

- I. What is the definition of meaningful service user involvement and what is effective service user involvement?
- II. Does health care policy and guidance on public involvement support effective service user involvement and how is it implemented in practice?
- III. What types of involvement are taking place and what is the impact of different types of involvement?
- IV. What is the impact of service user involvement in health care?

Methodological framework

The project involved a scoping and exploratory study of service user and carer involvement in mental health training and education, and research in West Yorkshire. The sites for the project were three specialist Mental Health NHS Trusts and four Universities. Service user and carer involvement in mental health services, and the training and education of clinicians, is further advanced in mental health than in many other aspects of health care therefore this was felt to be an appropriate base for an exploratory study. The findings from this study would be generalisable to other NHS organisations and Higher Education Institutes.

An extended literature review was undertaken as the first stage of the project. This was followed by a survey of senior NHS PPI, education and research managers and PPI and mental health nursing departmental leads within the Universities. Focus groups were held with service users and carers involved in teaching and research activity, students on mental health nurse training. Interviews were undertaken with service users and carers involved in University training or curriculum development. Using a mixed methodology, but similar topic areas within each data collection tool, allowed us to capture a range of views, using the means most appropriate to the respondent, and the ability to triangulate the data.

The study was lead by a multi disciplinary group with at least half the group having experience of using mental health services or caring for someone who does. The group had expertise in service user/survivor led research, training and education, service development and planning, collaborative and participatory research, project management, and clinical practice. The topic was selected by the service user and carer members as the most important in terms of understanding the value and effectiveness of involvement.

The research team met on a monthly basis during the early stages of the project, alternating the venue to allow people to attend meetings in their locality. During the data collection stages, local meetings took place where necessary to prepare for focus groups and interviews. The methodology was developed by the team over the course of 12 months. Differences of approach between academic and service user and carer team members became evident at an early stage. This resulted in members of the group feeling disempowered and the team re-visiting their approach and roles within the group. The result was use of a mixed methodology that service user and carer members of the team felt would be more acceptable to study participants.

Data collection tools

The survey questionnaire, focus group and interview schedules were developed by a sub group of the main project team and were checked and agreed by the whole team. Information sheets and consent forms were also written and agreed. The topic areas included in each of the data collection tools were broadly similar to allow for triangulation. They focused on: policy, understanding of the concept of involvement, opportunities for involvement, reasons for involvement, training and support needs of service users, and the impact of involvement. Each of the data collection tools was tested for relevance and applicability to the participants. Amendments were made, and some additional questions added to the focus group and interview schedules.

Study respondents

12 questionnaire responses were received from 18 requests; one response was a collective response from 4 managers within one organization therefore 15 out of 18 people who were approached took part. Of the responses, 5 were from NHS mental health or care Trusts and 7 were from Universities. All organizations and institutions within the study submitted a response. 3 service user and carer focus groups took place in Bradford, Leeds and Wakefield. Between 4 and 10 people with experience of involvement in research and/or teaching and training were involved in each of them. 7 service users and carers were interviewed individually about their experience of taking part in teaching, training or curriculum development within the Universities. One service user was interviewed for a second time to clarify some points made in the first interview. The data from another interview was removed from the analysis due to elements of bias and over identification that had been introduced.

Service user involvement in mental health training and research in West Yorkshire

West Yorkshire has 4 Universities, each of which has some mental health nurse training either at undergraduate or post graduate level. Leeds/Bradford also has a medical school. Each of the Universities engages service users and/or carers in its teaching or curriculum development. Most have either appointed specialist workers to lead this agenda or have a designated lead member of staff. The type of training or teaching undertaken by service users varies both in terms of topic and frequency. The majority of service users who were involved delivered one teaching session or talk during a course presentation. However, two people delivered more than 5 sessions with one contracted to deliver several sessions of teaching on psycho-social interventions. This appeared to be the exception to the rule with most commenting that involvement was on an ad-hoc basis. Other topics included advocacy, psychological approaches to eating disorders, recovery paradigms.

Mental health and learning disability research in West Yorkshire during the time of the project was managed and lead by a research and development (R & D) Consortium of the three specialist NHS mental health Trusts and 4 Universities in the county. A core element of the work of the Consortium was service user and carer involvement. This had largely been generated by a manager with experience and interest in this area. Each of the three Trusts

had developed involvement activity at a different rate, and, in two cases, in conjunction with the local University, but all of them had developed service users and carers with interest in research and varying degrees of expertise. Some time after the Consortium was set up in May 2006, the manager of the Consortium set up a county wide service user and carer working group to explore the potential for joint working. The current project was the first such enterprise to arise from the group.

As this project was jointly lead by service users and carers from the working group and other research groups across the county, and interviews and focus groups were conducted by service user and carer researchers from the groups, it was judged to be inappropriate to include their views as part of the evaluation. The researchers determined that they were likely to be too closely aligned to the research topic and design to be able to distance themselves to look objectively at their experience of being involved in research. This was further complicated by the fact that several members were involved in the research agenda at a strategic level and therefore able to exert direct influence on policy and strategy. The research team therefore decided that they would describe their involvement in research, rather than be interviewed, and also their experience of being involved in this project and others. A list of activities undertaken is included at Appendix 1.

Results

Policy

All the managers from the NHS organisations surveyed clearly indicated that their organisation had a service user involvement policy in place. Senior university staff were much less clear with opinion divided about the existence of specific policy. Service users were even less clear with only a few people being aware of where policies were in place and they were generally thought to be in the NHS rather than Universities. Despite this, many service users held the view that one of the main reasons for involving them in activities was because it was a mandatory requirement in both the NHS and higher education.

Involvement activity

It was clear from the responses from NHS and University managers, and service users and carers, that there was a wide variety of activities in which service users and carers were engaged. These included representation on committees, inclusion in planning, focus, reference and steering groups, staff recruitment, training, teaching, curriculum development, and research. It was in the definition of involvement that there appeared to be slight differences. Service users and carers took a broad view of involvement activity and outlined a wide variety of activity that they defined as involvement which was not limited to activities which could be seen as directly linked to organisational or service development. They included peer support activities within their definition of involvement. NHS and University managers, including Public Involvement staff, had a more instrumental focus and identified activity more closely linked to teaching, research or organisational and service development. The purpose and level of engagement identified could be interpreted as being different in terms of empowerment and support given by professionals or peers.

Senior managers from the 7 organisations were asked to outline their understanding of service user and carer involvement. Most respondents felt that involvement had to be meaningful i.e. it had to be active, have value and an impact and was based on partnership principles.

'Engagement of people.....in influencing service design and developing service quality' NHS manager.

'To make sure that the focus of our courses and research reflects the needs, interests and perspectives of service users and carers' University staff.

'It seeks to reach out to service users and members of local communities in order to promote the sharing and valuing of diverse understandings and approaches to madness and distress' NHS manager.

'Partnership working – co-designing education' University staff.

'Working in partnership and/or collaboration to deliver agreed objectives.' NHS manager.

Other respondents, particularly from the Universities, reflected that involvement should be inclusive:

'..embedding the service user and carer perspective in all that we do by involving people in all aspects of our business' University staff.

'planning, designing and determining The most appropriate method of involvement across a range of activities' University staff.

Service users took a pragmatic view of why organisations involved service users. Whilst many believed that it was because it was a requirement, they also thought that they brought expertise and their input was valued, although not by all stakeholders. This was in contrast to NHS and University managers who, with the exception of one, stated that one of the reasons for involving service users was belief in the value of doing so and to enhance their work. Departmental or organisational policy was a reason for 10 respondents to involve service users and the same respondents also reported that service users requested involvement. Service users believed that the NHS and Universities wanted to bring in the service user perspective, their real life experience and challenge student and staff views.

'It seems that sometime's it's quite tokenistic and ticking a box, you can say that there was a service user at the meeting, not really taking on board what's being fed back in terms of peoples' experiences and what they really want'. Service user.

'I think they have to demonstrate from on high now, Government is saying we want patient involvement in the NHS'. Service user.

'I'd like to be optimistic, really they're asking for service user opinion because they really heart and soul want to know what people think.' Service user.

'There are some good people around, there are people that are very caring and want to improve things'. Service user.

As indicated in the literature (e.g. Repper et al) Service users became involved for different reasons which could be divided into altruism and personal gains. For some it was a wish to give something back, interest, passion or commitment and a desire to improve services or the quality of clinicians, *'Ensure 'powers' act on research/user views'* (service user), whilst for others it was a chance to gain knowledge, meet people or gain skills to undertake an activity to improve health. Only two of those interviewed brought formal qualifications or training to their involvement activity but most pointed to life experience, having lived through mental health problems, skills gained through involvement activity, and personal qualities that they brought to the role.

All the organisation managers stated that service users were given the opportunity to choose what activities they were involved in and identified a range of means used to recruit people. These included recruitment through existing groups in the organisation, community, or voluntary sector, through direct invitation, advertisement, or through service users identifying themselves. Service users presented a different picture with the majority of people saying that they had been approached personally to be involved in a particular activity or group. They reported that they may subsequently have become aware of more activities but initially had been made aware of only the one they were invited to participate in. 'one thing leads to another' was a common theme. Participants in one focus group expressed a preference for the personal approach. They commented that they were less likely to seek opportunities themselves or respond to advertisements. This was partly due to lack of confidence and self esteem but was also related to the presentation style of many advertisements. The focus groups were particularly critical of access to opportunities and felt that lack of information, advertising, and support, limited choice.

'If I didn't have the illness I wouldn't have known because there's not enough information'. Service user.

'Sometimes you find there is a lot of events that happen in the community where service users are supposed to be involved but when you go to these events you find that there's a lot of people who are like managers, maybe professionals and not as many service users are involved, that is because of a lack of support, you need to support people to go to these events'. Service user.

A service user interviewee felt that the problem of inclusiveness in mental health teaching and research was entrenched and resulted from the dominance of the middle class professional perspective. Others are excluded through lack of education or simply follow the lead of the more articulate.

This study found that groups tended to be open to a wide range of people but teaching and training opportunities were likely to be more exclusive. 'One thing leads to another' was a theme that came through strongly from service users and carers. It was clear that many of the service users who were interviewed or took part in focus groups, were, or had been, involved in a number of activities. For some, this had become an issue as they had become overloaded. On the positive side, the choice of whether or not to attend and not having to provide an explanation in the case of non attendance was welcomed.

Support and training for service users

Service users and carers brought a range of experience and skills to their involvement activity. This included experience of mental health issues, service user involvement activity experience, personal experience, and for two people work related experience. A small number of people cited previous training they had undertaken, e.g. research, as being relevant to their involvement activity. However, few had any formal training for their involvement and when asked about their training needs found it difficult to identify specific topic areas other than, for one person, a wish to have an understanding of academia. The general view was that training needs should be assessed on an individual basis.

'You need to say what training do you want, where do you feel you want it, that's the first question'. Service user.

The lack of ability to identify training needs tended to relate to the individual nature of the projects they were engaged in not necessarily being related to training courses on offer. NHS and University managers outlined a range of training opportunities being offered (see Table 1). Some of this appeared to be fairly general in nature, e.g. meeting skills, understanding diversity, and not focused on specific activities. However, there was some scepticism, on the part of service users, that training that was on offer was actually available or widely advertised. Timeliness and relevance of the training on offer are perhaps issues to be considered.

Table 1 – Training opportunities offered by NHS and Universities

| SUC specific | Formal | Informal | Research | Other |
|--|--|--|--|---|
| Developing student case studies Workshops: 'Patients as Trainers'; 'Patient Learning Journey' | Meeting skills Presentation skills Recruitment and Selection Mentoring Access to university training | Open days / taster sessions One-to-one work depending on need | Research skills training, peer review, interview | Induction Self awareness Understanding University process |

Seventy five percent of the NHS managers and University staff who responded to the survey highlighted a range of resources and support dedicated to the PPI agenda. Three of the Universities identified dedicated part time or full time workers whose role was to develop or co-ordinate involvement. NHS Trusts had full time Patient Advice and Liaison Service (PALS) workers, development workers and, in one case, research assistants. A range of support mechanisms were identified by NHS and University respondents (see Table 2) but did not appear to be widely utilised by the service user and carer respondents who described the support available as informal and available for those who wanted to access it. Again few service users and carers identified support needs they felt should be addressed. Support needs were seen as an individual issue and most people seemed happy to rely on informal mechanisms for support. Members of one focus group commented on the need to feel comfortable with the nature of support offered and also confident enough to ask for support.

Service user and carer strategies for maintaining well being, whilst engaged in involvement activity, included utilising support of peers and not taking on too much at once. The importance of feeling peers understood the need to pace activity and periods of ill health was clearly important to people.

‘whatever training and support’s there needs to be able to take into account that people might not feel well at some point during what they’re doing and for there to be another opportunity because everything then feels like a failure, you need to be able to opt back in again when you’re feeling a bit better’. Service user.

NHS and University staff also saw personal responsibility as a key means of maintaining well being. Peer support was an element of this. They also identified the need to provide an environment where the service user felt comfortable in asking for support.

Table 2 – Support offered by NHS and Universities

| Personal support | Practical support | Peer support | Providing links |
|--|---|-----------------------------------|--|
| Mentoring/buddying Ensure SUC well informed, welcomed & engaged Briefing & debriefing Personal communication Openness to enquiries – phone, email, face-to-face Speedy response to enquiries Supervision | Training Dedicated staff member Financially Providing guidelines for involvement Admin/clerical support | Support Group Forum attendance | Links to PALS & PPI team Links to other support network Referral to Occ’ Health/mediation services Representation |

Payment for involvement activity is a key element of being valued and supported. However, the study showed a very mixed picture in terms of whether people were offered payment and travel expenses or whether payments were routinely made. All but one of the organisations were able to offer involvement fees and all had a budget which allowed them to pay travel expenses. Most managers reported being able to support activities and 7 were able to fund attendance at workshops and conferences but only 5 organisations had a budget for training. However, the resources available may not have been communicated to staff at operational level as service users and carers reported that there was inconsistency over payments. Payments were being offered in some circumstances but not others; there was not always a choice of being paid or not; there was payment of different rates for staff and service users

attending the same event. There were also hidden costs to involvement such as copying documents for meetings. Service users felt that being paid acknowledged their input and showed their work was valued. Having to ask for payments, or the assumption they would be involved for no payment, was difficult to deal with and made them feel unvalued.

‘It’s important because it values you as a service user and carer, it also helps people to get back into work’. Service user.

‘We’re all worried about saying well actually we’d like the money because we’re all embarrassed about it’. Service user.

‘The people that I’m there with don’t say we’ll pay you for that day, they take it for granted that you’ll do it for nothing but they’re being employed to be there’. Service user.

‘We actually have to pay a lot out ourselves anyway like for example if you use your own computer or whatever, it’s costing money. Telephone calls cost you money which you don’t get reimbursed for’. Service user.

Value and impact of service user involvement in teaching and research

All the managers surveyed rated service user involvement as ‘very valuable’. Asked whether their involvement was valued, service users had a very mixed response. 4 people thought it was but many expressed reservations and thought that, particularly when working at a University, some staff valued their input but others did not and did not listen to their experience. According to service user and carer participants in involvement activity, feedback was rarely formalised, or at least was not communicated to service users as few knew whether formal evaluation of their input took place. Some service users involved in teaching had received informal feedback from students or members of staff. Two people also relied on their own perception of the sessions they had attended and whether they felt listened to. In contrast, University managers, in particular, identified a range of ways in which they provided feedback (see Table 3). This was clear evidence of a lack of clear communication between organisations and the service users and carers engaged in activity.

Table 3 – Provision of feedback by NHS and Universities

| Direct Feedback | Formal evaluation | Other |
|--|--|--|
| Verbally: Supervision or phone (8) Personal contact (1) Written feedback (3) | Peer assessment (1) Reviews (1) Evaluation forms (1) Student feedback (2) Reflective sessions (1) Workshops (1) | Newsletter (1) Website (1) News media (1) References (1) Recommendations (1) |

It was clear from NHS and University managers and staff that organisations had no clear methodology for measuring the value of service user involvement. Seven NHS and University respondents suggested that value could be measured by feedback from students or service users and carers. Only one respondent spoke about identifying change or improvement that had resulted from involvement. Two other NHS and University respondents thought that value could be measured by the numbers of service users or carers involved, their continued involvement, and the impact on the person involved. No-one identified any specific measures they used other than feedback forms. Most thought this was an area that needed further work. It was clear from the many examples that were cited (see Table 4) that involvement activity

was valued but this value could not be quantified due to the variety of involvement activities and the lack of measures.

Table 4 – How service user involvement has added value from the NHS and University perspective

| Strategic direction | Service delivery | Improving learning experience | Staff recruitment | Other |
|---|---|--|--|---|
| Shaped strategic decisions; Service planning; Commenting on policy. | Improving quality of information; Drafting patient information leaflets; Making staff explain their work more clearly; Ensuring services are more responsive; Driving service improvement in developing a new unit; | Reality of experience; Involvement in assessment of students; Leads to re-evaluation of what is important in care delivery; Reinforces the importance of relationships; Keeping academic work real; Increasing students understanding of the user view; | Recruiting staff with right values and attitudes; Identifying poor attitudes; | Bridge gap between NHS, University, student, practice and service user; Partnership; Adding a creative dimension; Research: publications, posters, workshops, presentations, passing on expertise; |

A small number of service users thought the impact of their involvement could be seen in changes to services or improvements to training for health care professionals. Most saw their impact in bringing real life experiences to research or training. They also recognised the impact on themselves in terms of improving their understanding of services and increasing their well being. University and NHS managers also saw the impact that bringing the real, lived experience had on students and practitioners. Some of the following quotes illustrate their views:

‘Service user and carer involvement gives a deeper insight into what the ‘lived’ experience is. Who better to ask about a service than those people who are using it. Who better to ask what works and helps than those people coping with whatever their problems are. It’s first hand information from those that really know what it’s like 24 hours a day 7 days a week.’ NHS Manager.

‘Help to develop meaningful services truly based on service users’ needs and not others perceptions of need. Keeping the focus real.’ NHS Manager.

‘Plays a major role in ensuring the Trust provides services that are responsive to the needs and expectations of service users and carers and are therefore likely to be more effective.’ NHS manager.

By bringing in the service user view, NHS and University managers hoped that students and practitioners would achieve a greater understanding of the service user perspective and work towards delivering more responsive services which were more effective. However, one service user respondent articulated some of the issues and risks faced by service users and carers through involvement activity. Some of the risks related to maintaining recovery should

involvement not go smoothly but other issues identified suggested that the service user or carer might not always feel free to express their perspective openly. This respondent expressed the view that strong political or philosophical views may not be welcomed and feeling constrained in expressing their ideological framework.

Discussion

This study supports the national picture of there being a high level of service user involvement in a range of activity relating to mental health teaching, training and research. However, it has identified a number of issues which affect the quality of the service user experience, the effectiveness of their involvement and the potential value and impact. The issues are outlined below under three headings:

- access and opportunity,
- support and training, and
- value and impact.

Access and opportunity in Involvement activity

There are a range of opportunities for involvement, for at least some people. However, it seems that the opportunities are not necessarily equitable as there is a clear view emerging from this study that individuals are invited to take part in one activity by a member of NHS or University staff and this results in them being presented with further opportunities. Although the NHS and Universities respondents reported using advertising as part of their involvement strategy, we did not find any instances of opportunities being advertised leading to engagement. Each instance had been one where the individual service user or carer had been approached. This suggests that access to involvement activity is not as equitable and accessible as it might be given the fact much of it is by personal invitation. As this is often the result of relationships that have been formed between professionals and service users this may minimise any element of risk, for either side, of the involvement activity. Other opportunities and a choice only opens up once people are involved. This may lead to some service users becoming overloaded and requiring strategies for coping. Despite this obvious inequity, many service users and carers expressed a preference for the personal approach. It is possible that this is related to the respondents being mental health service users and carers and therefore experiencing more issues related to confidence and self esteem. It would be useful to examine this issue with a wider group of service users from across the NHS and Higher Education.

Staff, in striving to achieve involvement, seemed largely unaware of the inequity of opportunities that were being presented. To some extent, this was also true of service users who, for many reasons (both altruistic and personal) were engaging in activities. This underlines the importance of having clearly stated outcomes from user involvement activity as reasons for engagement might differ. If the reason for involvement is a personal one on the part of the service user, their ownership of the end product may be lessened.

Support and training for involvement activity

Few of the service user or carers involved in this study had formal qualifications or training to bring to involvement. This clearly did not prevent them being engaged in involvement activities but, as one service user respondent articulated, it may restrict their influence in the academic sphere. Their ability to challenge ideas that are taught may be limited or not taken seriously. However, the same respondent cited examples of how they felt their education and level of understanding had lead to them being excluded from events, possibly from a fear that they may challenge the status quo.

'---there's a key difference between being a service user or carer involved who hasn't had a higher education who might not be well educated ----- who say things like I really think that for instance social workers should work like this or I'd like to work like this or I'd like them to do this. It's a different thing from saying those sort of things to questioning the ideas that are taught and that's where the kind of risk comes in, how can I challenge?' (Service user).

It is clear that there a number of resources have been put in place in the NHS and Higher Education Institutions in order to support user involvement but these are not widely recognised by service users. It was not clear whether this related to a lack of information sharing or that the forms of support were not the ones service users sought. In this study service users identified very few support needs and appeared to prefer more informal peer support or to know that support was available if needed. Training was seen by service users as very much an individual issue with training tailored to the individuals needs. The specific nature of the teaching, training or research, service users and carers were engaged in meant that much of the training on offer did not seem relevant to them or was not presented at a time when it would be beneficial i.e. link directly to their involvement.

Payment for service user activity was a much more contentious issue with a great deal of inconsistency in the way service users were offered, and received, payments by different organisations and individuals. It was clear that service users preferred to be offered the choice of whether or not to receive payments but payments were not always available or offered.

Value and impact of service user involvement

There was little evidence of formal feedback to service users or carers even if evaluation had taken place. Although NHS and University managers or PPI leads in mental health services, training and research, placed a high value on service user involvement this could not be quantified due to a lack of baseline measures and outcome measures. NHS and University managers pointed to a range of ways in which service user involvement added value, particularly in bringing their real lived experience to learning, but also including: strategic direction, service delivery, staff recruitment, improving the learning experience, but this was not reflected in the service user and carer discussions. This suggested a lack of feedback to service users and carers and a lack of continuity in terms of maintaining communication to ensure the longer term impacts of involvement were disseminated. Service users and carers also tended to see the value and impact of involvement in terms of personal gains e.g. increased knowledge and well being. This was not something that NHS and University respondents focused on suggesting that their reasons for involving the service user and carer perspective was far more instrumental.

Conclusions

Service user involvement activity is clearly valued by those involved in mental health research, training and teaching. However, involvement covers a broad spectrum of activity, and, this study suggests, there may be slight differences in understanding and defining involvement activity between NHS and University organisations and service users and carers. A wide range of opportunities for involvement exist but there are issues of accessibility and inclusiveness to be addressed. Further work to understand how best to meet the support and training needs of service users and carers involved in involvement activity is needed. It is clear that mental health service users and carers, in this context, have very individual support and training needs and meeting these in an effective and timely way poses challenges for the NHS and University organisations. Despite the lack of take up of support and training, this study demonstrates the extraordinary work that service users and carers undertake, under the broad heading of involvement activity, by simply drawing on their experience of mental health, services, and past history.

There is a clear need to address the issue of how to measure the impact and effectiveness of service user engagement in education and research. There is, in published and grey literature, a lot of evidence of involvement using different methodologies. This must be valued and assessed on its merits, but there is also a sense that the more that is gathered, the less we feel we know, as it points to different things working in different situations and different values being placed on it depending on the stakeholder perspective. This lack of clarity, and clear methodologies, for both service user and carer engagement and measuring impact and effectiveness, is a reflection of how PPI activity was introduced and developed. There is a lack of synergy between policy, research and practice.

The study set out to discover whether it was possible to define meaningful and effective service user and carer involvement. It was clear that NHS and University staff wanted to involve service users and carers in a meaningful way. To some extent they achieved this and could point to the value of engagement. However, there was no clearly agreed definition of meaningful involvement and no clear inclusive and accessible strategy for engagement. The ad hoc nature of recruitment to activity increases the difficulty of defining meaningful and effective. Unlike the usual recruitment processes, there is generally no assessment of whether the most appropriate person is linked to a particular activity or an individual is linked to the activity that is appropriate to their skills. Only two respondents out of the total sample provided evidence of a data base, or record of service users, which might be used for recruitment, which suggested that the desired outcomes for each activity are either determined by the person recruiting or the service user or carer engaged in the activity.

The definition of meaningful involvement needs further clarification. Is it involvement which leads to measurable and defined changes in health education and training, NHS services, policy or practice, or something that benefits the service user engaging in the activity i.e. improving physical or mental well being? The latter may, of course, be an unintended outcome of the former.

Service user and carer involvement in mental health teaching, training and research has been widely embraced but policy and guidance has not ensured consistency in its application. Nor has it ensured appropriate and effective support and training is in place. This points to the ad hoc nature of early adoption of involvement activity and lack of clear direction in implementation in the NHS and HEIs. The lack of clear measures for determining the effectiveness of involvement activity, and lack of evidence of impact on practice, meant that this study was unable to clearly define the impact and value of service user and carer involvement in mental health teaching, training and research.

NHS, University and service user and carer respondents agreed that engagement in teaching mental health nursing students, involvement in curriculum development, and collaborating in research activity, were valuable involvement activities. Similarly, they agreed that introducing the service user experience and real lived experiences of mental health were extremely important. Key impacts, from the point of view of the NHS and University respondents, were on the learning experience and on service delivery but these were not evidenced in most cases for the service users and carers in the study. As SCIE (2007) and Nilsen et al (2008) also found, the true impact is difficult to determine without clear methodologies to do so. A further study examining the impacts of service user involvement in health services education and research, using agreed measures, would be recommended. A further study should seek to examine the links between service user lead mental health education and implementation in practice. Similarly, a further study should establish the implementation of service user lead research and its translation into practice.

Recommendations

- NHS, University organisations, and service users and carers, should build on the good practice and positive experiences identified in this study specifically in relation to the range of involvement activities offered and expertise of service users and carers.
- The NHS and Higher Education sector and service users and carers need to work towards a shared understanding of service user and carer involvement activity.
- Access to involvement activities needs to be more inclusive and transparent and not simply based on personal contact. Understanding the different motivations of each of the stakeholders is also important in recruiting the right people for the task.
- Although there is a broad range of support and training available, it needs to reflect the needs of the individual and the particular involvement activity or project. Accessibility and timeliness of training opportunities should be reviewed.
- Systematic reviews of the existing literature on the involvement of service users and carers in health and social care education, training and research are needed in order to synthesise, appraise and assess the value of the evidence in this topic area. This is of critical importance in defining and recognising effective service user involvement in this areas and providing a benchmark for recognising good practice.
- Further work to identify relevant outcome measures to determine the impact and effectiveness of service user and carer involvement in health and social care education, training and research needs to take place.

References

- Babu, KS., Law-Min, R., Adlam, T., Banks, V. 2008. Involving service users and carers in psychiatric education: what do trainees think? *Psychiatric Bulletin*, January 1, 2008; 32(1): 28 - 31.
- Bailey, D. 2005. Using an action research approach to involving service users in the assessment of professional competence. *European Journal of Social Work*. Vol 8, No 2, 165 – 179.
- Bennett L., Baikie, K. 2003. The client as educator: learning about mental illness through the eyes of the expert. *Nurse Educ Today*. February: 23(2): 104:11.
- Beresford, P. 2005. Theory and practice of user involvement in research. In Lowes, L., Hulatt, I. 2005. *Involving Service Users in Health and Social Care Research*. Routledge.
- Department of Health. 1998. *In the Public Interest: Developing a Strategy for Public Participation in the NHS*.
- Department of Health. 1999. *Patient and Public Involvement in the New NHS*.
- Department of Health. 2000a. *NHS Plan*.
- Department of Health. 2000b. *Research and Development for a First Class Service*.
- Department of Health. 2001a. *Health and Social Care Act 2001*. Department of Health, London.
- Department of Health. 2001b. *Involving Patients and the Public in Health Care*. Department of Health, London.
- Department of Health. 2004. *NHS Improvement Plan*. Department of Health, London.
- Department of Health. 2005a. *Creating a Patient Led NHS*. Department of Health, London.
- Department of Health. 2005b. *Research Governance Framework*. Second edition. Department of Health, London.
- Department of Health. 2006a. *Best Research for Best Health. A new national health research strategy*.
- Department of Health. 2006b. *Reward and Recognition*.
- Department of Health. 2007. *Health Committee's Report on Patient and Public Involvement in the NHS*
- Doel, M., Carroll, C., Chambers, E., Cooke, J., Hollows, A. Laurie, L., Maskrey, L., Nancarrow, S. 2007. Position paper 09: Developing measures for effective service user and carer participation. SCIE.
- Faulkner A., Morris, B. 2003. *User Involvement in Forensic Mental Health Research and Development*. National R & D Programme on Forensic Mental Health. [Involve: www.invo.org.uk](http://www.invo.org.uk) accessed 7.01.08.

Forrest, S., Risk, I., Masters, H., Brown, N. 2000. Mental Health Service User Involvement in Nurse Education: Exploring the Issues. *Journal of Psychiatric and Mental Health Nursing*. 7, p 51 – 57.

Happell, B., Roper, C. 2003. The role of a mental health consumer in the education of postgraduate psychiatric nursing students: the student's evaluation. *Journal of Psychiatric and Mental Health Nursing*. 10, p 343 – 350.

Involve. 2004. Involving the public in NHS, public health and social care research: Briefing notes for researchers. 2nd Edition. Involve.

Involve 2007. the impact of public involvement on research. A discussion paper from the INVOLVE Evidence, Knowledge, and Learning working group. Accessed: 5th January 2009. www.invo.org.uk.

Involve; National Institute for Health Research. 2008. Payment and reimbursement rates for public involvement. Revised July 2008.

Joseph Rowntree Foundation. October 2004. Older people shaping policy and practice. York: Joseph Rowntree Foundation.

Khoo, R., McVicar, A., Brandon, D. 2004. Service user involvement in postgraduate mental health education. Does it benefit practice? *Journal of Mental Health*. Vol 13, No 5, 481 – 492.

Lowes, L., Hulatt, I. 2005. *Involving Service Users in Health and Social Care Research*. Routledge.

Minogue, V., Boness, J. Brown, A., Girdlestone, J. The impact of service user involvement in research. *International Journal of Health Care Quality Assurance*. Vol 18 No. 2, 103 – 112. 2005

Narula, A., Furlong, E., Fung, NK. 2008. Trainees views on service user and carer involvement in training: a perspective from the West Midlands. *Psychiatric Bulletin*, May 1, 2008; 32(5): 197 - 198.

Nilsen, ES., Myrhaug, HT., Johansen, M., Oliver, S., Oxman, AD. 2008. Methods of consumer involvement in developing healthcare policy and research, clinical practice guidelines and patient information material. *The Cochrane collaboration*. Wiley.

Poulton B. (1999) 'Future directions for primary care'. In Elwyn G. and Smail J. (eds.) (1999) *Integrated Teams in Primary Care*. Radcliffe, Oxford.

RD Forum service user and carer working group. 2008. The impact of health service policy on Research and Development activity in NHS Trust Research and Development Offices. A survey of Research and Development Offices in England 2005/2006. RD Forum, August 2008.

Repper, J., Breeze, J. 2004. *A Review of the Literature on User and Carer Involvement in the Training and Education of Health Professionals*. University of Sheffield.

Rose, D. 2004. Telling different stories: user involvement in mental health research. *Research, Policy and Practice*. 27 – 35.

Samele, C., Wallcraft, J., Naylor, C., Keating, F., Greatley, A. January 2007. *Research Priorities for Service User and Carer-Centred Mental Health services. Overview Report*. Report for the National Coordinating Centre for NHS Service Delivery and Organisation R & D.

Simons, L., Tee, S., Judith, L., Burgess, A., Herbert, L., Gibson, C. 2006. A socially inclusive approach to user participation in higher education. *Journal of Advanced Nursing* 58 (3), p 246 – 255.

Simpson, E. L., House, A. O., Barkham, M. (2002) *A Guide to Involving Users, Ex-users and Carers in Mental Health Service Planning, Delivery or Research: A Health Technology Approach*. Leeds: Academic Unit of Psychiatry and Behavioural Sciences, University of Leeds.

Social Care Institute for Excellence. March 2004. Has service user participation made a difference to social care services? SCIE.

Staley, K., Minogue, V. 2006. User Involvement Leads to More Ethically Sound Research. *Clinical Ethics* 2006; 1.

Tait, L & Lester, H (2005) Encouraging user involvement in mental health services. *Advances in Psychiatric Treatment*, 11, 168-175

Tarpey, M. July 2006. Why people get involved in health and social care research: a working paper. *Involve*.

Telford, R., Boote, J., Cooper, CL. 2004. What does it mean to involve consumers successfully in NHS research? A consensus study. *Health Expectations*, 7, 1 – 12.

Trivedi P., Wykes, T. 2002. From passive subjects to equal partners. *British Journal of Psychiatry*. 181: 468 – 472.

APPENDIX 1

Service user and carer involvement in research and development

Service users and carers are involved in lots of different ways; some of the opportunities for involvement are outlined below:

Research Groups

In each of the Trusts there are opportunities to join research groups, some of which are led by service users and carers. Examples of these are:

Bradford District Care Trust and Bradford University: Centre for Citizenship and Community Mental Health.

Leeds Mental Health Teaching Trust:
Leeds Researchers.

South West Yorkshire Mental Health Trust:
Direct Impact service user and carer research group.
Learning Disability Research Forum.
SWYT Research Forum.
Social and Human Research in Kirklees (SHRINK).

South West Yorkshire Mental Health Trust and University of Huddersfield:
Ageing and Mental Health Research Group.
Mental Health Research Group.
Joint Mental Health Strategy Forum.

Research Projects

From time to time, there are opportunities to get actively involved as part of a research team. This might involve helping to design a survey or questionnaire, carrying out interviews or focus groups.

Committee Members

In the Consortium there are a number of different committees such as:

Joint Research Governance Committee – this committee represents the Trust Boards in order to discharge their research governance responsibilities. It manages and reviews the Consortium arrangements.

Joint Strategy Forum – this committee sets priorities for research and looks for opportunities for joint working. It also looks for ways to build service user and carer involvement.

Local Research and Development (R & D) committees - Bradford District Care Trust, Leeds Mental Health Teaching Trust, South West Yorkshire Mental Health Trust, each have their own R & D committee that puts together an action plan and decides their local priorities for research. Representatives of these committees sit on the Joint Strategy Forum.

Peer review of research projects

Researchers who want to carry out research in any of the 3 NHS Trusts have to ask for permission to do so.

Other opportunities

Making bids for funding.
Annual conference.