FACULTY OF HEALTH AND SOCIAL CARE SCIENCES

Service user involvement in the design and delivery of education and training programmes leading to registration with the Health Professions Council

Professor Mary Chambers
Faculty of Health & Social Care Sciences
Kingston University and St George's, University of London
Dr Gary Hickey
Faculty of Health & Social Care Sciences
Kingston University and St George's, University of London

Acknowledgements

We wish to thank the Health Professions Council for commissioning the research.

We also wish to thank members of the Steering Committee and Advisory Group for their guidance, help and support throughout the project with special thanks to Denise Forte for her assistance with the recruitment of Service Users.

Thanks also go to Sally Wilson Service User Researcher for her contribution to data collection and analysis.

To all Service Users and other study participants we wish to acknowledge the time and energy you gave to the project for which we are most grateful and we take this opportunity to thank you.

Executive Summary

Background

The HPC is a regulator of 15 health professions and its role includes approving and upholding high standards of education and training. Noting the trends toward greater SUI in education, the HPC is considering whether to develop a Standard of Education and Training (SET).

This would require education providers across all those professions which fall under its regulatory umbrella to ensure SUI in the design and/or delivery of education and training.

Purpose and objectives of the study

To help them reach a decision the HPC commissioned research to explore the current involvement of service users in the design and delivery of pre-registration education and training programmes approved by the Health Professions Council (HPC). More specifically the overarching research objectives were as follows:

- To gain improved understanding of the nature and extent of service user involvement in the design and delivery of approved education and training programmes which lead to registration with the HPC.

- To identify, analyse and evaluate the different types of involvement activities undertaken by approved education providers.

- To situate the above within the relevant literature on service user involvement (in particular, within education and the regulation of education).

The study objectives were to:

- Identify the existing approaches and types of SUI activity across the range of programmes regulated by the HPC
- Identify existing best practice criteria for SUI in education and training
- Identify the drivers, benefits and challenges of SUI in education and training
- Produce options for Standards of Education and Training (SETs) for SUI in the design and delivery of HPC regulated education and training programmes

Methods

The study was conducted in four interdependent stages, employing a mixed method approach utilising both qualitative and quantitative methods of data collection. Following the literature review, and building on the theoretical framework a matrix of benefits and barriers to, and facilitators of SUI was developed. This theoretical framework and matrix was used to inform the development of an on-line questionnaire and the key elements for discussion in the focus groups and individual interviews as part of three case studies. Findings were then discussed at a consensus workshop and options for SETs developed.

Findings

Three key sources of drivers can be identified: service users and public, professions and Government policy. Drivers include the emergence of the service user movement, public distrust of professionals, a shift away from a medical model of care with service users as passive recipients of services towards a more empowered approached where service users are involved in decision making; and a range of Government legislation, which encourages greater inclusion of service users than hitherto.

Service users were involved in various aspects of the design and delivery of education and training. Of particular note is involvement in programme planning, the development of teaching tools/materials, formative feedback on the programme, role play in the classroom and module planning. There were no professions, which responded to the questionnaire, which indicated that they did not involve service users in some way.

The range of perceived benefits of involving service users in education and training include those for students (for example, 'students gain insight from service users' perspective' (82%), 'challenges students' stereotypes/assumptions of service users' (73%)), the programme (for example, 'ensures the priorities of service users are reflected in the programme' (71%)) and also the service user (for example, 'provides an opportunity for service users to share experience and/or expertise' (74%) and ensures that 'service users feel valued' (73%).

One key issue was defining 'service user'. A suggested option is to use the phrase 'end recipient of a service'. Such a definition would be consistent with what is generally meant by the phrase 'service user' and is sufficiently broad to enable the inclusion of those few professions, for example biomedical scientists, who rarely, have face-to-face contact with the public. This definition excludes students and academics.

Some respondents have expressed concerns about the extra demands on infrastructure, culture and resources as a result of a SET. This issue is particularly

significant in a time of economic constraint. A variety of approaches were proffered for addressing these challenges.

Developing a SET

Although there was widespread support for including service users in the design and delivery of education and training there were many concerns about the value of introducing a SET and of introducing a SET immediately. This leaves the HPC with a range of options

- Change nothing
- Introduce a standard immediately requiring professions to involve service users in the design and delivery of education and training
- Recommend that all HPC regulated professions should include service users in the design and delivery of education and training, but stop short of introducing a standard
- A standard would be developed but not introduced until a specified time in the future

Any SET should not be a 'tick box' exercise or encourage tokenism. The SET should be encouraging of a 'meaningful' level of service user involvement. 'Meaningful' refers to the extent to which service users are involved and/or the level of influence that they have over an aspect of education.

In terms of standards, the following options were developed for HPC to consider:

1. 'Service users are actively involved in the design and/or delivery of the programme with supporting evidence.'

2. 'The design and delivery of the programme must be influenced by service users, carers and representatives.'

3. 'There must be a service users' group which considers that it has had appropriate input into the management, design and delivery of the course.'

Table of Contents

Tables and Figures

Chapter 1: Introduction and background

1.1 Introduction

This first chapter provides context and background to the research. The chapter begins by providing information on the purpose, objectives and background. It then explores the drivers for service user involvement (SUI) and the different models of SUI.

Chapter two is a literature review that includes research and other articles concerned with SUI in education including benefits, barriers and facilitators to SUI. A description of the data collection methods used in the study is the focus of chapter three with chapter four outlining the findings. Chapter five provides a discussion of the key issues including the limitations of the study.

1.2 Purpose

The overall purpose of this project is to explore the current involvement of service users in the design and delivery of pre-registration education and training programmes approved by the Health Professions Council (HPC). This information will assist the HPC in their decision making regarding what role, if any, they might play, in ensuring SUI in the design and/or delivery of the education and training programmes that they regulate.

1.3 Study Objectives

- Identify the existing approaches and types of SUI activity across the range of programmes regulated by the HPC
- Identify existing best practice criteria for SUI in education and training
- Determine the drivers, benefits and challenges of SUI in education and training
- Produce options for Standards of Education and Training (SETs) for SUI in the design and delivery of HPC regulated education and training programmes

1.4 Background

The HPC is a regulator of 15 health professions and its role includes approving and upholding high standards of education and training. Noting the trends toward greater SUI in education, the HPC is considering whether to develop a Standard of Education and Training (SET). This would require education providers across all those professions which fall under its regulatory umbrella to ensure SUI in the design and/or delivery of education and training.

The calls for greater SUI in the education and training of health and social care professionals have already impacted upon regulation elsewhere. For example:

- The UK White Paper 'Trust, Assurance and Safety – The Regulation of Health Professionals in the 21st Century' (DH 2007) advocates greater patient and public involvement.
- The Alliance of Health Care Regulators on Europe has argued that patient and public involvement in health care regulation should be regarded as good practice (Joint Health and Social Care Regulators' Patient and Public Involvement Group 2010).
- The Council for Healthcare Regulatory Excellence (CHRE), which oversees and scrutinises the work of 9 regulatory bodies including the HPC, regards user involvement in regulation as a necessity, not an option. CHRE (2010) consider it "important that patient involvement is reflected in the design and delivery of education programmes and that any course evaluation, has taken the views of patients into account" (CHRE 2010, p27).
- Various regulatory and educational bodies of health and social care professions have advocated, and sought to ensure, a greater level of SUI in the provision of education and training (e.g. GMC 1993, ENB 1996, UKCC 1999, GSCC 2005, NMC 2010). The Royal College of Psychiatrists declared in 2005 that all trainees in psychiatry were required to receive training from people with mental health problems (Haeney et al 2007).

The HPC already has initiatives to ensure greater SUI in the education and training of those professions which fall under its regulatory umbrella. For example, through its operational processes to approve and monitor programmes, and via its guidance, it encourages SUI in programmes. However, it does not, as yet, have any standards explicitly requiring SUI in education and training (HPC 2011). While recognising the value of existing practices of user involvement in education, the HPC states that they have yet to be provided with 'compelling evidence' that greater regulatory intervention would add value to the existing work of education and training providers. In addition, to date, they have found no direct link between involving service users and enhancing their regulatory role of protecting the public.

In August 2012, the HPC is due to become responsible for the regulation of social workers in England. The General Social Care Council (GSCC) currently regulates this profession and requires that service users are involved in all aspects of programme, including selection, teaching, assessment, design and quality assurance (DH 2002). As social workers in England are not currently registered by the HPC, and there is already good available information about the extent of service user involvement in social work education and training, they are outside of the scope of this research. However, any standard of education and training subsequently developed by the HPC would also apply to social workers in England once they join the HPC register.

1.4.1 A note on terminology

The term 'service user' is an amorphous concept which can refer to a variety of groups. As Morrow et al (2012) note in relation to SUI in research, 'the language is developing rapidly in this field and different terms are used to mean different things in different research and healthcare contexts, and internationally' (Morrow et al 2012, p19). Sometimes 'user involvement' refers to people who use, or have used, a service; or to the carers or parents of service users; other times it simply refers to lay people, the public or non-professionals; also it can be used to refer to all or any combination of these. The HPC, in their research brief, defined 'service user' as referring to 'those who typically use or are affected by the services of registrants once they qualify from programmes and become registered (e.g. patients, clients, carers, organisational clients, colleagues etc).' They excluded students from this definition. As will be highlighted in the findings chapter, some respondents regarded groups such as students and practice staff, as well as more traditional users as service users. However, such groups are not regarded in the literature as service users; this ambiguity is explored further in chapter 5.

Phrases such as 'design' and 'delivery', and indeed 'evaluation', are generic umbrella terms. Generally speaking, design refers to the development of modules, programmes and curricula; delivery refers to the different teaching/learning approaches which maybe classroom based or in clinical practice, while evaluation refers to a review either during a programme (formative) or on completion (summative), of the module or programme.

1.5 Drivers for SUI

There are a variety of interrelated drivers or rationales for the inclusion of service users in the development of health and social care services generally and education and training specifically. These have emerged over time and, in practice, combine and interweave to become mutually reinforcing in the promotion of greater SUI. As such, it is difficult to disentangle the themes and provide a definite chronology that may apply to these various drivers. Here, an overview is provided of the key drivers and those that provide the context for user involvement in the design and delivery of professional education and training.

Three key sources of drivers can be identified:

- Service users and public
- Professions
- Government policy

Each of the sources includes a variety of themes, which together, generate the demand for greater user involvement in the design and delivery of education and training. These themes include the advancement of consumerism, distrust of professions and a more demanding and discerning public.

The aspiration for greater user involvement is also underpinned by a belief, and some would argue evidence, that it can bring various benefits. These benefits perceived or otherwise, become drivers themselves, reinforcing the rationale for greater SUI in the design and delivery of education and training.

1.5.1 Service users and public

There are two broad drivers considered within this section:

- The emergence of the 'service user movement'
- Distrust of professionals

1.5.1.1 Emergence of the service user movement

Service users have long argued for a greater say in the services that they use. These groups of service users include a range of disenfranchised communities such as those experiencing mental health issues or disability, black and minority ethnic groups and women (Ocloo and Fulop 2010). The demands of these groups vary and include citizenship issues, welfare rights, challenging societal attitudes and barriers and the entitlement to be involved in decisions impacting upon them. In addition, there has been the emergence of a more diverse and discerning public with greater expectations, than hitherto, of service providers (Brodie et al 2009).

The education and training of health and social care professionals generally involves the inclusion of working in clinical practice. Consequently, hitherto service users have had a passive role in education and training (Livingston and Cooper 2004), usually as individuals with symptoms that need diagnosing and treating by the expert (Jha 2010, Rees et al 2007). Increasingly, this passive role has been questioned with a growing recognition that service users and carers have an expertise in, and valued experience of, their own illness (Department of Health 2001, Livingston and Cooper 2004, Ottewill 2006, Downe et al 2007, Skilton 2011). Therefore, it has been argued that they should be actively involved in the education and training of those providing the services which they will access, helping to ensure more targeted professional responses to the needs and wishes of service users (Lathlean et al 2006, Felton and Stickley 2004).

Within the service user movement it is then possible, to identify, a range of rationales for greater SUI in education and training. These include the benefits that the experiences and expertise of service users bring, the desire for service and education to reflect the needs and demands of a more diverse and discerning population, particularly where there may have been some history of oppression (such as users of services provided by social workers), and a drive to address issues of rights and power (Taylor and Le Riche 2006).

1.5.1.2 Distrust of professionals

Higgins et al (2011) suggest that a series of high profile 'cases' has diminished trust in professions leading to increased pressures to put service users at the heart of care and the design and delivery of health and social care provision. For example, the Kennedy Inquiry into the children's heart surgery scandal at the Bristol Royal Infirmary and the retention of children's body parts for research at Alder Hey Hospital in Liverpool (Morrow et al 2012). The former, assert Porter et al (2005), highlighted the role that education and training can play in ensuring that practitioners appreciate the roles that patients and the public can play. This in turn led educational establishments to consider service user and carer involvement in the education they provide to health and social care students.

Ocollo and Folup (2010) note that both the Kennedy Inquiry and a report into events at Mid Staffordshire NHS Foundation Trust have recognised that the involvement of service users (be they patients, parents or the public) are necessary to help develop a safety culture in health care. Despite this, Ocollo and Folup (2010) note a lack of progress in public and patient involvement in the patient safety agenda. This report will not explore patient safety in service delivery in great detail but it is worth noting as 'public safety' is a key regulatory role of the HPC (http://www.hpc-uk.org/aboutus/).

1.5.2 The professions

Although the themes covered above are clearly key drivers of SUI there is a danger of giving the impression that these are external events impacting upon professions that are entirely resistant to change. Various professions have, with varying degrees of enthusiasm, promoted a more 'partnership' approach to care and service provision. There have been shifts in what it means to be a 'professional' due to challenges to the medical model of care (Skinner 2010). The traditional paternalistic model of care whereby the service user was a passive recipient of care, dependent upon the expertise of the professional is regarded as outmoded (McAndrew 2003, Schneebeli et al 2010). In mental health there has been a shift away from professional dominance to the provision of a service based on a more equal relationship between service providers and the recipients of services (e.g. McAndrew and Samocouk 2003).

It can be argued that a change in the stance of the professions has been as a result of pressures from the 'service user movement'. A key point is that any change in the role of professions, for example a shift from professional dominance to a more equal relationship between service user and those receiving a service, becomes in itself a driver of change.

1.5.3 Government policy

The move towards the inclusion of service users in the design and delivery of health care is an international phenomenon (Brown and Macintosh 2006, Higgins et al 2011, Davis and McIntosh 2005). In the UK, a variety of legislation and policy documents have placed service users and communities at the centre of the design and delivery of services (e.g. DoH 1999a, 2000, 2001, 2004, 2005a, 2005b, 2006a, DeES 2004 Darzai 2008). No longer are service users perceived as passive recipients of care; rather, 'they are considered active participants in their own health and well-being' (Morrow et al 2012, p12).

Consumerism is a word often used to describe such developments (e.g. Collier and Stickley 2010, McKeown 2010, Rhodes and Nyawata 2011). This finds expression in such phrases as the personalisation of care and personalised care (McKeown et al 2010). A distinction has been made between consumerism on the one hand and democratisation on the other (Hickey and Kipping 1998, Beresford 2003) to describe different approaches to user involvement and different levels of user involvement in decision making.

Consumerism refers to service users commenting upon services rather than being actively engaged in partnership with service providers (e.g. Hickey and Kipping 1998, Collier and Stickley 2010). It is important to note that tension between the two approaches exist which can help explain 'levels' of SUI and some barriers to SUI as highlighted in other sections of this report. There have been moves in the UK toward a more user led service provision than hitherto. Despite the plethora of legislation

there is little evidence that involvement is an integral part of NHS organisation (Department of Health 2008), suggesting that there are barriers yet to be overcome.

The commitment to user involvement in public policy has prompted initiatives to ensure that this principle informs the planning and delivery of services as well as education and training (Porter et al 2005, Ottewill 2006, Townend et al 2008). For example, in 1999 the National Service Framework for Mental Health declared that 'service users and carers should be involved in planning, providing and evaluating training for all health care professionals' (Department of Health 1999). This was echoed in the Chief Nursing Officer's review of mental health nursing in 2006. Skills for Health, which is the Skills Sector Council for Healthcare employers, identifies SUI as one of its 11 key principles for the Quality Assurance for healthcare education (Skills for Health 2007). Also social work degrees require service users to be involved in the teaching, selection, admission and assessment of students as well as the design and evaluation of programmes (Department of Health 2002).

In short, Government has moved towards greater SUI in the provision of health and social care services generally, and education and training specifically.

Stickley et al (2010) note that greater SUI will, it is hoped, lead to improvements in the quality of care, greater accountability of health professionals and reduce the burden and cost of health care. Further discussion concerning the perceived benefits of SUI in education will take place in section '2.2 Benefits of SUI.'

1.6 Models of SUI

In this report we will use a series of models to conceptualise and explain the current status of SUI. These models are often expressed as ladders or continuums. However, these ladders/continuums do not provide an exact 'measure' of user involvement but serve as analytical tools, helping to explore and explain the extent of SUI.

A first continuum upon which we will draw is what we call the *'integration continuum'*, with the polar ends being 'systemic user involvement' and 'piecemeal user involvement'. The former refers to those instances where service users are involved in all aspects of the design and delivery of education from programme development, selection of students, delivery, assessment, through to evaluation whereas the latter involves service users in certain aspects of education and training (usually service delivery) such as 'classroom assessors'. The closer to 'systemic user involvement' the more integrated is SUI. There are some examples in the literature of 'systemic user involvement' (e.g. McKeown et al 2010) but the vast majority of publications suggests a more 'piecemeal' approach.

A second continuum, which we will call the *'engagement continuum'*, has 'active' and 'passive' involvement at its polar ends. This continuum refers to the level of

engagement or demands made of the service user role. Livingston and Cooper (2004), note that service users have always had a 'passive' role in clinical practice, whereby students develop their skills by practising on patients. However, there are also examples of more active roles where service users are engaged in classroom teaching. Moving further along the engagement continuum service users may have a role in assessing students.

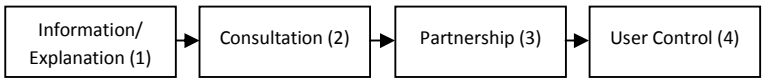
Blurring boundaries with the 'engagement' continuum is the *'participation continuum'* or ladder. Many authors have developed such a continuum (or ladder) including Arnstein (1969), Hickey and Kipping (1998), Tew et al (2004) cited in McKeown et al (2010), and the Supporting People service user best practice guide (http://serviceuserinvolvement.co.uk). These all help explain the level of user involvement and degree of power transferred from teaching staff/educational institution to service users. The figure below illustrates these ladders and continuums and the 'key' indicates the similarities between them.

Figure 1

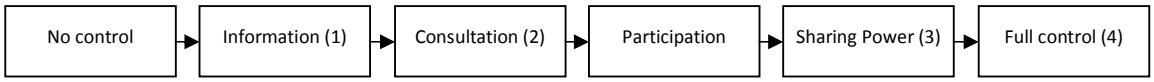
Models of Service User Involvement

Arnstein's ladder of participation (1969) (cited in Morrow et al 2012)

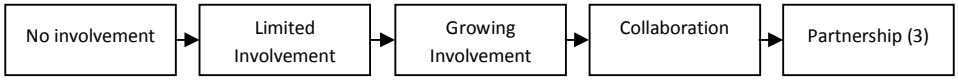
The participation continuum - Hickey and Kipping 1998



Supporting People: SUI best practice guide - http://www.serviceuserinvolvement.co.uk/whatisit_laderOfP.asp?id=1



Ladder of involvement – Tew et al 2004



Key

(1) Informing/Information
(2) Consultation
(3) Partnership
(4) Control

Some question the extent to which SUI in education is tokenistic (Felton and Stickley 2004); that is, it is not integrated but rather 'ticks' boxes without high level of engagement from the service user or any real shift in power.

1.7 Summary

The drive for involving service users in the provision of care and in education comes from a variety of sources, including service users and the public, the professions and Government policy. There are various models, outlined in this chapter, which can be used to conceptualise and explain 'user involvement'. These models will be used throughout this report to help explain the types of user involvement. The following chapter concentrates on a review of the literature, which helped identify the benefits, barriers and facilitators to SUI in education and training and also a theoretical framework to underpin the research.

Chapter 2: Literature review

2.1 Introduction

This chapter is a literature review undertaken to identify the key issues surrounding SUI in the education and training of professionals and in particular those currently regulated by HPC. In addition the outcomes of the review influenced the theoretical framework underpinning the study, provided the content for the matrix as well as the questions for inclusion in the online questionnaire, focus groups and individual interviews.

A search was undertaken using the databases CINAHL, AMED and MEDLINE. The parameters of the search were that articles be in English, and between 2001 and the present day. For CINAHL and MEDLINE the searches were made on the key words 'consumer participation' combined with 'education, health sciences+', while for the search of the AMED database a search was made on 'user involvement' combined with 'training' This search was supplemented by accessing references identified in these articles. The articles identified by the literature search are a combination of research projects, literature reviews, descriptions of particular initiatives and opinion pieces.

Appendix A lists the research articles, identifies the professions they cover, their purpose/aims and the methods employed. A loose definition of research has been used to enable inclusion of consultation exercises (e.g. Branfield et al 2007, Branfield 2009) and small scale evaluations.

The majority of the research is small scale qualitative, evaluations focussing on specific initiatives within a particular education institution. Only one piece of work (Branfield 2009), albeit a consultation exercise, gathered views on initiatives beyond a particular school.

Previous research has included the use of interviews and/or focus groups with, or questionnaires administered to, service users and/or students and/or academic staff to investigate their views following the introduction of a particular aspect of SUI. It follows, that much of the research does not enable a comparison of pre and post intervention data; instead, the research relies on respondents looking back and comparing. Furthermore, none of the studies evaluates the impact on practice post the course. The research identified is largely descriptive, identifying respondents' experiences, perceptions and views of a particular initiative, including perceived benefits, barriers and facilitators to user involvement.

A number of articles did include a longitudinal aspect, designed to test or explain the impact of a particular initiative that enabled some comparison of responses between at least two points in time (Greco et al 2001, Happell et al 2003, McAndrew and

Samociuk 2003, Barnes et al 2006, Brown and Macintosh 2006, Perry and Linsley 2006, Downe et al 2007, Anghel and Ramon 2009, Reinders et al 2010). Of these just two involved the use of controlled trials. Greco et al (2001) examined the impacts and implications of different models of systematic patient feedback on the development of general practice registrars' interpersonal skills. Reinders et al (2010) assessed whether a patient feedback programme led to better consultation skills in general practice trainees when compared with regular communication skills training. However, neither study collected data from service users.

Some larger studies used questionnaires as a method of data collection (Eagles et al 2001, Greco et al 2001, Barnes et al 2006, Horacek 2007, Haffling and Hakansson 2008, Anghel and Ramon 2009, Higgins et al 2011, Rhodes and Nyawata 2011).

The literature search suggested that few research articles included HPC regulated professions. There are articles on physiotherapy (Ottewill et al 2006, Thomas and Hilton 2011) and psychological therapy (Vijayakrishnan 2006, Dogra et al 2008) and the research by Cooper and Spencer-Dawe (2006) includes physiotherapy and occupational therapy; an American study included dietitians (Horacek et al 2006). Similarly, psychology, occupational therapy and speech and language therapy are included in the research by Higgins et al (2011). Some of the articles are about user involvement in clinical placement (Barnes et al 2006, Jones 2006, Haffling and Hakanason 2008, Monrouxe et al 2011) rather than in the classroom.

Despite the effort, over several years, to increase service user involvement in the design and delivery of education and training this review supports Thomson and Hilton's (2011) assertion that there 'is a paucity of papers reporting involvement in the education of health professionals other than nursing, medicine and social work' (doi: 10.1002/pri.510).

This imbalance across the professions may reflect the historical context of the service users who received services from nursing, medicine and social work which has led to demands for a greater level of empowerment than hitherto.

Townend et al (2008) offer some further explanations for the imbalance in the literature. Although focussing on psychological training and in particular the relative dearth of SUI in the education and training of psychological therapists compared to social work, or mental health nurse training, their rationale may also be extended to other professions. Townend et al (2008) reflect that a) these professions are older, consequently SUI has had a longer gestation and b) the status and power attached to some professions may act 'as a natural galvanizing focus' (p68) for those campaigning and advocating greater user involvement. They also suggest that there are diverse theories and practice bases in psychological theory which create barriers to SUI, which do not exist in other professional groups such as psychiatry or mental health nursing.

In addition to these research articles the review draws upon:

- literature reviews (Le Var 2002, Livingston and Cooper 2004, Porter et al 2005,Repper and Breeze 2006, Townend et al 2008, Morgan and Jones 2009, Jha et al 2010)
- descriptions of particular initiatives (Frisby 2001, Happell and Roper 2002, Davis and McIntosh 2005, Advocacy in Action 2006, Allain et al 2006, Stevens and Tanner 2006, Haeney et al 2006, Whitehead and Harding 2006, Lathlean et al 2006, Tyler 2006, Haeney et al 2007, Gupta and Blewett 2008, Jones et al 2009, McKeown et al 2010, Atkinson and Williams 2011, Stickley et al 2011)
- opinion pieces on barriers and how they can be overcome (Fadden et al 2005, Basset et al 2006)

Few of these articles include HPC registered programmes with the exception of physiotherapy (Jones et al 2009) and psychological therapy (Townend et al 2008); the majority from nursing, social work and medical professions. The Townend et al (2008) literature review used psychological therapy as a generic term and included professions such as specialist counsellors, psychotherapists, clinical psychologists, psychiatrists, mental health nurses and social workers. In terms of the scope of SUI in education and training, what evidence there is, indicates that the focus is on the delivery of education. Drawing upon the continuums referred to in chapter one this suggests that where user involvement exists it tends, as Repper and Breeze (2006) found, not to be systemic but rather piecemeal, and focussed on levels of consultation (and at best) participation.

There are some noticeable exceptions (Davis and McIntosh 2005, Barnes and Carpenter 2006, Lathlean et al 2006, Downe et al 2007, Anghel and Ramon 2009, McKeown 2010, Skinner 2010) where service users are involved in a more systemic way. However, even within this more systemic approach subtle variations exist in the types of design and delivery that service users are involved in and the extent of their involvement. In the Davis and McIntosh (2005) example service users contribute to the curricula, monitoring of the programme, development and strategic planning, the recruitment of students and staff and student assessment. Barnes and Carpenter (2006) report on the involvement of service users in commissioning, management, delivery, participation and evaluation of a postgraduate programme. In the Skinner (2010) example service users are involved with student and staff recruitment, teaching sessions, attending or chairing meetings, curriculum development, student assessment, staff training and meeting reviewers and commissioners. Lathlean et al (2006) for example have a service user and carer reference group which provides advice on curriculum development, and service users are involved in teaching. With the Anghel and Ramon (2009) example service users and carers are involved in teaching, assessing and the admissions process but not in curriculum development. Finally, McKeown et al (2010) describe an initiative within a faculty where the aim is to systematically involve service users and carers in all scholarly activity of the faculty.

There are examples of service users being involved in various aspects of education and training for example in:

- role playing (Eagles et al 2001, Jones 2006, Jha et al 2010, Mohler et al 2010, Monrouxe et al 2011)
- providing feedback on students' role play exercises (Greco et al 2001)
- recruitment and selection (Davis and McIntosh 2005, Branfield 2007, Rhodes and Nyawata 2011, Skilton 2011)
- involvement in teaching in the classroom (Costello and Horne 2001, Happell 2002, Happell and Roper 2002, Happell and Roper 2003, Happell et al 2003, Cooper and Spencer-Dawe 2006, Felton and Stickley 2004, Lathlean et al 2006, Ottewill et al 2006, Rush and Barker 2006, Stevens and Tanner 2006, Whitehead and Harding 2006, Haeney et al 2007, Simons et al 2007, Dogra et al 2008, Rush 2008, Jones et al 2009, Agnew and Duffy 2010, Schneebeli 2010,Skilton 2011, Thomson and Hilton 2011)
- assessing (Frisby 2001, Advocacy in Action 2006, Horacek 2006, Lazarus 2007, Reinders et al 2010, Stickley et al 2010, Skilton 2011, Stickley et al 2011)
- the development of learning tools and approaches (McAndrew and Samociuk 2003, Brown and Macintosh 2006, Simpson et al 2008, Wright and Brown 2008, Agnew and Duffy 2010)
- the development of a module (Gupta and Blewett 2008), and course planning (Davis and McIntosh 2005, Lathlean et al 2006, Branfield 2007, Skinner 2010)

There are various subtle differences and nuances in the classroom activities. For example, in the role of 'teaching' some service users are employed as service user academics (Happell and Roper 2002, Happell et al 2003, Happell and Roper 2003), others 'participate' in classroom teaching (e.g. Costello and Horner 2009) sometimes supported by a moderator (Haeney et al 2007). Some service users are interviewed in the classroom to share their experiences (Agnew and Duffy 2010) others are used as facilitators of learning, acting as 'storytellers' sharing journeys (Cooper and Spencer-Dawe 2006, Thomson and Hilton 2011) . Other interesting innovations in the classroom include the use of DVDs (e.g. Agnew and Duffy 2010) and video clips (Brown and Macintosh 2006) which include the stories of service users, service user written problem-based learning scenarios (Wright and Brown 2008) and on-line discussion forums (Simpson et al 2008).

It is important to exercise caution when considering the literature reviewed here. SUI can find expression via a variety of initiatives, from the recruitment of students through to systematic involvement in the design, delivery and evaluation of courses. Many of the benefits, barriers and facilitators apply across all of these activities but some may be specific to the type of involvement. Where the benefit may, we think, be related to a specific type of activity we make reference to that activity. Secondly, service users and carers are often grouped together and, as Fadden et al (2005) remind us, these groups are quite different and may have different issues. Given the diversity of professions covered by this review, and the fact that there is a dearth of literature on

those professions regulated by HPC, then caution is required when drawing conclusions and applying them to HPC regulated professions. What follows is a series of issues which are broadly applicable to all groups, although there may be subtle differences/nuances, associated with the particular client group or profession; where possible, reference has been made to these differences.

This review has highlighted some of the issues associated with SUI, in particular the benefits, barriers and facilitators. The literature review also identified a theoretical framework to underpin the project, the content for the matrix, and questions for inclusion in the online questionnaire, and development of the interview schedules for both the individual interviews and focus groups.

2.2 Benefits of SUI

The benefits of involving service users in the design and delivery of education can be considered in terms of benefits to service users, and to the education of students with much overlap across and between. For example, gaining insight into the service user experience, while clearly beneficial for the education of students, also has potential benefit to service users in that it potentially makes for a more empathic professional. It is worth noting that these benefits are 'perceived' benefits from the perspective of service users, students and/or academic staff; there has been no research that has assessed students' performance post qualification.

2.2.1 Benefits to service users

With the exception of the large scale consultation undertaken by Branfield (2009) and the questionnaire survey by Haffling and Hakansson (2008) the studies referenced here are small scale and focussed on specific initiatives within single institutions. For example, Skinner (2010) in an evaluation of SUI with a faculty undertook interviews with five academics, one carer, an administrator and a group interview with three service users and carers.

Several authors note the general feeling of empowerment that service users get from their involvement in the delivery of education (Frisby 2001, Masters et al 2002, Happell and Roper 2003, Rees et al 2007, Skinner 2010). Service users can feel a sense of altruism (Brown and Macintosh 2006, Haffling and Hakansson 2008) and that they contribute toward student development both in terms of skills and attitudes (Costello and Horne 2001, Jones 2006, Taylor 2006, Rees et al 2007, Simpson et al 2008, Skinner 2010), being valued, listened to and respected (Costello and Horner 2001, Brown and Macintosh 2006, Jones 2006, Taylor 2006, Simpson et al 2008, Branfield 2009, Skinner 2010) and, ultimately, shaping and improving future practitioners (Happell and Roper 2003, Taylor 2006, Rees et al 2007, Branfield 2009) and service provision (Speers 2007). It gives service users the opportunity to offer their

perspective (Le Var 2002). Other benefits include increased confidence and self-esteem (Stevens and Tanner 2006, Taylor 2006) and the development of new skills (Masters et al 2002, Simpson et al 2008). Last of all, it has been suggested that involving service users in training can increase understanding of the role and perspective of professionals (Stevens and Tanner 2006, Branfield 2009).

Similar benefits can be gained from the involvement of service users in recruitment. Rhodes and Nyawata (2011) note, from interviews with four service users and carers, that service users reported feeling valued and giving candidates a 'taste of reality' (p441).

2.2.2 Benefits to the education of students

It has been suggested that having service users involved in education initiatives enables students to gain insight into the service user experience (Costello and Horne 2001, Frisby 2001, Happell and Roper 2003, Felton and Stickley 2004, Brown and Macintosh 2006, Barnes et al 2006, Stickley et al 2010) including the impact of services and professionals on service users' lives (Anghel and Roman 2009). This exposure makes the student experience 'real' (Ottewill et al 2006, Rush 2008, Wright and Brown 2008, Anghel and Ramon 2009, Agnew and Duffy 2010, Schneebeli 2010, Atkinson and Williams 2011, Skilton 2011) and bridges the theory practice gap (Cooper and Spencer-Dawe 2006, Branfield and Beresford 2007, Simpson et al 2008, Agnew and Duffy 2010, Thomson and Hilton 2011). A cautionary note, however, comes from Happell et al (2003) who note that some students felt that the consumer perspective could be presented by an experienced psychiatric nursing academic.

The involvement of service users can help challenge student assumptions and stereotyping (Happell and Roper 2003, Stevens and Tanner 2006, Taylor and Le Riche 2006, Dogra 2008, Rush 2008, Anghel and Ramon 2009, Branfield 2009, Schneebeli 2010, Thomson and Hilton 2011), providing a positive (Lathlean 2006, Simpson et al 2008) or 'normalised' (Schneebeli 2010) view of service users, help students see the diversity of service users (Ottewill et al 2006, Dogra et al 2008) and encourage students to reflect on practice (Happell and Roper 2002, Barnes et al 2006, Taylor 2006, Skilton 2011).

Some of the benefits noted above can also be seen in having service users involved in recruitment and selection, with Rhodes and Nyawata (2011) reporting that interviewees felt that the experience of being interviewed by service users gave them some hands on experience of interacting with service users.

Other authors suggest that this exposure to service users increases students' skills, in particular communication skills (Greco et al 2001, Cooper and Spencer-Dawe 2006, Rees et al 2007, Simpson et al 2008, Agnew and Duffy 2010, Jha et al 2010, Thomson and Hilton 2011), and empathy (Branfield 2009,Thomson and Hilton 2011). That said, Reinders et al (2010), in their study to assess whether an additional patient

feedback training programme led to better consultation skills in general practice trainees, found that the programme did not lead to improved skills any more than regular communication skills training.

It may be that the classroom setting provides, when compared to a clinical setting, a more safe, friendly and relaxing environment for students to learn clinical skills (Rees et al 2007, Rush 2008, Thomson and Hilton 2011). Ottewill et al (2006) suggest that it may be easier for a service user to be more open and frank about their healthcare in an educational setting when compared to a clinical setting. Rees et al (2007) found that students also talked about how exposure to service users in the classroom helped them develop their own professional identity, determining 'how they should act and feel as professionals' (p375).

The issue of 'power' may also play a part in that a role reversal occurs in the classroom so that service users become the experts, and students accept this role, thus facilitating acceptance of the empowered service user (Rush 2008, Schneebeli 2010). A useful distinction was made in the Dogra et al (2008) research between 'expert professional' and 'expert patient'; the implication is that service users may not always have the qualifications and credibility for the former but they could bring something to the classroom as experts in terms of their experiences. Building on this theme of 'expert patient', Ottewill et al (2006) note that there are four key reasons for the involvement of expert patients in teaching in the classroom. Firstly, it provides an opportunity for the students to interact with recipients of a service outside of the clinical setting, providing an opportunity for less constrained engagement. Secondly, adverse comments tend to be made in terms of the profession as a whole rather than against individuals. Thirdly, students can explore the psychosocial aspects of care rather than just the body or condition of the person. Lastly, it enables students to combine concrete experience with reflective observation.

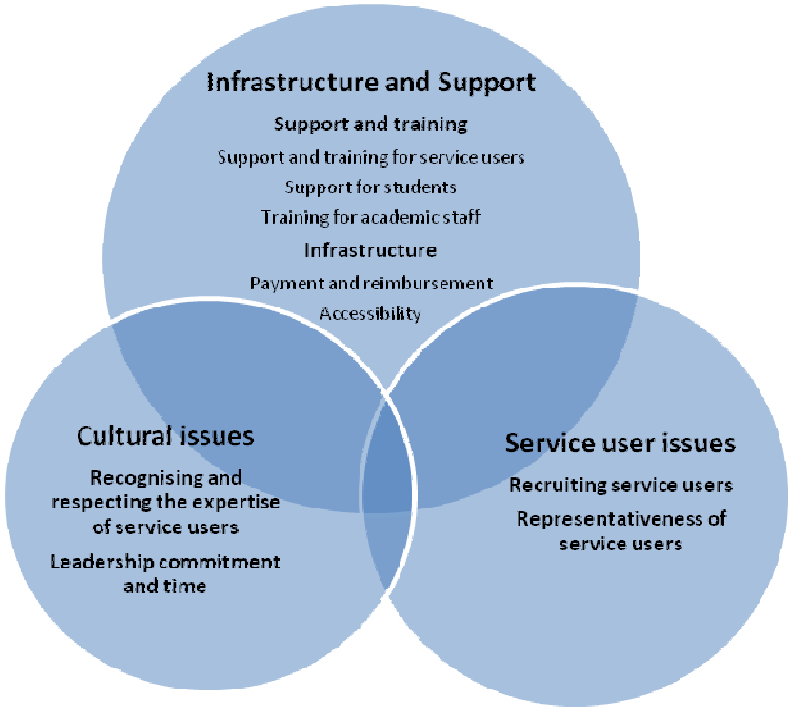
2.3 Facilitators and Barriers

Barriers and facilitators to SUI can be regarded as opposite sides of the same coin. For example, the issue of 'adequate payment and reimbursement mechanisms for service users' can be both a barrier, in that its absence may inhibit involving service users, and a facilitator in that the existence of such mechanisms could be regarded as a factor that enables SUI. In effect, both barriers and facilitators are challenges in that they must be either overcome or achieved. As such, they can be considered together.

Successfully involving service users requires a combination of infrastructure and support services, cultural changes and consideration of various service user issues such as the representativeness of service users. These categories are not mutually exclusive, but rather are closely interrelated, for example, a change in culture could lead to a change in infrastructure and support. Figure 2 below identifies the key issues from the literature.

Figure 2

Facilitators and barriers



Each of these categories, and sub categories, is explored in further detail in the sections which follow.

2.3.1 Infrastructure and support

Effective SUI means that organisations must have the necessary support infrastructure in place with some compatibility between the systems and processes of the organisation and the requirements of service users. Additionally, support and training for academic staff, students and service users should be provided.

2.3.1.1 Support and training

Support and training is a key theme and applies to the three key groups of service users, students and teaching staff.

Support and training for service users

Some studies raised concerns about the skills or abilities of service users (Vijayakrishnan et al 2006), others highlighted the need for support and training (e.g. Branfield 2009). This concern did not emerge just from staff and students; Masters et al (2002) found that service users themselves were concerned about their 'lack of expertise' in the design and delivery of a curriculum, while Rhodes and Nyawata (2011) noted that service users involved in recruitment wanted better preparation. Branfield's (2009) was the only work drawing on data beyond a single institution. However, some of the other studies did include relatively large numbers of respondents via questionnaire surveys. Vijaykrishnan et al (2006) undertook a survey of 52 trainees, while Rhodes and Nyawata (201) included responses from 80 nursing candidates.

Sometimes this perceived lack of expertise can lead to doubts about how and whether service users can be involved in the provision of education. Happell et al (2003) using a pre and post test design found that following the involvement of a service user in teaching fewer respondents disagreed with the statement 'Consumers do not understand the language and complexities of mental health services, which makes it difficult for them to have meaningful input'. Rees et al (2007) noted that some students questioned the expertise of service users in assessing the clinical skills of medical students; though service users and medical educators were both keen. Branfield (2007) suggests that if service users do not have the appropriate qualifications to be involved in training then there is a concern that any user involvement may not be valued and become tokenistic.

As well as ensuring that service users have the practical skills to be involved it may be necessary to ensure that they have the appropriate level of confidence (Branfield 2009).

Service users may need support because of their particular health needs. Some are vulnerable and can become unwell (Rees et al 2007, Simons et al 2007), with involvement bringing back memories of difficult, sensitive or emotional issues (Frisby

2001, Brown and Macintosh 2006) and /or lead to anxiety and distress (Frisby 2001, Felton and Stickley 2004, Atkinson and Williams 2011). There are examples where the mental health issues of service users were regarded by academic staff as a barrier to their participation in education (Felton and Stickley 2004) and by students (Stickley et al 2010) as negating the value of their contribution to the assessment of students. These studies were small scale and focussed on initiatives in single education institutions.

The issue of the rebalancing of power has been referred to earlier in very positive terms, helping the students to improve their practice. Skilton (2011), however, notes that the issue of power can also be a barrier, which needs to be overcome. In relation to the provision of feedback, Skilton (2011) suggests that, historically service users of social work have been powerless; this changes if they are to be involved in the provision of feedback to students and service users need training on how to use this 'power' effectively.

Support and training may need to come in a variety of guises before, during and after involvement. Before involvement service users may require training and/or preparation for their role (Masters et al 2002, Rees et al 2007, Rush 2008, Skilton 2011). Depending on their role, this training may be in committee procedure (Higgins et al 2011), educational systems and curriculum development (Masters et al 2002), providing feedback (Speers 2007, Jha et al 2010, Stickley et al 2010, Stickley et al 2011, Skilton 2011), challenging students (Barnes et al 2006), working with co-facilitators (Cooper and Spencer-Dawe 2006), presentation skills (Barnes et al 2006), and/or teaching (Rush 2008), and interviewing (Anghel and Ramon 2009).

In recognition of the need for training, Hanson and Mitchell (2001) report on a course designed to prepare mental health service users for work in the classroom. As well as training they may require some form of briefing (Rees et al 2007, Anghel and Ramon 2009) or guidance (Ottewill et al 2006) in preparation for their role. Also acknowledged was that service users may need support during and/or after, involvement. This could take the form of guidance (about how much, and which aspects of their lives, they should share in the classroom) (Dogra et al 2008), debriefing (Frisby 2001, Rees et al 2007, Anghel and Ramon 2009), mentor and/or peer group support (Higgins et al 2011), pairing service users with an experienced member of staff to ensure consistency in teaching (Barnes et al 2006) and finding time to reflect on their input (Frisby 2001). The Ottewill (2006) and Rees et al (2007) studies were small scale explorations while the Barnes et al (2006), Anghel and Ramon (2009), Higgins et al (2011) research, involved larger numbers of respondents via use of questionnaires.

Additionally, service users will need on-going support in the form of help with administrative tasks, for example students' names, room allocation and navigation of buildings (Cooper and Spencer-Dawe 2006).

Support for students

Students may also require support particularly with regard to receiving feedback from service users (Speers 2007, Stickley et al 2010), where they can feel vulnerable and powerless (Stickley et al 2010), potentially demoralised (Speers 2007) and get anxious and upset (Rees et al 2007). Clearly, the involvement of service users presents a challenge for students. For example, Happell and Roper (2003) report that, when asked 'what was the worst thing about being taught by a consumer academic?' nine out of 21 students reported the 'negative portrayal of psychiatric nursing' and that service users had not recognised the factors that impact upon staff.

Students can also feel inhibited by service users. Costello and Horne (2011) found that the presence of patients in the classroom can have an inhibiting effect on students (albeit a minority of students), as students can feel embarrassed and uneasy about, for example, asking service users about terminal care aspects of their illness or questions about their sexuality. Similarly, in relation to SUI in recruitment, some interviewees were concerned that the service users were vulnerable and could become distressed by questions of a personal nature.

As noted, sometimes there can be tension in the classroom between service users and students. There are examples in the literature of academic staff playing a role here. It may be that lecturers could play a mediation role to minimise this tension (Anghel and Roman 2009). Similarly, Thomson and Hilton (2011) reported that students appreciated the role that clinicians played in the classroom helping to mentor them in their interactions with service users. In terms of the provision of feedback Speers (2008) suggest that a mentor or advocate can play a role in filtering feedback from service users, so that it was balanced and constructive. Furthermore a mentor could help students reflect on this feedback.

Training for academic staff

As well as support and training for service users and students, staff may also require training in how to carry out SUI generally (Masters et al 2002, Branfield and Beresford 2007, Anghel and Roman 2009). For example, Masters et al (2002) found that academic staff were concerned that their lack of skills in involving service users would mean that they may only involve service users in a tokenistic way, while Anghel and Roman (2009) found that practice teachers wanted training and more guidance from the university. Costello and Horne (2001) found, in relation to supporting service users in classroom teaching, that the success of the exercise depended, at least in part, on the teachers' facilitation skills in the classroom. Other suggestions were that training in equality may help to address any cultural barriers as some institutions and staff have a 'patronising attitude and culture' (Branfield 2007, p8).

Fadden et al (2006) in their opinion piece on involving service users in the training of psychiatrists advocate advanced planning by academic staff with service users and students to prepare them for the issues raised here.

When involving service users there are a range of interrelated support and training issues for service users, students and academic staff. The evaluation by Anghel and Roman (2009) resulted in the development of a Protocol and Ethics document which included 'guidelines on preparation, involvement on the day, debriefing, and ethical aspects related to access and support' (p196) for students and service users.

2.3.1.2 Infrastructure

Successful SUI also requires a commitment from the wider organisation in terms of the processes and procedures for payment and reimbursement, thus helping to ensure a smooth route for recruitment and accessibility to venues and facilities.

Payment and reimbursement

Several authors noted that involving service users requires a budget for payment (Stevens and Tanner 2006, Haeney et al 2007, Rhodes and Nyawata 2011) and even where these were in place problems could still arise due to bureaucratic payment systems (McKeown et al 2010). Four aspects surrounding payment were identified:

- Ensuring that service users are paid and that this payment is fair (Rees et al 2007, Gupta and Blewett 2008, Higgins et al 2011)
- Payment for those service users who do not have a bank account (Gutteridge and Dobbins 2009)
- Developing a payment system so that payment does not negatively impact on benefits (Masters et al 2002, Allain et al 2006, Branfield 2007, 2009, Dogra et al 2008)
- Slowness of payment or reimbursement (Branfield 2009, Skinner 2010)

Masters et al (2002) in their research note that, as a result of these issues, the university paid service users at lecturer rates to the service users' and carers' organisations, rather than to individual service users.

It can also be important to value and acknowledge the role of service users in ways other than payment, for example a letter of thanks and/or a certificate (Stevens and Tanner 2006).

Accessibility

Some articles suggested that, due consideration needs to be given to accessibility for service users. Four issues can be identified:

- Getting to and from the venue (Costello and Horne 2001, Allain et al 2006, Stevens and Tanner 2006, Branfield 2009)
- The accessibility of a venue itself, for example wheelchair accessibility and physical barriers such as heavy fire doors , security systems and inappropriate seating (Branfield 2007, 2009)
- The timing of meetings/events can help or hinder accessibility (Allain et al 2006, Branfield 2009)
- Ensuring that information presented to, and verbal interactions with, service users (Allain et al 2006, Basset et al 2006, Monrouxe et al 2006, Branfield 2009, McKeown 2010) does not contain 'jargon' as this can make the course or interaction inaccessible to service users.

2.3.1.3 Cultural issues

It is not just processes and procedures that help facilitate SUI. The culture of an organisation is also important in terms of being both a barrier and facilitator. The extent to which culture change is necessary depends upon the level of integration, engagement and participation of SUI being sought. For example, the greater the level of integration, engagement and participation then the more emphasis must be placed on a leadership commitment on the part of the organisation.

Recognising and respecting the expertise of service users

Negative attitudes of students and staff (Branfield 2009) sometimes need to be addressed to facilitate SUI. Teachers can feel threatened if they perceive the role of the service user to be usurping their role be it in the classroom (Felton and Stickley 2004, Simons et al 2007) or recruitment (Rhodes and Nyawata 2011) and put up 'professional' barriers (Branfield 2007). Resistance can also occur if teachers doubt the expertise and credibility of the service users (Branfield 2007, Dogra et al 2008). It is important then that staff respect the role and listen to the views (Higgins 2011) of service users.

An example of this need for a cultural shift comes from Anghel and Roman (2009) who note, in their review of a social work course, that service users were not involved in marking assignments as they were not deemed as 'sufficiently qualified' (p189). However, it is argued here that some level of training and expertise is required to mark assessments and so alongside any cultural shift on the part of staff and students there may also need to be some support and training for service users.

Similarly, students also need to respect service users (Branfield 2007), for example in their teaching role and the feedback they provide (Haffling and Hakansson 2008).

Explanation for resistance to greater user involvement in education may lie in the 'medical model' approach of some professions. Felton and Stickley (2004) noting the resistance of some lecturers to the involvement of people with mental health problems in education, suggest that this reflects a medical model view of health care and nurse education. Professionals have the power to define those with mental health problems as lacking in the necessary competence for certain roles. Clearly, such an interpretation could also be applied to other scenarios such as students' resistance to receipt of feedback from service users. The role of the 'consumer academic' articulated by Happell and Roper (2003) can be viewed as a direct challenge to this 'medical model'. The consumer academic position was established at the centre for Psychiatric Nursing Research and Practice within the School of Postgraduate Nursing at the University of Melbourne. The person in this role participates in all aspects of the Centre's activities, including the education and training of psychiatric nurses at postgraduate level. Integrated across the course, rather than teaching in isolated sections of the course, the consumer academic ensured that students were exposed to the consumer perspective, as well as the medical model, on a weekly basis.

Leadership, commitment and time

Satisfactory and effective SUI can be resource intensive, and requires leadership, commitment, resources and effective support systems.

There are numerous examples in the literature of the resource issues which need to be addressed. Successful user involvement can place demands on staff time in a number of areas, including the provision of support for service users (Rush and Barker 2006), the 'time' to develop a relationship with potential service users prior to and during their involvement to develop trust (Downe 2007, Jones et al 2009), time for training, briefing and debriefing (Rees et al 2007) and time to attend meetings and other events (Lathlean et al 2006). Skinner (2010) notes that SUI champions were required to take on the role on top of their existing workload. Collier and Stickley (2010) state, in relation to the continuous development and support of service users as facilitators, 'ongoing and sustainable funding' is required (p9), while Taylor and Le Riche (2006) conclude, the resource intensive nature of SUI can lead to tokenism rather than genuine involvement.

Stevens and Tanner (2006) remind us that user involvement requires a cultural change that affects not only academic staff. They suggest that there needs to be a willingness from intermediary staff, such as managers and administrators, to overcome administrative procedures, for example payment difficulties. Indeed, the example of overcoming payment difficulties demonstrates how the culture and infrastructure are interrelated rather than separate entities.

Advocacy in Action (2006) highlight how difficult it can be to effect change in universities in the first instance. In relation to the introduction of a service user led assessment they note that university staff need to both accept the legitimacy of the changes and accommodate the revised processes and systems.

Even when change has been achieved, 'constant vigilance' is required to guard against, for example, floundering organisational commitment, changes in funding priorities and SUI 'champions' leaving (Lathlean et al 2006, p736).

2.3.1.4 Service user issues

Two key issues were identified:

- Recruiting service users
- Representativeness of service users

Recruiting service users

Gaining access to service users can be difficult (McKeown et al 2010). Rees et al (2007) advocate the use of clear and ethical policies regarding selection and recruitment. Clearly, the informed consent of service users (Repper and Breeze 2007) and the opportunity to withdraw (Costello and Horne 2001, Cooper and Spencer-Dawe 2006, Speers 2007) are required if they are to be involved in the design and/or delivery of education and training.

Several suggestions are offered for the successful recruitment of service users and include using existing groups of service users (Jha et al 20010), gaining access to local networks, service user and carer organisations (Branfield et al 2007, Gutteridge and Dobbins 2009) and advertising in newspapers and/or posters (Jha et al 2010). Frisby et al (2001) suggest that allowing service user groups to choose appropriate service users is one way of addressing concerns that service users may become distressed. McAndrew and Samociuk (2003) suggest that to overcome tokenism it is useful to establish a group of service users and have their involvement over a prolonged period of time.

Several articles note the need for clarity about roles and responsibilities of service users (Cooper and Spencer-Dawe 2006, Stevens and Tanner 2006, Simons et al 2007), the purpose of their role (Cooper and Spencer-Dawe 2006, Dogra et al 2008) and/or guidance (Ottewill 2006). This clarity may come in the form of briefing for service users for their role (Anghel and Roman 2009, Skilton 2011). Clarity could also extend to a job description (McAndrew and Samociuk 2003) and conditions of service and payment (Frisby 2011).

Representativeness of service users

Several papers raised the issue of the representativeness of the service users involved in education and training. Concerns included the lack of diversity of service users (McAndrew and Samociuk 2003, Cooper and Spencer-Dawe 2006, Skinner 2010), how the service users were selected (Masters et al 2002), the likelihood of students developing a stereotyped view of service users as educated and articulate (Rees et al 2007), that service users become 'professionalised' and distant from their experiences (Felton and Stickley 2004) and that service users will pursue their individual point of view (Felton and Stickley 2004, Stevens and Tanner 2006). Branfield (2009) reported on the views of service users and noted that there was a view that it was important to involve service users from a diverse range of people.

Clearly, when considering the involvement of service users from a range of backgrounds some may be hard to access and extra resources may be required in engaging with these groups, for example translation costs (Gupta and Blewett 2008).

2.4 Conclusion

This chapter has identified three sources behind the drivers to greater SUI: service users and public, the professions and Government policy.

Three types of continuum have been identified which can be used as analytical tools for assessing the levels of integration of SUI, the levels of engagement and the levels of participation.

A review of the literature reveals that research studies investigating SUI in education and training tend to be small scale studies focussing on developments within the classroom. Aside from some notable exceptions, SUI tends to be piecemeal, passive and involves little in the way of shifting power in decision-making to service users.

There are a range of perceived benefits to involving service users in the design and delivery of education including benefits for service users as well as for the education of students.

Considering facilitators and barriers together, three interrelated, key categories have been identified: infrastructure and support, cultural issues and service user issues. Infrastructure and support includes support and training for service users, students and staff as well as payment and reimbursement and accessibility issues. Cultural issues include recognising and respecting the expertise of service users and leadership, commitment and time. Service user issues include recruitment issues and the representativeness of service users.

In short, dealing with these various organisational and cultural issues is essential to facilitate meaningful user involvement.

The literature review also highlighted a relevant theoretical framework to underpin the study namely Lewin's Force Field analysis (1951). Lewin, a social psychologist began his original work in the 1940s yet his framework continues to be used extensively today. It has professional credibility and is utilised across a range of disciplines at both corporate and personal levels, where change is occurring. The framework is based on the premise that forces – persons, cultures and organisations both drive and restrain change; it suggests that for change to occur the driving forces must outweigh the restraining forces. Additionally, the framework accepts organisations as systems, in which the present situation is not static but rather a dynamic balance or equilibrium of forces pulling in opposite directions. For change to take place the facilitating forces must outweigh the restraining forces hence altering the balance of power. What has been highlighted throughout this literature review is the tension between the drivers for greater SUI on the one hand and the barriers on the other. The facilitating factors will act as the catalysts to support greater movement of the drivers in order to overcome the barriers or reduce the barriers so resistance to change is reduced hence shifting the balance of power. The tensions surrounding SUI in the design and delivery of education and training together with the implications will be considered in chapter five.

Chapter 3: Methodology

3.1 Introduction

The study was conducted in four interdependent stages, employing a mixed method approach utilising both qualitative and quantitative methods of data collection. Following the literature review, and building on the theoretical framework a matrix of benefits and barriers to, and facilitators of SUI was developed. This theoretical framework and matrix was used in stage 3 to inform the development of an on-line questionnaire and the key elements for discussion in the focus groups and individual interviews as part of the three case studies.

3.2 Stage 2 Development of a matrix of benefits and barriers to, and facilitators of, SUI to inform stage 3

A literature review, as presented in chapter two, was undertaken to identify approaches, benefits, facilitators and barriers to SUI.

The literature review considered HPC literature and the wider health and social care field of education. The intention was also to consider the grey literature on SUI. However, time demands led to a decision to focus instead on the information we had already gathered.

The outcomes from the literature review were used to guide the development of a matrix of benefits and facilitators and barriers for use in stage 3. The matrix can be regarded as part of the process of developing the questionnaire and interview schedules for stage 3. For the matrix, the articles were summarised in terms of purpose and research methods (where appropriate), as well as any benefits and barriers to, or facilitators of, SUI that were identified. A version of the matrix can be seen in appendix B.

The matrix served two key functions (1) a means of organising, analysing and managing the data from the narrative analysis of the literature review and (2) with the inclusion of the experiential knowledge from the research team influenced the nature and scope of the questions for inclusion in the on-line questionnaire as well as the key areas for exploration as part of the case studies.

3.3 Stage 3 Two concurrent phases; an on-line questionnaire survey and case studies

3.3.1 On–line questionnaire survey

As already outlined a questionnaire was developed using the material from a range of sources. It consisted of 12 questions of varying types including open, closed and free text questions as well as Likert type responses and covered a wide range of topics including the benefits of SUI, facilitators and barriers. It also included questions on respondents' views on SETS and the key challenges faced when seeking to involve service users in education and training.

Although not formally piloted the questionnaire was reviewed by both the advisory board and steering committee, the membership of which was multi-professional and included both academic staff and service users.

The questionnaire was distributed, via Lime Survey software, by the HPC to programme leaders of all programmes approved by the HPC. LimeSurvey is a highly effective method of reaching large numbers of participants is quick, cost effective and not overly labour intensive.

The questionnaire was distributed, with a covering letter from HPC, to all programme leaders on the HPC database. The request was for programme leaders 'or an appropriate person' to complete and return the questionnaire. The original intention was to survey 50% of the programme leaders; however, given the minimal amount of additional work involved in the analysis it was decided that the questionnaire would be sent to a full census of programme leaders.

A follow up process was built into the study design so that three reminder emails were forwarded by HPC; one after two weeks of the questionnaire being sent, and a second and third reminder at weekly intervals thereafter.

3.3.1.1 Data collection and analysis

Upon receipt of the returned questionnaires via LimeSurvey the data were entered into an Excel spread sheet. Excel was used to assist analysis of the closed questions. Data collected via open questions were manually coded using a modified grounded theory approach. The codes tended to be substantive or conceptual rather than descriptive (Glaser 1978). Because we were clear about our research questions and relatively clear about the themes and issues to be explored (for example, identifying benefits, barriers and facilitators of SUI) we were not seeking the emergence of a research question or issue; we did not therefore need to fracture the data by using descriptive labels and regroup into broader categories to enable us to develop a new theory. In determining codes, incidents in the data were constantly compared to

ensure that the incidents in the data were allocated the correct code. Following the coding, a second researcher checked the themes identified against the data to ensure credibility and trustworthiness. (Quinn-Patton 2002)

3.3.2 Case Studies

Case study methodology focuses on the circumstances, dynamics and complexities of a single case or small number of cases (Bowling 2002) and employs a range of data collection methods (Yin 2008). This study is exploring a complex issue therefore a case study design was appropriate as it would a) help us explore in greater depth, (in comparison to the questionnaire), the issues of benefits, barriers and facilitators to SUI and b) enable us to investigate how meaningful or tokenistic service user involvement was in the design and delivery of education and training.

Using the matrix developed at stage 2 as the guiding template three case studies were undertaken based within higher education institutions (HEIs). Within each HEI one profession was selected i.e. three professions in total. The intention was to undertake three separate focus groups with staff, students and service users within each of the three institutions. Programme leaders were to be interviewed separately so as to be sure that their presence did not influence the responses of other academic staff.

3.3.2.1 Selection and recruitment

The case study sites chosen were chosen for the following reasons:

a) a substantial number of the professions covered by the HPC were included in the programmes offered by the education institutions
b) the relative close proximity of the three sites would ease the burden of data collection in a project with a very tight timescale

One profession was chosen for each site; radiographers, dietitians and art, music and drama therapists. It is recognised that radiographers include two groups of professionals with aspects of the course common to both (diagnostic radiographers and therapeutic radiographers) and art, music and drama therapists are three separate groups with common aspects. Given the similarities and the small number of teaching staff and students it was considered appropriate to include both types of radiography courses and all three types of therapy courses. Initially, programme leaders were identified and approached by members of the advisory board. Once the programme leaders had been contacted and were willing to participate the researcher contacted them by telephone where the purpose of the research was explained. Individuals were then asked a) for permission to use the site for a case study in the research and b) for their help in identifying students, teaching staff and service users. They were also forwarded information about the research (separate information sheets

were developed for staff, students and service users) and asked to forward to students, staff and service users. This task was delegated by the programme leader to a member of the academic team.

Some adaptations had to be made to this plan. First, there were problems with getting access to service users. Two of the programmes did not include service users in the classroom and so it was not possible to undertake interviews with service users. Of these two programmes, one included interviews and commentary with service users downloadable from various websites, while the other had previously included users in the classroom but had not done so recently. The third programme did involve service users in the classroom but the service users only came to the University at a specific part of the programme (which was not when data were being collected). The programme leader was of the opinion that, given the illness and vulnerability of the service users and the distance they would have to travel, it would not be appropriate to ask them to attend the University for a focus group. The programme leader also rejected the suggestions of a researcher travelling to meet service users in a place of their choosing and/or a researcher undertaking telephone interviews; again, this rejection was motivated by a concern for the welfare of the service users.

Clearly, in research that is considering SUI it is crucial that the service user perspective is included and so an alternative approach was sought. A member of the steering committee with responsibility for liaising with service users involved in education and training at one of the study sites was able to recruit a sufficient number of service users for two focus groups. Some of these service users were involved in education and training programmes, notably social work. Although not one of the intended target groups for this study, social work is still highly relevant, given that from August 2012 the HPC is due to become responsible for the regulation of social workers in England.

A second issue was the interviewing of programme leaders separately from other academic staff. Time demands meant that although this was desirable it wasn't possible to achieve in two of the three instances. Last of all, there was one occasion when a student turned up late for a focus group and so was interviewed separately.

Krueger (1994) suggests that a focus group typically involves between seven and 10 people, while Frey and Fontana (1993) suggest between eight and 10. Some focus groups in this study involved fewer participants. The difficulty with recruiting service users has already been noted. Sometimes, as with teaching staff, the small numbers reflected the small number of teachers on a course. In terms of students the small number on some courses and the fact that many students were revising for upcoming examinations were likely key factors for the low numbers in one of the focus groups.

Table 1 provides a list of details of participants from the various programmes:

Group	Data collected
Service users	Two focus groups: Service users, FG1 n=6 Service users, FG2 n=7
Staff	Three focus groups and one individual interview: Staff, FG1 n=12 Staff, FG2 n=4 Staff, FG3 n=4 Interview with programme leader n=1
Students	Three focus groups and one individual interview: Students, FG1 n=8 Students, FG2 n=2 Students, FG3 n=8 Interview with student n=1

3.3.2.2 Data collection and analysis

Some of the advantages of the focus group method are that it enables the inclusion of a larger number of people than would be possible by interviews alone. The larger group may mean that participants feel more supported and empowered than with an individual interview (Sim 2008). This latter point may be particularly pertinent to service users. In addition, focus groups can be particularly useful when seeking to explore and clarify views and concepts (Sim 1998).

The intention was that there would be two researchers involved in the data collection for all focus groups; a full time researcher to lead the focus group with a service user researcher to co-facilitate, take notes and ensure that all of the key issues were covered. However, the service user researcher was working part-time and unable to attend all of the interviews. The full-time researcher was present at all of the interviews while the service user researcher helped facilitate two focus groups; staff from art, music and drama therapy programmes and students from both music and art therapy programmes.

All of the focus groups were between 25 minutes and one hour long. Data collected via the interviews and focus groups were tape recorded and complemented with written notes; the latter protects against the effects of machine failure and enables the researcher to note non-verbal interaction and cues (Krueger and Casey 2000).

The original intention was to use a data management software package such as NVIVO to assist thematic analysis of the data. However, the writing up of the literature review and questionnaire data was well advanced by the time the focus groups were completed and transcribed. After replaying the first three interviews it was clear that few new issues emerged. To be sure of this a thematic analysis was undertaken of the transcripts, which involved a researcher coding, by hand, data from the first three

interviews to identify emerging themes. That few new themes emerged from the interview data was not surprising; the same issues were being explored in both the questionnaire and interviews. A modified grounded theory approach was used to code the data. The interviews were analysed line-by-line and incidents coded (Glaser 1992). The mechanics of the line-by-line analysis was based on the work of Corbin (1986), who suggests leaving a margin on the right hand side of the transcribed interview to enable codes to be written next to an incident in the data. As with the coding of data in the questionnaire, the codes tended to be substantive or conceptual rather than descriptive (Glaser 1978). This coding was then reviewed by a second researcher to check for credibility and trustworthiness (Quinn-Patton 2002). The themes identified were then compared with those that emerged from the questionnaire data. As no new themes were developing a decision was taken to use the interview data to supplement the themes that had emerged following analysis of the questionnaire data.

A modified grounded theory approach was used in that as the data collection, via focus groups and interviews, progressed a deliberate attempt was made to focus on some issues which had already emerged and which required further exploration. In grounded theory terms this is referred to as 'theoretical sampling' (Glaser 1992). For example, the issue of 'representativeness' of service users was a theme from both the literature review, analysis of questionnaire data and also focus groups with staff and students. A conscious decision was made to explore this further in the focus groups with service users until 'saturation' (Glaser 1992) had been achieved i.e. no new themes were emerging.

3.4 Stage 4: Consensus workshop

Given that this study was examining a complex issue that could involve change, with implications across a range of professional groups within the higher education sector as well as the HPC itself, it was important to gain as wide an understanding of the implications and impact of such change with key stakeholders. To this end it was considered important that the final stage of data collection should attempt to gain a consensus about if the HPC should or could develop a SET in support of greater SUI and what that SET might look like. This final stage would draw upon the evidence collected via the research and involve key stakeholders.

A consensus workshop using a modified Nominal Group Technique (NGT) (Perry & Linsley, 2006) was the best approach to achieve these objectives. NGT is a decision making methodology that can be used with groups of different sizes who want to make quick decision and include the opinions of as many key stakeholders as possible (Potter et al 2004). This technique is considered a good alternative to brain storming and widely used in social science research. It is a variation of small group discussion but, because of its structured nature, helps prevent domination of the discussion by

any one person, encourages wide participation and results in a set of solutions and/or recommendations. Hence it was appropriate to our needs.

The main objectives for the workshop were to engage with key informants (including members of HPC) to:

- Discuss the findings from the earlier stages of data collection, namely the on-line survey, focus groups and individual interviews
- Consider whether a SET requiring education providers to involve service users in the design and/or delivery of HPC regulated education and training programmes would be useful
- Develop SETs as options for SUI that HPC can consider.

The format for the event was in keeping with NGT in that it was a structured session of four hours duration with open questions for consideration within groups, plenary sessions with opportunity for feedback and further discussion and culminating in a decision. Each group activity had a facilitator with a specific remit to ensure that key areas were addressed.

3.5 Service User Involvement in the study

Given the nature of the project, SUI in education and training programmes, it was necessary to actively involve service users throughout. Consequently, we included service users from a range of disciplines throughout all aspects of the study. They contributed to the development of the proposal, data collection, reviewing questionnaires and other documents and overall management of the project including membership of the steering committee and advisory board.

This approach to SUI builds on the model already in operation at the Faculty of Health and Social Care Sciences, Kingston University and St. George's University of London and the Division of Mental Health, St George's University of London, and reflects the model outlined by INVOLVE. INVOLVE suggest different levels of SUI in research, ranging from consultation, collaboration through to user control (Hanley et al 2004, Brodie et al 2009). This hierarchy of levels of involvement means that the balance of power in decision making moves closer to the service users. For this study a collaborative approach was used.

As the primary objective of this study is developing SETs for the design and delivery of SUI in education and training it is particularly important that service users are involved in the development of these standards. Such involvement will help ensure that the outcomes do not only reflect the views of professionals (Hanley et al 2004) but also those of service users. The Research Governance Framework for Health and Social Care (2003) asserts that service users should be involved in the design, conduct, and analysis and reporting of research.

3.6 Ethical approval

Since data were being collected from academic staff, students and service users the research and research instruments had to receive ethical approval from the Faculty Research Ethics Committee (FREC).

Chapter 4: Findings

4.1 Introduction

The benefits, barriers and facilitators identified via the literature review, combined with the expertise of the steering committee, informed the development of the questionnaire and the topic guides for both the focus group and individual interviews.

Firstly, the questionnaire data were analysed and these data have primarily shaped the structure of this chapter. As the focus groups and individual interviews examined many of the same topics and themes, these data have been merged with the questionnaire findings to further highlight and explain topics and themes. This approach has the added benefit of avoiding unnecessary duplication.

To help the reader distinguish between questionnaire and interview data the responses from focus groups and other interviews are in italics and double quotation marks.

The chapter begins with a description of the questionnaire respondents. This is followed by an analysis of closed questions on the benefits and facilitators of SUI in education and training. There then follows an analysis of open questions on respondents' views regarding any SETs, which would require the involvement of service users in education and training, experiences of key challenges and additional information provided by respondents. Last of all there is a section on the consensus workshop.

4.2 Questionnaire respondents

The questionnaire was distributed electronically, by the HPC, to the programme leaders of all programmes under the HPC's regulatory umbrella. The HPC approves more than 500 programmes across 15 professions. Most of the programmes are delivered by or validated by a HEI, but a small number are delivered by ambulance training centres or are awards of professional bodies. The number of approved programmes within each profession varies so that, for example, in November 2011 (when the questionnaire was distributed) there were 93 practitioner psychologist courses, 73 occupational therapist courses but only 1 clinical scientist course (HPC 2012). In total, 572 potential respondents were sent the questionnaire. However, thirty of these resulted in an address delivery failure, one respondent stated they were not responsible for any HPC registered programmes and another was a mental health nurse answering on behalf of a mental health nursing course which is not HPC approved. Therefore, the study population was 540.

An initial response rate of 210 was achieved. However, following data cleansing this was reduced to 191; 19 respondents had logged on to the questionnaire but did not answer any questions.

The final response rate was 191 out of 540 which represents 35%. However, given the points raised above the actual response rate is likely to be higher.

In three of the 15 professions, there are discrete modalities or domains of practice that respondents were asked to indicate: Arts therapists (art therapists, music therapists, drama therapists); Practitioner psychologists (clinical psychologists, counselling psychologists, educational psychologists, forensic psychologists, health psychologists, occupational psychologists, sport and exercise psychologists); Radiographers (diagnostic radiographers, therapeutic radiographers).

Figure 3 below indicates that physiotherapists (26) were the highest group of respondents followed by occupational therapists (24).There were no respondents who indicated that they were from forensic, health, occupational or sports and exercise psychology, drama therapy or orthoptics. One anomaly is that two responses were received from clinical scientists, but HPC have only one approved programme for this profession. A second anomaly is that one of the responses refers to both art therapist and biomedical scientist – two distinct professions. Given the small number of respondents within particular professional groups it is therefore impossible to do any comparative analysis across the professions.

Figure 3: Questionnaire Respondents

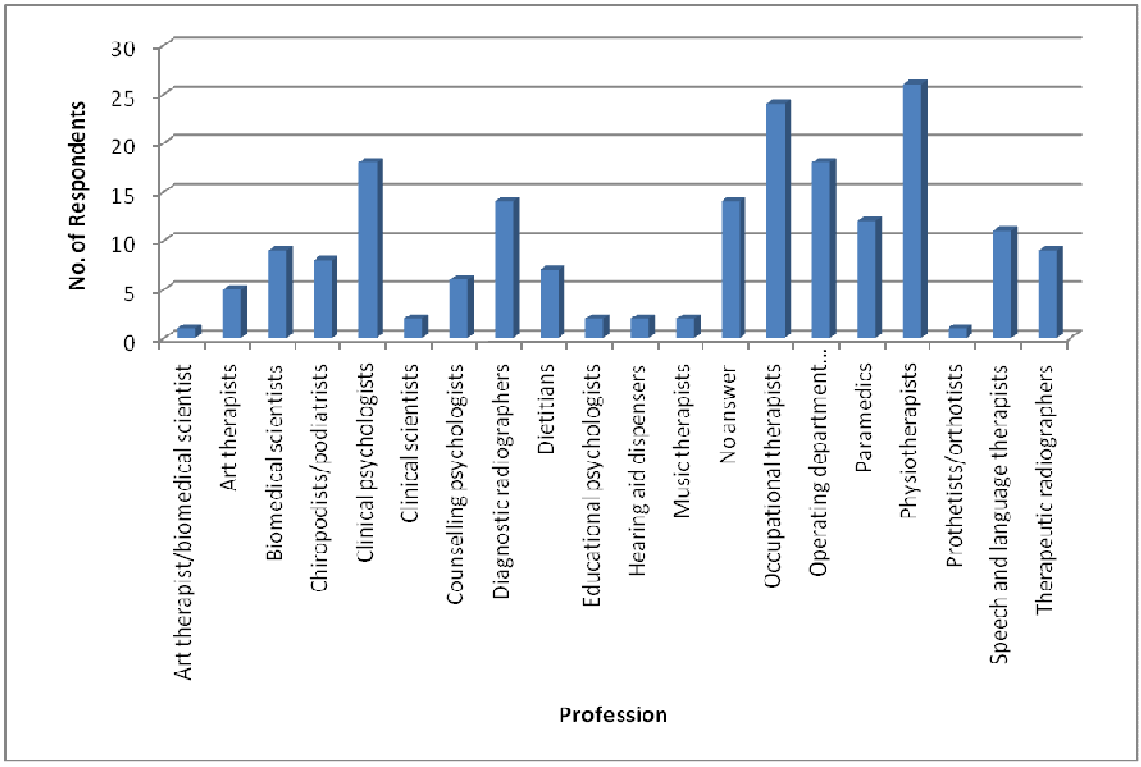


Table 2 below illustrates that the vast majority of respondents were from higher education institutions, consequently making it impossible to undertake any comparative analysis of the different types of education provider.

Table 2: Type of education provider

Education provider	Number of respondents
Higher education institution	179
Independent provider validated by a higher education institution	2
Ambulance training centre	2
Professional body	1
No answer	7

4.3 Who are service users?

Respondents were invited in an open question to indicate who they regarded as service users. From a range of responses we have identified five categories (see table 3). It is worth noting that these five groups are, in some cases, quite broad. For example, within the group 'user and public' are included those who receive a service e.g. patients and clients as well as lay people and the carers of patients and clients.

The various interpretations of service users are exemplified in the following quote from a focus group with academic staff. Members of staff were asked what they meant by 'service users':

> *"Patients. Only because we have worked with clinical psychology and they use the term service users all the time, up until that point I didn't have a clue. But they talk about service users as the patients that xxxxxxs or psychologists would see, or clients.*
>
> *It could be the employers of our students.*
>
> *It could be qualified health care professionals who are working with our students. So other xxxxxxx but also other health care professions interact with us.*
>
> *It does make you wonder that if you step one further back in that the students are using our University and our placement providers as service to a means to an end. So I guess you could look at it that it is our clients and who is benefiting from our knowledge.*

It's broader than that though isn't it? Because if you think that dietetic services are bought by other fund holders now so they are our service users. GPs."

(Staff, FG2)

Table 3: Category of service user

User and public	Service providers/employers	University staff	Students	Professional body
• patients • clients • carers • service users • user groups • lay adviser	• health care employer • placement managers • service managers • NHS stakeholders • voluntary agencies • external staff • supervisors • service providers • organisational clients • professional colleagues • managers • employers practitioners • NHS trust staff • organisational colleagues • trust partners • charities • clinicians	• colleagues • academics • lecturers • library • IT • other HEIs • teaching team		

4.4 Aspects of education and training in which service users are involved

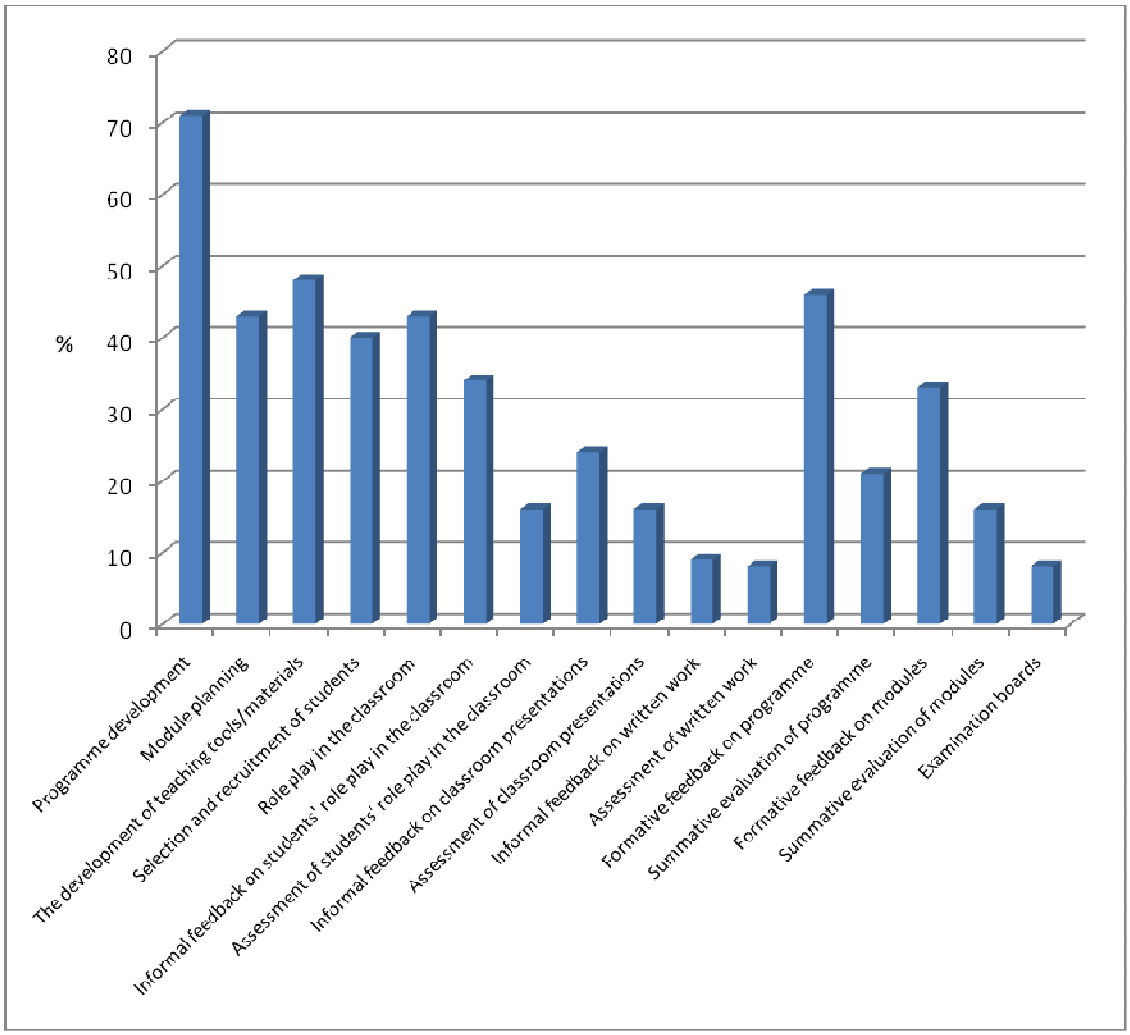
Figure 4 below shows the percentage of respondents who indicated that service users were involved in various aspects of education and training. Programme development (71%) was the aspect in which service users were most likely to be involved and is probably a reflection of broad service user groups that many universities now use to consult over the development of programmes. This was the only aspect in which over 50% of respondents indicated that service users were involved.

Some aspects referred to in figure 4 may require further explanation. Programme development is distinct from module planning as the former refers to a whole programme whereas a module refers to a particular part or parts of a programme. Involvement in module planning indicates a more piecemeal approach than involvement in the development of a whole programme. It is recognised however that the boundaries are likely to be blurred in these definitions. 'The development of teaching tools/materials' refers to service users being involved in, for example, the development of e-learning materials for students.

Where service users are involved in giving feedback in the classroom then it is likely to be informal rather than formal as part of a standardised assessment. Similarly, feedback and evaluation of modules is more likely to be summative rather than formative. With reference to the participation continuum referred to in chapter 1 this suggests that, at least in these aspects, service users are closer to the consultation stage rather than partnership or user control.

The relatively small numbers within each profession do not enable any meaningful comparison across professional groups. However, it is worth noting that all professions included service users in at least some aspects of the design and delivery of education programmes.

Figure 4: Aspects of education and training in which service users are involved

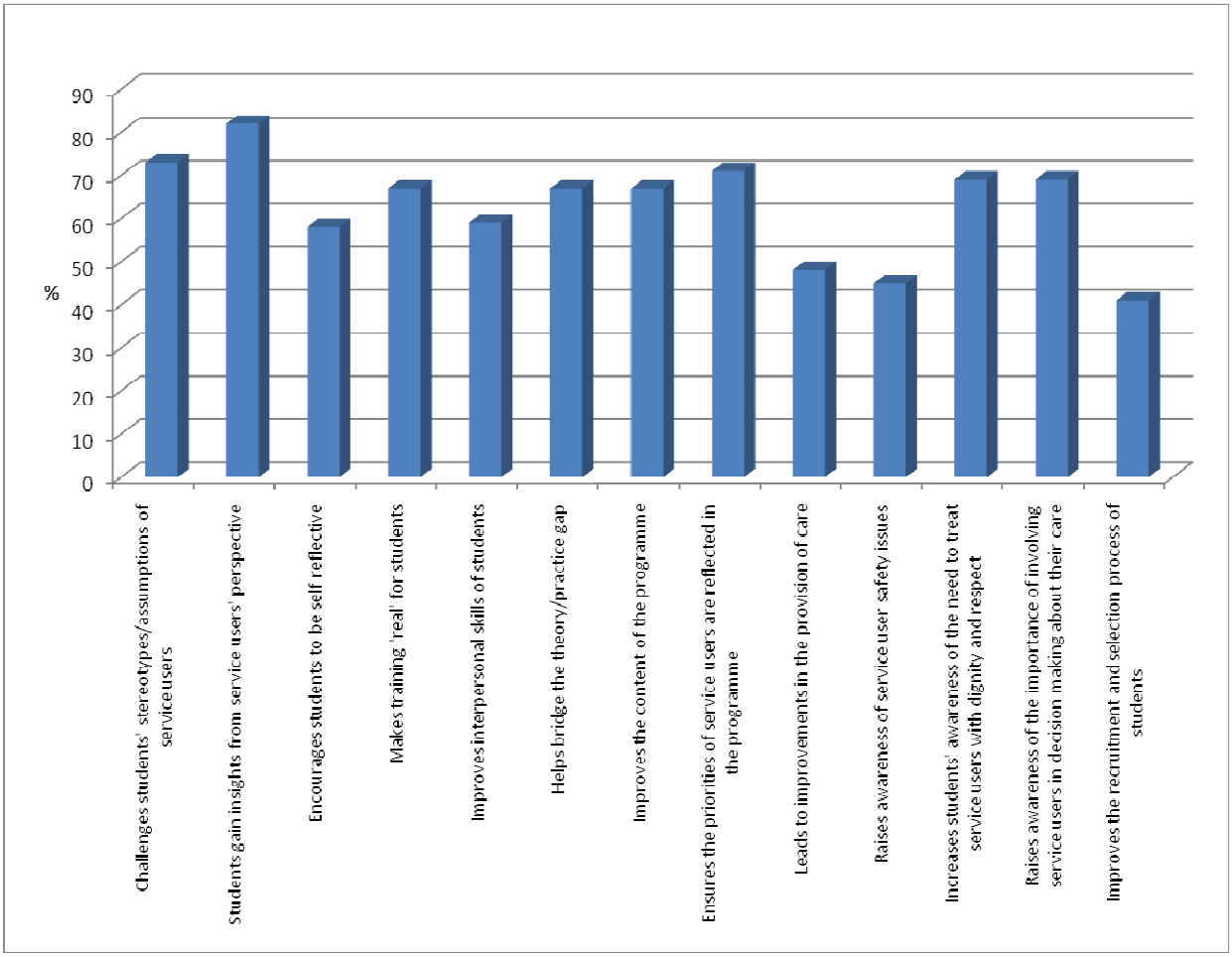


4.5 Potential benefits of Service User Involvement

Figure 5 highlights that for each of the potential benefits of SUI listed in the questionnaire, over 40% of respondents indicated that they would benefit. Indeed, with the exception of three options (improves the recruitment and selection process of students- 41%, raises awareness of service user safety issues – 45%, leads to improvements in the provision of care – 48%) 58% or more of respondents perceived the listed options to be a benefit.

Of particular note are the options 'students gain insight from service users' perspective' (82%), 'challenges students' stereotypes/assumptions of service users' (73%) and 'ensures the priorities of service users are reflected in the programme' (71%).

Figure 5: Benefits of Service User Involvement



Data from the focus group interviews with students further highlights how the interaction with service users in the classroom is perceived as making the experience more 'real' for students and leading to improvements in the provision of service. The students, in the excerpt below, were suggesting that they would benefit from the inclusion of service users, in role playing, in the classroom prior to their placement:

> *" Especially in the first year if service users do get involved before we actually go into clinical that would give us the chance to find out what position works and what doesn't, instead of someone saying to you, get a breast board out and get a patient on the bed. You're thinking 1 – what is a breast board and 2 – how do I get the patient on the bed".*

(Students, FG1)

> *"We have a virtual simulator for therapy students, which is like a doll on a bed almost. So we get to use that and move the machine around, so that's our practise. We don't get to talk we just move around the machine and positions. I had to be told on my first day (on placement) to remember to tell the patient what you are doing because you forget. Or someone gives you a pillow and says set up to the pillow but the pillow doesn't have contours on it like a patient would. When moving a patient you do have to remember, OK I don't want to smash you in the head with the machine so I need to watch out. When it's a pillow you're not really bothered because you're not going to harm the pillow."*

(Students, FG1)

Similarly, students in the focus group excerpt below highlight how having service users describe their experiences in the classroom challenges students' assumptions and stereotypes:

> *"Quite a good example was the guy who had pancreatitis, what we learn in science is however many percentage of people have chronic pancreatitis, it's involved with alcohol consumption and he felt very offended because every time he saw someone, a lot of the time they would ask him about how much he had been drinking etc and he was actually very offended by that. So that was a very good example of making sure that we leave our science to one side and base each person as they come, otherwise I might have asked him how much alcohol he had been drinking and I might have upset him."*

(Students, FG2)

The service user in the excerpt below notes how they believed their involvement in a teaching session helped raised students' awareness of the need to treat service users with dignity and respect:

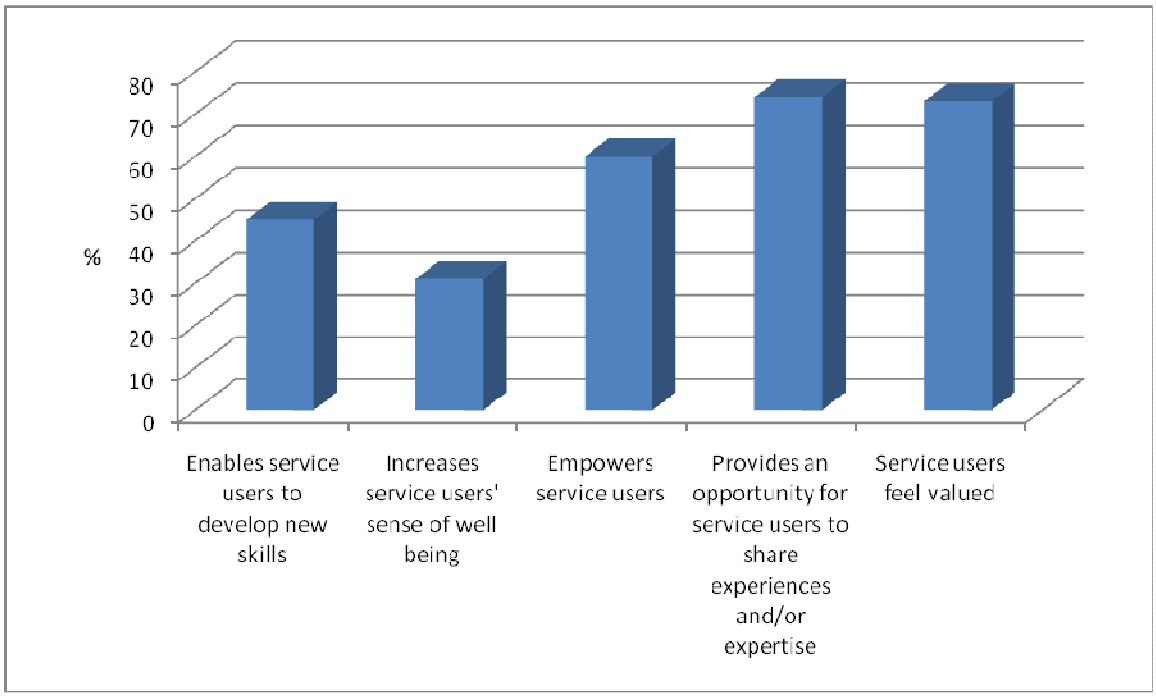
"I think it definitely was an eye opener to some of the students that we had opinions ... we are individuals, we are human beings and we like to be treated with dignity and respect. And for some of them it hit them quite hard that we weren't numbers, we are not just a case. We can understand that they might see hundreds of people but that's the first time you're on an individual basis. Please treat us as an individual and not just 'next one please' sort of thing."

(Service users, FG2)

4.6 Perceived benefits to service users

Respondents were also asked what they perceived to be the benefits to service users. Figure 6 shows that nearly three quarters of respondents believed that it 'provides an opportunity for service users to share experiences and/or expertise' (74%) and ensures that 'service users feel valued' (73%). Also suggested is that being involved helps empower service users (60%).

Figure 6: Perceived benefits to service users

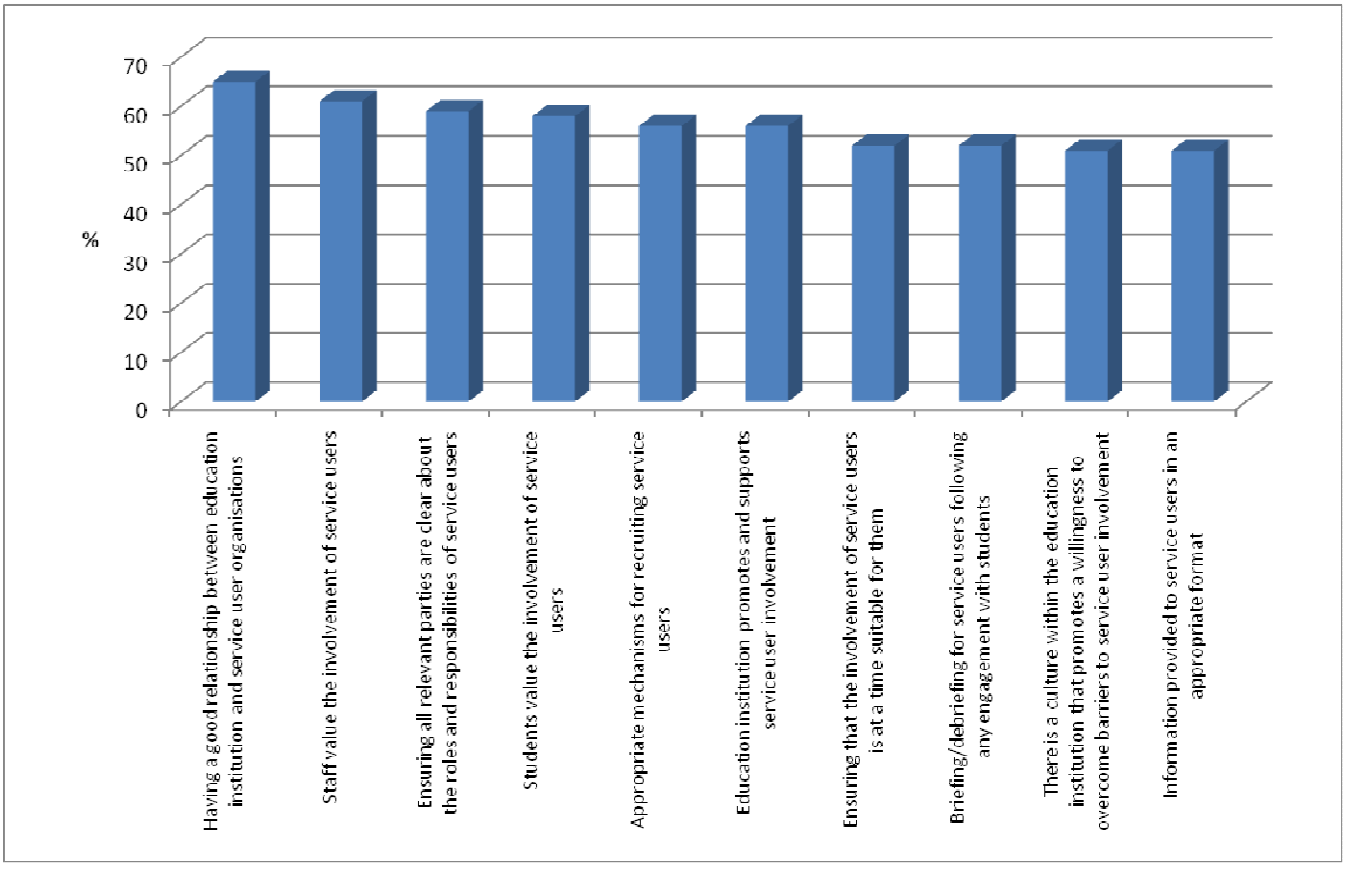


4.7 Potential facilitators of SUI

Respondents were offered a list of options of potential facilitators of SUI. Figure 7 below shows those, which over 50% of respondents believed to be facilitators. With reference to the literature review, it is clear that 'cultural issues' (staff and students valuing the involvement of service users, 'there is a culture within the education institution that promotes a willingness to overcome barriers to SUI' and 'education institution promotes and supports service user involvement'), 'support and training' (for example 'briefing/debriefing for service users following any engagement with students'), 'infrastructure' issues ('ensuring that the involvement of service users is at a time suitable for them', 'information provided to service users (is) in an appropriate format) and 'recruiting service users' issues ('appropriate mechanisms for recruiting service users', 'ensuring all relevant parties are clear about the roles and responsibilities of service users', 'having a good relationship between education institution and service user organisations') are all regarded as facilitators.

Of the remaining 15 items (see Appendix D) over a fifth of respondents indicated that each option was a facilitator.

Figure 7: Factors that facilitate Service User Involvement



4.8 Views on standards in education and training

Respondents were asked their views on what a standard, requiring SUI in the design/and or delivery of education and training approved programmes, might look like, and also whether they would be able to meet such a standard.

Table 4 outlines the key themes that emerged from the data. It is important to note that the number of respondents who referred to this theme does not necessarily indicate the level of importance attached. This was an open question and just because a respondent did not raise an issue it does not mean that they would necessarily disagree with those who did – it may simply be that they did not think of it when completing the questionnaire. The analysis is interspersed with data from the focus groups and individual interviews.

Table 4: Themes on standards in education and training

Support to opposition	Concerns about tick boxing and tokenism	Service user 'challenges'	Resource issues for education institution
•support •qualified support •opposition		•disablity/illness •lack of expertise •representativeness •demands on service user •accessing service users	

Defining service users	Design or delivery?	Scope of a standard	Rationale for SUI
		•compulsory vs recommendation •prescriptive vs broad interpretation	

4.8.1 Support to opposition

This category serves to reflect the range of views from fulsome support, through to qualified support and finally, opposition.

Many questionnaire respondents expressed support for the development of such standards. Some were unequivocal in their support, commenting for example 'HEIs should have evidence of the role of service users in the design, development and evaluation of their programmes' and 'This would be an excellent idea and in keeping with the current priorities in health and social care.' Others, however, expressed support along with caveats such as 'I think that service user involvement should be incorporated but would not be in favour of specific formats being dictated.'

While some respondents were supportive, albeit with concerns and caveats, a small number expressed a view that the development of a standard would not be a good idea. Some just did not think it a good idea without giving a reason, for example, 'I don't think this would be at all appropriate', while others proffered reasons for their concerns, which are included in the explanation of the categories below.

4.8.2 Which service users?

It has already been noted in section '4.3 Who are service users?' that a range of different categories of service users have been identified by respondents.

One questionnaire respondent suggested 'First, define who exactly are the service users of an NHS ambulance service and who from this list represents the wider population' while another noted that the definition of a service user 'could be very different in all professions'.

The following questionnaire respondent suggests that different types of service user could be involved at different stages:

> 'I struggle to see how service users (patients) can be involved in design but could provide useful input into delivery, assessment and student selection. Colleagues and Employers can input into the design however. I therefore think the SETS should be more explicit about what they consider service users to be and identify who should be involved in various aspects of the curriculum.'

Another respondent suggested a very broad definition of service user would enable them to meet a standard:

> 'I would rather the focus was on all 'stakeholders' – this would include 'students, clinical colleagues, service users etc' and therefore would require the programme to identify and list key stakeholders and then describe how they have involved and engaged them in design and delivery.'

The following excerpt, from a focus group with students, gives an insight into why it is possible to regard students as service users.

> *"I would say that while we are on the course we're service users as well because we have to see our own therapists one day a week. If that's the case then we all work with each other so we are constantly interacting with other service users."*

(Students, FG3)

However, the service user in the following focus group excerpt makes a crucial distinction between people such as the student above, who has volunteered, for a service and those who had little choice but to use a service:

> *"…there's a lot of problems that just go with that issue that you're being given something and there's no choice and that's very frustrating for any human being and that's very different from the situation you described with the xxxxxxx who volunteer, ultimately they do have a choice – we don't."*

(Service users, FG1)

As was noted earlier even within the group of service users labelled 'service users and the public' there can be both narrow and broad interpretations. This is illustrated by the following excerpts from a focus group with academic staff:

> *"I suppose in a way it is that definition that is the key issue because if that definition is that a SU is someone who has xxxx therapy as a user in say a health setting and we've always got to deliver that every year that could cause us some problems. If the definition is much broader, so it could be someone from Mind or People First or any of those campaigning organisations…"*

(Staff, FG3)

In short, the above respondent raises the issue of whether a service user has to have received a particular service to make them eligible for classification as a service user. The following quotes, from an academic and student respectively, raise a further issue in defining a service user - how recent must their experience be?

> *"I don't think anyone would want to be overloading a service user whilst they are in therapy but I couldn't see that as a concern if in 10 years time after therapy someone decides to bring their experiences to the training to inform its development. That could be an asset. So how you define service users is important."*

(Staff, FG3)

"Again we come back to the same problem of which service users would come in. Would it be people who are still using the service, or people who haven't used it for 10 years?"

(Students, FG3)

4.8.3 Service user 'challenges'

Quotation marks have been used in the title to recognise that, for some service user respondents, if the following are challenges at all, then they are challenges for education institutions and not service users. Five issues emerged from the data:

- The level of disability/illness of some service users
- The technical expertise required
- The representativeness of service users
- Demands on service users
- Recruiting service users

4.8.3.1 The level of disability/illness of some service users

There was concern amongst many respondents that the involvement of some types of service users would be very difficult. Reasons proffered were the level of disability, for example 'A high percentage of the service users with whom..... work cannot give capacity to consent. They may have autism, severe learning disability, mental health problems etc. I would firstly be concerned about their vulnerability in these kinds of situations.'

4.8.3.2 Technical expertise required

Others queried the expertise of some service users. The first quote below comes from the questionnaire and the second is an excerpt from a focus group:

'I feel that .....is a very difficult field to incorporate service users into, other than in behavioural science aspects. I feel that service users do not have the understanding of use of medical xxxx that would be required to make their input relevant to designing the scientific aspects of the course.'

"I do feel very strongly that when you are working with people who are so profoundly disabled that they don't understand words, we've got to be realistic about how we can involve them."

(Staff, FG3)

The excerpts from a focus group with service users suggests that when the 'lack of expertise' of a service user is questioned then perhaps there is a lack of understanding or appreciation of the role of the service user:

> *"…the reason we are there in the first place is to, is to, give them what it is like for us to go through this. It isn't about, this is what it felt like, if we've had radiography, say for instance then obviously we can reflect on that but basically you involve us because you want them to know what it's like to be on the other side.*

(Service users, FG1)

> *"I think it brings in that age old saying 'who feels it knows it' so the service user who is actually feeling it and experiencing it, they might not be particularly eloquent at presenting it but they can give a first class idea of the experience."*

(Service users, FG1)

4.8.3.3 The representativeness of service users

Some questionnaire respondents expressed concern regarding representativeness of the service users who would be involved: 'This would prove very difficult as service users are not representative of all service users…' The following quote highlights concerns about the development of the 'professional' patient: 'There is an issue of when does a service user become a 'professional' patient and lose their ability to represent the day to day experiences of service users?'

The following excerpt from a focus group interview with academic staff shows how the issues of service user disability level and representativeness can combine to create a barrier to involvement:

> *"You see I'm not sure thinking about the people I worked with in my career which has been mentally disordered offenders for a long time. So people who are really psychotic or people who are really disabled or with learning difficulties and challenging behaviour. I am thinking about how would that process happen. And the reason I am saying that is because I am thinking, I know I have worked in a particular area with people who are very ill or very disabled that just happens to be where my life has taken me and I can see that there are other areas of work where people would be able to look at documents and read them and think about them and process them. But would that leave us with a one sided input so if you think our work with adult learning disabilities where people can't read, none of the people that I work with can read, about 70% of them can't talk. They can't understand really complex information, how would we put it across?"*

(Staff, FG3)

However, service users gave several reasons for why representativeness was, for them, not an issue. In the first focus group excerpt the service user explains that representativeness is not the purpose of involvement; sometimes it is the service users' presence, which can change the behaviour of people:

> *"…but we're not there to be representative of service users. We don't need to be. You mentioned earlier that being there changes the way people are but even if you were at a meeting and never said anything, I mean if you never ever said anything that might be different, but if you sit at one meeting and it's the first time they know you are there and you never said anything, the conduct of the people and the way they talk about service users and their clients would be different because they have you there and you would be in their mind. So many of the things you achieve by participating don't require that you're representative. It's not like you're there as a mini referendum thing – like what do service users think about the independence of Scotland or anything."*

(Service users, FG1)

The following two quotes from focus groups with service users highlight that service users will give their own individual accounts acknowledging that covering every single experience for each individual is not possible or indeed necessary, rather, it is about capturing the general views of service users:

> *"If you have enough of a representation of service users and carers from different fields and that is the responsibility of the organisation to do that, then what you are getting are personal experiences. You can't cover every personal experience but you will have, be having, some personal experiences to be able to relate to."*

(Service users, FG1)

> *"But it's the fact that you are getting individual, idiosyncratic stories with all their peculiarities that makes it valuable. If you homogenise them all and had an 'average' case the student wouldn't then be prepared for that idiosyncrasies."*

(Service users, FG1)

There is an acknowledgement, however, that education providers should seek to include service users who have had both good and bad experiences:

> *"Making sure they have bad and good experiences because you get a lot of people with bad experiences and they just want a chance to bang the drum and although that is valuable in some ways it can be something that happened years and years and years ago so it's not necessarily as valuable. But I think people need somewhat of a balanced view."*

(Service users, FG1)

4.8.3.4 Recruiting service users

Questionnaire respondents highlighted that the recruitment of service users posed problems 'as the pool of service users who are willing to contribute is very small.' A respondent noted 'We have tried to involve service users in our last two reviews without success so I would be very angry if this prevented us from gaining approval from the HPC.'

A possible explanation for the limited pool of service users willing to participate is the issue of payment; 'Service users generally do not like to be paid as this can affect their Department of Health benefits, therefore we rely on voluntary offers to contribute to the programme.'

4.8.3.5 Demands on service users

Currently, it would appear that, in some instances the availability of service users is limited due to other competing demands. For example one person reported 'If HPC explicitly require service users in the design, it will put more pressure on the programmes to ensure that this happens, which could put more pressure on the clients.' Another respondent considered the potential detrimental impact this could have on the relationship between the education provider and service users – 'to have that extra pressure may impact negatively on relationships with service users and carers.' The following questionnaire respondent noted the time demands on patients – 'Few patients are available with the time to spare to engage as fully as necessary to take on this role.'

4.8.4 Resources issues for education institution

There was concern from some respondents to the questionnaire about the impact that any standard may have on the education providers' resources in terms of time and money.

Some respondents used the opportunity to emphasise that there is a financial squeeze on services at the moment: 'With the continuing squeeze on pathology services within the NHS it will become increasingly more difficult for service users to engage with education and training.' Others noted that HEIs would need some support to ensure that any standard could be met, for example 'I think it is a good idea, but needs to be accompanied by appropriate support to enable the HEI to implement such a standard.' Other questionnaire respondents suggested that service users may require training:

> 'It would require good training initially for the service user. We are trying to educate our students to meet the demands of a complex work force requirement based on private and voluntary sectors along with the NHS. To

have a service user that may have experience in all these areas is a challenge to find. This means that their limited experience would need supporting to contextualise the educational needs of undergraduates.'

The potential regulatory burden was referred to by one respondent: 'More regulations and a heavy handed approach will result in closure of these (already cost-ineffective) professional programmes.'

And, inevitably, some respondents noted the need to reimburse service users:

'There is also a financial implication since service users should be paid for their time as well as expenses with the option to refuse if it impacts on their benefits.'

4.8.5 Concerns about tick boxing and tokenism

Some respondents expressed concern about how meaningful any standard would be. One questionnaire respondent, with reference to the dangers of tick boxing, wrote:

'I think it's very important to involve service users, the problem is when it becomes a required standard, people might do this simply to tick the box in order to be revalidated, and this devalues the entire point of involving service users'. Another respondent noted that 'it is important to ensure that this is real involvement and not tokenistic.'

Yet another respondent made a link between tick boxing and tokenism arguing that:

'Standards can sometimes be seen like a box-ticking exercise, and I would be concerned that this would lead to even more tokenism and (ab)use of the one or two willing service users.'

The following quote suggests that service users may lack the necessary expertise and that any SET requiring SUI may result in tokenism: It 'is a very challenging thing to do and runs the risks of tokenism in design because it is a very difficult area for non-specialists to engage in a meaningful way.'

4.8.6 The rationale for SUI

A number of questionnaire respondents, although not necessarily opposed to the development of a standard for having service users involved in education, questioned the rationale of involving service users in education and training. Implicit in their remarks is the suggestion that the HPC should be clear about their reasons for, and benefits of, SUI:

'Why would involving service users in any aspect of my programme improve care delivery'

'It is not clear to me that we fully understand what the advantages of involving service users in (the) design of programmes would be'

This issue also emerged in some of the interviews. The programme leader, in an interview, articulates these concerns:

"…What are you trying to achieve? And does involving the patient, if we all had patients or clients achieve whatever it is that you are wanting to achieve? I think that is part of the problem of all of this, they don't really know what they are trying to achieve. They are just trying to obey political will from above."

(Interview with programme leader)

Similarly, the student in the next focus group excerpt queried the purpose of involving service users and what was to be gained:

"But if you are trying to empower service users, I'm not sure if that is the purpose of involving them in this or not, how will that help them, what benefit will they gain from it and in terms of the course"

(Students, FG3)

The academic below queried what expertise service users would bring that was not there already:

"But what would we be asking service users to do because that's not clear. Would it be advising with their expertise as a service user? Because in a sense the fact that we might all, or some of us be in personal therapy and therefore existing service users and bring that into the way we think and develop. It's like, what expertise are we drawing on? Would we be getting people to come in? So what is the expertise that the service user is going to be bringing?"

(Staff, FG3)

4.8.7 Design or delivery of education?

This category refers to respondents' views on what aspects of education and training it is possible to involve service users. Some questionnaire respondents were of the opinion that service users should be involved in all aspects: 'HEIs should have evidence of the role of service users in the design, development and evaluation of their programmes.'

Others were quite specific about which aspects service users could or should be involved in. Some respondents were of the view that service users should be involved in the design of a programme: 'The programme must evidence how they have implemented service user involvement in the programme design.' However, others were of the view that it would be difficult to involve service users in the design: 'I struggle to see how service users (patients) can be involved in the design but could provide useful input into delivery, assessment and student selection.'

Still others suggest that the HPC should not prescribe the aspects of education and training in which service users should be involved but instead keep it 'broad' to 'allow HEIs flexibility'. One respondent suggested the following standard, 'service users are actively involved in the design and/or delivery of the programme.'

The interview data suggests a link between the expertise of the service user and what aspects of education they can be involved in. In the excerpt below a programme leader suggests a lack of expertise means that service users would not be able to be involved in the design of the programme:

> *"We do have patients (involved), it's not a lot. We have this AD2 (module), I'm sure the others told you, where we get patients coming in and talking about what it's like to be on the receiving end, which I think is useful. But they are certainly not involved in course design and personally I don't think that is useful.*
>
> *G: What are your reasons for thinking that that wouldn't be useful?*
>
> *Because I think it is an academic course and I think it's very hard to find someone who would be able to deliver at the broad level of what is expected. Because clearly some of the people coming in if they've got renal disease what they want to know is that xxxxx know everything there is to know about renal disease but they wouldn't necessarily be able to identify other areas because they just wouldn't know."*

(Interview with programme leader)

Similarly, the programme leader suggests that this lack of expertise means that service users would also have difficulties in being involved in assessing and evaluating in the classroom:

> *"They would have to know as much as the students in order to assess them and if they are assessing in areas of strength, like evidence of practical skills and valuing and demonstrating respect and making sure people were treated with dignity was upheld then you can't do that by marking a piece of coursework, I don't think. So if you are setting a piece of coursework that is demanding knowledge, it's a very complex subject,*

the biochemistry and the physiology and by and large our course work assesses knowledge."

(Interview with programme leader)

4.8.8 Scope of a standard

There were a variety of views on the scope of any standard. These views can best be expressed by posing two sets of juxtaposing positions:

Compulsory standard vs recommendation

Prescriptive standard vs broad standard

Beginning with the former, some questionnaire respondents, although often supportive of the principle of involving service users, have reservations (for all of the reasons articulated above) about making this involvement a standard. As such some suggest that the involvement of service users 'be a recommendation but not mandatory', or 'a best practice aspiration'.

Others have suggested a standard but that it should only be implemented where possible. So, for example, one respondent suggested 'Service users should be involved in advising on design and delivery of programmes where possible and appropriate at all levels.'

Some respondents expressed views on how broad or prescriptive any standard might be: 'I think that service user involvement should be incorporated but would not be in favour of specific formats being dictated.'

On a similar note some questionnaire respondents suggest that, at least initially, any standard should be very broad before more specific requirements are attached:

> '…given the wide variety of levels of involvement across different programmes, it might be necessary to follow a similar model to that followed by the British Psychological Society, whereby standards are rather watered down initially to provide courses time to think about how to achieve involvement well in their area, before making more specific/thorough requirements.'

The academic in the following focus group excerpt notes the difficulties of developing a single standard for all of the professions:

> *"It's got to be something simple because if it is going to be an HPC standard then it has got to include all the HPC regulated professions. There is no similarity between any of the professions, well that's a bit of an exaggeration but they are so different."*

(Staff, FG2)

Others favoured something more prescriptive. The quote below comes from the questionnaire:

> 'I think example standards would need to be concrete and could be around having a service user committee – which inputs into decisions around teaching and selection.'

4.8.9 Suggested standards

Some respondents to the questionnaire used the opportunity to proffer their opinion on how any standard might be worded.

> 'Service Users should be involved in advising on design and delivery of programmes where possible and appropriate at all levels.'

> 'Service users are actively involved in the design and/or delivery of the programme.'

> 'The design of the programme must be influenced, in part, by service users.'

> 'Evidence that the training providers have consulted service users of the relevance of course content.'

> 'HE programmes must make facility to engage service users in the revalidation and delivery of relevant modules in the programme.'

4.9 Challenges

Questionnaire respondents were asked to describe a maximum of two key challenges they had faced when seeking to involve service users and how they had sought to address them. What is striking is that the categories developed, following an analysis of responses, mirror those developed following analysis of the responses asking about SETS (see section 4.8 above) and also the literature review section '2.3 facilitators and barriers'. It is also worth noting that many respondents did not proffer a solution to the challenges they raised.

Table 5 below shows the key challenges.

Table 5: Key challenges to involving service users

Recruiting service users	Infrastructure challenges	Cultural challenges	Other issues
Recruiting appropriate service users	Strategic support	Valuing service users	Tokenism
Disability/illness of service users	Payment and reimbursement	Resistance of staff	Achieving a balance between maximising SUI vs doing it well
Confidence	Resources accessibility	Building relationships	Interviewing questions
Cancellations			
Time tabling			
Continuity			

4.9.1 Recruiting service users

Many respondents made reference to the problem of 'getting' service users. Some respondents raised the general issue of 'no volunteers came forward' and some suggested general solutions of 'incentive payments for their (service user) time and travel'. What follows is a consideration of the more nuanced challenges of 'recruiting appropriate service users', and the challenges raised by 'disability/illness of service users', 'cancellations' and 'timetabling'. It should be noted that these issues are often interrelated; for example the 'time tabling' of events may be a reason for the difficulties of getting volunteers in the first place; the difficulties in finding a larger pool of service users creates problems finding a replacement when service users have to cancel (which can be due to their health problem).

4.9.1.1 Recruiting appropriate service users

There are six aspects to the recruitment of appropriate service users, which emerged from the data:

- Service users following own agenda
- Representativeness of service users
- Lack of expertise of service users
- Confidence of service users
- Service users with experience of the service
- Continuity

Service users following own agenda

Some questionnaire respondents made reference to service users who had their 'own agenda' or 'issues' that they wanted to get across:

> 'finding appropriate service users who are able to see the big picture and understand the aims of what the students need to achieve in a particular session rather than getting their particular 'issue' across.'

Academic staff highlighted the problem of service users with 'an axe to grind' in the following excerpt from a focus group interview:

> *"I think it is better therefore to choose them, rather than ask for volunteers. If you ask for volunteers as lay representatives on committees, you tend to get people with an axe to grind. You want negatives but you want objective opinion.*
>
> *Yes you don't want someone who's had a horrible experience with xxxxxx and is just using that forum to sound off."*

(Staff, FG2)

Representativeness of service users

Others couched the challenge in terms of 'representativeness' of service users: 'outspoken service users with their own particular agenda not being representative of the group we'd like to be a voice for.' Another noted that although a service user had just been recruited 'He is representative of a very small category of patient (male, white, elderly with experience of skeletal and general radiography) – what about all the other sorts of people radiographers come into contact with – how can he give us the perspective of a young woman who is having a mammogram for a breast lump for instance, or a child having an MRI scan.'

A slightly different issue related to representativeness was articulated by the following respondent. More specifically, it seems that it was the attempt by the education institution to ensure all views were represented which created a problem – 'Service users often can't agree with what they need and this leaves us with the difficulty of meeting many different needs.'

Lack of expertise of service users

A perceived 'lack of expertise' was also a challenge when it came to recruiting appropriate service users. For some respondents to the questionnaire the nature of the care they provided meant that it was difficult to recruit service users with sufficient expertise:

> ‘In operating department practice it has been historically very difficult to recruit patient representatives to contribute constructively to our programmes, as the majority of patients have very limited awareness of the care they actually receive during their treatment in theatres.’

Another respondent commented that ‘Service users have given erroneous information to students.’

Confidence of service users

Questionnaire respondents noted that finding service users with ‘The confidence to work with students’ could also be a challenge’ and the ‘confidence to challenge points in group discussions.’

This issue was also raised in the focus group interviews. The following excerpts link the issue of confidence to the emotional trauma of particular illnesses:

> *“I haven’t been involved here with it yet but certainly in previous experience with medical students you have to be quite careful who we chose. Finding the patients can be quite tricky because it has to be a certain person who can do that, who has the confidence. They need to be able to talk about the condition and not find it too traumatic.”*

(Staff, FG2)

> *“But with xxxxxx I think the barrier with having a patient come in is it’s harder for the patient to come in and talk about what’s happened to them, especially if they know its terminal or if they know it’s real or it might metastasise elsewhere and they know it’s going to come back. If I was in that situation I wouldn’t want to be standing at the front of a classroom saying ‘I’m a cancer patient and this has happened to me’. If you are willing to put yourself out there and go through all the emotional stress of talking about everything, bringing everything back and not be afraid to have an emotional breakdown in front of a class of 30 students then that’s fine.”*

(Students, FG1)

Service users with experience of the service

Some questionnaire respondents noted that recruiting service users who had received, or had experience of, ‘that’ particular service could be a challenge: ‘Often the service users that have been sent to sessions have been inappropriate for undergraduate physiotherapy students (e.g. they have not had or got a physiotherapy problem).’

The above quote highlights again the question of ‘who is a service user?’ Are we referring to a lay person and/or someone who has actual experience of receipt of a service?

Continuity

One questionnaire respondent raised the issue of continuity, noting that 'Sometimes it is helpful to have key service users involved in a number of aspects of the programme.'

4.9.1.2 How overcome?

Selecting appropriate service users could sometimes be via 'clinical colleagues' as their own 'Service user networks are relatively undeveloped.'

Other suggestions, from the questionnaire responses, can be described as support and training issues. A debriefing session with service users was advocated as one way of addressing service users who proffered 'extreme or political views upon which we would rather take a more neutral standpoint.' Another alternative is to guide the service user before the session - 'work with SUs to ensure that we have a shared understanding of what is planned' and 'meeting with the client and advise them of the module content'. Another means was to ensure 'good facilitation of the session.' Similarly one respondent noted that they reiterated to service users 'the need to remain focussed on (the) set criteria.' Training for both staff and service users was also identified as a means of ensuring that the service users were 'appropriate'.

One respondent advocated attention to be given to the recruitment process so that 'we recruit service users who have the potential or pre-existing skills and/or understand that we need them to be a spokesperson for others in a similar position.' Failing this, the institution can review whether they should make alternative arrangements.

Where service users had given erroneous information to students, 'Academic staff had to debrief students.'

The issue of confidence to challenge in a group setting was addressed by regularly asking, verbally, for the thoughts of service users as well as getting their thoughts in other ways such as asking them to write down their thoughts on post-its and telephoning them after the event.

The respondent's approach to addressing the issue of continuity was to 'have a number of service users in different roles.' It is worth noting that the respondent also commented that 'I don't think this is ideal, but better than nothing.'

4.9.2 Infrastructure challenges

Reference was made, in the questionnaire, to a variety of challenges which can best be described as 'infrastructure issues'. This refers to a commitment from the wider organisation in terms of strategic support, payment and reimbursement, resource issues and accessibility.

4.9.2.1 Strategic support

One respondent to this question noted the challenge of 'Ensuring that the infrastructure within the faculty supports service user and carer engagement.' Another respondent emphasised the challenge of 'Ensuring that SUI is woven into the training programme, rather than tacked on.'

4.9.2.3 How overcome?

One respondent noted that the faculty was developing a three year strategy to ensure that SUI was embedded 'within all aspects of its activity' and that 'service users and carers are fully supported.' This strategy was being developed with local NHS partners, the local authority and their patient and public involvement groups.

4.9.2.4 Payment and reimbursement

Payment and or reimbursement for service users is again cited as a problem for many questionnaire respondents. The challenges are:

- Finding resources to make payment – 'Financial constraints affect how many service users we bring in to university to assist in the delivery of the programme.'
- Timeliness of payment - 'university payment mechanisms are slow and inflexible.'
- Ensuring payment does not impact upon allowances – 'Payment of SUs via the normal salary mechanisms can push the SU income over a limit that affects their benefits.'

4.9.2.5 How overcome?

Various options were proffered to the problems. Some institutions paid service users in 'gift vouchers' or 'book tokens' to ensure that their benefits were not affected while others paid travel and expenses only. Another respondent makes reference to a 'payment information sheet' for staff and service users and training for staff on how to book users onto programmes and access money from their finance department so that service users can receive immediate payment. One respondent had to find money for payment from their own budget while another made a contribution to a charity of the service users' choice instead of payment direct to service users.

4.9.2.6 Resources

The resources required for involving service users, in terms of both time and money, was identified as a challenge by several questionnaire respondents: 'We cover many different service user groups and it is hard to include all, but we do invite one or two each year to teach. This is not enough and time and money prevent involving more.' Another respondent commented that 'The staff are fully stretched with their current duties so asking someone to devote time to recruiting service users is very difficult.'

One respondent suggested that having insufficient resources for the 'creation of a service user and carer co-ordinator role was limiting the developing of SUI.'

Another respondent referred to both 'time' and the 'Lack of admin staff to help with arrangements'.

4.9.2.7 How overcome?

The development of a role of someone, within the education institution, dedicated to finding and/or supporting service users has been cited as a means of overcoming the resources issues. Giving SUI 'a high priority' was also proffered as a means of addressing the challenges of a perceived lack of resources. Long term planning was also advocated as a means of managing time and resources.

4.9.2.8 Accessibility

There are three aspects to accessibility identified from analysis of the questionnaire responses:

- Getting to the venue
- Moving around once in the venue
- Jargon

One respondent commented on the difficulties in 'Encouraging services users to attend the university (new campus – outwith the city centre)'. Another noted that 'Our building is not terribly accessible.'

The jargon used can also be a challenge – 'Ensuring medical language is not used in meetings and clarity is given to the service user'. This is exemplified in the following excerpt from a focus group with service users:

> *"Also jargon we talked about jargonise. Please explain and any acronyms please explain because we don't like to say, no we don't understand although these days we do – 'Would you like to explain that please?'"*
> (Service users, FG2)

4.9.2.9 How overcome?

One respondent noted that the challenge of getting to the venue had been overcome by reassuring service users and demonstrating 'the ease of public transport.'

Accessibility problems once at a venue were overcome by 'good planning and the willingness to be flexible.' Another respondent noted the value of a 'Key person who is responsible has championed the issue at University level.' They have now 'negotiated suitable rooms and have raised awareness with room bookings' staff of the reasons for our special requirements.'

Moving on to the use of jargon, one respondent explained that the issue was overcome via a combination of the development of a good relationship with the service user, staff seeking to ensure that the service user understands and the assertiveness of the service user in querying anything she doesn't understand.

A number of other challenges were outlined and included in table 6 below along with how the challenge was overcome (not all respondents specified how challenges were overcome) and any supporting comments.

Table 6: Key Challenges of Service User Involvement

Key Challenges Involving Service Users	How Addressed	Supporting Quotations
Disability/illness of service users	'Provide support' to service users who experience illness.	'a service user who is becoming 'increasingly unwell in interactions with our programme' is being 'encouraged to access appropriate external mental health support... and this will be reviewed regularly by the staff member who knows the service user best'.
Cancellations	One respondent noted cancellations were a perennial hazard.	Having enough patients to approach in the event that one or two cannot attend due to health or other issues arising.' 'Build up a relationship with some service users who are known to deliver and are integrated within the team.'
Timetabling	'flexibility with timetabling and early communication.	'Service users are becoming increasingly busy in their workplace.'

Key Challenges Involving Service Users	How Addressed	Supporting Quotations
Commitment of service users	Make service users aware of the time commitment.	'The time and commitment required and the fact that interviewing can be a demanding process.'
Cultural challenges: Valuing service users	Having a dedicated staff member to support service users. Facilities in place to mentor and support service users; the university contributed financially to the cost of service users and carers being involved; senior managers received annual reports and newsletters about SUI.	'Ensuring that the university values the contribution made by service users.'
Resistance from staff	'hosting training events to discuss the benefits (and costs) of involvement; having a mechanism to feed into university sub-committees, where decisions about involvement are made; having designated web-pages that are regularly updated and publicised; having a service user carry out a large scale service evaluation study of all aspects on involvement on the training course.' Everyone understanding the 'aims of why service users are involved.' 'Joint training with university staff and service users.' 'Having a physical presence in the Department (e.g. at meetings, etc).'	There are still some who are sceptical about involvement. Engaging all staff 'is a gradual process' and that they have learnt by working 'interprofessionally, sharing our expertise and learning from different 'pockets' of good practice.

Key Challenges Involving Service Users	How Addressed	Supporting Quotations
Building relationships		'a lot of this depends upon the willingness for individual staff members to find time to establish rapport'
Tokenism	'Initial consultations with users and a workshop to help decide where user input would best fit our programmes.'	'The risk of tokenism whereby a service user sits on a committee, feels bored or overwhelmed and unable to contribute usefully' Be 'meaningful and not just something that is done.'
Maximising SUI vs doing it well	'Compiling a list of priority areas and addressing them one by one.'	Balance needs to be struck between maximising SUI across the programme and ensuring that any area of SUI is done well. Failing to do so can lead to service users and staff becoming 'overwhelmed'.
Interviewing questions	A workshop of academics, practitioners and service users to develop more appropriate questions.	Where service users were involved in interviewing students, questions 'did not cover' the requirements of service users.
The impact on students of negative feedback from service users	Service users 'need to go through a selection process before taking part in face to face contact.'	'Underestimating the preparation of service users and staff for teaching sessions.'

4.10 Additional Comments

Questionnaire respondents were given the opportunity to add any comments they thought might be useful and had not already been covered in the questionnaire. Many respondents referred to the problem of 'defining service user' which has already been covered in this section of the report, and many emphasised points they had made earlier about the difficulties of involving particular types of service user, encouraging comments about SUI or barriers to involving service users (for example, resources).

Some respondents provided information on particular initiatives. These include the need for a 'clear policy for service user engagement and having a service user working group involved in the development of this policy', a dedicated project worker/central person for SUI, and championing and acknowledging SUI as good practice.

Others suggested that 'service user' could be a 'clumsy' term and preferred alternatives such as 'expert through experience' or 'expert voice'.

It was also noted by some respondents that they had not been asked about clinical practice and that this was an area where service users could be involved.

4.11 Issues emerging from the focus groups and interviews not addressed elsewhere

A small number of issues emerged from the interviews which have not been addressed elsewhere.

4.11.1 Cultural issues

The following excerpt suggests that education institutions may have to be creative in how they involve service users who, for example, may struggle to understand current university documents:

> *"To get back to your question, are we saying if the only way service users can be involved in our programmes is that it is reliant on degree level capacity to use English then that's not going to work.*
>
> *So it is a limitation and it's about being realistic.*
>
> *And then it's that thing of thinking well how can we adjust. Could we have a group where we talk about, these are the things we do with students and what could we do differently. That's the thing; the university likes people to scrutinize documents.*

Personally I feel we are dealing with non verbal processes. So we could get service users to come in and do a workshop."

(Staff, FG3)

4.11.2 Providing support for service users for their role in classroom teaching

The case studies raised the issue of the provision of support for service users who were to be involved in the classroom. This support was in terms of both preparing the service users for their role and support while in the classroom. In terms of preparation the service user below notes the lack of information they were given:

"I think in all honesty we … weren't quite aware of what we were doing there and I think that was a comment from all of us on the feedback. We would have liked to have known why we were going and what for and then when it became clear, because you can get your thoughts together before you go"

(Service users, FG2)

The student below notes the role that qualified staff can play in helping to support service users in the classroom:

"G: You said that you enjoy it when the service users come in to do the talks, what do you think are the facilitating factors that make that work?

There was a xxxxx there that had treated the patient, knew the patient, knew the story and where we had a question for the pancreatic guy about the anatomy of the operation, he might not have been able to answer for us but the xxxxxx is always there with them and could answer the more complicated questions and then any other questions we had about his treatment we could ask him. I think it needed to be backed up with a xxxxxx.

G: So you don't think the patient could have done it on their own?

I don't think it would have been so useful.

A lot of our questions would be – why did he have this or that done – and the xxxxxxx would have a better answer from our perspective."

(Students, FG2)

4.11.3 Access to service users

The following excerpts show the reliance of academic staff on practice staff in gaining access to service users:

> *"G: What factors go into facilitating that user involvement, the various things you spoke about, what enable it and make it run smoothly?*
>
> *I think the main thing, going back to the service users as patient or clients; just because that's the bit I know most about, it's the relationships that are built up. It wouldn't work if they didn't have a good relationship with the xxxxxx who invites them and that xxxxx didn't have a good relationship with us. We don't pay them, we don't pay the xxxxxx, we don't have a finder's fee, it's all done on goodwill. Our placement providers want to help us because they want the course to be good, then the patients or the clients they invite want to do something good for that xxxxxx because they have helped them in the past. So that involvement is all based on goodwill. We are reliant on our placement providers having good relationships with their patients and us having good relationships with our placement providers otherwise it's just another thing we are asking them to do. And they could say - actually no I haven't got time."*

(Staff, FG2)

4.11.4 Professional relationship as a barrier

It was suggested by students that it would not be appropriate to involve service users with whom they have been working on placement; service users with whom they have a therapeutic relationship:

> *"It's not like a relationship with your GP where you'd expect certain things, like them greeting you and civilly explaining what's happening and communicating well and you can understand them. It's a very different criteria in an xxxx therapeutic relationship where it's very long term and can build up over time."*

(Students, FG3)

> *"I think it really depends on what it looks like. I think if it means someone coming and speaking about their experiences that's one thing. If it means you get feedback from the client you've been working with on placement that could be really unhelpful. I can see how on other training courses that are HPC regulated it could be useful to have it but in a psycho-therapy context which is what we are talking about I think it is really difficult. I work in policy - so I think about these things quite a lot, if you are looking at it across*

the whole of the professions that HPC regulate, you would need to think very carefully about how psycho-therapy related professions – how it would work for those, because if it is about what you are talking about great but if it is defined or interpreted more closely than that then it could be quite problematic."

(Students, FG3)

4.12 Consensus workshop

This final stage of data collection was a consensus workshop focusing on the evidence collected via the focus groups and individual interviews and involving key stakeholders.

. The objectives for the workshop were to engage with key informants to:

- Discuss the findings from the earlier stages of data collection, namely the on-line survey, focus groups and individual interviews
- Consider whether a SET requiring education providers to involve service users in the design and/or delivery of HPC regulated education and training programmes would be useful
- Develop SETs as options for SUI that HPC can consider

Following presentations outlining the background to the research and key issues to emerge from the research, the participants were allocated to one of four break out groups to discuss the findings from the earlier stages of data collection, which were formulated into key questions. Finally, again in break out groups, participants were asked to discuss the development of a SET. Information is presented below on the participants as well as the outcomes from the breakout groups.

4.12.1 Participants

Participants in the workshop were a mix of academic staff, service users and students as outlined below in table 7. The groups were facilitated by staff involved in the research.

Table 7: Workshop Participants

Type of participant	Number
Service users	8
Students	4
Academic staff	4
HPC staff	4
Facilitators	4

4.12.2 Discussion topics considered within the groups

Each of the four groups was charged with addressing one of the questions in the left hand column in the table 8 below. The key points made by the groups are in the right hand column.

Table 8: Workshop questions and key points

Questions	Key points
1. What is the purpose of involving service users in education? To help you address this question the group may want to consider the following issues: - What are the benefits? - What are we trying to achieve by involving service users? - What factors might the HPC identify as a justification for involving service users?	Involving service users: • Can help manage and reduce risks. Service users can make sure that students know what works, what issues need attention, and help students cope with risks and their downfalls. • Can help professionals improve their contact skills and ethics of practice. • Can help focus training on the patients/service users and give students the opportunity to reflect on reality from a service user perspective. The service users are 'experts by experience' bringing their different experiences and views.

Questions	Key points
	• Will give students better insight and understanding and therefore behave more sensitively and appropriately with service users. • Increase service users' position/confidence. • Will have a knock on effect on future generations of professionals, improving standards, making students more confident and addressing power imbalances.
2. Who are service users? What is your rationale for including/excluding certain groups? To help you address this question the group may want to consider the following issues: - Must it be someone who is currently receiving a service? - Can it be someone who has received a service? If so, does it depend on how long ago they received a service? - Can potential users of a service be classified as service users? - Does the definition depend upon which aspect of the design and/or delivery of education you are addressing?	• Service users are the end 'recipient' of a service. This would enable the inclusion of those few professions who do not provide direct services to the public. For example biomedical scientists. • Carers should also be included in the design and/or delivery of education and training. A carer is someone who would be eligible for a carer's assessment. • Students are not service users; they are users of the education service. • Someone who may use a service in the future i.e. 'a hypothetical service user' is not a service user • Personal assistants are not carers. • Biomedical scientists should meet SUs during their education even though it is acknowledged that they don't do this in their everyday job.
3. In which aspects of the course design and/or delivery can service users be involved?	• It is not appropriate to use service users too soon after the receipt of poor care or bereavement.

Questions	Key points
To help you address this question the group may want to consider the following issues: - Can service users be involved in the following? - interviewing students, design of curriculum, teaching, 'experts by experience' story telling stories, storytelling via videos, assessing students' practical work, assessing students' written work, evaluation of a course - What support would education institutions require? - What support would service users require? - What support would students require? - What support could the HPC provide? - How achievable is any of this?	• Given the above, it is important that the involvement of service users is a 'managed' process. • 'Protection of the public' is an important element of the work of HPC: It would be useful to have evidence of the extent to which the involvement of service users led to better practitioners which, in turn, led to improved safety. (Some members of the group believed there was a link.)
4. Some people argue that when involving service users in education and training there is a need to: - ensure that the service users are 'representative' - Consider whether some service users are too ill/disabled/vulnerable/young to be involved in certain aspects of the design and delivery of education and training. - What is your response to these assertions?	• If a definition of service users included carers and advocates then this would enable professionals to reach a wide group of service users. • The difficulties of including varying groups of service users should not prohibit having a standard for all professions.

Questions	Key points
To help you address this question the group may want to consider the following issues: - What ethical issues might need to be addressed when involving some service users? - Would a Code of Conduct, or set of guiding principles on how to involve service users, be useful? - Is it realistic to expect service users, who are involved in education, to be representative of all service users? If not, then what do we mean by 'representative'?	

4.12.3 Final discussion topic

Each of the four groups was asked to address the question below. The responses are summarised.

Should HPC develop a standard, which requires service users to be involved in the design and/or delivery of education and training, and if so, what should this standard look like?

All of the groups were of the view that a standard should be developed. The following three standards were developed by the groups:

1. 'Service users are actively involved in the design and/or delivery of the programme with supporting evidence.'

2. 'The design and delivery of the programme must be influenced by service users, carers and representatives.'

3. 'There must be a service users' group which considers that it has had appropriate input into the management, design and delivery of the course.'

In the light of the findings from the research, which documented the difficulties some professions experienced in involving service users, the groups were keen to allow

flexibility. This is evident in option 1 where the phrase 'actively involved' was used rather than something more prescriptive. Similarly option 2 uses the phrase 'influenced' without prescribing how much 'influence'. This option does, however, advocate that users should be involved in the 'design *and* delivery'. And the final option allows the level and type of involvement to be left to the discretion of service user groups.

There was much debate about whether the phrase 'service users and carers', 'service users, carers and/or representatives' or more simply 'service user' should be used. Advocates of the latter option suggested that guidance accompanying the standard could explain that 'service user' includes carers and representatives. However, others were concerned that this approach would lead to carers and advocates being overlooked and, consequently, ignored; their preference therefore was to include carers and advocates explicitly in the standard.

Option 3, above, is different in kind to options 1 and 2 in that it involves, potentially, a greater shift in power to service users; it would be the service user group who provided evidence for the standard and it would be the service user group who determined whether or not their input was 'appropriate'. The rationale behind this option was that the establishment of an empowered service user group would more likely lead to the support and change in culture which is necessary for effective user involvement; the hub around which the spokes, for example service user involvement in teaching, could flourish.

Some participants were concerned that using phrases such as 'where appropriate' or 'where possible' could provide education institutions with an 'easy opt out.'

There were varying views over how quickly education institutions would be expected to adhere to the standard. Some expressed the view that it would be unreasonable to expect this to happen 'overnight' and that a first stage could be that education institutions show evidence of a plan of how they would meet the standard. Others, however, were of the view that the issue of 'service user involvement in education' had been debated for years and were concerned that further delay could lead to drift.

The issue of developing the capacity of education institutions and service users, to enable service user involvement, was raised. It was noted that HPC need to be aware of any additional costs and one suggestion was for the HPC to be involved in finding a solution to this issue.

One of the groups did not develop a standard but noted that any standard needed to include 'service user engagement' and 'management of the course' and 'where appropriate'. Furthermore, this group suggested that the involvement of service users and carers could be used as a good practice exemplar within an existing standard.

4.13 Conclusion

The findings from this research echo many of the themes that have been identified in the literature. The various benefits of SUI identified in the literature and factors that facilitate and act as barriers resonate in this research.

The questionnaire data suggests that the involvement of service users is prevalent in the programmes which fall under the umbrella of the HPC and that this is particularly so in the area of 'programme development.' Where they are involved in feedback to students this is likely to be informal rather than as part of a formal assessment. Similarly, any feedback on the evaluation of the programme and module is likely to be formative rather than summative.

The range of perceived benefits of involving service users in education and training include those for students (for example, 'students gain insight from service users' perspective ' (82%), 'challenges students' stereotypes/assumptions of service users' (73%)), the programme (for example, 'ensures the priorities of service users are reflected in the programme' (71%)) and also the service user (for example, 'provides an opportunity for service users to share experience and/or expertise' (74%) and ensures that 'service users feel valued' (73%). These benefits could be used by the HPC as a contribution towards developing a strong rationale for the involvement of service users.

Numerous factors which facilitate SUI were identified, reflecting cultural, support and training issues, infrastructure issues and recruitment of service users. However, these issues, if not addressed can also be regarded as 'barriers' or 'challenges' and they have found expression in the open comments in the questionnaire and the interviews.

There appears to be general support for the involvement of service users albeit with some caveats and concerns about the need to develop a SET, the scope of any SET and the practicalities of meeting any SET.

Finally, at the consensus workshop the key issues that emerged from the research were addressed, including a definition of 'service user'. There was agreement that a SET should be developed and options were proffered for the HPC to consider.

Chapter 5: Discussion

5.1 Introduction

There is increasing emphasis on the need to engage with service users when both developing and delivering education and training programmes for professionals involved in the health and social care sectors. At present there is a considerable literature exploring and defining the nature of such involvement but much of what exists tends to relate to mental health nursing, medicine or social work (Thomson and Hilton 2011). The literature represents a mix of material from research to opinion pieces and illustrates a relative dearth on user involvement in the education and training of HPC regulated professions.

In terms of research, reported studies investigating SUI in education and training tend to be small scale descriptive accounts concerned with individual experiences of initiatives within single institutions, consequently not generalisable. To date none of the research has evaluated the immediate impact on clinical practice on completion of courses.

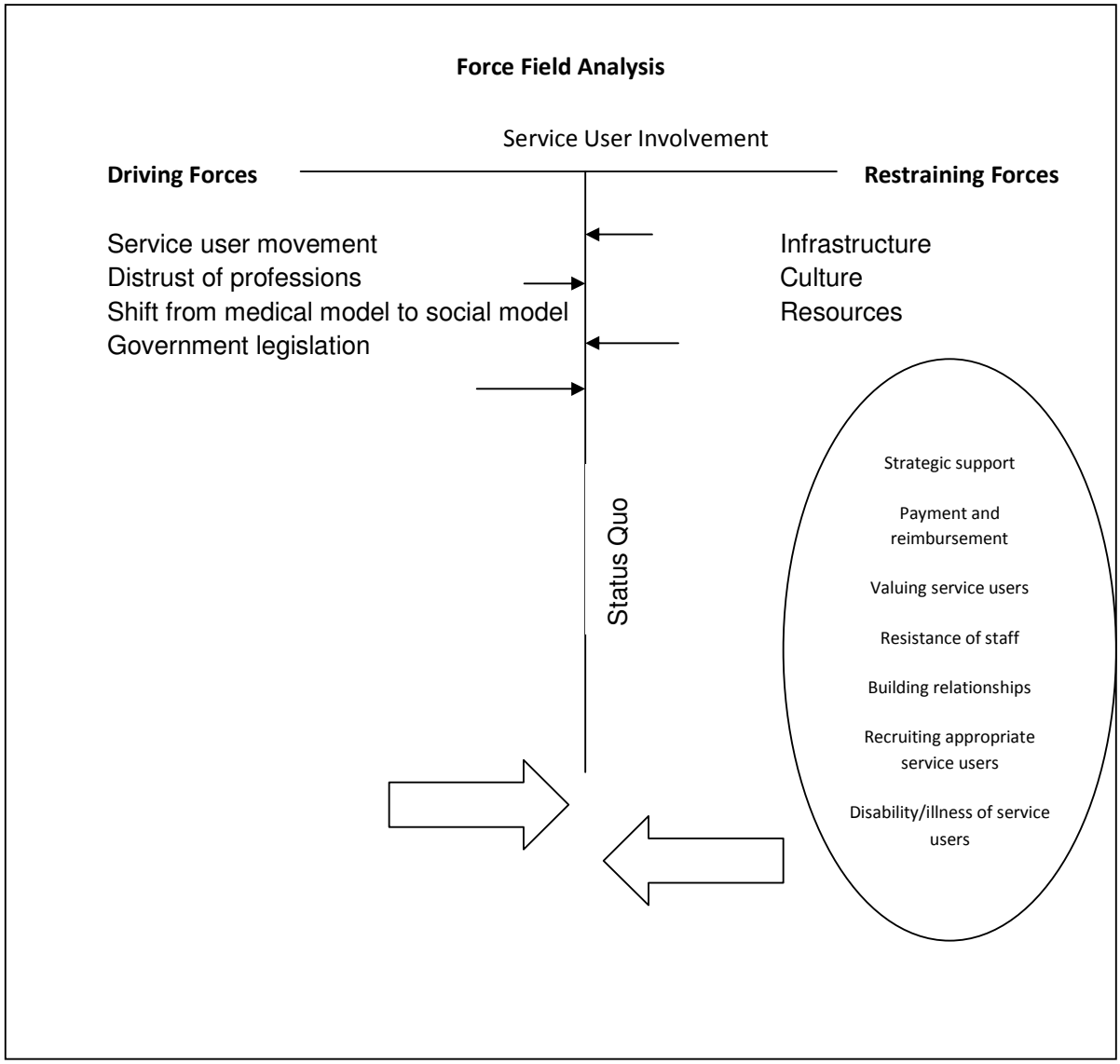
Whilst this study does not address the point immediately above it does add significantly to the body of research knowledge in that it looks at SUI in education and training across a range of professions and a variety of institutions. It also provides a broader picture of SUI activities together with the benefits, barriers and facilitating factors. Furthermore, it explores in greater detail many of the benefits, barriers and facilitators raised in the literature. The study used a mixed method approach involving both qualitative methods of data collection (interviews and/or focus groups) and quantitative (questionnaire) administered to, service users and/or students and/or academic staff. This mixed method approach together with a larger mixed study population than hitherto in any one study enhances the empirical basis to the work.

This chapter considers the outcomes of the research and the relationship to the overall objectives as outlined in the response to the HPC call for research proposals. It also considers the limitations of the research.

Figure 8 below shows how the theoretical framework of Lewin's force field analysis was used to help organise the material from the literature review and also to organise the data that emerged from the different stages of the study.

The figure indicates the nature of the facilitating and restraining forces and how they interact to retain the status quo and what needs to change in order for SUI to become mainstream and sustainable. To address the issue of SUI the pressure of the driving forces on the left hand side of the diagram need to overpower the restraining forces on the left hand side. Alternatively, the restraining forces need to be lessened. Failing to lessen these forces will not enable the issue of SUI to move beyond the status quo.

Figure 8: Force Field Analysis of Service User Involvement



The key objectives of the study were to:

- Identify the existing approaches and types of SUI activity across the range of programmes regulated by the HPC
- Identify existing best practice criteria for service user involvement in education and training
- Determine the drivers, benefits and challenges of SUI in education and training
- Produce options for Standards of Education and Training (SETs) for SUI in the design and delivery of HPC regulated education and training programmes

5.2 Existing approaches and types of SUI activity in HPC regulated programmes

The wider literature on SUI suggests that service users do contribute to the education and training of health and social care professions ranging from course design to student assessment. However, the majority of the involvement tends to focus on teaching in the classroom (e.g. Cooper and Spencer-Dawe 2006, Haney et al 2007, Thomson and Hilton 2011).

It was suggested that the classroom, as opposed to clinical practice settings, provides an environment which is safe and relaxing for students (Rees et al 2007, Rush 2008, Thomson and Hilton 2011). According to Rush (2008) this is where the balance of power moves from the student to the service user; the service user is expert based on personal knowledge and experience. Also the classroom gives the service user 'permission' to be more open and frank than they would be in a clinical setting (Ottewill et al 2006). Participants in this research indicated that the classroom provides an opportunity for students to 'put the science to one side' and the space and time for service users to give students insight into their perspective and experiences. Ottewill et al (2006) offered four key reasons for the involvement of expert patients in classroom teaching; 1) it provides an opportunity for students to interact with recipients of a service outside of the clinical setting, 2) adverse comments tend to be made in terms of the profession as a whole rather than against individuals, 3) students can explore the psychosocial aspects of care rather than just the body or condition of the person, 4) it enables students to combine concrete experience with reflective observation. Findings from this research study concur with these key points emphasising the psychosocial aspects and being able to interact with service users outside the clinical environment.

Additionally, the data generated here indicates widespread support for the principle of involving service users in the design and delivery of education and training. The data also, highlighted that service users are already involved in a variety of ways in HPC

regulated courses. Of particular note is involvement in programme planning, the development of teaching tools/materials, formative feedback on the programme, role play in the classroom and module planning. There were no professions, which responded to the questionnaire, which indicated that they did not involve service users in some way.

The students who participated in this study were of the view that service user involvement in their programmes had many benefits, for example, it made the classroom experience real for them, and it challenged their assumptions and stereotypes and raised an awareness of the need to treat service users with dignity and respect. This latter point is highly pertinent in the current political and health care climate with the increasing concerns regarding the care and treatment of individuals, especially elderly people.

Other authors have referred to students being inhibited by service users in the classroom (Costello and Horne 2011) and others note that tensions can exist in the class room between students and service users and suggest that academic staff have a mediation or facilitation role to play in such circumstances.

A view that it would be difficult to involve service users in certain aspects of course delivery as they lack expertise emerged from both the literature (e.g. Masters et al 2002) and the primary research. The literature did not make it clear whether this lack of expertise was in the 'topic' being taught or lack of expertise in 'being involved' in a particular aspect of education and training. This research suggested that the concern was related to the lack of expertise with respect to the topic under discussion.

A further suggestion is that this concern arises from a lack of clarity about the role of service users in the classroom. Again, and using Dogra et al's (2008) notion of 'expert patient', a counter argument regarding 'lack of expertise' is the notion that service users are 'experts by experience'; they are not in the classroom to provide expertise on a particular area of the course but rather to provide an example of how a particular initiative, theory or service impacted upon them.

As well as lack of expertise being raised as an issue, with accompanying different views, so too was the representativeness of service users both within the literature (McAndrew and Samociuk 2003, Cooper and Spencer-Dawe 2006 and Skinner 2010) and in the primary research. Drawing on the work of Dogra et al (2008) it is possible to conclude that the issue of 'representativeness' emerges again ,as a result of a lack of clarity about the role of the service user in the classroom. Dogra et al (2008) makes a useful distinction between 'expert professional' and 'expert patient'. The expert professional is the lecturer who has the skills and knowledge to deliver a curriculum while the latter refers to the service user who is an expert in terms of their experiences. Service users are, as one service user in this study noted, 'experts by experience', each with their unique experiences of using a service. Being representative of the whole service user group would be impossible. What they are

able to do is to proffer *an* example of a service user perspective or experience rather than *the* service user perspective.

Where there is an issue around representativeness it is to ensure that the education institution involves those service users who have had positive as well as less positive experiences. In this way, along with ensuring service users are briefed, supported and prepared, the students will get a range of perspectives on the service user experience rather than just the views of those 'with an axe to grind'.

With reference to the various 'models of user involvement' referred to in the introductory chapter, Repper and Breeze (2006) suggest that, bar a few notable exceptions, user involvement tends to be ad hoc and piecemeal rather than fully integrated. While this issue was not explored specifically in this research the data does point to service users not being involved in all aspects of education and training.

5.3 Identify existing best practice criteria for service user involvement in education and training

An objective of this study was to identify existing best practice criteria for SUI in education and training. The findings from both the literature review and the data collected do not enable us to identify best practice criteria with an empirical basis. However, it is possible to identify specific approaches that respondents had adopted to address some of the key individual/institutional challenges that arose when involving service users in education and training. Table 9 below identifies various challenges and the approaches used to address them.

Table 9: Challenges to SUI and approaches to overcoming them

Individual/institutional Challenges	Approaches used
Recruiting service users	- Use links with clinical colleagues to gain access to service users - Take care during the recruitment process to ensure appropriate service users are selected - Develop relationships with enough service users to enable replacements in the event of cancellations - Develop relationships with service users who are known to be reliable - Plan ahead and try to be flexible with time tables - Ensure service users are aware of the time commitment
Supporting service users in the classroom	- Prepare service users about expectations - Debrief service users - Ensure good facilitation during service user session - Ensure staff are adequately trained in how to involve service users - Regularly seek service users' views
Payment and reimbursement	- Develop clear instructions, and train staff, on how to book and pay service users - Pay users in gift vouchers or tokens to overcome problems with the impact of payment on service user benefits - Pay a contribution to a charity of the service user's choice
Finding time to recruit and involve service users	- Appoint someone who has the responsibility to find and/or supporting service users - Give SUI a high priority
Getting to the venue	- Demonstrate to service users how to get to the venue using public transport - Provide transport
Support for service users at the venue	- Appoint someone with responsibility for ensuring that service users' needs are addressed
Jargon busting	- Ask service users if information is clear - Encourage service users to be assertive in raising issues of 'jargon'
Valuing service users	- Appoint someone with responsibility for supporting service users - Provide mentoring and support facilities for service users - Update senior management about SUI developments
Overcoming resistance from staff	- Provide training events on user involvement - Create a web page on SUI - Carry out an evaluation study on SUI - Provide joint training with university staff and service users
Strategic support	- Develop a long term strategy to embed service user involvement into a faculty/institution
Avoiding tokenism	- Consult with service users to help determine where SUI would be most appropriate

5.4 Determine the drivers, benefits and challenges of SUI in education and training

5.4.1 Benefits

Figure 8 (page 77) highlights the range of facilitating and restraining forces that surrounds SUI in education and training. It has already been emphasised that several drivers exist for increased SUI emanating from service users themselves and the public, professional groups and government policy. Service users are keen to have a more active role in education and training; they have always been engaged passively as health care professionals 'learn on the job' in clinical practice, however they want more than that. Their desire for involvement is also motivated by the mistrust of professionals, mainly based on high profile incidents of poor practice such as that at Bristol Royal Infirmary. From a professional perspective some of the changes that have taken place have been influenced as much by service users as by professionals, for example in the area of mental health service provision and education. In this context service users were extremely vociferous in their arguments for involvement at all levels. In the UK the Government have produced several legislative and policy statements in support of SUI, which is echoed internationally. It is recognised that service users have expertise in, and valued experience of, their own illnesses (Department of Health 2001, Livingston and Cooper 2004, Ottewill 2006, Downe et al 2007, Skilton 2011). The ambition is to ensure that service users are partners in decision making about care and treatment.

However, despite this emphasis there remains little empirical evidence to support or refute the benefits of SUI beyond very small scale studies involving a single initiative in an individual institution, for example Skinner (2010). Some articles did include a longitudinal aspect, designed to test or explain the impact of a particular initiative. This approach enabled some comparison of responses between at least two points in time (Greco et al 2001, Happell et al 2003, McAndrew and Samociuk 2003, Barnes et al 2006, Brown and Macintosh 2006, Perry and Linsley 2006, Downe et al 2007, Anghel and Ramon 2009, Reinders et al 2010).

There were some larger studies, which used questionnaires as a method of data collection (Eagles et al 2001, Greco et al 2001, Barnes et al 2006, Horacek 2007, Haffling and Hakansson 2008, Anghel and Ramon 2009, Higgins et al 2011, Rhodes and Nyawata 2011).

Throughout this research some respondents requested a rationale for service user involvement and an indication of the associated benefits of such involvement. Clarity was considered necessary in terms of ensuring the subsequent support of educationalists who, if a standard were developed by the HPC, would have to adhere to that standard.

Previous research has identified benefits of involving service users to both service users themselves and the education of students (for example Costello and Horne 2001, Frisby 2001, Happell and Roper 2003, Felton and Stickley 2004, Brown and Macintosh 2006, Barnes et al 2006 and Stickley et al 2010).

Examples of the former are feelings of empowerment that service users get from their involvement in the delivery of education (Frisby 2001, Masters et al 2002, Happell and Roper 2003, Rees et al 2007, Skinner 2010) and a sense of altruism that service users feel (Brown and Macintosh 2006, Haffling and Hakansson 2008). In terms of benefits to the education of students the involvement of service users can help challenge student assumptions and stereotyping (Dogra 2008, Rush 2008, Anghel and Ramon 2009, Branfield 2009, Schneebeli 2010, Thomson and Hilton 2011), providing a positive (Lathlean 2006, Simpson et al 2008) or 'normalised' (Schneebeli 2010) view of service users.

In this research whilst there was no evidence of anyone being opposed to SUI, not all participants were convinced of the need to involve service users further and there were various concerns about the development of a SET which would require them to do so. Some queried what they would bring that was not already there and how would involving service users improve the quality of care? This is an excellent point and referred to many times in this report – there is no evidence base to support the proposition that there is a direct causal link between SUI and improved quality of care. Some participants were of the view that as service users were not educational experts they could not contribute to programme development. This position would reinforce the view that some academics remain unsure as to the role of service users in education.

Overall, however, the outcomes from this research not only supports the perceived benefits of SUI as outlined in the existing literature but adds to it by emphasising that SUI in education and training is likely to:

- Lead to improved programmes which reflect the needs and wishes of service users ('students gain insights from service users' perspective', 'ensures the priorities of service users are reflected in the design of the programme', improves the content of the programme)
- Provide a link between theory and practice '(helps bridge the theory/practice gap', 'makes training 'real' for students')
- Result in practitioners more able to provide a service user focused service in which service users are able to involve service users in decision about their care ('increases students' awareness of the need to treat service users with dignity and respective', 'raises awareness of the importance of involving service users in decision making about their care' 'challenges students' stereotypes/assumptions of service users'). In the consensus workshop there was a suggestion that service user involvement led to better practitioners and improved safety.

5.4.2 Barriers and facilitators

The literature identified a range of barriers and facilitators which were grouped within the themes of infrastructure and support, cultural issues and service user issues. Within these themes, key issues were supporting and training, recruiting service users, representativeness of service users, recognising and respecting the expertise of service users, leadership, commitment and time. Effective user involvement means that organisations address the support infrastructure, and have compatibility between the systems and processes of the organisation and the requirements of service users. All of these issues were evidenced in the research undertaken here. There were some challenges which emerged from the research that merit further attention below.

5.4.3 Challenges

Two key challenges were:

- What is meant by the term 'service user '?
- Addressing infrastructure, culture and resource issues

5.4.3.1 What is meant by the term 'service user'?

Throughout the data collection stages of this study a constant question asked was 'who are the service users?' For a few participants this was problematic. For example, some questionnaire respondents reported difficulties in answering certain questions as they considered themselves as having various types of service user and were not sure which group they should be responding about.

The term 'service user' can be 'used to mean different things in different research and healthcare contexts, and internationally' (Morrow et al 2012, p19). There is, however, a general consensus in the literature that it refers to people who are using, or who have used a service, for example, carers or parents of service users, lay people, the public or non-professionals.

However, the findings from this research suggest that there are various groups who are considered by different professions to be service users: 'user and public', 'service providers/employers', 'University staff', 'students' and 'professional bodies'. Consequently, the outcomes of this study suggest that confusion still exists, especially amongst academic staff as to who are the service users. The group 'user and public' is the group that corresponds with the way in which 'service user' is interpreted in the literature, including patients, clients and carers.

Given the range of professional groups covered by the HPC achieving a definition agreeable to all may be difficult, as some professions, for example biomedical

scientists, have limited direct face-to-face contact with those groups included in the category 'user and the public'. Too broad a definition would lead to a lack of clarity, confusion and the inability to compare like with like as each course could potentially, adopt its own definition. However, too narrow a definition would result in a small number of the HPC regulated professions struggling to adhere to the standard.

At the consensus workshop it was suggested that an option might be to use the phrase 'end recipient of a service', and make quite clear that in the vast majority of cases this refers to those people who are included in the category 'user and public'. Such a definition would be consistent with what is generally meant by the phrase 'service user' and is sufficiently broad to enable the inclusion of those few professions, for example biomedical scientists, who rarely, if ever, have face-to-face contact with the public. It was clearly stated that, in this context any definition of SUI would have to exclude students and academic staff as they are users of the education service not health and social care.

The question was asked if there was a timeframe restriction on being considered a service user, for example, did someone's experience of a service have to be current or in the past? However, no agreement was reached.

5.4.3.3 Addressing infrastructure, culture and resource issues

This report has noted various infrastructure, culture and resource issues that can act as a barriers or facilitators to the involvement of service users. Some respondents have expressed concerns about the extra demands on resources as a result of a SET. This issue is particularly significant in a time of economic constraint. There are demands on finances, for example paying service users, employing someone responsible for recruiting and supporting service users, as well as demands on staff time, for example recruiting service users.

However, other respondents have given examples of how addressing the infrastructure and cultural issues in the organisation have facilitated the involvement of service users; and these have been listed in section 5.3. Of particular note is the development of a post where someone is given responsibility for recruiting and championing service user issues. Although few details were proffered on good or effective practice in overcoming barriers or developing facilitators to service user involvement we do have a table (table 9) of all of the factors that facilitate the involvement of service users. The HPC could consider research which would seek to highlight effective practice; in the absence of guidance such research could prove to be a valuable tool for education institutions as they seek to ensure service user involvement in the design and delivery of education and training.

The extent to which all of these issues need addressing will depend upon, and with reference to our continuums, on the level of integration being sought. For example is

involvement throughout all aspects of the design and delivery of education and training or just a few aspects? It will also depend upon the related issue of how much power is being passed from teaching staff to service users, for example how influential will service users be in determining programme content? There was a concern, raised at the consensus workshop, that where insufficient attention is paid to the infrastructure, culture and resource issues, this will result in an unsupported and unsustainable approach to service user involvement.

5.5 Produce options for Standards of Education and Training (SETs) for SUI in the design and delivery of HPC regulated education and training programmes

At the consensus workshop, there was a firm view that a standard should be developed. That said, the research revealed various concerns or issues about developing a SET, which might make such SUI compulsory and/or extend the ways in which education providers involve service users already.

On the one hand, there seems to be widespread support for the involvement of service users. There is also strong evidence from both previous research and this research, that involving service users is perceived as a benefit to students, the course and to service users themselves. Furthermore, other regulatory and educational bodies have already advocated and sought to ensure a greater level of service user involvement in the provision of education and training (e.g. GMC 1993, ENB 1996, ULCC 1999, GSCC 2005, NMC 2010). A view, articulated at the consensus workshop, was that the issue of service user involvement has been around for several years and that further delay will result in the issue drifting on for longer.

On the other hand, there are also concerns, for all the reasons already noted here, about how achievable service user involvement might be.

Based on the evidence obtained from this study the HPC has four possible broad options:

1. ***Change nothing***

This option would have the advantage that no additional, perceived burdens are placed on education institutions. Disadvantages are that it would not encourage institutions in the promotion of SUI, and consequently they would lose out on the perceived benefits of SUI.

2. ***Introduce a standard immediately requiring professions to involve service users in the design and delivery of education and training***

Here would be the advantages of ensuring that this important issue was not lost or forgotten and of ensuring that the HPC standards are in line with current thinking on SUI. A disadvantage is the concern that some courses and professions may struggle to adhere to the standard, at least in the short term, meaning their programmes may not get validated and professional discontent with the HPC may arise.

3. ***Recommend that all HPC regulated professions should include service users in the design and delivery of education and training, but stop short of introducing a standard***

This option would have the benefit of keeping the issue on the agenda but not risk professional discontent with the HPC and programmes failing to get validated. A disadvantage is that it does not ensure any definite change in the activities of education providers and may lead advocates of a standard to question the commitment of the HPC to this issue.

4. ***A standard would be developed but not introduced until a specified time in the future***

This option would have the benefits of allowing institutions time to develop plans for the involvement of service users while ensuring that the issue does not get 'lost' or forgotten. A disadvantage, from the perspective of advocates of a standard, is that this option still delays the implementation of a standard.

Fundamental to any SET, and strongly reflected in these data, is that any SET should not be a 'tick box' exercise or encourage tokenism. The SET should be encouraging of a 'meaningful' level of service user involvement. With reference to our continuums, see figure 1 (page 9), 'meaningful' refers to the extent to which service users are involved and/or the level of influence that they have over an aspect of education.

In terms of standards, the following options were developed by the consensus workshop participants:

1. ‘Service users are actively involved in the design and/or delivery of the programme with supporting evidence.’

2. ‘The design and delivery of the programme must be influenced by service users, carers and representatives.’

3. ‘There must be a service users’ group which considers that it has had appropriate input into the management, design and delivery of the course.’

It is not however for the research to give particular weighting to the relative merits of these options.

It is worth noting that, whilst respondents across the different forms of data collection were of the view that SUI in both design and delivery were important, there was a focus on the perceived benefits that service users could bring to the classroom. Students and teachers both believed face-to-face contact, in the classroom, made the teaching/learning more ‘real’ and meaningful. There was a concern, from some teaching staff, that service users may not have the required expertise to participate in some aspects of teaching and/or the design of a programme. Overall, there was consensus that service users should be involved in education and training of students on HPC approved courses.

5.6 Limitations of the research

Most surveys attempt to have a response rate of 60% and this work was no exception with three reminder emails having been sent by HPC. The response rate to the on-line survey, 35%, was not as high as we would have liked, but in keeping with most surveys. This response rate means that one should err on the side of caution when making generalisations from the research. The low response rate also prevented comparisons between professions. That said, the research is still the largest investigation into SUI in HPC professions.

The research looked at perceived benefits and facilitators of, and barriers to, SUI. It would be useful to undertake research which evaluated the impacts of the various benefits, facilitators and barriers to identify those which were key.

Our intention had been to compare and contrast experiences and views between service users, students and staff across the three professions in the case studies. However, the limited involvement of service users directly engaged with the HPC approved programmes we chose for our case studies, prevented this comparison. The inclusion of service users with experience of contributing to the education and training of social workers meant that we did achieve good SUI overall. Although social workers were not one of the intended target groups for this study, they are relevant given that, from August 2012, the HPC is due to become responsible for the regulation of social workers in England. The challenges encountered in the recruitment of service users to this research mirrors that experienced by education institutions when trying to involve service users.

References

Advocacy in Action with staff and students from the University of Nottingham (2006). Making it our own ball game: Learning and assessment in social work education. *Social Work Education* 25 (4), 332-346

Agnew A and Duffy J (2010) Innovative approaches to involving service users in palliative care social work education. *Social Work Education* 29 (7), 744-759

Allain L, Brown HC, Danso C, Dillon J, Finnegan P, Gadhoke S, Shamash M and Whittaker F (2006) User and carer involvement in social work education – a university case study: Manipulation or citizen control? *Social Work Education* 25 (4), 403-413

Anghel R and Ramon S (2009) Service users and carers' involvement in social work education: lessons from an English case study. *European Journal of Social Work* 12 (2), 185-199

Atkinson S and Williams P (2011). The involvement of service users in nursing students' education. *Learning Disability Practice* 14 (3), 18-21

Barnes D, Carpenter J and Dickinson C (2006). The outcomes of partnerships with mental health service users in interprofessional education: A case study. *Health and Social care in the Community* 14 (5), 426-435

Bassett T, Campbell P and Anderson J (2006) Service user/survivor involvement in mental health training and education: Overcoming the barriers. *Social Work Education* 25 (4), 393-402

Branfield, F (2007) *User involvement in social work education: Report of regional consultations with service users to develop a strategy to support the participation of service users in social work education*. Social Care Institute for Excellence, London

Branfield, F (2009) *Developing user involvement in social work education*. Social Care Institute for Excellence, London

Brown I and Macintosh MJ (2006) Involving patients with coronary heart disease in developing e-learning assets for primary care nurses. *Nurse Education in Practice* 6, 237-242

Butler A (2007) Students and refugees together: Towards a model of practice learning as service provision. *Social Work Education* 26 (3), 233-246

Collier R and Stickley (2010) From SUI to collaboration in mental health nurse education: Developing a practical philosophy for change. *The Journal of Mental Health Training, Education and Practice* 5, 4: 4-11

Cooper H and Spencer-Dawe E (2006) Involving service users in interprofessional education narrowing the gap between theory and practice. *Journal of Interprofessional Care* 20 (6), 603-617

Corbin J (1986) Coding, writing memos, and diagramming. In *From practice to grounded theory; a qualitative research in nursing* (Chenitz WC and Swanson JM eds), Addison-Wesley, California, pp102-120

Costello J and Horne M (2001) Patients as teachers? An evaluative study of patients' involvement in classroom teaching. *Nurse Education in Practice* 1, 94-102

Council for Healthcare Regulatory Excellence (2010) CHRE performance review report 2009/10 http://www.chre.org.uk/satellite/311/

Darzi A (2008) High quality care for all: NHS next stage review final report. London: Department of Health

Davis D and McIntosh C (2005) Partnership in education: The involvement of service users in one midwifery programme in New Zealand. *Nurse Education in Practice* 5, 274-280

Department for Education and Skills (2004) *Every child matters: Change for children.* The Stationery Office: London

Department of Health (1999a) *Patient and public involvement in the new NHS.* London: The Stationery Office

Department of Health (1999) *The National Service Framework for Mental Health.* Department of Health

Department of Health (2000) *The NHS Plan.* London: The Stationery Office

Department of Health (2001) *The expert patient: A new approach to chronic disease management for the 21st century* London: Department of Health

Department of Health (2002) *Requirements for social work training*

Department of Health (2004) *The NHS improvement plan: Putting people at the heart of public services.* London: The Stationery Office

Department of Health (2005a) *Commissioning a patient-led NHS.* London: The Stationery Office

Department of health (2005b) *Independence, well-being and choice: Our vision for the future of social care for adults in England*. London: The Stationery Office

Department of Health (2006a) *Our health, our care, our say: A new direction for community services.* London: The Stationery Office

Department of Health (2006b) *From values to action: The chief nursing officer's review of mental health nursing.* London: Department of Health

Department of Health (2007) *Trust, assurance and safety – the regulation of health professionals in the 21st century.* London: The Stationery Office

Department of Health (2008) *Real involvement: Working with people to improve health services.* London: The Stationery Office

Dogra N, Anderson J, Edwards R and Cavendish S (2008) Service user perspectives about their roles in undergraduate medical training about mental health. *Medical Teacher* 30, 152-156

Downe S, McKeown M, Johnson E, Koloczek L, Grunwald A and Malihi-Shoja L (2007) the UCLan community engagement and service user support (Consensus) project: Valuing authenticity, making space for emergence. *Health Expectations* 10, 392-406

Eagles JM, Calder SA, Nicoll KS and Walker LG (2001) A comparison of real patients, simulated patients and videotaped interview in teaching medical students about alcohol misuse. *Medical Teacher*23, 5: 490-493

English National Board (1996) *Learning from each other*. English National Board, London

Fadden G, Shooter M and Holsgrove G (2005) Involving carers and service users in the training of psychiatrists. *Psychiatric Bulletin* 29, 270-274

Felton A and Stickley T (2004) Pedagogy, power and SUI. *Journal of Psychiatric and mental Health Nursing* 11, 89-98

Fox J (2003) Consumerism 2: Preregistration nursing and midwifery curricula. *British Journal of Nursing* 12 (6), 378-386

Frey JH and Fontana A (1993) The group interview in social research. In *Successful focus groups* (Morgan DL ed), Sage, London, pp20-34

Frisby R (2001) User involvement in mental health education: Client review presentations. *Nurse Education Today* 21, 663-669

General Medical Council (1993) Tomorrow's doctors: Recommendations on undergraduate medical education. GMC, London

General Social Care Council (2005). Towards full participation. GSCC, London

Glaser BG (1992) *Basics of grounded theory analysis.* Sociology Press, California

Greco M, Brownlea A and McGovern J (2001) Impact of patient feedback on the interpersonal skills of general practice registrars: Results of a longitudinal study. *Medical Education*35, 748-756

Gupta A and Blewett J (2008) Involving service users in social work training on the reality of family poverty: A case study of a collaborative project. *Social Work Education* 27 (5), 459-473

Gutteridge R and Dobbins K (2010) Service user and carer involvement in learning and teaching: A faculty of health staff perspective. *Nurse Education Today* 30, 509-514

Haeney O, Moholkar R, Taylor N and Harrison T (2007) SUI in psychiatric training: A practical perspective. *Psychiatric Bulletin* 31, 312-314

Haffling AC and Hakansson (2008) Patients consulting with students in general practice: Survey of patients' satisfaction and their role in teaching. *Medical Teacher* 30, 622-629

Hanson B and Mitchell DP (2001) Involving mental health service users in the classroom: A course of preparation. *Nurse Education in Practice* 1, 120-126

Happell B, Pinikahana J, and Roper C (2003) Changing attitudes: The role of a consumer academic in the education of postgraduate psychiatric nursing students. *Archives of Psychiatric Nursing* XVII (2), 67-76

Happell B and Roper C (2002) Attitudes of postgraduate nursing students towards consumer participation in mental health services and the role of the consumer academic. *International Journal of Mental Health Nursing*11, 240-250

Happell B and Roper C (2002) Promoting consumer participation through the implementation of a consumer academic position. *Nurse Education in Practice* 2, 73-79

Happell B and Roper C (2003) The role of a mental health consumer in the education of postgraduate psychiatric nursing students: the students' evaluation. *Journal of Psychiatric and Mental Health Nursing* 10 (3), 343-350

Health Professions Council (2011) Service user involvement in the design and delivery of education and training programmes (Education and Training Committee, 10 March 2011)

Health Professions Council (2012) Management Information Pack, Marc Seale, Chief Executive & Registrar, Report to Council meeting 9 February 2012

Hickey G and Kipping C (1998) Exploring the concept of user involvement in mental health through a participation continuum. *Journal of Clinical Nursing* 7, 83-88

Higgins A, Maguire G, Watts M, Creaner M, McCann E, Rani S and Alexander J (2011) SUI in mental health practitioner education in Ireland. *Journal of Psychiatric and Mental Health Nursing* 18, 519-525

Horacek TM, Salomon JE and Nelsen K (2007) Evaluation of dietetic students' and interns' application of a lifestyle-oriented nutrition-counselling model. *Patient Education and Counselling* 68, 113-120

Jha V, Setna Z, Al-Hity A, Quinton ND and Roberts TE (2010) Patient involvement in teaching and assessing intimate examination skills: A systematic review. *Medical Education* 44, 347-357

Jones C (2006) Involving service users in teaching advanced clinical skills. *British Journal of Nursing* 15 (8), 462-465

Jones D, Stephens J, Innes W, Rochester L, Ashburn A and Stack E (2009) Service user and carer involvement in physiotherapy practice, education and research: Getting involved for a change. *New Zealand Journal of Physiotherapy* 37 (1), 29-35

Krueger RA (1994) *Focus groups: A practical guide for applied research.* Sage, London

Lathlean J, Burgess A, Coldham T, Gibson C, Herbert L, Levett-Jones T, Simons L and Tee S (2006) Experiences of service user and carer participation in health care education. *Nurse Education Today* 26, 732-737

Lazarus PA (2007) Patients' experiences and perceptions of medical student candidates sitting a finals examination. *Medical Teacher* 29, 484-489

Le Var RMH (2002) Patient involvement in education for enhanced quality of care. *International Nursing Review* 49, 219-225

Livinston G and Cooper C (2004) User and carer involvement in mental health training. *Journal of Continuing Professional Development* 10, 85-92

Masters H, Forrest S, Harley A, Hunter M, Brown N and Risk I (2002) Involving mental health service users and carers in curriculum development: Moving beyond 'classroom' involvement. Journal of Psychiatric and Mental Health Nursing

McAndrew S and Samociuk GA (2003) reflecting together: Developing a new strategy for continuous user involvement in mental health nurse education. *Journal of Psychiatric and Mental health Nursing* 10, 616-621

McKeown M and Malihi-Shoja L (2010) *Service user and carer involvement in education for health and social care*. Wiley-Blackwell, Chichester

Mohler MJ, D'Huyvetter K, Tomasa L, O'Neill L and Fain MJ (2010) Healthy aging rounds: Using healthy-aging mentors to teach medical students about physical activity and social support assessment, interviewing, and prescription. *Journal of the American Geriatrics Society* 58, 2407-2411

Monrouxe LV, Rees CE and Bradley P (2009) The construction of patients' involvement in hospital bedside teaching encounters. *Qualitative Health Research* 19, 918-930

Morgan A and Jones D (2009) Perceptions of service user and carer involvement in healthcare education and impact on students' knowledge and practice: A literature review. *Medical Teacher* 31, 82-95

Morrow E, Boaz A, Brearley S and Ross F (2012) *Handbook of SUI in nursing and healthcare research.* Wiley-Blackwell, Chichester

Nursing and Midwifery Council (2010) Pre-registration nursing education in the UK. NMC, London

Ottewill R, Demain S, Ellis-Hill C, Greenyer CH and Kileff J (2006) An expert patient-led approach to learning and teaching: the case of physiotherapy. *Medical Teacher* 28(4), 120-126

Perry J and Linsley S (2006) The use of the nominal group technique as an evaluative tool in the teaching and summative assessment of the inter-personal skills of student mental health nurses. *Nurse Education Today* 26, 346-353

Porter E, Hayward M and Frost M (2005) Involving service users and carers in healthcare education. *Community Practitioner* 78 (9), 327-330

Potter M, Gordon S, Hamer P. (2004). The Nominal Group Technique: A useful consensus methodology in physiotherapy research. New Zealand Journal of Physiotherapy, 32(3) 126-130.

Quinn-Patton M. (2002) *Qualitative Evaluation and Research Methods (3rd ed)* California, Sage

Rees CE, Knight LV and Wilkinson CE (2007) 'User involvement is a sine qua non, almost, in medical education': Learning with rather than just about health and social care users. *Advances in Health Sciences Education* 12, 359-390

Reinders ME, Blankenstein AH, van der Horst HE, Knol DL, Schoonheim PL and van Marwijk WJ (2010) Does patient feedback improve the consultation skills of general practice trainees? A controlled trial. *Medical Education* 44, 156-164

Repper J and Breeze J (2007) User and carer involvement in the training and education of health professionals: A review of the literature. *International Journal of Nursing Studies* 44, 511-519

Rhodes CA and Nyawata ID (2011) Service user and carer involvement in student nurse selection: Key stakeholder perspectives. *Nurse Education Today* 31, 439-443

Rush B (2008) Mental health SUI in nurse education: A catalyst for transformative learning. *Journal of Mental Health* 17 (5), 531-542

Rush B and Barker JH (2006) Involving mental health service users in nurse education through enquiry-based learning. *Nurse education in Practice* 6, 254-260

Schneebeli C, O'Brien A, Lampshire D and Hamer HP (2010) SUI in undergraduate mental health nursing in New Zealand. *International Journal of Mental Health Nursing* 19, 30-35

Simons L, Tee S, Lathlean J, Burgess A, Herbert L and Gibson C (2007) A socially inclusive approach to user participation in higher education. Journal of Advanced Nursing 58 (3), 246-255

Simpson A, Reynolds L, LightI and Attenborough J (2008) Talking with the experts: Evaluation of an online discussion forum involving mental health service users in the education of mental health nursing students. *Nurse Education Today* 28, 633-640

Skills for Health (2007) Enhancing quality in partnership: Healthcare education QA framework. Skills for Health, Leeds

Skilton CJ (2011) Involving experts by experience in assessing students' readiness to practise: The value of experiential learning in student reflection and preparation for practice. *Social Work Education* 30, 3, 299-311

Skinner J (2010) *Valuing service users and carers in education: Evaluation report*. Faculty of Health and Social Care Sciences. Kingston University and St George's, University of London

Speers J (2008) SUI in the assessment of a practice competency in mental health nursing – stakeholders' views and recommendations. *Nurse Education in Practice* 8, 112-119

Stevens S and Tanner D (2006) Involving service users in the teaching and learning of social work students: Reflections on experience. *Social Work Education* 25 (4), 360-371

Stickley T, Stacey G, Pollock K, Smith A, Betinis J and Fairbank S (2010) The practice assessment of student nurses by people who use mental health services. *Nurse Education Today* 30, 20-25

Stickley T, Stacey G, Smith A, Betinis J, Pollock K and Fairbank S (2011) Developing a service user designed tool for the assessment of student mental health nurses in practice: A collaborative practice. *Nurse Education Today* 31, 102-106

Supporting People
http://www.serviceuserinvolvement.co.uk/whatisit_laderOfP.asp?id=1

Taylor I and Le Riche P (2006) What do we know about partnership and service users and carers in social work education and how robust is the evidence base? *Health and Social care in the Community* 14 (5), 418-425

Thomson D and Hilton R (2011) An evaluation of students' perceptions of a college-based programme that involves patients, carers and service users in physiotherapy education. *Physiotherapy Research International* doi: 10.1002/pri.510

Townend M, Tew J, Grant A and Repper J (2008) Involvement of service users in education and training: A review of the literature and exploration of the implications for the education and training of psychological therapists. *Journal of Mental Health* 17 (1), 65-78

Tyler G (2006) Addressing barriers to participation: SUI in social work training. Social Work Education 25 (4), 385-392

United Kingdom Central council for Nursing and Midwifery (1999) Fitness for practice – the UKCC commission for nursing and midwifery education. UKCC, London

Whitehead C and Harding T (2006) Excellence in education: Involving the patient, clinician and commerce. *Gastrointestinal Nursing* 4 (4), 10-15

Viyayakrishnan A, Rutherford J, Miller S and Drummond M (2006) SUI in training: The trainees' view. The Psychiatrist 30, 303-305

Wright K and Brown C (2008) Considering the 'client' not the 'problem' – an evaluation of client-led nurse education. Journal of Psychiatric and Mental health Nursing 15, 864-867

Appendix A

A summary of research articles reviewed for this project.

Profession	Authors	Purpose/aims	Methods
Dieticians	Horacek et al (2007)	Evaluation of dietetic students' and interns' application of a lifestyle-oriented nutrition-counselling model.	Supervising registered dieticians and students (n=99) evaluated transcripts of the counselling sessions using a modified Dietician's Interviewing Rating Scale. Service users (n=108) evaluated counsellors' skills.
Physiotherapy	Ottewill et al (2006)	Explore third year physiotherapy students' experiences of a teaching session led by expert patients.	Semi-structured interviews with students (n=6).
Physiotherapy	Thomson and Hilton (2011)	Evaluation of students' perceptions of a programme involving patients, carers and service users as facilitators of learning.	Grounded theory approach. Three focus groups with students (n=10, 8,12) and semi-structured interviews with students (n=7).
Psychological therapy	Dogra et al (2008)	Exploration of service user perspectives on the role of service users in the delivery of teaching psychiatry.	Four focus groups (n=28 service users including one carer).
Psychological therapy	Vijayakrishnan et al (2006)	Exploration of trainees' attitudes towards SUI in training.	Survey of trainees (n=52).
Social work	Skilton (2011)	Review of the development of an experiential learning exercise designed to involve service users and carers in assessing students' readiness to practise.	Two evaluations. Evaluation one: verbal feedback from students during a lecture; questionnaire to students (n=39); individual consultation of experts by experience as well through the Service User and Carer Steering Group. Evaluation two: questionnaire to students (n=58).
Social work	Agnew and Duffy (2010)	Comparison of two methods of user involvement employed with undergraduate and post qualification students.	Questionnaire to undergraduate students (n=12) and postgraduate students (n=12).
Social work	Anghel and Ramon (2009)	Evaluation of the involvement of service users and carers in the training of	Case study. One-cycle action research design. First year students completed baseline and end of year

Profession	Authors	Purpose/aims	Methods
		an undergraduate degree course.	questionnaires (n=167). In the second year students were involved in focus groups (n=22). Service users and carer consultants were interviewed in the second year of the course (n=15). Lecturers were interviewed in the first year (n=13) and completed questionnaires in the second year (n=11). Project advisory group (for the course) was interview in the first year (n=15). Practice teachers were interviewed in the first year (n=22).
Social work	Branfield (2009)	Consultation exercising to find out from service users how their involvement in social work education had been going.	Data gathered from: four group discussions with service users (n=33); wrote to 1,300 service users and their organisations to ask if they were involved in social work education and training and, if not, would they like to be; emailing 300 service-user controlled organisations them to describe their experiences around training social workers.
Social work	Branfield et al (2007)	Consultation exercise on service users' views on SUI in social work education.	Five group discussion with service users (n=36).
Social work	Taylor and Le Riche (2006)	A knowledge review of partnership working with service users and carers in social work education.	In-depth research review. Primary data was also collected via a survey asking programme directors (of graduate and/or postgraduate degree providers) to provide copies of 'operational literature' (n=33); four focus groups with undergraduate students (n=15) and postgraduate students (n=15). Four focus groups with academic staff and practice educators (n=10); three focus groups with service users and carers (n=25).
Medical	Monrouxe et al (2011)	Investigation of doctors' bedside teaching encounters	Case studies of six BTEs. Analysis of six transcribed BTEs.
Medical	Mohler et al	Assessment of the use of healthy older adult mentors	Assessment form completed by

Profession	Authors	Purpose/aims	Methods
	(2010)	to provide students with an opportunity to gain a broader understanding of health ageing.	students (n=26) and mentors (n=31).
Medical	Reinders et al (2010)	Assessment of whether an additional patient feedback training programme leads to better consultation skills in general practice trainees (GPTSs) than regular communication skills training, and whether process measurements predict the effect of intervention.	Controlled trial where GPTs were allocated to an intervention group (n=23 gpts) or a control group (n=30 gpts). Trainees were assessed by simulated patients who videotaped the consultation at baseline and after three months. Eight trained staff members used the MAAS-Global Instrument to assess any changes in trainee consultation skills.
Medical	Haffling and Hakansson (2008)	To investigate a) patients' attitudes to consultations conducted by senior students b) enquire into patients' perceptions of their teaching role	Questionnaire survey of patients (n=495).
Medical	Rees et al (2007)	Examines the views and experiences of stakeholders concerning user involvement in medical education.	Eight focus groups of service users (n=19), medical students (n=13), medical educators (n=15)
Medical	Lazarus(2007)	Identifies the perceptions and opinions of patients (who have been involved in consultations with students) of students, and whether these may be used to enhance the training of students	Loosely structured group interview (n=5) and semi-structured single interviews (n=8) with patients.
Medical	Eagles et al (2001)	To compare three methods of teaching medical students about alcohol abuse.	Questionnaire survey (two measures of attitudes towards alcohol abusers and a questionnaire tailored to assessment of the teaching session) of students following the three methods of teaching (n=156).
Medical	Greco et al (2001)	To examine the impacts and implications of different models of systematic patient feedback on the development of general practice (GP) registrars' interpersonal skills.	Longitudinal study in which GP registrars (n=210) were randomly assigned to three models of patients' feedback: a control group and two intervention groups. Questionnaires were used to collect data from GP supervisors (n=104).

Profession	Authors	Purpose/aims	Methods
Nursing	Rhodes and Nyawata (2011)	Evaluate an innovation where service users and carers were involved in the recruitment of child and adult nursing students	Questionnaire survey of nursing candidates (n=80). Semi-structured interviews with service users (n=4), carers and academics (n=6).
Nursing	Collier and Stickley (2010)	A consideration of the collaboration between nursing educationalists and service users.	Participatory action research. Data collected via analysis of documents, questionnaires, focus groups, interviews and participant observation.
Nursing	Schneebeli et al (2010)	Evaluation of service users involved in a mental health nursing course.	Questionnaire survey of students (n=30).
Nursing	Stickley et al (2010)	Assessment of SUI in the practice assessment of student nurses.	Participatory action research. Interviews with students (n=23) and service users (n=16).
Nursing	Gutteridge and Dobbins (2009)	Evaluation of the impact of service user and carer involvement on learning and teaching.	Semi-structured interviews with teaching and administrative staff (n=20).
Nursing	Rush (2008)	Investigate the impact of SUI in the classroom on student nurses' practice and the underpinning mechanisms and contexts.	Group interview with students (n=7). Semi-structured interviews with student nurses (n=26), service users (n=12).
Nursing	Simpson et al (2008)	Evaluation of an online discussion forum involving mental health service users in the education of nursing students	Semi-structured interviews with service users (n=12) and students (n=13).
Nursing	Simons et al (2007)	Evaluation of a Service User Academic post in mental health nursing in relation to student learning and good employment practice in terms of social inclusion.	Observational case study. Data also collected via Included group discussions with a user and carer reference group (n=6), students (n=35). Four in-depth interviews with the Service User Academic (n=1). S semi-structured interviews with lecturing staff (n=10).
Nursing	Rush and Barker (2006)	Evaluation of the involvement of mental health service users in nurse education through enquiry-based learning	Written evaluations from students (n=26).

Profession	Authors	Purpose/aims	Methods
Nursing	Speers (2007)	Investigation of the views of stakeholders about the potential involvement of service users in the assessment of student mental health nurses' competence in forming therapeutic relationships.	Semi-structured with service users (n=5). Focus groups with lecturers (n=2), mentors (n=6), ex-students (n=4) and student nurses (n=7).
Nursing	Brown and Macintosh (2006)	Evaluation of patient involvement in the development of computer-based learning materials.	Twenty-four patients. Data collected from process notes, recording of meetings, telephone contacts and oral and written feedback obtained from the patients (n-24) and students (n=10). Questionnaires were used to collect data at the end of the project.
Nursing	Perry and Linsley (2006)	Evaluation of a module using approaches to the teaching and assessment of interpersonal skills.	Annual nominal group technique with students (n=36) over three years.
Nursing	Felton and Stickley (2004)	Exploration of mental health nurse educators' perceptions of the involvement of service users in preregistration nurse education.	Semi-structured interviews with lecturers (n=5).
Nursing	Happell et al 2003	The impact of a mental health consumer academic on the attitudes of postgraduate psychiatric nursing students towards consumer participation.	Longitudinal questionnaire survey. Questionnaires to postgraduate students prior to training (n=25) and after training (n=19).
Nursing	Happell and Roper (2003)	Evaluation of the consumer academic role in teaching within the postgraduate diploma in Advanced Clinical Nursing.	Questionnaire to students (n=21).
Nursing	McAndrew and Samociuk (2003)	Evaluation of a method (service users and students jointly reflecting upon mental health issues) of SUI in the preparation of mental health nursing students.	An evaluative case study with features of action research. Data collected via participant observation, non-participant observation, audio taped reflective sessions, field notes and written evaluations after each reflective session. A pre-study attitudinal survey to post graduate students (n=7), service users (n=5) and researchers (n=2).

Profession	Authors	Purpose/aims	Methods
Nursing	Masters et al (2002)	Evaluation of the process of developing partnerships between service users and carers and education professionals..	Questionnaires to lecturers (n=6) service users n=3), carers (n=2), students (n=2), a user organisation manager (n=1) and an education manager (n=1).
Nursing	Happell et al 2002	The impact of a mental health consumer academic on the attitudes of postgraduate psychiatric nursing students towards consumer participation.	Longitudinal questionnaire survey. Questionnaires to post graduate students prior to training (n=25).
Nursing	Costello and Horne (2001)	Evaluation of the participation of patients in classroom-based teaching within a pre-registration programme.	Case study design. Discussions with patients (n=3) and questionnaires to students after each of the three sessions (23 students and 67 questionnaires were returned).
Mental health courses: Psychiatrists, nurses, social workers, psychologists, occupational therapists, speech and language therapists.	Higgins et al (2011)	Exploration of SUI in mental health practitioner education in Ireland.	Questionnaire survey of course coordinators/directors (n=137).
School of health sciences; physiotherapy, medicine, occupational therapy, nursing and social work	Cooper and Spencer-Dawe 2006)	Investigate the involvement of service users in the delivery of interprofessional education (IPE) for undergraduate students	Students' reflective narratives (n=63). In-depth interviews with service users (n=10). Focus groups with IPE facilitators and their trainer.
Faculty of health; nursing, midwifery, social work, postgraduate medicine and allied health professionals.	Downe et al (2007)	To develop and evaluate service user, carer and community involvement in health and social care education.	Participatory action research. Data collected at four stages of a meta-cycle: planning, action, observation and reflection. Tools for data collection: project notes, field notes, minutes of meetings, audiotapes of meetings, interviews with project staff, evaluation sheets.
Mental health – post qualification programme.	Barnes et al (2006)	Five year evaluation of a post qualifying programme in community health in England which sought to develop	Participant observation, interviews with students (n=23), group interviews with students (n=18), group interviews with students'

Profession	Authors	Purpose/aims	Methods
		partnerships with service users.	managers (n=13) student ratings of knowledge and skills at the beginning and end of the programme (n=49), service users' ratings of care provided by students (n=120). A comparison of quality of care, and mental health and quality of life outcomes were compared to those for two comparison groups (n=44).
Faculty of health and social care	Skinner (2010)	Evaluation of the implementation of service user and carer involvement in a faculty of health and social care.	Interviews with academics (n=5), a carer (n=1) and an administrator (n=1). Group interview with service users and carers (n=3). Analysis of documentation.
Faculty of health and social care	Wright and Brown (2008)	Evaluation of SUI in problem-based learning (PBL).	Evaluation questionnaire to students (n=45)
Nursing	Jones (2006)	Exploration of the views and experiences of NHS service users in a clinical skills programme for postgraduate nurses	Semi-structured interviews with service users (n=6)

Appendix B

A matrix of indicators for service user involvement in the field of Health and Social Care Education

Dietetics

Research	Type of involvement	Benefits	Facilitators	Barriers
Horacek et al (2007). USA. Evaluation of counsellors' abilities to effectively apply a lifestyle-oriented nutrition-counselling model. Subject under-grad & post-grad (n=121). Clients (n=108) A post survey method.	Service users evaluating a nutrition counsellor's skills and effectiveness.	-	-	-

General

Research	Type of involvement	Benefits	Facilitators	Barriers
Repper and Breeze (2006). Review of 38 papers.	Various forms across the range of papers	Users: Cathartic Increase in confidence and self-worth	Requires on-going commitment and motivation Involvement initiatives single course rather than organisational strategies to be approached at a systems level ie	SU remuneration Orgs develop systems for training and support Information about the

Research	Type of involvement	Benefits	Facilitators	Barriers
		Feeling of empowerment Can influence content, teaching methods/personnel to ensure their priorities are reflected Students: Hearing real life experiences enhances understanding	involvement in selection of staff and students, development of portfolios of courses, planning of curricula and delivery and assessment of training.	implications of SU involvement, the role of the involved SU and their rights Teachers/academics worried threat to their role. Ethical concerns re users advocating something that would compromise professional accountability and users having to revisit a painful experience
Higgins et al 2011. Ireland. Questionnaire survey – 149 returned, 137 valid. 37% of courses had SUI. Of 50 courses with SUI 90% of involvement was teaching about their experiences. 63% of courses planned and delivered without consultation or input from service users/carers ie level 1 of Tew et al's (2004) ladder of involvement.	Mental health. Included psychiatrists, nurses, social workers, psychologists, occupational therapists, speech and language therapists. '…current service user involvement in mental health education in this study is limited to tokenism in planning and delivery with little involvement in programme management, recruitment and selection or the assessment of students' work.' P523	Difficult to determine as SUI was tokenistic	Commitment, time, strategic planning as well as the financial resources and infrastructures to support such an initiative	Raised concerns about: Training on committee procedure Clarifying technical language Designating time during the meetings for service user input Flexibility of approach Respecting and listening to service users' views Negotiation fair payment for participation Putting service users in a

Research	Type of involvement	Benefits	Facilitators	Barriers
				position of authority on the committee Providing mentors and access to peer group support Addressing prejudice and stigma
Porter et al (2005). Not research but rather identifies principles of best practice which value and respect the views of those in receipt of healthcare.		Highlighted the role of education and training in appreciation of SUI	Reinforces the need for public policy – SUI in service delivery	Highlighted the need for confidentiality of personal information - due regard for the rights of SUs and carers. Users and carers to be adequately prepared Users and carers to expect adequate remuneration Educationalists can expect training in preparation or SUI especially with eg children and young people etc Informed consent of service users and carers
Morgan and Jones 2009. Literature review of the involvement of service users in healthcare education – pre and post reg.	-	-	-	-

Research	Type of involvement	Benefits	Facilitators	Barriers
Jha et al 2010. Review of studies involving real patients (RPs) and simulated patients (SPs) in the training of health care professionals in intimate examination skills. Includes USA, Sweden, Canada, UK, Austria and Belgium. Undergraduates, post grads, practising clinicians.	The authors identify various drivers: - Use of SPs addresses some of the drawbacks of learning from RPs in clinical settings eg feelings of inhibitions - Use of manikins lacks realism, unable to provide feedback, does not emphasise interpersonal skills - Anaesthetised patients involves obtaining informed consent plus lack of feedback from patients, and can focus on technical skills only - Empowering patient to achieve enhanced health information	Improved clinical performance Positive evaluative of the teaching programme (learners, patient, faculty staff); Learner – enhanced understanding of doctor/patient relationship, immediate and constructive feedback on performance, less threatening than examining RPs, facilitated better understanding of the examination process. Patients – embodied knowledge of their own bodies, promoted a proper approach to intimate examination, redrew private boundaries and active partnership with learner, feeling confident, doing something meaningful. Faculty staff – students came to clinics better prepared in technical and communication skills, savings re instructor and faculty staff time	Patient selection: Use existing groups. Advertise in newspapers or via posters Use existing training bodies Purposive recruitment of subjects Training of patient-teachers: Teaching, assessment and providing feedback Sustainability of the training programmes: Payments to patients	Some evidence of no improvement re either technical performance scores or changes in distress on examination Students found it distasteful to examine healthy volunteers and could not ask questions; some students less anxious while practising on manikins Difficulties in rescheduling sessions Reports from GTAs of relationship problems, increased risk of vaginal infections, reports from teaching associate simulated patients of discomfort during genital and rectal examination
Cooper and Spencer-Dawe (2006). England. Interprofessional education (health and social care) at both pre and post-reg levels.	Trained service-users co-facilitated with practitioners (including from medicine, nursing, health visiting, physiotherapy and social	Students: Addresses need to bridge gap between academic and practice	Students: Need exposure to a variety of service users	Inadequate information for SUs Implication/role

Research	Type of involvement	Benefits	Facilitators	Barriers
Evaluation focussed on narrowing the gap between theory and practice. Data collected from students' reflective narratives (n=63), focus group with practitioners and individual semi-structured interviews with service users (n=10).	work).	Increase awareness of patient-centred approaches to care Linked theory to real life experiences Located teamwork theory in context Improve interprofessional communication skills Service users: Sharing of life skills, experiences and personal expertise Provides a link between theory and practice Encourages interprofessional communication Personifies patient-centred approach to care Facilitators (?Benefits): Service users had provided a service user centred focus for students Service users provided real life example of how they had learnt	Better role clarification More time for discussion Needed early in training Service users: Clarity of info on aims of IPE and their role Clarity of info on role and responsibilities of co-facilitators More time for discussion with students Support with admin tasks eg students' names, movement around building Facilitators: Recruitment should be based on a clear person spec based on the perceived benefits to students' education Provide service users with opportunities to withdraw	responsibilities Admin support Training for service users Recruitment process

Research	Type of involvement	Benefits	Facilitators	Barriers
		Through experience, helped emphasise the value of interprofessional team working Service users provided added value in relation to learning, particularly communication	Greater clarity of roles and responsibilities Training in how to work with co-facilitators	
Livingston and Cooper 2004. UK. Literature review	Mental health. Use of carers and SUs in teaching	Benefits to carers and users: Allows people to learn more about themselves Provides a sense of personal satisfaction Empowers the individual Increases confidence Enables them to earn money Provides a positive use for people's illness Acknowledges their expertise Improves their understanding of mental social service staff Offers an opportunity to help future patients	Promoting active SUI	
Downe et al 2007. England. Participative action research.	A Faculty wide community	Relationship building/trust	Accessibility:	Need to make launch event material accessible. More

Research	Type of involvement	Benefits	Facilitators	Barriers
Covers the early stages of the project – recruitment.	engagement project.	Description of illness experience	Involving a wide range of health and social care groups demanded a significant investment of time and energy. Spent time with people, to build up trust, prior to setting up advisory group	pics and simpler language needed Time
Carpenter 2006. England. 5 year evaluation of post qualification programme. Participant observation, 23 individual and 18 group interviews with students and their managers (n=13), student ratings of knowledge and skills at end of programme (n=49), quality of care of students rated by service users using a questionnaire (n=120). Quality of care and mental health and quality of life outcomes compared with two comparison groups (n=44) where no training ad taken place.	Mental health. Post qualification. Users involved in commissioning or programme, evaluation, trainers and course members.	Students: Service users offered an alternative Changes in knowledge and skills: knowledge gained about working from a service user and family perspective led them to review their own practice Changes in attitudes: students reported seeing things from the service user perspective. Changes in behaviour: awareness of the imbalance of power had made students conscious of sharing decision-making and a needs-led approach. Students introduced changes to the workplace eg setting up and running of service user groups.	Workshops to train service users in presentation skills. Pair service user trainer with an experienced member of staff. Annual development day to discuss students' feedback with service-user presenters. Support group for service users who contributed to programme. Commitment to partnership working needs to be explicit and evident from the start. Constant reminder of the programme's partnership aims in the make-up of the mgt board, staff team student body and	SU teaching skills/ ability to give feedback Lack of respect from other lecturers Preparation for teaching staff for when SUs become unwell Tokenism

Research	Type of involvement	Benefits	Facilitators	Barriers
		Outcomes for users as service recipients: service users (compared with comparator groups) improved significantly over 6 months in terms of their social functioning and life satisfaction.	programme content means that partnership working was integrated into student's learning experience.	
Skinner 2010. England. Interviews with 7 academics, 1 admin, 1 carer. Group iv with 3 service users and carers; analysis of 21 docs	Evaluation of SUI in a faculty of health and social care. Student and staff recruitment; teaching sessions; attending or chairing meetings; curriculum development; student assessment; staff training; meeting reviewers and commissioners.	Service users and carers: being listened to and respected - Empower - Role - Impact SUC are viewed as having a positive impact on students' learning and preparedness for practice SUCI in student recruitment highly valued by staff.	Support for SUC Leadership necessary for such organisational change Need a dedicated infrastructure to support SUCI eg payment systems A comprehensive and strategic policy	Ethical aspects of involving vulnerable people Lack of diversity of service users The costs and benefits of SUC becoming professionalised Time consuming; SUI champions taking on role on top of existing workload
McKeown et al 2010. England.	SUI across a range of faculty activity initiative within University of Central Lancashire.	Integrated involvement which impacts on all faculty activity	Providing adequate information for SUs	Hierarchies that exclude Stigma and discrimination Validation and accreditation processes Academic jargon and put-downs Clever people/clever excuses

Research	Type of involvement	Benefits	Facilitators	Barriers
				Classifying knowledge Individual. Not a team approach Gaining access in the first place Bureaucratic payment systems Lack of support for trainers/educators

Medicine

Research	Type of involvement	Benefits	Facilitators	Barriers
Lazarus 2007. England. Group and individual interviews of patients who had participated in examination diets	Summarises findings from a study which asks about users' perceptions of students.	-	-	-
Monrouxe et al 2009. England.	About the role that patients play in 'bedside teaching encounters.'	-	-	-

Research	Type of involvement	Benefits	Facilitators	Barriers
Eagles et al 2001. Scotland. Questionnaire survey (n=156) students – assessed a measure of knowledge, two measures of attitudes towards alcohol abusers and an assessment of the teaching session. Rationale – doctors perform poorly in treating patients with alcohol problems and this has been linked to inadequate undergrad education.	Comparison of teaching using simulated patients, real patients and videotaped interviews.	-	No differences in end of session knowledge levels or attitudes.	No difference in students level of knowledge or attitudes Live patients simulation was rated as significantly better than real or videoed interview with regard to interview skills.
Haffling and Hakansson (2008). Sweden. Questionnaire of patients' attitudes to consultations conducted by senior students and patients' perceptions of their teaching role. (n=495) General practice setting. Less about user involvement and the benefits etc and more how they felt about consultation with students and the role they had re teaching students.	Patients involved in consultations.	Patients perceived that they facilitated the development of professional skills and appropriate attitudes Patients learn more about their problem Case thoroughly reviewed Feelings of altruism	Offers patients opportunity to talk Benefits for patients can be enhanced by strengthening their teaching role, respecting their views and valuing their feedback	Future consultations for some would be conditional on type of complaint; younger women especially had problems in seeing students for emotional problems; patients reluctant to let a student perform an intimate examination
Mohler et al 2010. USA. The goal was to provide undergrads with an opportunity to gain a broader and evidence-based understanding of healthy	Students engaged in one-on-one conversations with healthy older adult mentors and practised assessment, interviewing and prescription	Students gained important practice in health promotion assessment, interviewing and prescription counselling Reinforced the importance of		

Research	Type of involvement	Benefits	Facilitators	Barriers
aging. Students (n=26) and mentors (n=31) completed an end-of-session evaluation form.	counselling for physical activity and social support. Role play	health promotion to participating senior members		
Reinders et al 2010. Netherlands. Controlled trial, two sub-cohorts of general practice trainees gpts (n=23 intervention group; n=30 control group). Trainees assessed following video recording with simulated patients were assessed by 8 staff members using the MAAS-Global Instrument. Rationale for research: concerns re conventional teaching because gpts have been shown to demonstrate no improvement in communications skills during training.	Patient feedback programme. Project assessed if a patient feedback programme led to better consultation skills in general practice trainees (gpts) than regular communication skills training.	No data collected from service users	No data collected from service users	The patient feedback programme did not improve consultation skills more than regular communication skills training.
Rees et al 2007. USA. Examines views and experiences of 47 stakeholders (19 service users, 13 medical students, 15 medical educators) concerning user involvement in medical education. 8 focus groups.	The medical school employs real and simulated patients as teachers and assessors. However, ad hoc rather than strategic.	Students develop and maintain humanism/ clinical and communication skills/ways of knowing/ 'partnership' relationships with patients Service users feelings of empowerment	Use 'patient' only when referring to individuals using acute medical services Recognise no clear consensus/preferred terminology of individual	Concerns about: Students acceptability and accessibility of support mechanism for students Detrimental impact on service users' psychological

Research	Type of involvement	Benefits	Facilitators	Barriers
		Opportunity to influence medical education and 'shape' future doctors Therapeutic to talk to students Receiving more time and attention from clinical teachers Institution: Fulfilling social accountability agenda of school	users Who: Include a wide variety of individuals and groups (ensures students learn about diversity) Clear, ethical policies regarding selection and recruitment Include service users as teachers, assessors, curriculum developed and evaluators Include SUs in conversation between medical educators and students about their healthcare/University, clinical setting and service users' own environment Additional support for SUs When: Involve SUs throughout the programme Simulated patients to begin	well being Should be paid appropriately for their time Training for SUs Students develop stereotyped view of service users (the service users involved tend to be educated and articulate) Time required to train, brief and debrief Service users feeling 'used' or it interfering with their health/treatment Service users participating for personal and negative reasons Tokenism

Research	Type of involvement	Benefits	Facilitators	Barriers
			with then later for more challenging experiences eg breaking bad news SUI User involvement is complex and depends on student development, service users' illness journeys and broader curriculum Adequate support to students (re anxiety, upset) Adequate training, payment and support for users Ensure a safe, comfortable and healthy environment in which service users can work with students	
Greco et al 2001. Australia. Longitudinal study. 'Doctors' Interpersonal Skills Questionnaire administered to patients. Three groups – control group who received feedback at the end of two terms (pre and post-test), a serial feedback group who in addition to pre and post-test received feedback at other intervals, a third group who	GP registrars' interpersonal skills as they progressed through a GP vocational training programme.	Patient feedback interventions made a statistically demonstrable difference in interpersonal skills (listening skills, ability to elicit concerns and fears, time given to patients' reassurance) But not explanation skills, consideration of patient context, concern for a patient as a person, warmth of greeting, respect shown to	A greater focus on preceptor skills is likely to enhance the effectiveness of systematic patient feedback	

Research	Type of involvement	Benefits	Facilitators	Barriers
received the same feedback as the serial group and also got feedback from their supervisors.201 GP registrars, 104 GP supervisors, 28,156 patients		patient.		

Midwifery

Research	Type of involvement	Benefits	Facilitators	Barriers
Davis and McIntosh 2005. New Zealand. Not research but a description of user involvement in various aspects of midwifery training.	Contribution to the curricula Programme monitoring Development and strategic planning Recruitment of students and staff Student clinical experience and assessment	-	-	-

Nursing

Research	Type of involvement	Benefits	Facilitators	Barriers
Rush 2008. England. Semi-structured interviews with 26 student nurses and 12 service	Users involved in classroom learning. Mental health.	12 students were identified as undergoing a transformative learning process.	Hearing the lived experience of service users	Preparation of Service users to undertake teacher role

Research	Type of involvement	Benefits	Facilitators	Barriers
users, group interview with 7 students		Awareness of power relationships Make less assumptions about service users	The emotional impact The reversal of roles Reflection by the students Training/preparation for service users Important that learning took place in the classroom – they learnt from the patient in the classroom rather than about the patient (on placement) - Equal status in the classroom.	Payment/reimbursement for Service users
Simons et al 2007. England. Observational case study of a service users academic post. Participants: user academic, 6 members of a user and carer reference group, 10 educators, 35 students. Data collected by group discussions and interviews.	Service User Academic. Mental health.	Raised the social esteem of academic team A strong, positive role model for students More widespread inclusion of service users in all aspects of the curriculum.	Address personal support needs so that work did not contribute adversely to postholder's well-being	Tension between academic staff and service user regarding their roles. Academic resistance. Other staff may abdicate their responsibility re user involvement.
Simpson et al 2008. England. 10 service users interviewed, 13 students. Enquiry –Based Learning - . Rationale – develop positive appreciation and empathic understanding among	Service user involvement via an online discussion forum. Mental health.	Students improve communication and computer skill Improve linkage of theory to practice Understanding of users'	SU feeling valued Contribution towards positive change in the attitudes of staff and the delivery of mental health	SU computer literacy

Research	Type of involvement	Benefits	Facilitators	Barriers
mental health service users.		experiences of admission to hospital and of being spoken to/interacted with in a particular way Gave SU a 'voice' SU gained confidence in using computers SUs valued and taken seriously Improve SU confidence and self esteem	services	
Stickley et al 2010. England. Participatory Action Research: focus groups and individual interviews od students, qualified nurses and service users	Assessment of student mental health nurses in practice.	Increased mental health nurses' insight into the experiences and consequence of using mental health services 1:1 interactions enabled the development of therapeutic relationships between service users and students	Trusting relationship between the students and Service User Assessor The successful incorporation of service users in the assessment of student practice depends on a more positive and professional valuation of students	The assessment process was not proscribed and so some students developed strategies to avoid risk of receiving critical feedback Some SUAs reluctant to give critical feedback Some students had difficulty accepting negative feedback
Gutteridge and Dobbins 2009. England. Interviews with 20 members of staff.	Investigated the impact of service user and carer involvement on learning and teaching.		Leadership and direction – strategic leadership needed to ensure effective systems and adequate resources and also to drive creative	User involvement needs planning and preparation

Research	Type of involvement	Benefits	Facilitators	Barriers
			solutions and sharing of good practice, evaluative and continuing development Links and networks: need to identify appropriate people, gain access to local SU networks	Organisational and cultural barriers: identifying and supporting training without being patronising or unrealistic; some users may not have a 'phone or bank account etc. Staff did not have adequate time or resources to facilitate all aspects of SUI. Payment and reimbursement
Rush and Barker 2006. England. 26 students provided written evaluations of their experiences.	Mental health. Service users and carer involvement in Enquiry-based learning.	Service user involvement strengthens EBL Added an inspirational factor	Small groups enabled everyone to contribute Facilitators had experience of EBL, facilitating and working with service users Support for service users before, during and after each session	Teacher time
Rhodes and Nyawata 2011. Questionnaire to nursing candidates (80), semi structured group interviews with service users and carers and also academics	Recruitment of adult and child nursing students.	Help students understand what would be expected in clinical practice Service users have opportunity to influence future nurses/influence who would be chosen	Funding to maintain the scheme Respecting the expertise of SUs	Attitudes of academic staff threatened by users on 'their territory'. Who should have final say?

Research	Type of involvement	Benefits	Facilitators	Barriers
		Make candidates think of service users as 'real people' Enabled SUs to feel valued/ personal development	SU personal development	Issues of confidentiality ie users having access to candidates' personal details. Concern about the 'quality' of service users if the scheme is to be expanded.
Stickley et al 2011. England.	Mental health. Development of a service user designed tool for the assessment of student nurses.	SU perspective to the assessment process	Changed name to 'student nurse reviewer' and the term 'assessment' with 'review' Training for SUs Reviewers may require support from students' mentors	SUs feel awkward with the title 'service user assessor'; it challenged traditional positions of power Students vulnerability and powerlessness SUs support Expertise of SUs
Lathlean et al 2006. England Service user academic: case study design – interviews with service user academics, 35 students/trainees; 6 members of the user group; 10 academic staff	Service user and carer reference group; provides advice on curriculum development, assisting in the planning and delivery of curricula. Service user academic post Co-operative inquiry which sought to engage service users in the clinical decisions of mental health student	SU group a 'culture carrier' – shared belief in the value of participation as an essential contributing factor to organisational change toward more user centred services Service users academic initiative: raised esteem of the academic team (students and lecturers); knowledge source for staff and students and prompting others on the involvement agenda; provided	Budget and other resources A culture of true participation with constant vigilance	Time to attend regular meetings and take part in planning and presenting events Stigmatising nature of the title; mixed excitations of role ie expected to take a lead in the involvement agenda but had none of the time consuming responsibilities of a lecturer. Therefore, not fully integrated into overall

Research	Type of involvement	Benefits	Facilitators	Barriers
	nurses	an optimistic model of service users for students		education delivery.
Jones 2006. England. Semi-structured interviews with six service users	Teaching advanced clinical skills.	Sense of being valued by students (empowering) Sense of inclusion/empowerment Sense of improving future healthcare initiatives Opportunity for service users to learn and grow	-	
Schneebeli et al 2010. New Zealand. Questionnaire survey of students (30)	Mental health nursing students. Service users teaching.	Normalised the experience of mental illness 'Real' Challenged stereotypes	-	Adherence to medical model
Speers 2007. 24 stakeholders were interviewed or focus groups (semi-structured) (5 service users, 2 lecturers, 6 mentors, 4 ex-students and 7 student nurses)	Mental health. Assessment of practice	Service users: Enhanced student learning Better patient care Empowerment/respect for service users	For service users the development of a therapeutic relationships depended upon trust and the ability of students to listen Allow service users to remain anonymous if they wish feedback via an intermediary (eg mentor)	Nurses could become demoralised SU ability to give fair/honest feedback Potential lack of confidentiality/ anonymity Students may pick and choose the feedback they share with mentors or the

Research	Type of involvement	Benefits	Facilitators	Barriers
		Stronger validity of assessment Nurses: Enhances student confidence Enhances validity of assessment Philosophical fit with user empowerment Improved service provision	might provide for a more balanced/constructive means of providing feedback Mentors to help students reflect on feedback Ensure service users are free to opt in or out of the assessment and feedback process Offer service users a choice of methods and safeguards re their involvement	service users they approach for feedback Potential for SU to be fearful about the repercussions of giving negative feedback Concern that users may feel obliged to participate against their will and thus have damaging consequences for them
Collier and Stickley 2010. England. 40 service users, a series of focus groups	Mental health. Evaluation of the philosophy of Participation in Nurse Education project.	Leadership/commitment	SU support	Funding
Atkinson and Williams 2011. England. Not research – rather a description of the benefits and challenges.	Learning disability. User and carer input on a learning disability training programme.	The presence of service users and carers makes the issues 'real'; also candidates can gain greater insights into the role Service users and carers can sometimes notice things about candidates that other interviewers have not picked up on	Educational establishments should produce formal benchmarks that encourage inclusion but protect against exploitation	SU support

Research	Type of involvement	Benefits	Facilitators	Barriers
Brown and Macintosh 2006. England. E-learning course focussing on prevention and management for people with heart disease. Evaluation involved analysis of data from process notes recording meetings, oral and written feedback from volunteers and students (who tested the new materials)/ Short questionnaires at end of project. (24 volunteers and 10 students)	Involved in the development of computer based learning materials. Part of project steering group (4) and contribute their experience to learning materials (24).	Volunteers got sense of altruism/ Feeling valued Students gain insight into patients' perspective	Supportive context for sharing experiences and the comfort of participants	Involvement can bring back memories of difficult and sensitive issues
Whitehead and Harding (2006). England. Evaluation and development of a gastrointestinal and liver post-qualifying diploma/degree module.	Patients involved (along with commerce and clinicians) in a conference within the module.	-	-	-
Felton and Stickley 2004. England. Semi-structured interviews with 5 lecturers.	Mental health. The intention was to explore mental health lecturers'' perception of the practice of involving service users in pre-reg education of mental health nursing students.	Students gain insight into the experiences of service users	Need for support mechanism if involved in teaching Authors identify the need to address power issues – adopting the role of 'teacher' implies a power shift	Anxiety provoking for SUs Unrepresentative of client group/ an individual view point can be presented Difficulties in contacting service users Issues of payment Lack of clarity about what the advantaged were (to

Research	Type of involvement	Benefits	Facilitators	Barriers
				lecturers) Tokenism Threat to role of lecturers 'professionalised' service users have little to contribute – too distanced from their experiences Inequality of power between service users and educationalists puts service users at a disadvantage
Wright and Brown 2008. User and carer led group. England. Students perception of a PBL involving a scenario from a letter by a service user with mh issues compared with traditional PBL Questionnaire - 45 students	Letter from service user as a scenario in PBL. Development of educational told	Increased students learning opportunities A helpful learning approach Relevant to practice/real experience for students Majority thought it more appropriate Majority thought it more interesting	-	-
Frisby 2001. England. Rationale – raise students' awareness of client-centred perspectives. Not	Mental health. Users evaluating students' client review presentations.	SUs feel empowered Students gain an insight into service user	Developing effective working relationships with user orgs.; discuss issues of concern, negotiate	SU biased toward a non-accountable position which, if carried through, might reflect

Research	Type of involvement	Benefits	Facilitators	Barriers
research.		perspective/experiences	conditions of service, agree payment; user organisations select appropriate service users (therefore overcoming teachers' concerns/fears that users may be distressed) Time before each session to reflect on previous work, and identify areas where users might most be able to contribute, clarify the user role and help them gain confidence Time and support to deal with revisiting experiences that trigger emotional distress Systematic debriefing of users and lecturers following each session to resolve outstanding issues	unethical practice
McAndrew and Samociuk 2003. England. Evaluative case study. But no findings yet – just a description how they have begun. Participant observation, non-participant observation,	Mental health. Service users join students in a group to reflect on mental health issues.	SU perspective in the development of an approach	A consistent group of service users engaged with a specific student group over a prolonged period of time.	Tokenism Role clarity SU distress

Research	Type of involvement	Benefits	Facilitators	Barriers
audiotaped reflective sessions, field notes, written evaluation after each session. 7 students, 5 service users, two lecturers, two researchers.			Established a job description and person spec for the role Representation not based on diagnostic categories of SU.	Lack of diversity of SU group
Perry and Linsley 2006. England. Nominal group technique. 36 students, over three years.	Mental health. Rationale – concerns re interpersonal skills in nurse education. Evaluation of changes made to curriculum (not specific to SUs). Service users and professionals assessed students' interpersonal skills (videoed role play in which students interviewed a client)		Authors speculate that the small number of comments re user involvement may be an indication that increasing involvement of service users in curricula has served to reduce the threat posed by this type of involvement.	
Happell and Roper 2002. Australia. Not research but personal case study by consumer academic.	Academic role for consumer of mental health services. Post grad.	Students reported thinking about how they could do things differently	Positive course co-ordinator who did not express frustration about students' time being taken up with a consumer perspective	Service user with a negative view of psych nursing
Happell et al 2003. Australia. Questionnaire to postgrad students before (n=25) and after training (n=19). Looked at students' views on consumer participation in mental health service delivery in general and in	Consumer academic. Post grad.	Students' approval rating of consumer involvement improved in all areas surveyed: mental health service mgt, treatment, planning and service delivery, planning and delivery of staff education and professional		'They may abuse the system' re involvement in service delivery

Research	Type of involvement	Benefits	Facilitators	Barriers
psych nurse academia in particular.		development sessions following exposure to consumer academic.		
Happell and Roper 2003 n=23	Consumer academic. Evaluative form to students on completion of semester	Changing attitudes Consumer empowerment Insight into SU experience Impact on practice/increased awareness/understanding Best thing was being taught by user academic Viewing consumers as human beings Challenge assumptions	Social model in place	No benefit No impact No positive aspects Worst thing: Negative portrayal of psych nursing/confronting/ disorganised/ waste of time Ltd to one perspective
Masters et al 2002. Scotland. Evaluation of a strategy to involve service users (3) and carers (2), lecturers (6), students (2) and managers (2) in the design and delivery of a nursing diploma. Questionnaires (n=15)	Evaluation study	Learning new skills Increased self-confidence SU empowerment	Issues rated as important were: Support, information, feedback and knowledge Need for training and support (users and carers on educational systems and curriculum development; lecturers in relation to their lack of experience and knowledge	Financial systems/ benefit issues/reimbursement SU representativeness Training for academic staff Those lecturers not involved in team felt excluded SU expertise Tension for students re teaching the ideal of service user involvement and the

Research	Type of involvement	Benefits	Facilitators	Barriers
			of involvement) High levels of energy and commitment needed to carry project forward	reality the students face in practice
Costello and Horne (2001). England. Case study design. Evaluation. Following a teaching session small group discussions with students plus Questionnaires to 23 students	3 patients participated in classroom teaching. Adult branch.	Student gained an understanding of patient problems Patient found it a cathartic experience Make a contribution to nursing Students gained patient perspective	Success depends upon: Skill of the teacher (teacher and patient discuss their roles in advance; teacher plays role of facilitating students engagement in discussion with patient) Co-operation of the patient Willingness of the student to engage in discussion with the patient in the classroom A 'cooling off' period from the initial contact with patient to enable them to reflect on what is involved in teaching Allow patients to opt out even if they have agreed to take part	Student perspective: The presence of patients can have an inhibiting effect on students Logistics of getting patients to and from classroom Attitudes of other teaching colleagues
Hanson and Mitchell (2001). England. Describes a course to	Mental health.			Power structures militate against equal partnerships; a

Research	Type of involvement	Benefits	Facilitators	Barriers
prepare service users to take an active part in the teaching and learning process				change in culture is necessary to ensure that student nurse education can make a difference to mental health users ie one can make changes in the classroom but this may not impact upon empowerment re service users collectively
Wright and Brown (2008). User and carer led. England. Evaluation questionnaire, 45 students	Students perception of a PBL involving a scenario from a letter by a service user with mh issues compared with traditional PBL	Use of consumer/user seen as potentially advantageous: helping student to appreciate the student as a person and full implication of the patient's healthcare intervention		Difficulty in trying to identify appropriate users Staff unable to identify specific preparation or development to support user involvement in the curriculum
Le Var 2002. Not research. UK.		Encourages participation and debate Curriculum grounded in the reality of human experiences Students learn users' perception of need and responses to it Students learn equality, greater understanding and better interpersonal skills Students self-reflect Students ensure that	Need for strategic approach to users/carers in all curricula and the development of a culture where this is the norm. Careful planning and organisation eg practical arrangements Consideration to selecting suitable people Users/carers should be full embers of curriculum	

Research	Type of involvement	Benefits	Facilitators	Barriers
		patients/clients are able to make real choices	development teams On-going support Communication needs to be open, using straight forward language Time to develop relationship Confidentiality Funding needs to be built into programme#	
Fox 2003. UK. Explored extent to which consumerism had been incorporated into the pre-registration nursing and midwifery curriculum. The issues identified here are from a small group discussion		Use of consumer/user seen as potentially advantageous: helping student to appreciate the student as a person and full implication of the patient's healthcare intervention		Difficulty in trying to identify appropriate users Staff unable to identify specific preparation or development to support user involvement in the curriculum

Physiotherapy

Research	Type of involvement	Benefits	Facilitators	Barriers
Jones et al (2009). England. User refers to patient, carer, client or member of the public. Debriefing interviews take place	Physiotherapy programme's attempt to create a circle of involvement in a UK university.		Need to build trust and be genuine in relationships with patients	

Research	Type of involvement	Benefits	Facilitators	Barriers
with physiotherapy service users and lecturer facilitators.	Notes a dearth in evaluative studies re the benefits of user involvement		The need for coherence between organisational systems and the lives of individuals coping with long term conditions	
Ottewill et al 2006. England. Six students interviewed in depth.	Teaching session led by two expert patients.	Made clear how life altering having a stroke is Because the two patients were so different it emphasised the diversity and individuality of patients Fostered a deeper appreciation of the psychosocial aspects of physiotherapy Recognition that there are limits to professional practice ie where their own competence ends	Make clear at the beginning of the value of insights of someone with direct experience of a particular condition Emphasise that such a session complements clinical placements The setting (classroom) may make it easier for patients to speak more frankly than in a clinical setting	Not sure how much guidance the expert patients had been given re the session Students a little disconcerted and unsettled by format
Thomson and Hilton (2011). England. Evaluation of students' perceptions of the programme, appraising the outcomes of their learning. Grounded theory approach using focus groups (3) and semi-structured interviews (7).	Patients, carers and service users as facilitators of learning. Pre-registration programme. Level 4– patients act as storytellers sharing journeys; also nurtured students' interviewing and clinical reading skills. Level 5 – carers shared experiences of caring for relatives. Level 6 – patients assess students'	Students: made aware of the gap between the knowledge they acquired at university and that required to effectively interact with patients, carers and service users. Opportunity to improve communication skills Challenged their assumptions of	The environment was a half-way house between academia and practice (safe environment) Mentorship – the clinicians and lecturers involved did guide the learning process	

Research	Type of involvement	Benefits	Facilitators	Barriers
	posters on health promotion and discussed and debated critical appraisal of service provision.	patients Empowerment		

Psychological therapy

Research	Type of involvement	Benefits	Facilitators	Barriers
Townend 2008. England. Literature review on user involvement in the education and training of psychological therapists.	Found no articles on service user involvement in psychological therapies			
Dogra et al 2008. England. Four focus groups (28 service users – including one carer).	Undergraduate psychiatry. Explored service users' and carers' views on the role of service users in the delivery of teaching psychiatry.	Helps students see the 'whole person' rather than someone defined by their diagnosis Counterbalances negative stereotypes of mental ii-health Can illustrate the importance of hope and recovery Can help students recognise diversity ie different experiences of mental health problems even within a single diagnostic category	Need for reaching staff to understand a) the potential barriers to involvement (eg potential loss of financial and disability benefits) b) how these can be overcome eg teamwork and support Must be clarity about the purpose of their involvement	Service users need to support to make choices about how much info, and which aspects of their experience, they elect to share Resistance of teachers re lack of expertise and educational credibility Conversely need to recognise that service users aren't experts

Research	Type of involvement	Benefits	Facilitators	Barriers
Fadden et al (2005) UK. Psychiatry training. Not research. Advice and guidance on involving service users			Culture supportive of SUI Openness to service users and carers' must be an integral characteristic through the whole training Develop relationships with different local service user and carer organisations Invite those with tutors experience of carer and user involvement Have a range of SUs involved Have carers and service users presenting together on some topics – different perspectives Preparation eg pre-training workshops. For service users and carers and trainees Clarity of expectations On-going support for service users and carers	Medical model

Research	Type of involvement	Benefits	Facilitators	Barriers
			Information on venue Someone responsible for well-being or person presenting Budget for payment A good chair A debriefing system Thank you letters Follow-up support Preferable to establish an on-going relationship based on trust	
Haeney et al (2007). England. Not research. Trainees complete a feedback form	Psychiatry. Service users involved in teaching supported by a moderator.	Trainees liked alternative viewpoint	Involvement of service users became more structured Recruit a core group of service users and carers More support for those involved Remuneration Feedback Representation of users and carers on the course	Not directly relevant to their exam preparation

Research	Type of involvement	Benefits	Facilitators	Barriers
			board	
Vijayakrishnan et al (2006). England. Questionnaire survey of psychiatry trainees (n=52)	Surveyed trainees for their views on user involvement in teaching, during examinations and in service planning.	67% agreed that user's opinion should be taken into account in examinations	Ensure that patient/user ratings are transparent to the candidate and objective Participate in user-led teaching may allay some trainees' fears	User involvement in examinations; reservations that user's rating not being subjective and indicative of clinical skills of the candidates; stress of an examination situation might render them less empathic than normal; user might dislike candidate or give a deliberately poor rating

Social work

Research	Type of involvement	Benefits	Facilitators	Barriers
Basset et al (2006) (not research). Identified 10 barriers	Mental health			Institutional hierarchies that exclude Stigma and discrimination Validation and accreditation process Academic jargon and 'put-downs' Clever people/clever excuses Knowledge as King and

Research	Type of involvement	Benefits	Facilitators	Barriers
				topics/levels Individual and not team approach Gaining access in the first place Bureaucratic payment systems Lack of support for trainers/educators
Anghel and Ramon (2009). England. Student questionnaires (189), SU carer interviews (15), Lecturer interviews (13), lecturer questionnaires (11), programme advisory group members (15), practice teachers (22)	Involvement of service users and carers in undergraduate training; teaching; co-assess with lecturers students' presentations; admissions process (suggesting questions for admission iv); Information Fair (event that enables students and lecturers the opportunity to meet informally with users, carers and reps of local orgs).	Students: Opportunity to empathise, see them as human beings How theory relates to practice Awareness of impact of social work services and professionals on lives Consultants: A platform for highlighting important issues Lecturers: Counteracted stereotypes Brought students closer to what	Support Infrastructure	Students struggled when service users presented an exclusively negative feedback about social work Consultants: -Lack of briefing and debriefing - Fatigue - Access problems - Time allocation - Better induction re aims, planning and expectations - Wanted a mediation role between students and

Research	Type of involvement	Benefits	Facilitators	Barriers
		was real Information fairs: Gave attendees insight in to issues eg stigma associated with accessing social services		consultants by lecturer to ease tension Lecturers: Insufficient preparation of students; Practice teachers: Most found it difficult to implement the new requirements for service user and carer involvement due to lack of specific policy and training
Taylor (2006). UK. A systematic knowledge review using the Evidence for Policy and Practice Information and Coordinating Centre system. A survey of the teaching, learning and assessment of partnership in prequalifying programmes in England, Wales and NI (document search, 14 telephone interviews; focus groups in 4 unis with students (4 groups: 15 undergrads, 15 post grads), academic staff (4 groups: 10 educators), service users and carers (3 groups: 25 users and	Looked at partnership. 'Few studies though are sufficiently outcome-focused to judge whether partnership education made a difference.' P442	Lit review: Improves the quality of experience for users Improves the quality of practitioners Encourages students to reflect on practice Reduces stereotyping and stigmatisation Improves skills in listening, showing empathy and respect and recognising the strengths and		

Research	Type of involvement	Benefits	Facilitators	Barriers
carers))		wisdom which users bring to the relationship Users feel valued as individuals rather than victims Users think they make a difference to practice in the future Practice survey: Users benefitted from an increase in confidence and self-esteem		
Skilton 2011. England. Evaluation of an exercise whereby students iv service users and carers – SU and carers provide feedback. Evaluation one – verbal feedback from students and questionnaire (n=39); service users and carers consulted individually; module leaders – face-to-face discussion. Students got more preparation re working with service users/carers and self-reflection and analysis of practice. Questionnaire to students (n=58)	'Experts by experience'. Students iv service users and carers (to help with basic communication and self-presentation skills prior to going out on placement) and received feedback from service user and carer...	Evaluation one. Students: encouraged reflection ; encouraged students to consider students and carers as different groups; increased awareness of how to iv; constructive feedback from service users and carers Experts by experience: enjoyed Evaluation two. Students: majority thought it felt 'real'; evidence of transfer of learning; led to reflection on own values and prejudices; most responders thought feedback from service user/carer was helpful/valuable	Preparing, briefing and supporting 'experts by experience'. Support infrastructure	Evaluation one. Students: lack of equity in the level of feedback – eg use of voice box, more positive than that from 'marker'. Experts by experience: some students had difficulty evaluating their own performance; service users and carers needed training on how what they should expect from students and on how to structure and give feedback. Module leaders: differences in expectations of some service users/carers which

Research	Type of involvement	Benefits	Facilitators	Barriers
				affected feedback. Evaluation two: students: some service users/carers too positive with comments
Gupta and Blewett (2008). Not research.	Experiences of attempting to bring together service users, academics and practitioners to develop a module. Families living in poverty.	Planning and adequate funding (includes remuneration, engaging with users from a range of backgrounds) Adequate support and preparation for service users Importance of working in a group (regular meetings) Preparation of social work students (and therefore less defensive towards service users)		
Stevens S and Tanner D (2006). England. Not research. A description of what they did. Accounts from a service user and an academic member of staff.	Various roles in teaching and learning.	Challenged students' expectations and assumptions about service users Improved confidence and self-esteem of service users Service users had a better understanding of concerns and restrictions of social workers Influencing service provision	Time/flexibility and a proactive approach is necessary (eg visit users on their own ground) Tailor support for the diversity of users' needs eg payment, transport Support from intermediary staff eg managers and	Representative – recruiting users affiliated to user led orgs may promote certain viewpoints; need to recognise the strengths and weaknesses of lay users vs expert users Invitations tend to attract less marginalised people Some service users find it difficult to move beyond their

Research	Type of involvement	Benefits	Facilitators	Barriers
			administrators eg finance staff being willing to overcome administrative procedures Acknowledge and value service users' participation eg letter of thanks and certificate Clarity about what is required from service users and make sure they have the skills and values to work in participatory ways	individual agendas
Advocacy in Action (2006). England. Not research. Involves an assessment of the achievements of Advocacy in Action in one social work course – includes user led assessments.		Student benefits: -Reacquaints students with their key motivations to be social workers ie help improve opportunity and life chances Encourage them to think of service users as human beings first Encourage view that social work involves feelings and emotions as well as the ability to think/analyse A corrective to the bureaucratic and procedure driven forms of	University must be willing to accommodate different ways of doing things A university-based contact for students to mediate when students become resistant/uncomfortable re service user educators	

Research	Type of involvement	Benefits	Facilitators	Barriers
		practice Enables a sense of student group cohesion which has advantages in the rest of the academic curriculum		
Allain et al (2006). England. Not research. Article written by staff and service users. A description.	Undergrad and post grad courses.		Meet service users in an environment they feel relaxed in Need to recognise service user/carer knowledge as expert knowledge Workers need to be willing to take ownership of the barriers that prevent service users participation and focus clearly on ways to overcome them.	Transport Childcare costs/carer costs Payment which doesn't interfere with benefit claims Information produced in a format that suits individual requirements Jargon Times of meetings
Beresford et al (2006). Not research. Written by service users.	Looks at user involvement in social work education at national policy level.	-	Need to increase the 'capacity' of service user and user controlled organisations if user involvement is to develop well in social work education Some of the money for user involvement (given to facilitate user involvement	-

Research	Type of involvement	Benefits	Facilitators	Barriers
			in social work education) should go to user controlled organisations and not just to universities	
Agnew and Duffy (2010). NI. Questionnaire to evaluate the teaching session. Students n=12 undergrads, n=12 post grads	Compares two methods of involving service users in pre and post grad social work courses. Students' a) observed and discussed DvD excerpts of people affected by cancer and b) observed a young man sharing his experience of being diagnosed with cancer (facilitated iv).	DvD led to following learning points: The power of hearing real stories from service users The demonstration of integrating theory to practice Importance of seeing the person not the illness Importance of communication skills DvD led to following learning points: importance of hearing the service users' perspective Importance of communication skills Importance of demonstrating respect (particularly for faith) Other comments re whole	-	-

Research	Type of involvement	Benefits	Facilitators	Barriers
		session: Increased confidence of students; demystified assumptions regarding palliative care, increased self-awareness, increased confidence re application of theory and skills		
Branfield F, Berseford P and Levin E (2007) England. A consultation exercise with 36 service users in 5 consultation days. 'Common aims: a strategy to support service user involvement in social work education: social work education position paper 07. Social care institute for excellence		Learn from service users Bridge theory practice gap Practitioners can have assumptions challenged	Universities could: Address issues of equality Address issues of access Develop stronger links with the community Employ more service users on their staff Enrol more service user students Train staff and service users Government could: Allocate secure funding to SU organisations Review welfare benefits in relation to service user	Academics do not attach higher enough value to service users' knowledge Culture of universities: does not embrace user involvement; systems and structures are rigid; staff put up professional barriers Access requirements not fully met Students sometimes disrespectful Service user organisations lack capacity and infrastructure Lack of training and support for service user trainers and their organisations Payment policies, practices

Research	Type of involvement	Benefits	Facilitators	Barriers
			involvement Close all segregated schools Enforce representation of service users in the media Promote social work and social workers in a more positive light Service user organisations could: Network more widely with other service user orgs and publicise themselves better Develop their own training, support and mentoring for service user trainers Coordinate sui and training in social work education through a national user-controlled organisation	and benefits system discourage involvement
Bradfield (2009). Wrote to service users and their groups and four regional events (n=33) Developing user involvement in social work education: Workforce		For service users: -More say and control in services - Better mutual understanding of	Arrange alternative accessible transport Take this into account when drawing up	No accessible transport to training venue Early morning start – for many service users this is not appropriate for many

Research	Type of involvement	Benefits	Facilitators	Barriers
development report 29. Social care institute for excellence		social worker/user perspective For social work students: Help challenge stereotypes leading to better social workers Students learn empathy from direct contact Improves practice	timetables Identify, with service users, what training is needed and ensure it is available Negative attitude and assumptions made by students and staff Being open and receptive to service user knowledge –listening to what service users say	impairment related reasons Inadequate or lack of appropriate training for service users Reimbursement of expenses is very slow Negative attitude and assumptions made by students and staff

Appendix C

Membership of Steering Committee and Advisory Group

Steering Committee

Mary Chambers	-	Professor of Mental Health Nursing
Ann Arber	-	Faculty of Health and Medical Sciences, University of Surrey
Roy Benjamin	-	Service User
Janek Dubowski	-	Principal Lecturer, Psychology, University of Roehampton
Denise Forte	-	Principal Lecturer, School of Nursing
Steven Gillard	-	Senior Lecturer in Social and Community Mental Health
Gary Hickey	-	Research Associate, Faculty of Health and Social Care Sciences
Hansa Jadva-Patel	-	Principal Lecturer in the School of Radiography
Chris Manning	-	Senior Lecturer, School of Rehabilitation Sciences, Faculty of Health and Social Care Sciences
Alan Parker	-	Service User
Christine Skilton	-	Senior Lecturer, School of Social Work, Faculty of Health and Social Care Sciences

Advisory Group

Mary Chambers	-	Professor of Mental Health Nursing
Ann Arber	-	Faculty of Health and Medical Sciences, University of Surrey
Iain Beith	-	Head of School, School of Rehabilitation Sciences
Michael Guthrie	-	Director of Policy and Standards, HPC
Gary Hickey	-	Research Associate, Faculty of Health and Social Care Sciences
Jane Lindsay	-	Head of School, School of Social Work
Sharlie Manning	-	Service User
Graham Morgan	-	Head of School, Radiography & Associate Dean (Learning, Teaching & Interprofessional Developments)

Appendix D

Factors that facilitate SUI

Facilitating factors	**%**
Having a good relationship between education institution and service user organisations	65
Staff value the involvement of service users	61
Ensuring all relevant parties are clear about the roles and responsibilities of service users	59
Students value the involvement of service users	58
Education institution promotes and supports service user involvement	56
Appropriate mechanisms for recruiting service users	56
Briefing/debriefing for service users following any engagement with students	52
Ensuring that the involvement of service users is at a time suitable for them	52
Information provided to service users in an appropriate format	51
There is a culture within the education institution that promotes a willingness to overcome barriers to service user involvement	51
Provide service users with the opportunity to withdraw	49
Support for service users during teaching/training sessions	46
Ensuring that service users have access to/can move around the venue	45
Ensuring appropriate levels of payment for service users	43
Training for service users for their role	42
Adequate time for staff to build trust with service users	42
Staff member(s) with designated responsibility for recruiting service users	40
Staff member(s) with designated responsibility for supporting service users	39
Ensuring service users have transport to get to the venue	37
Ensuring payment system does not have a significantly negative impact on service user benefits	35
Staff given appropriate time and resources to facilitate user involvement	35
Support for students after receiving feedback from service users	31
Ensuring rapid payment for service users	31
Support and resources built into programme planning	27
Training for staff in how to work with service users	21