

**Service User and Carer Involvement in Mental Health Education,  
Training and Research – A Literature Review**

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### **Abstract**

As part of an evaluation of service users' and carers' experience of involvement in mental health education, training and research, an extended literature review was undertaken. The purpose of this was to review policy underpinning service user and carer involvement in those areas, identify the extent and range of involvement, the processes involved, and the extent to which the effectiveness and impact of involvement had been evaluated. The review found that there was a range of different ways in which people were involved. It identified different types and levels of involvement and different motivations for taking part in involvement activities. Government policy and guidance on public and patient involvement (PPI) in health services has clearly been a driver and has resulted in widespread involvement activity but this has developed on an ad hoc and inconsistent basis.

There are benefits for service users and carers, the NHS, and educational establishments arising out of involvement activity. These include improvements in the health and well-being of service users, enhancing the student experience, and improvements to service delivery. However, there are still barriers to involvement including organisational factors and unintentional discrimination. Payment for involvement activity remains an under researched area. Service users value payments but welfare benefits rules, and inconsistent interpretation of good practice guidance, mean this can be a further barrier to involvement. Currently, the evidence base evaluating the effectiveness of service user involvement in a range of activities including service planning, delivery, education and research is limited.

**Key words:** service user and carer involvement; mental health; education and training; research; Government policy and guidance; effectiveness.

### **Introduction**

A collaborative study, led by service users and carers, of service users' and carers' involvement in mental health education, training, and research was undertaken. This took place in 2008 and comprised a literature review and a study across the three specialist mental health NHS Trusts and four universities in West Yorkshire, comprising a survey, focus groups and interviews. 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.

The rationale for the study was:

- A lack of routine evaluation of service user and carer involvement in mental health research, training and education.
- Lack of understanding of which model(s) of involvement were the most effective and in what situations.
- Different types of evaluation taking place for different purposes thereby making it difficult to determine which types of evaluation are most appropriate.

- Lack of methodology and theory underpinning this area and a lack of connectivity between policy, education and research.

This paper deals specifically with the literature review which comprised stage one of the study, but reference will be made to findings from the broader study.

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

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

These areas also formed the content of the survey, focus groups and interviews which were the elements of the second phase of the project.

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 or engagement was identified as the terminology used in policy and guidance documentation, and within 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. However, within mental health services, service user and carer involvement tended to be the most frequently utilised terminology and was adopted for this study. Although, as discussed by Wallcraft and Nettle (2009), this is by no means universally accepted. The search for literature focused primarily on the period from 1999 – 2009 and encompassed health databases accessed through Health Information Resources including NHS Evidence, journals and health care databases, and evidence based reviews. Library searches were also undertaken and identified a range of edited texts. Internet searches also identified Government and health policy and guidance, publications produced by organisations with a primary focus on public involvement, and some unpublished reports.

## **Policy context**

The literature review identified a raft of policy and guidance, emanating from the Department of Health over the last 10 years, advocating patient and public involvement (PPI) in 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 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 (1999a) – 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.

Other mental health policy and guidance, such as the National Service Framework for Mental Health (Department of Health 1999b), Mental Capacity Act 2005 and Mental Health Act 2007, specifically refers to the need to engage service users and carers more fully with treatment, service planning and delivery. Also underpinning the inclusion of service user and carer involvement in mental health education, particularly nursing, have been the Disability Discrimination Act 1995, the Employment Act 2002, and the Human Rights Act 1998.

However, despite the wealth of policy and guidance, PPI has lacked consistency in its application as was clear from phase two of the study undertaken as part of this research. This demonstrated a lack of awareness of organisational policy on service user involvement and, whilst there was broad support for the ethos of involvement, inconsistency in applying policy and guidance. The Health Committee's Report on Patient and Public Involvement in the NHS (2007) echoed this and 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.

## **A Note About Defining Service User Involvement**

Hubbard et al (2004) point to the need for clarity in relation to defining service user and carer involvement. Involvement may simply mean 'taking part', whereas participation can suggest something more active. As was clear from this research project, implementation of involvement is inconsistent and therefore definitions varied and had an impact on levels of participation and recruitment to activity. Finding a clear definition of involvement within Higher Education was difficult and within health services involvement in the broadest context can refer to participation in decisions about the person's own care, or in health service planning or delivery, or research. However, the level of involvement may range from consultation through collaboration to control. INVOLVE, for example, define public involvement in research as: '... people who use services are active partners in the research process rather than 'subjects' of research'. (INVOLVE 2004).

In the context of this research, the research team wanted to explore how different participants in the process of mental health training, education and research defined involvement, the level of engagement and participation, and therefore did not present a definition when inviting participation in phase two of the study. A survey of Higher Education and NHS professionals and service users and carers found that there were differences in professional definitions of involvement activity and service user definitions with the latter embracing a broader range of activity including peer support.

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

A review of the literature demonstrates that PPI or service user involvement is taking place in a number of areas within mental health including: education and training, evaluation and research, as well as service planning. 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; Beresford 2009; Simpson et al 2002). This underlines the complexity of this area which is underpinned by issues of power, culture, and politicisation.

Power as a concept is embedded within mental health systems, in the legal framework underpinning service delivery, in relationships between clinicians and patients, in the social perspectives of mental illness, and within educational structures (Rose 2004; McGowan et al 2009). Similarly, the competitive arena in which mental health research exists means it is increasingly difficult for service user led research to secure funding (Grant et al 2006). References to service user involvement in mental health service delivery, education and research frequently talk of empowerment of the service user, but there is little evidence that this leads to a shift in control over the process or that the balance of power has changed (Hubbard et al 2004; Faulkner 2004, 2009; Doel et al 2007a). Organisations such as the Mental Health Foundation ([www.mentalhealth.org.uk](http://www.mentalhealth.org.uk)) and Shaping Our lives ([www.shapingourlives.org.uk](http://www.shapingourlives.org.uk)) play an important role in supporting and facilitating user involvement in general but also in education and research.

Davidson et al (2009) argue for a move away from the managerialist/consumerist approach to involvement to a transformative approach where the questions and problems are defined by those with the lived experience of mental health rather than those who hold the power. Adopting a more democratic approach to involvement by allowing the service user or carer to define the research or teaching topics leads to more relevance and inclusivity, and may also lead to more employment opportunities and associated benefits for them. Involvement in curriculum development, research or service design places the service user in a more

influential position and increases the potential for political empowerment. However, for the professional this can present a loss of control, for example, over the content of teaching. Moreover, for some service users the dominant middle class professional perspective, and focus on educational attainment, prevalent in education and research, is a barrier to full inclusion as illustrated here:

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/educator, Minogue et al 2009)

Rose (2004) also explores power differentials between user researchers and professionals in a collaborative arena and found that differences in status, salary, and issues of discrimination arose as a result of being a mental health service user. It is clear that the future of involvement activity, such as mental health education and research, has to be based on clear strategies and theoretical perspectives if power differentials and culture are to change. It also has to demonstrate its complementary value to policy, practice and research if it is to escape the critical view that involvement is predicated on lived experience which is in itself subjective and biased.

### **Benefits of Involvement**

The benefits of involving service users and carers in the planning and delivery of mental health services, including through the education and training of professionals, and research, have been well documented (Happell et al 2003; Clark et al 2004; Bennett et al 2005; Repper et al 2004; Khoo et al 2004, Staley and Minogue 2006, Wallcraft et al 2009). Benefits include:

- Learning from the knowledge and perspective of service users and carers of living with and managing mental health problems and using services.
- Asking more relevant research questions and using more culturally relevant research methodologies.
- Challenging professional perspectives.
- Valuing of the service user and carer perspective.
- Increasing the confidence, self esteem and well being of the service user or carer.
- Development of new skills and knowledge for both professionals and service users and carers.
- Development of a greater understanding of health services and higher education for the service user or carer.

### **Barriers to Involvement**

Despite the many opportunities identified for involvement activity, and detailed in this review, there are still barriers and challenges to patient and public involvement in mental

health education, training and research (Clark et al 2004; Nilsen et al 2008; Delman and Lincoln 2009). These include:

- Lack of information about opportunities for involvement and resources available.
- Funding/resources to adequately support service user and carer at both strategic and practice level.
- Systems of remuneration being unclear within organisations and also in terms of impact on welfare benefits for the unwaged.
- Funding for service user and carer 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 service user/carer groups.
- The focus on large multi centre research projects rather than the local concerns expressed by service users and carers and the public.
- The lack of cross fertilisation between the NHS and HEIs.
- The perception many service users and carers 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), change the nature of teaching sessions, or due to its challenge to traditional researcher led ideologies and processes, (Telford 2004). Staff may also mistrust service user motivation for participation, perceive them as unrepresentative or challenging.
- 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 chose to be involved in research or other involvement activities.

## **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 led training, curriculum development, the production of learning materials, and assessment. (For examples of the different approaches see: Forrest 2000, Bennett et al 2003; Happell et al 2003; Bailey, 2005; Khoo et al 2004; Simons et al 2006; Repper et al 2004). As with other areas of PPI, involvement requires a fundamental shift in culture within Higher Education (HE) in order to incorporate the service user view. To support this agenda, a network (Development of User and Carer Involvement in Education - DUCIE) has been developed to support the growing number of service user and carer development workers within HE (Ducie 2009).

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.

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. This was borne out by the findings from phase two of this study which identified a lack of feedback to service users, erratic and non existent remuneration, and inequitable systems for recruitment (Minogue et al 2009). Recruitment for involvement was a particular issue as it was almost exclusively by invitation and personal approach. This clearly limited access and the potential to engage a diverse range of people.

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 (Tew et al 2004; Trent NHS 2005) but this study demonstrated that timely and targeted training was more important than simply offering a range of training (Minogue et al 2009).



## **Research**

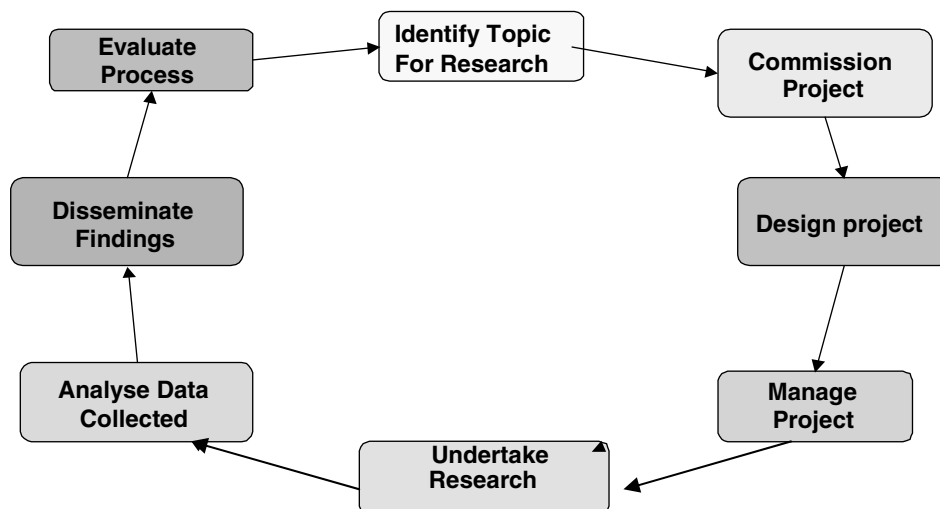
Service user involvement in mental health research is not a new phenomenon, indeed participatory research has been in common use in developing countries for several decades (Frideres 1992). In the UK, involvement really began to evolve in the 1990s and, despite some initial cynicism, has been accepted 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, with limited resources (RD Forum 2008: [www.rdforum.nhs.uk](http://www.rdforum.nhs.uk)).

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 business 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 and service user and carer involvement. The research element of the NIHR, comprising 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 led by the Mental Health Research Network and a series of regional hubs (<http://www.mhrn.info/index.html>).

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](http://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**



Although well established, service user led research is not without its critics and occasionally there may be differences of opinion when service users' 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 led 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 impact and effectiveness of service user involvement in health and mental health training, education and research, is limited although interest is growing (Hubbard et al 2004, Doel et al 2007b, INVOLVE 2007, Nilsen et al 2008). 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 suggests 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.

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

- Empowerment of service users and carers – improving self identity.
- Innovation.
- Services redefined and therefore becoming more effective .
- 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.

Specific impacts in the research process include:

- Impact on funding/commissioning.
- Impact on the type and quality of research.
- Impact on research ethics.
- Impact on implementation and change.

It was also recognised that not all impacts might be positive and that there may be harmful effects for service users if good practice guidance is not followed (Faulkner 2004, 2009; Delman and Lincoln 2009). However, traditional interpretations of impact may not be satisfactory measures of the impact and effectiveness of user involvement. The impact of research, for example, is measured, in academic terms, through the Research Assessment Exercise and publication in high quality journals. Defining and enumerating impact in the context of user involvement in education or research presents challenges. The impact, for example, on student learning or understanding may be long term and may be difficult to verify as its manifestation within the practice context may well be attitudinal or cultural. Guidance produced by the DUCIE network suggests using a range of existing tools such as the National Quality Impact tool, Ten Essential Shared Capabilities, or Principles for Practice, to evaluate user involvement in HE (Ducie 2009).

Oliver et al (2008) suggest drawing on already tested methods of evaluation which examine involvement from the organisational, community, interpersonal, and impact perspective. Applying their own framework analysis to involvement in health services research, they concluded that it was less influential when involvement methods were determined by the professionals rather than jointly owned. 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; INVOLVE 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.

However, this still does not address the issue of how to measure the impact and effectiveness of service user engagement in mental health 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 (Doel 2007b) 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 and education 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](http://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 scoping study undertaken in this research found that payments for involvement were a major issue. 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, levels of payment varied and sometimes were not offered at all.

## **Conclusions**

The review of the literature established that there is a strong base of service user and carer involvement in mental health teaching, training and research and that it has been widely embraced by the education and health community. There are many positive examples of good practice in involvement and reported successful outcomes of how involvement has enhanced the teaching experience or improved the quality or outcome of research. However, the early development and implementation of involvement policy and guidance, in the NHS and higher education, was largely on an ad hoc basis, albeit underpinned by strong motivation, and has not ensured consistency in its application. Nor has it ensured appropriate and effective support and training is in place. It would be beneficial if the NHS and Higher Education sector and service users and carers could work towards a shared understanding of service user and carer involvement activity. Access to involvement activities needs to be more inclusive and not simply based on personal contact as this study found. Understanding the different motivations of each of the stakeholders is also important in recruiting the right people for the task. Appropriate remuneration remains a key issue as it is an expression of the value placed on involvement. Lack of consistency in the application of good practice, and variations in payment methods and levels of payment, can only undermine the contribution of service users and carers. Consistent application of policy and guidance is imperative as is governance of the system.

The lack of clear measures for determining the effectiveness of involvement activity, and lack of evidence of impact on practice, meant that this review was unable to clearly define the impact and value of service user and carer involvement in mental health teaching,

training and research. 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.

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.

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