

# **A qualitative study to investigate service user experience of participating in research**

**by**

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## Abstract

Service user and carer involvement in research and health services is mandated by policy and has been taken up with different degrees of success in the NHS. This study employs a phenomenological approach to consider the service user and carer experience of participating in a service evaluation of a health centre in the North West of England. This was a small-scale study nested within a larger knowledge transfer project. Semi-structured interviews were undertaken with members of the review team, comprising a service user and carer assuming research roles, as well as an academic, an NHS manager and a project coordinator. Data was subject to qualitative, phenomenological analysis. The service user and carer perspectives take centre stage in this thesis, but are framed by the perspectives of the other participants in the study. Findings account for the features and experiences of involvement as described by the participants and exemplify how they made sense of involvement practices. They are structured in three broad themes: Work/Occupation, Personal Identity/sense of self, and Purpose. Several subthemes reflect wider discussion around the key concepts. Work/Occupation comprises the sub-themes: *Motivation/background*, *Professionalism*, *Experience transfer* and *Relations with staff*. Personal identity/Sense has subthemes: *Yearning for a different status*, *Duality of role* and *Fulfilment or reward*. Finally, the Purpose theme was constituted by four subthemes including: *For self/for others* dichotomy, *Opportunity*, *Gaining transferrable skills* and *Social relations/democratic*. Notions of *Professionalism* were prominent in the participants' narratives, both as perceived requirement and personal development opportunity. This contrasts with existing literature in the field of service user and care involvement on professionalism. Competition within a work context is seen as positive and motivating and is not seen as antithetical to cooperative ideals. Reflexivity is found to be an important added dimension for the participating service user and carer.

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## List of Abbreviations

ACHCEW	Association of Community Health Councils England and Wales
C	Carer
CCG	Clinical Commissioning Group
CHC	Community Health Council
DH	Department of Health
EP	Evaluation participant
ER	Evaluation respondents
KTP	Knowledge Transfer Partnership
MHIP	Mental Health Improvement Programme
NCB	National Commissioning Board (presently NHS England)
NHS	National Health Service
NHS BwD	NHS Blackburn with Darwen
NIHR	National Institute for Health Research
PC	Pilot coordinator
PIM	Perspective Involvement Model
PPI	Public and Patient Involvement
SU	Service user
SUCEP	Service user and carer evaluation participant
TSB	Technology Strategy Board
UCLan	University of Central Lancashire
WCC	World Class Commissioning
[...]	Text missing

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# Chapter 1: INTRODUCTION

## 1.1 Background

The study presented in this thesis formed part of a wider research project, a knowledge transfer partnership (KTP) between the University of Central Lancashire (UCLan) and NHS Blackburn with Darwen Teaching Care Trust Plus (NHS BwD). Within this broader project, a specific piloting of a model for supporting sustainable service user and carer involvement was the focus for my MSc studies and is reported on in this thesis.

The piloting of the service user and carer involvement model focused on an evaluation of health services offered at a new health centre. This study explored the perspectives of the team that coordinated and carried out the pilot, including a service user and a carer, employed as researchers, the pilot project coordinator, an academic and an NHS manager. There was a primary focus on making sense of the experience of involvement from the service user and carer perspective but this is also framed by the views of the other participants. This multiplicity of backgrounds provides an array of views on the topic of service user and carer involvement in a research context. The analysis also affords reflection on the legitimacy of the different viewpoints.

In order for the reader to better understand the wider context of this study, the Background section will explain in turn

- what KTPs are;
- the rationale of the UCLan – NHS BwD KTP project;
- the pilot which was organised as part of the wider research project;
- the focus on service user and carer involvement;
- the rationale for the MSc study.

### 1.1.1 Knowledge Transfer Partnerships

KTPs are research and development collaborations between a knowledge base (most commonly a university or research institute) and the host organisation, referred to as 'the company'. Organisations involved in KTPs can be private, public or third sector organisations. KTPs are formed when the company identifies a gap in knowledge and works together with the university on a project of strategic importance. The partnership is facilitated by a KTP Associate, or a research officer, who

liaises between the knowledge base partner and the company and manages the project. KTP projects benefit from continuous input from academics. The academic team ensures academic rigour and supervision of research activity. Company supervisors ensure company strategic needs and interests are at the forefront of the research project, and outcomes are directly aligned to the company's needs and interests (KTP, 2013). KTPs are partially funded through the Technology Strategy Board (TSB), which monitors progress and provides impartial advice to aid partners in the project to achieve the stated outcomes.

The UCLan – NHS BwD KTP commenced in February 2011 and ran for 24 months. The aim was to develop a mechanism to improve efficiency, effectiveness and co-ordination of service users' and carers' contribution and involvement in future health and social care service developments. The prototypical approach for supporting involvement arising from the KTP was named the 'Perspective Involvement Model' (PIM). My role within this partnership was that of KTP Associate<sup>1</sup>.

### **1.1.2 Rationale for the UCLan – NHS BwD KTP project**

As mandated by the NHS Constitution and the Local Government Act (2007), NHS BwD had a statutory obligation to engage with local communities to inform the commissioning of new services. Public engagement was considered to be a catalyst to improve health and social care services (Department of Health (DH), 2005; Coulter & Ellins, 2006). Specifically, public engagement addresses competency 3 in the World Class Commissioning Competencies (WCC): Engage with the public and patients (DH, 2009).

In the North West region, there has been evidence of service users and carers (SUs and Cs) participating in training and education initiatives designed to equip them with the skills necessary for meaningful involvement in health and social care services, as mandated by the WCC framework. Examples include learning within Comensus, an initiative set up by UCLan which facilitates SU and C involvement in teaching, learning and research. The Leadership and Empowerment in Mental Health course organised by Liverpool John Moores University and the Video Diary Room Project, which was undertaken under the aegis of the North West Mental Health Improvement Programme similarly aimed to build capacity amongst service users. The report '*A Better Future in Mind*' (MHIP, 2008) found that efforts have on the whole been uncoordinated, lacking standardisation and the skills of

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<sup>1</sup> KTP Associates are recent graduates selected by academics and company supervisors to cover project management aspects of the KTP. Tasks for KTP Associates can include designing and introduction of new systems, processes, or products. Similarly, tasks can include improving or enhancing existent systems, processes or products with help from academic experts, to improve competitiveness for the company. One of the objectives of the KTP programme is to provide for graduate employment.

the SUs and Cs were often not deployed effectively across public involvement opportunities. The lack of a systematic mechanism to ensure appropriate engagement has meant that NHS and local government organisations within the region have often resorted to contracting out this work to consultancy companies (Smith, 2012).

PIM would offer a solution to this by matching SUs' skills and abilities to extant demand for involvement and institutions' requirements. The existence of a coordinated mechanism would not only result in financial savings on the part of commissioning organisations such as NHS Trusts; involvement of SUs and Cs from the local community would enable statutory organisations to become more relevant to the public they serve and more responsive to their needs. It would also enable statutory organisations to forge closer links with communities and enable individuals to develop and increase chances of recovery in some instances (Carr, 2004; Evans & Jones, 2005, pp. 132 – 139).

A distinctive feature of PIM as envisaged in the model devised throughout the KTP is that PIM would be run as a social enterprise, for instance a co-operative or an employee-owned enterprise. It will be concerned with maximising the benefits for the SUs and Cs involved, and will include socially leaning tenets in the day to day practices and running of the enterprise.

### **1.1.3 Service user and carer involvement: the status-quo**

Health and social care SU and C involvement is a relatively new concept, driven largely by a wave of consumerist ideology from the 1980s onwards (Barnes & Cotterell 2012). Earlier assertions of user voice have been variously grounded in SUs rejecting psychiatric knowledge and existing imposed models of care (Pilgrim 2009; Wallcraft & Nettle, 2009; McKeown et al, 2012), wider disability rights politics (Oliver & Barnes, 1995), or a panoply of differently constituted health social movements (Brown & Zavetoski, 2005). Involvement of SUs and Cs in consultations, planning of the provision of services, service delivery and design is now supported and encouraged through government policy (DH, 2006; DH, 2007; DH, 2011). The outlook and desired relation between SUs and health professionals is that of equal partners in the care process (Trivedi & Wykes, 2002; Breeze & Repper, 2007; Lester & Gask, 2009).

Involvement of SUs and Cs is not without its problems. Currently, academic debate revolves around a number of issues such as perceptions over who has the power in this relationship (Braye & Preston-Shoot, 1999; Chamberlin, 2005), concerns over the 'authenticity' and 'appropriateness' of

the service users' voices being heard (Campbell, 2001) or benefits and hazards to partnership work between researchers and SUs (Trivedi & Wykes, 2002), one of the hazards being the risk of incorporation of user voices (Rogers & Pilgrim, 2005).

Most of the literature in the area of SUs' involvement and experiences is generated and led by academics, health practitioners or health professionals (Knapp et al, 2007; Felton & Stacey, 2008). Academic enquiry into SUs' perceptions, experience and knowledge share (Wedgbury et al, 2005; McKeown, Malihi-Shoja & Downe, 2010) is a recent development in the field, though academic/service user research alliances are now more common in health (McKeown et al, 2010; Gosling & Martin, 2012; Newbigging et al, 2012; "Shaping Our Lives", 2013) and social care (Lavalette, 2011). Latterly, there has been a growth in the first person accounts (Amering and Schmolke, 2009) and user-led research, including inquiry into involvement practices, but this body of knowledge remains proportionately small. This study takes into consideration the available published literature; however, acknowledges the relative paucity of data as far as the views of SUs and Cs are concerned.

The most recent change of government in 2010 did not have a direct impact on the direction of SU and C involvement in public services, reflecting the hegemony of consumerism. The *Equity and Excellence: Liberating the NHS* White Paper reiterated the aim to put patients and the public first (DH, 2010). Developments in healthcare post-2010 moved a step forward, especially following the Francis Report (2013), with the emphasis now being placed on patient centred behaviours such as compassion, respect and dignity in care giving (DH, 2013). SU and C involvement into service design or delivery is not limited to NHS organisations. Further in this thesis (see Chapter 2) there will be a discussion concerned with the rhetoric on SU and C involvement and action. The discussion will consider if rhetoric and action develop in tandem.

#### **1.1.4 Perspective – The Pilot**

The project team agreed that the PIM would make a more valuable contribution to knowledge and practice in health and social care systems if piloted. Congruent with the design of the PIM, the pilot would be run by a local third sector organisation. The aim of the pilot was to undertake an evaluation of the health services offered at a recently opened health centre in the North West of England.

The team discussed the implementation of the principles underpinning the PIM from the recruitment stage to delivering the planned outcome. The planned outcome of the pilot was a report based on an evaluation of the services offered at a newly built health centre. Not only would a pilot confirm the validity of the values and practices recommended in the PIM, it would also facilitate a better understanding of SUs' and Cs' views of the model after testing it, and a better understanding of the SUs and Cs' experience of being part of the service evaluation. An agreement was reached with a local Primary Care Trust (PCT) to carry out an evaluation of the services offered at a recently opened health centre using the PIM.

The role of SUs and Cs employed in the pilot was to recruit and assist patients and public using the health centre to take part in a survey completing questionnaires on their opinions on the health centre. The questionnaires were constructed in the course of the pilot process.

#### **1.1.5 The rationale for the MSc study**

Early work within the KTP project exposed a wide range of SU and C involvement issues, all worthy of further academic exploration. However, the priority was for the development of a feasible model for organising involvement, and an effective pilot was warranted. The piloting process and its evaluation were chosen to be the focus for the MSc studies. Following piloting the PIM and undertaking the literature review, it became clear that analysis of the lived experience of SUs and Cs in the context of a formal partnership, but where they have the autonomy to form their own opinions and are willing to share their views, would make an interesting contribution to the scholarly debate in the field of involvement. A better understanding of the lived experience of being involved is likely to improve outcomes of SU and C involvement, for individuals involved and for other users of health and social care services. It also became apparent that the methodology selected for this study had to allow for the participants' lived experience of involvement to be understood. Phenomenology was considered to be the approach that would best facilitate understanding and explaining participants' lived experience in the PIM pilot (see Chapter 3).

#### **1.1.6 Terminology used**

SU and C involvement is encountered in academic literature and in health and social care practice under different guises. Within a health service context, it is likely that 'Public and Patient Involvement' will be often used to mean the same thing. This is why, depending on the context,

Public and Patient involvement and 'Service user and Carer involvement' will be used interchangeably throughout this thesis.

## **1.2 Research question**

The published literature in the field of user involvement often considers different aspects related to involvement, and often from the viewpoints of outsider observers. What are the main themes of the lived experience of SUs and Cs involved in partnership work with large organisations such as NHS or UCLan?

## **1.3 Research Aim**

The aim of this study was to explore the views of stakeholders involved in piloting the PIM: the SU and C, key personnel in the hosting voluntary sector organisation, relevant members of the KTP team. The emphasis was placed on the experiences of the SUs and Cs of being involved in a context of partnership and working closely with NHS managers and academics.

## **1.5 Summary**

This chapter has firstly set out the background to this study which included the story of how the study came about, and why it has been necessary. In order to achieve this, an explanation has been provided for what KTPs are and what their relation with academia is. A rationale has been offered for the particular topic of SU and C involvement being explored by in this study. The PIM pilot was outlined, and more in-depth information and reference to the pilot will be made in the following chapters. The aim of the SU and C status quo section was to prepare the reader for what can be expected to be the results and the findings. Finally, it was important to set out what this study aims to achieve, and this was outlined in the research question and research aim sections.

## **Chapter 2: LITERATURE REVIEW**

### **2.1 Introduction**

In order to achieve breadth and depth for framing of the topic in question, a wide range of sources including peer reviewed journals, health periodicals, health policy updates and books has been consulted. To ensure relevance, published academic references have been selected using a structured search process which is further explained in the second part of this chapter.

This literature review chapter is structured in two main parts. The first part presents contextual literature. Studies and commentary on aspects such as barriers to involvement, tokenism, power differential and meaningful support inform the debate and provide a general background to SU and C involvement.

In this preliminary section the methods employed for sourcing relevant academic data and analysis were wide ranging. Electronic and hand searching of academic journals and books available in the library of UCLan were main methods. Similarly, a large part of the background literature was based on reading lists suggested by supervisors. Because of the cross-cutting nature of the topic, one of the most effective means to consult relevant literature was following up references from Bibliography lists.

The second part of this chapter presents a structured search for literature and studies directly relevant to the study focus on involvement in research practices, with 13 relevant papers identified.

### **2.2 Contextual literature**

As explained above, the contextual literature section informs the reader with contemporary issued related to SU and C involvement. Inclusion of this literature facilitates understanding of the service user and carer evaluation participants' (SUCEPs) experience in the context of work already published in the field of involvement.

#### **2.2.1 Barriers to involvement**

The literature review provided detailed accounts of barriers to meaningful involvement (Anthony & Crawford, 2000; Felton & Stickley, 2004; Tait & Lester, 2005; Bassett et al, 2006; Tyler, 2006; Gutteridge & Dobbins, 2010; Speed et al, 2012). Similarly, a significant amount of literature outlines

the benefits of involvement, both for service users and carers and organisations willing to involve service users and carers (Lakeman, 2008; McKeown et al, 2012).

Before exploring the views of the participants in the current study, it is important to survey the wider field of involvement in anticipation to issues and difficulties the SU and C might have encountered or perceived throughout the PIM pilot. The wider literature points to several issues that stand in the way of SU involvement becoming a meaningful reality. SU involvement can be categorised into individual and institutional or collective level. At individual level, one of the issues raised which goes towards explaining the inefficiency of involvement is the representativeness of the SUs involved (Forrest et al, 2000; Hodge, 2005a). SCIE (2004) highlights the managerial concern of achieving 'representativeness' in involvement. However, definitions for this term are very difficult to come by. Horrocks and colleagues (2010) raise the difficulty of SUs aspiring to be representatives of either a wider group, or a wider geographic area. Clear parameters for the concept of representativeness continue to be debated. McLaughlin (2009) argues that SUs are not a homogenous group and their contribution is important through the experience, not through representativeness. The requirement of representativeness of service users as a *sine qua non* is seen by Beresford and Campbell (1994), the issue having the potential of being used to devalue and disempower disabled people. Forrest and Masters (2005) support McLaughlin's argument with regards to the futility of attempting to achieve user representativeness; they also recognise that SUs are not a homogenous group.

### **2.2.2 Tokenism**

Tokenism in individual SU involvement is also a much debated problem (Stickley, 2006; Beresford, 2003). The need for forging real partnerships between health professionals and SUs wishing to be involved, rather than a tokenistic approach to SU involvement is widely accepted as the route-map to improve services (Buckley, 2004). Some authors consider the governmental policy has been conducive to tokenism (Bradshaw, 2008) while others question if SUs can really achieve what they want from participation (Hostick, 1998). There are, however, positive views over what is generally considered to be problematic; Stickley allows for the possibility that the debate around tokenism as a concept '[...] means that at least the concept of service user involvement has been recognised' (2006 : 573). Finally, there is an argument that SU involvement needs not be tokenistic if due planning and support has been provided in advance (McKeown et al, 2010 : 18).

The aspect of tokenism can be equated with organisational commitment to user and carer involvement, or the lack of it. Lathlean et al (2006) point to the impact of 'institutional userism', associated with individual 'champions' leaving and changes in funding priorities for organisations, leading to tokenistic involvement.

### **2.2.3 Power differential**

The power differential between the SUs and service providers is another difficulty often cited (Myers & MacDonald, 1996; Simmonds & Birchall, 2005), applicable to both individual and institutional SU involvement. Chamberlain (2005) argues that professionals rarely address the issue of power differential. Hui and Stickley (2007) add that power transfer from the professionals to the SUs would help improve SU involvement. One form in which the power differential manifests itself is the attitude of health care or other professional staff to service users and carers. Lyons and colleagues (2009) report on SUs and Cs feeling discriminated against and being treated in a way that suggests very little understanding on the part of health care professionals. Sheldon and Harding (2010) suggest that the power differential between SUs and health professionals could be addressed if professionals would gain exposure to 'service users' and carers' ideals and practices' throughout their training (p.9). However, Aiken and Thomson (2013) find that when dealing with service user involvement, some staff respond positively, whereas others can display territorial traits. Hodge provides extensive analysis of the power differential between service users and professionals in different contexts; discursive inequalities can reinforce a wider institutional power differential (Hodge, 2005a). Similarly to Horrocks, Hodge (2005b; 2009) and Holloway (2010) argue that skewed power differentials limit the scope of agendas up for discussion.

In the case of social services, Carr (2004) acknowledges in her message for the policy makers the need for organisations to change structurally and culturally in order to allow SU involvement to take place in a meaningful manner. Carr (2004) articulates that the principle has been set. As already addressed above, setting the principle forms part of the rhetoric, and by demanding organisational changes, this is an implied acceptance of the fact that practice has not kept up to speed in the case of SU and C involvement.

### **2.2.4 Meaningful support**

The point of adequate planning, structure and support for service users who are willing to be involved in service delivery, service design, education or training for health staff is one which deserves further attention (McKeown et al, 2010; Wilks & Green, 2010; Morrow et al, 2012 : 91)). In

the North West of England, the work of the Mental Health Improvement Programme (MHIP) highlighted that involvement initiatives have been un-coordinated, lacking sustainability and standardisation. In the context of the research programme, this constituted a solid case for the need of a structured approach to SU involvement, an innovative model of involvement (Seden, 2008) which would consider the lessons learnt from past experiences, as well as the complex requirements of the organisations which have a statutory obligation to involve SUs.

The literature review undertaken for this study demonstrates that although SU and C involvement has been given ample thought from the point of view of process, barriers and challenges, there is little evidence of the meaning to self, or the lived experience resulting from involvement for the individual, which is the main aspect the present study explores.

Simpson and House (2002) undertook a systematic review of studies which provided details on the outcomes of SU involvement in various settings. The literature selected included published work regarding active SU involvement in design and collecting data for research, as well as studies focused on users involved in training of mental health professionals. Their review of 298 papers concluded that while “[...] involving users as employees, trainers or researchers has no negative effect on services and may be of benefit, further similar evaluations are needed”. This review provides valuable information on how involvement impacts on service delivery’ however, there is no mention of what proportion of the studies are from the UK, which is why the results obtained may not be generalised in the context of the UK.

One of the few UK based studies to look exclusively to the outcomes of SU and C involvement (Horrocks et al, 2010) highlights the fact that in the case of mental health services, it is difficult to articulate a link between SU involvement and better outcomes for all. Furthermore, the authors argue that implementation of involvement policy takes place in a symbolic manner. The possibility of creating partnerships is upheld by Horrocks et al as significant. Also, partnerships have the potential to evolve further (Rush, 2004); however, they find no obvious relation between SU involvement and an improvement of services.

The findings of this study relate to public involvement into decision making structures at an individual level. Horrocks and colleagues (2010) follow a case-study approach in order to gain a deeper understanding of the SUs’ experiences involved in the Lancashire Partnership Board (LPB). While their findings are context-specific from the point of view of the locality covered by the study, the analytical aspects of the study can be generalised and there is a degree of transferability to other

similar situations. Contrary to the generally held assumption that mental health SU involvement in the planning, design and commissioning of mental health services will lead to improved services for all, Horrocks and colleagues find that this is not necessarily the case.

Horrocks and colleagues make an important contribution, in indicating that SU and C involvement does not automatically translate in improved health services; more investment into adequate training and support is needed in order for SU and C involvement to be meaningful. Yet again, the analysis of participants' experience of involvement could have helped indicate: a) what the likelihood of being involved in health service delivery would be; and b) what improvements can be made in the engagement process so that SU and C involvement becomes a demonstrable part in improving services.

Crawford and colleagues (2002) undertook a systematic review of research papers and grey literature detailing involvement of patients in the planning and development of health care. The majority of the papers included in their study are UK based research papers. This makes their systematic review both relevant and valuable in assessing the outcomes of SU involvement. The findings of this report are mixed; some service improvement has taken place following involvement of SUs. This cannot, however, be considered to be a clear trend or trajectory. What has been noted following collaborations between SUs and professionals was increased self-esteem on the part of the SUs, improved communication, and promotion of further involvement. The outcomes of two of the papers included in this review were patient and carer dissatisfaction. The two studies confirm and reinforce the suggestion that SU involvement on its own does not automatically result in improved services (Horrocks et al, 2010). In relation to the present study, Crawford's review provides a valuable overview of the evidence base which suggests that in the area of SU and C involvement, evidence on the impact on the quality and effectiveness of involvement is absent, but this should not be interpreted as 'absence of effect'. Qualitative research of individuals' experience of involvement may offer clues as to how to improve SU and C involvement both for the individuals and from the point of view of outcomes for service design, delivery or evaluation.

The search process used in this study revealed no studies using a phenomenological approach and focusing on participation in a formal setting; the contextual literature is important in order to gain an understanding of the wider context and particularities of service user and carer involvement.

### **2.2.5 Summary on governmental policy on service user and carer involvement**

The history of the government's policy of SU and C involvement starts with the establishment of Community Health Councils (CHCs) in 1974 (ACHCEW, 2013), followed by the NHS Community Care Act in 1990 which established the concept of user involvement in community care assessments. More recently, government policy has been vociferously requesting for statutory health and social care organisations to accommodate SU and C involvement (DH, 2006; DH, 2010), and has been emphasising the importance of public engagement in service delivery. Statutory organisations such as the NHS have responded by including pledges to involve the public and patients (NHS Constitution, 2010 : 12). It is, however, questionable if governmental policy is only rhetoric or reality (Waldman, 2005 : 152; Cowden & Singh, 2007; Kemp, 2010 : 23). SU and C involvement rhetoric is stating principles (Simpson & House 2003); and although rhetoric has been dense, it is unclear if involvement activity, or efforts to facilitate SU and C involvement activity, parallels the rhetoric.

There is acknowledgement of the readiness of professional organisations to “publicly encourage the greater involvement of service users (and carers) and acknowledge the legitimacy of experience” (Campbell, 2001). This opinion refers particularly to psychiatric services. In Campbell's view, such rhetoric detracts from reality, from different agendas and imbalances of power.

In 2007 the Local Government and Public Involvement in Health Act (2007) introduced a conceptual legal framework which placed local authorities providing care services under the duty to promote and support public involvement in ‘commissioning, provision and scrutiny of local care services’ (p. 174).

The Equity and excellence: Liberating the NHS White Paper (2010) was among the first documents issued by the government which articulates acknowledgement of the importance of involving patients and public in all aspects of health care. The White Paper recognises limitations of progress in this respect and advocates for the concept of ‘shared decision-making’ to become the norm if the best healthcare outcomes in the world are to be achieved (DH, 2010 : 13).

The most recent major piece of legislation in health and social care, the Health and Social Care Act (DH, 2012) places a duty on health governing bodies such as the National Commissioning Board (NHS England) and the Clinical Commissioning Groups (CCGs) to ensure that patients, their carers or representatives are involved in the decisions related to care and prevention. In the case of CCGs, the

Act stipulates the duty of CCGs to involve public in the planning stage, commissioning stage and in implementation.

In response to governmental policy many service users and carers organisations, NHS Trusts, third sector organisations representing service users and carers and academic bodies have published good practice guidelines for involvement in education and research mainly, but also in health service delivery and design (BPS, 2008; MHRN, 2012). It is questionable if this is a reactive, rather than proactive response to policy activity or if the ample guidelines translate into more and more efficient involvement.

### **2.3 The structured literature search process**

A structured literature search was undertaken, using several research databases, to selectively garner published work relevant to the study focus on service user and carer involvement in research. Papers utilising phenomenology to study service user and carer involvement were also sought. Academic research databases provide the facility to use key words in order to display results directly relevant to the research topic. Three different combinations of keywords and phrases were used in order to capture relevant published academic papers. These were:

1. 'service users and carers involvement' AND 'health and social care services'
2. 'service user and carer involvement' AND 'phenomenology'
3. 'service users and carers' AND 'as researchers'

The research databases used were CINAHL, MEDLINE and PubMed.

The same limiters, or exclusion criteria were used for all the databases consulted, as enumerated below:

- The availability of the source as full text
- The availability of the source in English language
- That articles selected were peer reviewed

The combined search for the three different search combinations yielded a total of 70 results. The full results generated by the search process described above can be found in Appendix F. An initial scanning of the titles and abstracts helped reduce this to 13 articles, as in the table below. The rest of the articles were deselected because their content was not directly relevant.

In order to focus the literature review process, two questions were devised to ensure relevance for selected literature:

- i) Has the experience of SUs and/or Cs in this study been sufficiently detailed to generate an informative narrative?
- ii) Is the study concerned with conveying the meaning of participating for SUs and Cs, or changes in outlook post participation?

The articles sourced through this process were measured against two criteria: a) being able to demonstrate a satisfactory response to one of the two questions listed above; and b) studies included had to have been focused on SU and C involvement in health, health education and research or social care services.

**Table 1: Literature search results**

No.	Year	Authors	Title	Journal	Findings
1.	2012	Webber, M. and Robinson, K	The Meaningful Involvement of Service Users and Carers in Advanced-Level Post-Qualifying Social Work Education: A Qualitative Study	British Journal of Social Work	Webber and Robinson distinguish between four different models of involvement: consultation, partnership, political and user control. The stakeholder group in this study comprised SUs, Cs and social work professionals. The study highlighted difference in perception over what the aim of SU and C involvement in education and the author's view that meaningful involvement for SU and Cs in advanced Social Work education has not yet been achieved.
2.	2011	Benbow, SM et al	Design, Delivery and Evaluation of Teaching by Service Users and Carers	Educational Gerontology	Benbow et al discuss involvement in the context of postgraduate education and highlight the potential subversive nature of teaching, which can be a consequence for both teachers and SUs and Cs involved in teaching activities.
3.	2006	Hall, JE	Professionalizing action research – a meaningful strategy for modernizing services?	Journal of Nursing Management	This article proposes professionalising action research as a vehicle for change for services with poor practice development. The three components of professionalising action research are seen to be the Educative base, Problem focus and improvement and involvement strategies. The main advantage of professionalising action research is its capacity to integrate collaborative reflection in services.
4.	2010	Ridley et al	Partners in care?: views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003	Health and Social Care in the Community	Ridley et al find that carers of people under different compulsory measures were unaware of provisions for carers' assessments and felt unsupported. The authors report carers being in favour for hospital detention at crisis point, rather than in the community and on the impact of the Named Person initiative.

5.	2007	Downe, S. et al	The UCLan community engagement and service user support (Comensus) project: valuing authenticity, making space for emergence	Health Expectations	The authors discuss the process of setting up a SU and C advisory group which comprised four themes: building accessibility; being 'proper' service users/carers; moving from suspicion to trust; and, mutually respectful partnerships.
6.	2012	Lloyd and Carson	Critical conversations: Developing a methodology for service user involvement in mental health nursing	Nurse Education Today	This study is based on service user involvement in education and highlights three aspects valued by SUs involved, namely, universal goals, diverse needs and encouraging recovery as being important.
7.	2012	McKeown et al	The value of involvement from the perspective of service users and carers engaged in practitioner education: not just a cash nexus	Nurse Education Today	This paper talks about the impact of experts by experience being involved in participatory action research, and the three themes derived for individuals following their involvement experience: a more positive sense of self, social and relational benefits and altruism in activism/
8.	2011	Hitchen et al	Lone voices have an emotional content: focussing on mental health service user and carer involvement	International Journal of Healthcare Quality Assurance	This article highlights the experience and findings for SUs and Cs involved in an action research study. The aspects described as barriers to involvement on the part of mental health professionals include professional language, emotional impact and power imbalances.
9.	2009	Jones et al	Illness careers and continuity of care in mental health services: a qualitative study of service users and carers	Social Science and Medicine	This study considered the experiences of relationships, care, continuity and that of transition. The themes emerging in this qualitative study were: relational (dis)continuity; depersonalised transitions; invisibility and crisis; communicative gaps and social vulnerability.
10.	2006	Rapaport et al	Carers and confidentiality in mental health care: considering the role of the carer's assessment: a study of service users', carers' and practitioners' views	Health and Social Care in the Community	This study highlights the importance of carers' assessments in a context where demonstrably, communication between carers, or relatives of people with mental health problems and mental health professionals has been inadequate.

11.	2013	Kroese et al	Mental Health Services for Adults with Intellectual Disabilities - What Do Service Users and Staff Think of Them?	Journal of Applied Research in Intellectual Disabilities	This study, based on initial focus groups followed by interviews with a group of stakeholders comprising staff and service users (adults with intellectual difficulties and mental health problems) makes recommendations based on what desirable qualities are thought to be for staff. Desirable qualities include: being interested; communication skills; competence-promoting support; awareness of past, present and future; regular reviews, early intervention and working with carers.
12.	2004	Allam et al	Commentaries. Our experience of collaborative research: service users, carers and researchers work together to evaluate an assertive outreach service	Journal of Psychiatric and Mental Health Nursing	This study considers a commissioned evaluation of a service by a research team comprising professional researchers and service users and carers. Lessons learned revolved around the need of support for SUs in the research process, NHS Trust) bureaucracy can be a significant barrier', ethics committee procedures, communication, travelling and meeting interviewees in unfamiliar places, training in research skills, time to air anxieties and concerns, time consuming nature of collaborative work. The concluding reflections of the experience revolve around the beneficial outcomes for the SUs and Cs involved, positive sense of self, new skills acquired, increase in confidence and widened horizons.
13.	2010	Wilson et al	A potential model for the first all Wales mental health service user and carer-led research group	Journal of Psychiatric and Mental Health Nursing	This study considers the experience of establishing a service user and carer-led group in a university, and the subsequent training provided on research skills and empowerment as an example of good practice.

## Chapter 3: METHODS

### 3.1 Methodology

The present study aimed to explore the experience of the PIM pilot team – the SU, the C, the PC and the members of the KTP team – the academic, manager, and researcher, with an emphasis on the SUCEPs experience of participating in the evaluation of services at a recently opened health centre. Chapter 3 presents a brief overview of the qualitative research methodologies. Then, it details the research methodology and protocol applied to this study. Finally, the case is made for phenomenology, the research method selected for this study.

This study employed qualitative research methods drawing on phenomenological research principles. Qualitative methods are particularly suitable for social sciences, nursing and health care studies (Bowers, 2013). Avis (2005) argues that reasons why qualitative research is particularly suitable for nursing and healthcare include allowing for understanding emotions, perceptions and actions; interactions and the experience of interactions; the fact that it is person-centred and takes into consideration the whole human being. Phenomenology, within a qualitative enquiry, seeks to uncover the meaning of the experience and is concerned with in depth examination of how participants understand phenomena, situations, or experiences, thus addressing ‘real life concerns’ (Tracy, 2013 : 4). The core of this study is understanding how participants, specifically SUCEPs make sense of the experience of having been involved in a service evaluation, the experience of having participated in a formal partnership. Their perceptions, emotions and interactions are scrutinised in this study, but taking a person centred approach. This is why a qualitative approach to research is suitable in this study.

The most prominent and often used qualitative research methods include ethnographic research, grounded theory, reflexivity and phenomenology. In this study, the research method considered to be most suitable is phenomenology. A very brief description of the individual methodologies will help the reader understand the rationale of this decision.

Murchison (2010) describes ethnography as a ‘research strategy’, concerned with examining cultures and societies, as part of the wider human experience, where the researcher’s experience becomes the lens through which data is gathered and analysed. In this study, the sample is heterogeneous, comprising a SU, a C, an NHS manager, an academic and project manager. It does not represent a population, a community or a culture. An emphasis will be

placed on the SUCEPs experience, which means findings will not be representative of the entire group, or sample.

The basic tenet of grounded theory is that theory can be generated by data which has been systematically gathered and analysed, or '[...] a way of arriving at theory' (Glaser & Strauss, 2012 : 3). Grounded theory as a method is specifically concerned with verification of the theory, or comparing the categories emerging from analysis with the available data (MacDonald, 2001). For the current study, the aim was not to determine a theory, but to understand the lived experience of being involved in the PIM pilot. Considering the heterogeneity of the group and the mix of views anticipated, the grounded theory method was too restrictive to allow for a variety of themes and also, to allow for the reflexive process on the part of the researcher.

The PIM pilot was a new learning experience for all involved in the KTP project, that is, SUCEPs, PC, academics, NHS managers and the researcher. Holloway and Wheeler (2010) argue that reflexivity, which makes explicit the stance of the researcher, is one of the main features of qualitative research. This is why, alongside the phenomenological principles used to analyse the data, a reflexive approach was applied to explore the researcher's learning experience in the PIM pilot as part of the wider KTP project.

Phenomenology was selected as the most appropriate research method to inform the reader on the lived experience of the participants and contribute to the existing body of knowledge on SU and C involvement.

### **3.1.1 Research methodology**

In the following section of this chapter an introduction to Phenomenology as research methodology will be made. Further information supporting the choice of phenomenology as the most suitable method for this study will be provided.

To this day, the question over what phenomenology remains unanswered (Merleau-Ponty, 2002). The term 'phenomenology' has been defined and described in different ways (Earle, 2010). Sion (2009) argues that phenomenology is a less presumptive study of appearance (p.11) whilst Merleau-Ponty (2002) considers phenomenology to be the study of essences, such as the essence of perception or the essence of consciousness. Lewis and Staehler (2010) state that phenomenology is the science of a phenomenon, more precisely, the appearance of

a phenomenon. As yet, there is no consensus over a generally agreed definition. What the different views do have in common is an emphasis on 'appearance'. *Appearance* as conceptualised by Lewis and Staehler in this instance does not refer to *what appears*, but to *how things appear*; in what context, and what constitutes the background to phenomena appearing? Phenomenology is less concerned with analysis and classification, and more concerned with allowing phenomena to exist and develop without interpretation based on prior experience. Phenomenology encompasses accepting phenomena as they appear in the first instance and allowing detail to surface on its own, without being prompted by preconceived ideas. In phenomenology, it is detail that adds richness to individual experience, and at the same time, provides individuality and uniqueness to phenomena of interest to researchers.

A different perspective proposes phenomenology to be the study of experience (Smith et al, 2009). Smith et al build on the significance of experience in individuals' lives by using Interpretative Phenomenological Approach (IPA), which is an approach to qualitative inquiry. IPA is a particularly significant approach in phenomenology which will be discussed in more detail further in this chapter. The authors associate the experience with the way in which individuals make sense of their experiences and hone in on the detail which makes experience meaningful (Smith et al, 2009 : 11) as being key to phenomenology as an approach. Thus, this approach is in keeping with the research question and aim of this study.

Phenomenology has been described as a practice, or a new style of philosophy intent on uncovering the truth and avoiding any constructed perceptions about a phenomenon; a phenomenon has to be understood from within before it can be explained (Moran, 2000). Interpretative phenomenology or hermeneutics is concerned with the meaning and understanding of the context (Charalambous, 2008). This is believed to be a better methodological prism for health sciences, as it generates broader knowledge (Benner et al, 2011). It is acknowledged that phenomenology does not provide predictive or prescriptive theorising; however, thoughtful reflection on the meanings of lived experience can have an impact on practice (Van der Zalm & Bergum, 2000).

In this approach, the role of the interpreter is acknowledged as important (Earle, 2010). On the part of the researcher, it is considered to be essential to have a clear understanding of forestructures, the parts, the whole of the phenomenon and the relation between the parts and the whole, before attempting to understand the studied phenomenon.

### **3.1.2 Why is this approach particularly pertinent to this enquiry?**

In preparation for this study the researcher participated in a seminar conducted by an experienced phenomenologist where a demonstration was made as to how detail and essence can be extracted from a personal account and how listening can help in extracting the essence. In addition, a thorough review of phenomenological theory was undertaken.

The sample used in this study has been purposely selected for their lived experience, be they from the perspective of a service user, academic, or health professional. Van Manen considers phenomenology to describe lived experience (1990). The lived experience of taking part in the PIM pilot is the phenomenon examined by this study, particularly for the lived experience of SUCEPs, making phenomenology a method well suited to this study.

The current study aims to explore the experience of the SU, the C and the PC of participating in the PIM pilot. Emphasis will be placed on the lived experience of the SUCEPs involved in the service evaluation. The SUCEPs include a user of mental health services and a carer. The SUCEPs are part of a wider group of individuals with a dual identity of having accessed health services in the past and with a more recent experience of evaluating a service. McKeown and colleagues (2011) point to the fact that phenomenology is particularly well suited as a research method when perspectives from a certain group are sought.

Dual identity is a common point for all participants in this study. In the case of SU and C, they hold the identity of users or former users of health services, as well as the identity of workers, the latter identity being conditioned by the former. This is to say that participation as worker in the service evaluation pilot would have not been possible, had participants not had prior experience of using services.

By the same token, the academics and professionals who participated in this study have prior experience of caring for service users in mental health settings, researching and teaching different mental health aspects including involvement and being involved in health service delivery.

Phenomenology as a research method facilitates uncovering deeper insights into the duality of being health service user and participant in a service evaluation pilot, or being an academic and at the same time, a participant.

Balls (2009) provides further arguments for a phenomenological approach being best suited for this type of study; she argues that this approach values the individual's experience. This method will enable the different experiences to contribute to building a more accurate picture of participation in piloting a new service. In addition, phenomenology requires listening, understanding and believing, all of which provide an original and in depth account of the experience of participating.

In the context of this study, it is considered that the phenomenon in question is participation in the service evaluation at the health service. Phenomenology as a research method helps to explore in depth the experience of participating in the service evaluation. Further academic guidance from researchers experienced in phenomenology ensured rigorous application of phenomenological principles.

It is conceivable that the experience of academics and professionals participating in the proposed service evaluation might differ to some extent from that of the SUCEPs involved, because of their individual and different perception of reality. Symon and colleagues (2000) propose phenomenology as the research method which allows for and analyses 'different realities'. They acknowledge the difficulty of achieving objectivity and suggest this research method allows different subjective accounts to construct valuable meanings, allowing different perspectives on the same phenomenon. In the same vein, Tudor and Worrall (2006) reinforce this view by pointing out the value of the subjectivity of individual experience, and that individuals bring different filters to the same phenomenon, differently (p. 27-28). The aspect of subjectivity in perceiving and experiencing a phenomenon is important to point out, as it provides early hints to differences in views between participants in the study.

Phenomenology is described by Hycner (1985) as an approach, or a way of analysing data collected which should not be imposed on participants; an imposed methodology might tamper with the integrity of a phenomenon. Based on the principles of listening, understanding and believing, this approach can be considered to be kind and considerate towards participants. This further increases its appeal in this study. Furthermore, phenomenology allows participants to provide personal answers. Participants, who may otherwise find the experience of being interviewed threatening or intimidating, can provide answers in their own time and in their own way.

Dahlberg, Todres and Galvin's work on the lifeworld-led healthcare theory (2009), which is their interpretation of patient-led care, includes a phenomenological framework. In their view,

phenomenology provides an understanding of care which considers ‘complexities of personhood, health and illness’. The SUCEPs who will participate in this study are eligible to do so, that is, to participate, because of their dual identity. Conceptually, the dual identity referred to is akin to Dahlberg and colleagues’ ‘complexities of personhood’ which is why, phenomenology is considered to be the most appropriate methodological framework for this study.

### **3.1.3 Which type of phenomenology?**

This section of the study clarifies the difference between descriptive and hermeneutical phenomenology. Detailing the features of each type explains the choice of hermeneutic phenomenology in this study.

The origins of phenomenology can be traced back to Immanuel Kant. He saw reason (in the sense of understanding) acting as a filter for experience, and therefore, shaping experience and knowledge. Later, Hegel attempted to more clearly articulate Kant’s concepts and named phenomenology as *the science of experience of consciousness* (Sembera, 2007 : 7).

Edmund Husserl (1859-1938) coined the term *transcendental phenomenology*. The new approach developed by Husserl sought to accurately describe acts of consciousness. Sembera (2007) considers Husserl’s phenomenology to be ‘*the descriptive study of foundational structures of consciousness*’ (p. 13). The method of achieving pure descriptive phenomenology involves adopting bracketing out of the world to avoid contamination of knowledge. The innovative aspect of Husserl’s approach is that by using bracketing, accurate, detailed description enables researchers to develop unbiased accounts of phenomena they are describing.

Smith, Flowers and Larkin (2009) describe Giorgi as a proponent of the descriptive approach to phenomenology, who considers accounts of commonality to provide a comprehensive picture of a phenomenon. Smith, Flowers and Larkin (2009) argue that the result of taking a descriptive approach to phenomenology following Giorgi’s approach will lead to entirely different results than using an interpretative approach. Such studies will most likely ‘*take the form of a third person narrative, a synthesized summary statement outlining the general structure for the phenomenon in question*’ (Smith, Flowers & Larkin, 2009 : 200-201).

A variation on the approach was introduced by Heidegger. In his approach to phenomenology, Heidegger considered some of the detail in Husserl's phenomenological approach, but felt necessary to make provisions for complexity of phenomena. This is why Heidegger believed that hermeneutics, or interpretative description better describes experience.

Moran (2000) points out that Gadamer was an influential phenomenologist who brought a new perspective to phenomenology. Under the intellectual influence of both Husserl and Heidegger, Gadamer finds an intrinsic link between phenomenology and hermeneutics; and thus, has an affinity with interpretative, rather than descriptive phenomenology. The view most often associated with Gadamer's philosophy is that understanding is '[...] *the central act by which humans engage with the world*' (Moran, 2000 : 250).

In line with broad philosophical understandings of phenomenology, it is apparent that there are two distinctive approaches: descriptive and interpretative, or hermeneutic.

One example of interpretative phenomenology is the approach adopted by Jonathan Smith who developed the interpretative phenomenological approach (IPA) as a response to the need of supplementing quantitative data with enriching insights. Smith (1996) states that the aim of IPA is to '[...] *explore the participant's view of the world and to adopt, as far as is possible, the 'insider's perspective'* (p. 264) of the phenomenon under study. The IPA approach is thus, directly relevant to this study, as what is hoped to be achieved is an understanding of the SU's and C's perspective, considering their position as insiders.

In this process, Smith acknowledges the importance of the researcher's own conceptions which will provide a filter for the process of interpretative analysis. The researcher's input is complemented by a structured approach to research which includes the following steps:

- Transcripts are read several times and descriptive notes are taken; researcher's initial interpretation is recorded;
- Emerging themes are identified from transcripts and early notes.
- Themes are ordered and clustered.
- Themes are ordered in a table in the best achievable hierarchy (Coolican, 2009).

Another approach is provided by Max Van Manen who applies phenomenology from a human science, pedagogical perspective. Van Manen sees the essence of phenomenological research as being 'a search of what it is to be human' (Van Manen, 1984) and results of it being '*carefully edified thoughtfulness*' (p.36). Van Manen claims that phenomenology is not just an abstract concept; it can only be understood by 'doing it', and he provides a suggested methodological outline for doing phenomenology.

Broadly, the steps suggested by Van Manen aim to bring to the fore what tends to be obscure by:

- Turning to the nature of lived experience;
- Conducting existential investigation;
- Engaging in phenomenological reflection;
- Employing phenomenological writing.

Both interpretive phenomenological approaches described above result in rich insights into lived experience and both could be applied in this study. However, Jonathan Smith's more structured approach is considered to better address the need of understanding what broad themes can be drawn from the experience of participating in a service evaluation pilot, and it is the approach used to analyse the data gathered throughout this study.

### **3.2 Research Method**

This is a qualitative study in which semi-structured interviews were used as a data collection method. The interview as a research method has been described to be 'a purposeful data-generating activity, characterised and defined by the particular philosophical approach adopted by the researcher' (Lowes and Prowse, 2001). Further, the role of the researcher within the interview is emphasised by Wimpenny and Gass (2000) who note that interviews for qualitative research emphasise the dialogical relationship between the researcher and the interviewee, thus acknowledging the importance of the researcher in the research process. Nunkoosing (2005) points to what can be considered to be a downfall of interviews; namely, the issue of truths and authenticity in interviews, or the process of self-censoring interviewees may apply to their narratives. This, however, becomes less of a problem if the attitude applied is that all the information provided by interviewees is equally important and paints a picture of their experience.

The stated aim of this study as outlined in the original research proposal was to gather, analyse and interpret qualitative data from n=6 service users and carers. However, the numbers of SU and C participating in the PIM pilot were less than anticipated at the study design stage, with one SU, on C and the pilot coordinator (PC) from the third sector organisation which conducted the pilot. This was because of low take up to the invitation to participate in the PIM pilot.

### **3.2.1 Ethics**

Approval from the School of Health's Ethics Committee at the University of Central Lancashire was sought prior to contacting participants for this study. The documentation provided for the application included copies of the consent form and the information sheet for the research study. The application to the ethics committee was approved on 10<sup>th</sup> May 2012, Ref. BuSH063 (Appendix A).

The participants were informed about the more detailed study of their experience in the pilot service evaluation and were invited to take place. In addition, participants were provided with information on the wider project, the participation procedure, and the explicit statement that they were able to withdraw from participation at any point and an outline of the questions to be asked.

### **3.2.2 Location and context**

This study took place in the North West of England. Throughout this study there is no assumption of a direct relation between location and context and findings from this study. The SU and C involvement policy which forms the context is one that applies across England. It is also not presumed that the lived experience of the SUCEPs is location-specific, therefore in this study location and context are not believed to impact on the findings.

In order to protect the anonymity of the participants, the names of all the participants have been changed. The third sector organisation that co-ordinated the recruitment process and the running of the PIM pilot is not identified. The precise health centre in the North West where the service evaluation took place is also not identified.

## **3.3 Recruitment**

### **3.3.1 Participants**

In order to gather a broad spectrum of experience and views, participants selected for interviews included a service user, a carer and the pilot coordinator (PC) involved in the service evaluation at the health centre, as well as an academic with an interest in service user and carer involvement and a health service manager with expertise in patient and public engagement. Throughout this study they will be referred to as the Evaluation Participants (EP).

In this study there is an emphasis on the experience of the SU and C involved. In order to distinguish them from the other EPs, they will be referred to as the service user and carer evaluation participants (SUCEPs). Fictitious names have been given to participants in order to preserve anonymity.

**Table 2: Demographics of participants in the PIM pilot**

Gender	Male	√
	Female	√
Ethnicity	White	√
	BME	√
Age range	16-24	
	25-34	√
	35-44	√
	45-54	√
	55-65	
	>65	√
Role	Service user	√
	Carer	√
	Manager	√
	Academic	√
	PC	√

The above table shows the diversity of the participants in this study. Including the academic and the NHS manager and the Project Coordinator (PC), the group included two women with ages between 29 and 50, ethnically diverse (White British and Asian British) and three men aged between 35 and 70, all white British.

### 3.3.2 SUCEPs recruitment

The selection of the SUCEPs was made on a voluntary basis. Details of the PIM pilot were disseminated to members of the third sector organisation selected to run the PIM pilot. Information events were held in different locations throughout North West detailing the involvement opportunity in the service evaluation of health services offered at a new health centre in the North West of England. Any questions members of the network had were answered by Karen Wilks, the PC. Karen Wilks had been briefed on the specifications of the evaluation. The SU and C who came forward to be part of the evaluation did so based on the information offered, in their capacity as citizens with experience of having used health services or cared for people who have used services.

The SUCEPs involved had experience of participating in different projects and in different organisations, however, that have not collaborated with a university and the NHS in the past.

### **3.3.3 Participant Information and Consent**

All participants were able and willing to communicate via email in the initial stages. They were forwarded the Participant Information Sheet and Consent form (Appendix B and C) at least a week prior to the interview, then again, hard copies of the Information Sheet and Consent form were provided on the day of the interview. The information sheet provided to participants provided details of the research, contact details for researcher and the UCLan School of Health, as well as exit procedure, should any participant chose to no longer be involved in the research. Security measures have been taken in line with the University's policy on data protection, in order to protect confidentiality and anonymity for all participants.

### **3.3.4 Data Protection and Information Storage**

In line with the university's Data Protection policy, the researcher submitted a detailed questionnaire on the use and storage of the data gathered for this study. Recorded material (i.e. interviews) and any other electronic data has been stored on password protected devices. Transcripts of the interviews will be stored for up to 5 years in a locked cabinet in the School of Health.

### **3.3.5 Data collection: semi-structured interviews**

The topic of this study lends itself well to qualitative research methods, as they allow an explorative approach to issues uncovered (Diefenbach, 2008). The proposed interview schedule can be inspected in Appendix E. Semi-structured interviews as a method confer the researcher the flexibility to be '[...] sufficiently open that the subsequent questions of the interviewer cannot be planned in advance but must be improvised' (Wengraf, 2004, p.5). As the interview schedule shows, the questions asked were fairly general and phrased in such a way to allow participants to develop new meanings in the context of the topic (Galletta, 2013).

Interviews were mainly conducted face to face and recorded on a digital recorder. The only exception was one interview which was carried out over the phone with the NHS manager. Face to face interviews were particularly important for the SUCEPs in the PIM pilot. Face to face interviews allow the interviewer to ensure questions are understood by participants and followed up if required (Martin et al, 2010). It was important that alongside the narrative provided via the semi-structured interview, the body language and non-verbal cues offered by interviewees would contribute to a fuller picture of their experience of being involved in the PIM pilot. Interviews lasted up to 1.08 hour, with an average of 49.4 minutes.

As per the Ethics Approval submission to UCLan’s Research Ethics Committee, the face to face interviews took place in public places, on the UCLan Preston Campus and Blackburn College. All interviews were listened to and transcribed verbatim.

### 3.4 Data analysis

In accordance with quality research principles, the gathered data was interpreted by the researcher, and then separately by academic supervisors, to allow for any potential variations in interpretation to be identified and noted. Rapport (2005) argues that in hermeneutic approaches to data collection and data analysis researchers should work closely with others and should be open to challenges (2005 : 133). Early data interpretation and analysis allowed identifying existing patterns before hypotheses were made. Organisation of data was aided by collaborative work and several data interpretation sessions. Emerging themes were identified by unanimous accord between the researcher and the supervisory team. In order to reduce the number of themes identified, together with the supervisors, sub-themes were agreed that were related to or subordinated to one of the overarching themes.

On several occasions, combining sub-themes to create overarching themes was difficult, because of what was perceived by the researcher to be a substantial crossover, with some subthemes sitting well in more than one overarching theme. The tables below show possibilities of arranging different sub-themes (or concepts) under different headings:

**Table 3: Overarching themes emerging from interviews with the allocated sub-themes**

Overarching themes	Work/occupation	Personal Identity/Sense of Self	Purpose
Subthemes	professionalism	Subjectivity/objectivity	gaining transferable skills
	business like	status/ hierarchy	for self
	authority	yearning	for others
	competition	dual identity	social relations
	suitability for the role	opportunity	reciprocity
	strategy/tactics	autonomy	engagement
	functional role	control	democratic
	self-esteem	impostor syndrome	relationships
	successful	fulfilment/reward	opportunity
	achieved aims	personal attributes: personable	managerial

	symbols: clipboard, badge	belief in himself/herself	well-organised
		valuable (gives meaning)	
		self actualisation	

**Table 4: Overarching themes emerging from interviews with different allocations of sub-themes**

Overarching themes	Work/occupation	Personal Identity/Sense of Self	Purpose
Subthemes	professionalism	Subjectivity/objectivity	gaining transferable skills
	business like	status/ hierarchy	for self
	authority	yearning	for others
	control	dual identity	social relations
	suitability for the role	functional role	reciprocity
	strategy/tactics		engagement
	self actualisation		democratic
	self-esteem	impostor syndrome	relationships
	successful	fulfilment/reward	opportunity
	achieved aims	personal attributes: personable	
	autonomy	belief in himself/herself	competition
	opportunity	valuable (gives meaning)	symbols: clipboard, badge
	well-organised		

Together with the supervisors, it was resolved that there is a high likelihood that there will be an overlap between the sub-themes and that some of the sub-themes are transferrable between the overarching themes. With steer from supervisors, the researcher determined the position of sub-themes from the context that applied to the sub-theme during the interview.

## **Chapter 4: PERSONAL REFLEXIVITY**

### **My journey through the project**

Prior to the Results and the Discussion chapters, this section will be used to explore my journey of learning and understanding throughout the KTP and Masters study. The present chapter refers to the personal, un-intermediated experience, which is why I will revert from using the third person to using the first person, as will be explained further.

Previous chapters of this study have followed academic writing conventions which recommend a detached positioning on the part of the researcher. Indeed, the Introduction, Methodology and Literature Review parts warrant an objective outlook. The reflexivity chapter however, is largely based on the researcher's subjective, and personal experience of participating in the project, therefore I use the first person in the following section.

Some of my reflections relate to the totality of the KTP project; any attempt to disentangle personal reflections between the pilot and the whole project would be disingenuous and fairly impossible in any event. I have been acquainted with the concept and practice of SU and C involvement for the first time through the wider KTP project. I then delved deeper into the academic debate as I commenced my learning for the Masters' degree. That said, some of my personal development and feelings about the project do relate specifically to my interactions within the context of the pilot. Some of key examples I believe to illustrate this include:

- Emphasising contact/interaction:

The experience of interviewing one of the EPs: after completing the interviews, I felt I held a much clearer understanding of the predicament of carers. I also believe the interviews gave me a deeper understanding of the SUCEPs learning journey throughout the PIM pilot

- Impact on self – knowledge, understanding

This was evidenced in the multiplicity of feelings, emotions and reactions faced throughout the wider KTP project and especially during the gathering of the data for the current study which impacted on my identity as a researcher and precipitated some unsettling moments of dissonance, conflicting thoughts and emotions, and sometimes placed me in uncomfortable positions, in a context of varying institutional support for involvement.

Reflexivity allows the researcher to both question and position himself or herself within a research locum, and to critically explore understanding of events or phenomena (Clancy, 2013). In the context of this project however, positionality, from the point of view of adopting an 'insider' or an 'outsider' stance, proved to be challenging. In simplified terms, the 'insider' position implies knowledge through experience, an experience shared by other participants. By contrast, the 'outsider' is the researcher with no *a priori* knowledge or experience, an individual who can be 'objective' in data collection and data analysis, and in no way 'contaminated' by the findings in the research process (Hellowell, 2006). Indeed, Hellowell points that it is both difficult and not always conducive to richness of data for researchers to maintain absolute positions as insider or outsider in the research process.

As I embarked on the Perspective KTP project I thought of myself as an 'outsider'. I commenced my researcher role on the assumption that no formal links with the field of service user and carer engagement meant that I was an 'outsider'. I expected to be treated as an 'outsider' and believed it was right to maintain the researcher 'distance' to the topic and especially to participants. I had a special interest in community engagement, inherent issues such as power differential, elitism practiced by public sector organisations at national and local levels, having been active in my own neighbourhood in various grass-roots initiatives. I did not initially make a connection between these seemingly different forms of involvement and SU and C involvement.

By the time the Masters study begun in earnest, I knew that my position had shifted on the 'insider' – 'outsider' continuum. During the desk based research stage into SU and C involvement, and reading and hearing narratives from SU and Cs at academic conferences and elsewhere, I recognised all that was raised as very familiar to me. My initial understanding of SU and C involvement specifically, however, came from another context and from quite literally, another country, Romania. This might have been the reason why I did not, right from the start, see myself as an 'insider'. My knowledge and understanding of any SU and C involvement aspects were intimately linked to a context where formal SU and C involvement is not mandated, required, expected or thought of as a viable proposition by SUs and Cs, health practitioners or decision makers. That is to say, the concept of such involvement does not exist. This meant that although I had intimate knowledge of the plight of SUs and Cs relating to a close family member with significant health needs, I knew nothing about formal involvement and the obligations placed on health providers to engage and of the fact that there was a well-established academic debate around the topic.

In the initial stages, this was perhaps problematic; I found it difficult to reconcile what appeared to me to be unbridled access to involvement with the well documented barriers to involvement, that are a feature of the debate in the UK. Understanding of new concepts takes time to digest and absorb. I was in full agreement with the philosophy and basis of involvement of SUs and Cs as detailed in policy documents, but still could not see the practicality in real life. This posed further personal dilemmas: by not seeing how involvement can be practically achieved, it felt like I might be disloyal to the concept, which I felt was not the case.

Throughout the KTP project I was hosted and based in an NHS organisation. This allowed me to see and understand difficulties in achieving meaningful SU and C involvement at a time of turmoil and change in the NHS. This is why, at times I felt like although involvement was desired and would have been highly beneficial, the human and financial resources were unavailable to thoroughly and comprehensively establish it across the organisation. Admitting this felt like claiming that user and carer involvement is not possible and explaining the unexplainable. Practical difficulties of involvement, however, were a reality that I was aware of. This raised the researcher's dilemma: that of understanding the complex realities of phenomena, practices and relationships, often with at least two-sides to any story. In the case of this study, one of the 'sides' was awareness to the benefits of involvement for individuals who become involved, and for organisations that use involvement, with the other 'side' being the realities and constraints on resources available to support this.

Throughout the duration of the Perspective project and in my many dealings with SUs and Cs I felt as an undisclosed 'insider'. Retrospectively, the question I have been asking myself is what difference it would have made if I would have disclosed my links with, and knowledge of disability and using services? I also question why had I not disclosed my knowledge of disability and mental health issues, and why did it feel appropriate at the time to maintain the 'researcher' distance? Furthermore, I question if I should have, or if that might have given the wrong impression.

During the KTP, before the PIM pilot was discussed, I came into contact with the Community Engagement and Service User Support (Comensus) initiative. Comensus are a group of service users and carers that support teaching, learning and assessment at UCLan (McKeown et al, 2012). Members of the Comensus group participate in lectures and seminars, providing health and social care students with the perspective of the SU and C as recipients of care. Members of

Comensus have been involved in the Perspective KTP project, with a representative on the steering group and research group.

Comensus were the first time I had encountered organised and supported service user and carer engagement. Initial feelings were anxiety – SU and C involvement was new and complicated; outsidership – I was introduced to the group, I was not one of them. At this stage, I had still not seen SU and C involvement ‘in action’, which made it difficult to understand how it actually worked. It was at a SU and C run and organised workshop that I finally began to understand ‘involvement’. After hearing several personal narratives I realised that I have never before heard personal stories made public in this way, personal accounts and journeys through illness or disability. I realised that someone having the opportunity and courage to stand up and tell their own story is one form of SU and C involvement. In my capacity as a researcher, listening to a powerful narrative and seeing that person in a new light *was* SU and C involvement.

More importantly, as a collective, Comensus members have always been welcoming and ready to answer any project related questions I had. The interactions with Comensus members were for me an opportunity to both gain further insight and to reflect on my positioning as a researcher. My perception was that as far as any of my interlocutors were concerned, I was an outsider. With hindsight, I had opportunities to disclose my knowledge and experience of service user and carer aspects which might have changed my positioning.

At the beginning, I was thinking this would be unthinkable in places like my country of origin. I then had the opportunity to see SU and C involvement in many other guises and wondered if it is something that might actually be achieved. Retrospectively, I would call these instances ‘glimpses of optimism’; thoughts of what might be possible. At the end of my studies, I draw a parallel between SU and C involvement in the UK and the other country: in the UK, SU and C involvement may have to overcome barriers; it is nevertheless a well-established and accepted concept, having long broken out of policy-speak and policy documents. This is because socio, culturally and economically the environment is much more amenable for the development of SU and C involvement. This, however, is not universally applicable, and it will be a long time until this concept roots and develops in other countries.

The current study is concerned with the SUCEPs experience of having been involved in the service evaluation of a health centre. Upon reflection, participating in the PIM pilot as researcher has been very insightful and a steep learning curve for me, as a person. It helped

me develop a vision for what could be possible in other countries as far as SU and C involvement is concerned. It changed my view of the world as regards SUs and Cs completely. I am using my new understanding to disseminate this knowledge in other circles. It enabled me to see that I was perhaps sceptical that SU and C involvement can be so effective and efficient – from the point of view of delivering the output, and I should perhaps have been more confident. As regards the SUCEPs, the interviews demonstrated in no uncertain terms the benefits of participation to individuals, but also, to the NHS organisation that commissioned the service evaluation.

### ***Summary***

Allowing myself time and space to reflect from the vantage point of the researcher gave me the opportunity to raise questions on my participation in the project. This, in turn, allowed me to develop awareness to my personal levels of involvement and disclosure, and to the fact that as a researcher, there are often intrinsic, tacit reasons for becoming involved with a certain research project. Subjectivity and knowledge in the topic can be disclosed. Further research should be done on the reasons why researchers do not disclose links or knowledge with the topic studied.

# Chapter 5: FINDINGS

## 5.1 Introduction

In the previous chapter a reflexive stance over the personal journey throughout the KTP project and the Masters study was presented. This chapter considers the emerging themes following the interviews with participants in the PIM pilot. Three overarching categories of themes have been devised which reflect views, language and concepts mentioned in interviews repeatedly. The three broad emerging themes have been titled:

1. Work/Occupation
2. Personal Identity/Sense of Self
3. Purpose

Sub-themes were then identified, and assigned under the most appropriate overarching categories. It was discussed and agreed that it is likely for themes to overlap and that some of the sub-themes could be assigned to different categories. The results have been finalised in this format based on the researcher's analytic thinking; involving intuition and interpretation of information received from participants in a particular conversational context.

## 5.2 Work/Occupation

The SUCEPs described in detail the opportunity of being involved, and sense of being entrusted to carry out the work, and more so that of working with apparently prestigious institutions such as the university and the NHS. Interviews revealed other concepts associated with the notion of work which were of importance to the SUCEPs. These include Motivation/Background, Professionalism, Experience transfer, and the Relationship between health centre staff and participants. The following section will discuss each of these aspects in turn.

### 5.2.1 Motivation/Background

Among the participants in this study motivation for being involved had a common denominator for the participants involved, namely, professional or experiential background.

*'[...] my degree was in occupational psychology, so I suppose there's a bit of a background [...]' (project coordinator)*

*'I've been in a managerial role for many years before [...] in my later work so I've always had to, I've been in charge, so I've had to a lot of authority in seeing what I did'* (service user)

*I have worked, erm, alongside lots of people in different communities at different times* (carer)

In the above context the professional background is linked to motivation as additional endorsement for the suitability for the role, but also as a pointer to the fact building on skills acquired from a past professional context is important for the SUCEPs.

Throughout the interviews, all participants continued to make references to the factors driving their motivation to participate in the PIM pilot, and to a large extent associating such factors with their backgrounds. On some occasions, background was being used as a qualifier:

*'I have had an experience of doing what I'm doing, and that's probably why I was put forward'* (carer)

Confidence in their own ability to carry out the tasks was also a feature for all the participants involved, and it can be argued that confidence was linked to background. The SU and the C confirmed that they had initial reservations because of the novelty of the task of completing questionnaires evaluating services offered at the health centre; however, practice enabled them to become more confident and they spoke with ease about the experience:

*'I mean, from my perspective, it's not really difficult at all... to ask people questions...'* (service user)

It was acknowledged that not only confidence grew as more questionnaires were completed with members of the public, but for the individuals involved, there will be a longer term impact:

*'[...] because it boosts my self-esteem, knowing I've actually done some research today, that's hopefully gonna better the future of the building and the patients that are going to be using it'* (carer)

The academic perspective, perhaps coming from a different angle on participants' motivation to participate in the service evaluation chimed in with the emphasis on impact:

*'[...] people who are often interested in getting involved in something that's called 'involvement', might be interested because their prime motivation is to actually change things in services, so it's not just telling stories for the sake of telling stories, there's some*

*purpose to it for them, which is about changing those services hopefully for the better'*  
(academic)

This was confirmed by one of the participants who indicated that providing ultimate help and assistance for the users of the health centre was a driving force behind involvement in this particular project. One of the participants suggested that a requirement of involvement on the part of service users is that:

*'It has to be somebody who knows that they can take – give and take – from the service users, and that they'd be able to go back, feedback, and do something about it as well'*  
(carer)

This implied the impulse to do good for the wider service users and carers' community is a key motivation of being involved.

### **5.2.2 Professionalism**

Throughout the interviews, one of the characteristics most often cited by all the participants was professionalism. Each individual involved in the PIM pilot, that is to say the SU, C, and the PC considered that professionalism, which was an essential feature of their involvement, assisted them in successfully completing the evaluation. This professionalism was a complex, multi-dimensional and nuanced concept that resonated with issues of individuals' status in the job role, skills in its execution and value for the work done. Objectivity was considered to be an important dimension of professionalism:

*'[...] if I go onto it as an objective person, as a professional outside'* (project coordinator)

*'I felt as though I was doing a professional job'* (service user)

*'I think they did feel I was very professional in what I was doing. I think it's the way I was dressed, as well. I always made sure that I was dressed in a sense that, you know, would make me feel – not stand up over them, but would give them the, you know, the idea that I am professional in what I am doing'* (carer)

A professional attitude was considered by all the participants to be conducive to building the right relationships with both staff at the health centre and other users of the health centre, as well as to successfully fulfil the task that was required of them. Throughout the interview it emerged that a conservative view of what 'professionalism' might be and entail was a view taken by participants:

*'[...] if you approach everything correctly, and, you know, do the thing as it should be, I think it – they look upon you as if 'oh yes, yes' (carer)*

Professionalism in this context is seen by the participant to be maintaining a comparable status or esteem with other 'professionals'.

However, as far as the academic and the NHS manager involved in this study were concerned, 'professionalism' was not viewed as unequivocally a positive identity or in precisely the same terms with regard to how it may manifest itself or its necessity in accomplishing such tasks:

*'[...] professionalism, I think it's a good thing and a bad thing [...]of course you should at the very least have the opportunity to refine your approach and all that sort of thing. That said, many people can do that anyway, without any outside professional support to achieve those competencies, 'cause we don't want to, you know, the whole of society here, aren't we? Erm, but I think if the quest for a sort of professional presentation is used to exclude some people, I'd be more uncomfortable (academic)*

This view as to what is the usefulness of professionalism in relation to SU and C involvement is further clarified in the following quote:

*'[...] one of my worries is that, well, a number of things, really, one is as you say, that if people feel they have to be subject to a whole load of training and preparation, or even credentialisation – you've got to get the credentials to be a service user, there's a strong possibility that people morph into something that's less than what was valuable about them in the first place, which was that first hand experience' (academic)*

Similarly, the actual experience of having used services and therefore providing the authentic view of the user was important and made the contribution valuable from a managerial perspective. Professionalism – as denoted by conduct, appearance and ability did not appear to be of consequence:

*'I think, I think just to go over, re-focus our thinking it was very important, to get people who have actually used – used services, or carers of people who have used services, who've got that proper experience behind them, of what it means to be a patient or a carer, because I think that gives them that automatic rapport and understanding with people, and I think it's more genuine when it's done peer to peer' (NHS manager)*

In the interview analysis it became apparent that the SU and C involved placed great emphasis on symbols associated with professionalism, competence and power, such as the researcher badge and clipboard. For both individuals these symbols played a dual role: they felt reassured about their legitimacy as lay researchers on one hand and on the other, they felt enabled and empowered to carry out their roles:

*'I've got a badge and think that yeah, whatever I've got, I am gonna go back, take it to somebody higher, 'cause I can't exactly deal with it myself. That is gonna come across as strongly to the, to the people, and they might actually want to engage and get the points – that's exactly what they did' (carer).*

*'I can feel stronger, knowing that they're believing in me. They're putting their faith in me by telling me these things that is up to me to go and get this back (sic) [...]' (carer)*

*'Yes, I think it does, I think it [the researcher badge] puts you in a... puts you in a.... gives you the upper hand slightly. Cause they think of you as somebody who's knowledgeable' (service user)*

*'[...] us being carers, and to be given the opportunity of a professional role is really important. Because we know, erm, we know our feelings as service users, and we also know our boundaries as professional. But to be given that opportunity to go out and represent service users AND have the authority to be a professional, it makes me a stronger person' (carer)*

While the stances over what professionalism entails might have differed at times, there seemed to be a tacit consensus over the association between 'professionalism' and 'objectivity', and on the part of the SUCEPs, an implicit assumption that objectivity was expected and required in the particular role of doing a survey. However, there was also an objective-subjective dichotomy, or conflicting views over the ability to be objective at the same time as being a user of services:

*'If I used that health centre, and I was conducting the work that we did, but I also used it every week or every day or something like that, and I might have a real gripe about the car parking there or something like that [...].I would be focusing all the time of people talking about the car parking. I'd want to bring that to the fore, because that was what I felt is wrong [...] ...so I couldn't be impartial' (project coordinator).*

Professionalism as a concept was pervasive throughout the interviews. At times, this raised the problem of objectivity vs. subjectivity. The consensus among the SUCEPs seemed to be that objectivity is the desired and expected stance.

In the case of the PIM pilot, there is no doubt that SUCEPs were motivated by wanting to help other users of health services. It was, however, made plain that the opportunity of gaining, or building on existent transferrable skills was equally important for the SUCEPs. This view was shared by the NHS manager:

*‘[...] and I just think it’s been a really positive experience for them, giving them the confidence, erm, to be part of something on a larger scale, and it’s something even after they’ve finished they can look back on and think ‘I’ve helped review that service’ (NHS manager)*

### **5.2.3 Experience transfer**

The SUCEPs involved have both described taking part in the service evaluation as having been a ‘nice experience’ (carer). This theme can be considered to have two separate dimensions. Firstly, there is the overall new experience gained as a result of having been part of the service evaluation at the health centre:

*‘[...] it was a new experience for me [...] ‘cause it was the first time I’ve actually done a survey asking people questions, erm, and it was, I enjoyed it actually, it was very good. Erm, it’s something new to me [...]’ (service user)*

*‘Overall I think it’s been a nice experience. It’s a new experience’ (carer)*

*‘This was more on the health side, so it was like a totally new experience for me’ (carer)  
‘[...] my feel for it is that they found that an enjoyable experience, and in some sense, it’s a way of being valued... and I don’t just mean in a material sense’ (academic)*

#### **5.2.3.1 Intra- Team experience**

Secondly, it should be noted that as reported by participants, intra- team experience transfer has taken place during this assignment. Intra-team experience refers to the learning that has taken place from other participants in the PIM pilot. This applies the learning gained by participants from the PC, and the learning that participants gained from each other:

*And we worked really well as a team, like that. [...] it was an experience in itself; we were sharing each other experiences, and if Daniel has felt as though he was struggling, ‘cause he’d ask me, and then sometimes I’d say to Daniel ‘Daniel, how do I approach this?’ (carer)*

The intra- team transfer was supported by the fact that the SUCEPs acknowledged each other’s lived experience as being different and rich. Furthermore, it suggests that SUCEPs were not only aware of different experiences, but also, willing to draw on each other’s knowledge and to learn from peers:

*‘[...] my experience of working has always been on building sites, so it’s always been working with males, you know, rather than females. Erm, so working with, you know, a female colleague, was, yeah it was a nice change for me’ (service user)*

From the point of view of the PC, reports of the team work and team dynamics were similarly positive:

*'I got reward from doing the health centre work because I met two people who I liked, you know, got on with, and I thought we worked well as a little team together'* (project coordinator).

The current section emphasised the relations formed between the PIM pilot participants – the SUCEPs and the PC. Forming and maintaining relations is a very important part of professionalism. The next section will consider what the SUCEPs' experience in forming relations with the staff at the health centre was like.

#### **5.2.4 Relationship between health centre staff and participants**

Because the evaluation took place in an organisational context, it was predictable that relationships with the existent staff in the organisation would form. The participants involved however, had different perceptions of the relationships in question.

*'It depended what department we were in. Every department was different. But they seemed fine after a bit. I think the first one or two times that we went, it was difficult, but they got used to us'* (carer)

*'[...] when you're working in your working environment, that's your space, it's your own comfort zone, and anybody who tries to come in your comfort zone it's like you're, you know, weary about who this is, what they're gonna do with it, it's like anybody who comes into your home, really...'* (carer)

*'I sort of like, moved in quite quickly and... but they were a very nice – they were all nice people the staff anyway'* (service user)

*'I felt as though I had to take charge of the situation, in general [...] otherwise I'd be getting 'well, can you come back later, can you do this?'... so I went in there with authority of voice on, and 'Do you mind if I do this?', and you know, put them in a position to make them feel difficult to turn me down'* (service user)

The relationships developed could have been conditioned by a range of factors such as age, gender, personality. However, the relationship with the staff was one of the few aspects experienced differently by participants.

Throughout the interviews SUCEPs entered a narrative where the tasks required by the service evaluation were fulfilled because of existing abilities, namely, well developed interpersonal and communications skills:

*'... I think one of the reasons why I got so many people – feedback from most people was me old technique of the way that I approached them. 'Cause I always try to approach people with a smile and a... and a bit of banter...'* (service user)

*'I did try and get in and blend in with them. [...] I think icebreakers were very important, so I did do a lot of ice breaking first, I didn't just jump in [...], we gave them like a few, a bit of breathing space, and then go in and try and, maybe ask them how their day was, and then ask them if they, if it was ok with them that, I mean basically say that I'm only gonna take little – two minutes of their time and stick to that two minutes'* (carer).

The PC, however, highlighted the importance of a structured, managerial approach being taken to tasks alongside communication skills, even when they are of a social nature:

*'It is not good enough to be good... it's not good enough to have a passion to save the children, or whatever. You know, that's not enough. [...] You need to be able to manage it, that's absolutely crucial'* (project coordinator)

### **5.3 Personal Identity/ Sense of self**

#### **5.3.1 Yearning for a different status**

In the context of performing a professional task, and the accompanying sense of direct and authentic contribution, participants uncovered a new temporary identity, that of researchers. The interviews uncovered personal reflections akin to revelations of the sense of being something that the participants have not been before. The new identity has the potential to open new possibilities and connects with some of the issues raised in thinking about the notion of professionalism.

The SUCEPs involved in the PIM pilot talked about their experience with enthusiasm and acknowledged the benefits of participating. The opportunity to participate had not only revealed to them strengths and abilities which they may have not been aware of, but also broadened their horizons and for one of them, opened up possibilities not considered before.

*'[...] if I can work with so many different people, you know, different cultures, different age, different, you know, different backgrounds, then I can do anything in future as well'* (carer)

*'I felt as though I was doing... I was doing a job. You know, I was doing some work I didn't feel as though I was just... how can I put it? ...As just... erm... passing time of day*

*asking a few questions to people. I felt as though I was doing a professional job' (service user)*

*[...] 'cause I am now a volunteer, rather than just a service user, erm, there's lots of courses, which I qualify to go on and to try boost me (service user)*

Interest in and awareness to personal development opportunities from other organisations further denote a yearning for a different status and for testing newly acquired skills and knowledge.

*I'm so grateful to this experience, you know, to be able to be given this chance, to know, because it's bettered me, it's given me a higher self-esteem, knowing that I, the way I'm coming across to people it's actually making them want to speak to me (carer)*

*'Every minute that I was there, I was growing as a person. And I, I felt as though I was taking away something that I could hopefully later relate on to other experiences' (carer)*

As earlier in the interviews, the carer implies aspiring to a different status. She substantiates and consolidates her aspirations by making references to prior experience.

*[...] when I walked away from [the health centre] it was like, it felt as though I was saying good bye to something that I was really, it helped me grow as a person... and I feel as though it's not just ended there... that was just the beginning for me! And I'm just growing, and growing and growing after that...' (carer)*

The SUCEPs talk about newly found strengths and qualities that make them aspire to a different status. As with the ability to perform professional tasks, the new identity is seen to have a life changing potential.

### **5.3.2 Dual role: service user/carer and researcher**

The context of this study made allowances for participants to reflect upon role, or identity duality. The option was taken to different degrees; for one of the participants the involvement seemed to have acted as a journey of self-discovery and to have opened new windows of opportunities:

*'It made me feel strong, to be honest with you [...] it made me feel good, that you know, just because I'm professional doesn't mean I'm not human' (carer)*

*'It was a bit like I was, I was on stage with an audience. And I was getting through to them, you know...' (service user)*

*'I didn't tell anybody, no, no [that DB was a service user] [...] ...there was actually no real reason, I just felt as though if I'd have said that I was just a, erm, patient of one of the doctors there, [...] I think it would have lowered me position' (service user)*

It can be argued that the experience of dual identity has left an imprint within the participants, as reflection over the predicament has taken place. While the experience of a dual identity was novel and by all accounts enjoyable, mindfulness and awareness of the temporary predicament was mentioned throughout the interview:

*'I didn't know whether I was part of that 'team' or this 'team' [carer or researcher] (carer)*

*'I knew I was in that role only for the time that I was there [...] it wasn't something that was long going [...], I haven't been in it for long enough to start to feel the proper, proper professional –lism. It's more that I'm feeling that I'm more towards the service users, so, click out of it (snaps her fingers), snap back into professional role, listen to what they've got to say [...]' (carer)*

The duality of the role can include the competitiveness reported by the SUCEPs in getting a higher number of questionnaires completed by ERs at the health centre:

*'[...] sometimes me and Daniel would have a competition, as in how many we could get first, [...] Rather than make it feel like it's a drag, [...] ...you've got to put in a bit of humour and liven up the experience, so what we were doing is we'd do a bit of individual work, and then we did a bit of team work' (carer)*

*'[...] she'd done better than me. So the same day – I don't know what I did about the approach – but the second day I tried to approach it slightly more authoritatively, and on the second day – cause we've had a bit of a competition going – [...] ...on the second day I outdid Sara. [...] Yeah. So, and then, of course, the two or three times we did after that – (it was) 'how many have you done? How many have you done? – so, we had a little competition going' (service user)*

Dual identity in this instance is on one hand that of user of services and on the other hand, that of professional, more so than researcher. This is highlighted by the concern to uphold certain standards and deliver at least equally as much or as well as his peer delivered.

### **5.3.3 Fulfilment/Reward**

The service user and carer involved in the service evaluation reported how undertaking and completing the assignment brought feelings of personal fulfilment and reward:

*'And my, my statements are actually valued, and it makes a big, it makes a big difference; is not just about the authority, and that they've gone and done that [...] taking into consideration the service users and everything. So that is a big thing, and that's what makes it more rewarding for me' (carer)*

The managerial perspective over fulfilment or reward was slightly different and conditioned by how recommendations made in the final report may or may not be implemented by the commissioning organisation:

*'I guess there's the short term gain, if you will, the short term gain – in terms of how did I feel having just done the process in this dementia work, and did I get a reward for the activity that I did, erm, versus what I might feel like in two or three months' time, to feel that there was actually an impact as a result of that, ok... I, erm, I got reward from doing the health centre work because I met two people who I liked, you know, got on with, and I thought we worked well as a little team together. Erm, I got to kind of see part of a community in Lancashire which I didn't really know, you know, an awful lot about community level before, which I found interesting, erm, I got to know just a little bit about the health centre, which is something different, I wouldn't know anything about – that was all quite interesting...'* (project coordinator)

Furthermore, the academic perspective over how fulfilment might have come about for participants provides a slightly different reasoning:

*'[...] my feel for it is that they found that an enjoyable experience, and in some sense, it's a way of being valued... and I don't just mean in a material sense, 'cause I know there was some payment involved here, but in a sense that there's value in it because there's some implicit value in the work that's getting done, and it's nice to be asked to do stuff that you think it's worthwhile, so there's more, if you like, job fulfilment in that'* (academic)

It is true to say that in the case of fulfilment, or sense of personal reward, different interpretations and worldviews colour individual perceptions of what might be rewarding for self and others.

## **5.4 Purpose**

### **5.4.1 For self/for others dichotomy**

Among the emerging themes from the interviews the beneficence of participants' involvement for themselves and on behalf of other users of health and social care services was a clear strand. A sense of purpose in doing work which will be of benefit for the wider public was pervasive throughout the interviews.

*'it does help me immensely, you know, to... I'm not, erm, I haven't got a problem with mental health on a, like a daily basis, where I don't like getting out of bed in the mornings, mine's a... I'm glad to say that I'm (unintelligible) ...erm..., but it does help me to... you know, these sort of things, it helps me to cope with meself as well as helping other people, really'* (service user)

*'[...] she's saw it as help of giving her more purpose, more confidence in herself, which she should have, but not everybody has, you know, and that, so, it served a purpose, a dual purpose from that point of view. In terms of Daniel, [...] he's there, he's retired, he clearly enjoyed doing it, he was quite keen he would do more because he's got the time and so, again, I was helping him as an individual I think, because it gave him something to do that maybe he, you know, could have done with, he was grateful for, yeah, definitely... so I would definitely, definitely, I think it's using erm, you know, service users, carers and that, erm, it's good, yeah, definitely...'* (project coordinator)

Purposefulness as a characteristic of the SUCEPs was acknowledged by the academic:

*'[...] they projected a sense of themselves as people who were interested in keeping busy, and making the most of experiences that they've had'* (academic)

Purposefulness was illustrated under different guises by participants. It was, nevertheless reported as an important factor both as motivating and a driving factor for the SUCEPs.

#### **5.4.2 Opportunity**

All participants in the study mentioned the importance of the opportunity to participate in the PIM pilot and the importance of opportunity as a more general concept. In some cases, 'opportunity' was used to describe a set of circumstances':

*'Well, the opportunities at [third sector organisation], which I was brought in [the PIM pilot] through, erm, I'm now the volunteer – they brought out a new role. They wanted a leader for – it's a funny word in that actually my position it's like liaison officer'* (service user)

Or as a set of circumstances beneficial for self and peers, leading to purposefulness:

*'I certainly think they [other SUs] should try the opportunities, yes, because the knowledge is always there to be gained, erm, and if it can help you in a different way, you can help whatever you're actually doing yourself, you know, work-wise, service-users-wise or volunteer-wise, erm, is, you're always able to – if you're like me, I'm always able to pick up one or two things which I can use that again'...* (carer)

In the academic view, opportunity is seen as a door open to a new life, new understanding and new possibilities of imparting support to peers for the SUCEPs and more generally, for SUs and Cs who become involved with health services, education, or other similar activities:

*'[...] people who [SUs and Cs], you know, they come in, and they're very... almost silent to start with, they get the opportunity to sort of, you know, [...] they get allowed a voice, and, and the next thing is, couple of years down the line, they're supporting the person who was like them previously.'* (academic)

The managerial perspective took a wider view of opportunity. This included NHS emerging structures being exposed to a new way of engaging with SUs and Cs and the community at large, in light of their public engagement responsibilities:

*'GPs' primarily engagement is in their practices, so for them to see it done in another way, in a different style, and actually, not in their service, I think it's been very useful, and I think it's given confidence to actually know that there are other people who can engage with the community on their behalf, very well, and get genuine, positive outcomes, erm, and useful data'...* (NHS manager)

From the point of view of the carer involved the concept of 'opportunity' was at times explicitly and intrinsically linked to the concept of professionalism, and also, illustrated well the relation between opportunity and purpose:

*'I think it's really valuable, because obviously, us being carers, and to be given the opportunity of a professional role is really important. Because we know, erm, we know our feelings as service users, and we also know our boundaries as professional. But to be given that opportunity to go out and represent service users AND have the authority to be a professional, it makes me a stronger person. It gives me a meaning, really, in life.'* (carer)

Although closely linked with the concept of professionalism as highlighted above, in this context the carer emphasises the opportunity of 'being' a professional as being crucial to her experience of the PIM pilot.

### **5.4.3 Gaining transferrable skills**

It was acknowledged by all interviewees that while participation in the PIM pilot did not have future involvement prospects attached, the skills acquired through this exercise would enable the SUCEPs to take advantage of future involvement opportunities. A different angle for the benefits of transferrable skills was, on the part of the SUCEPs, the realisation that they have such skills at their disposal and can use the skills to their advantage:

*'I think there's a lot of transferable skills, you know, across the – you know, management, all sort of things... [...] in terms of going activities, going about tasks, erm, going about, erm, you start of, you know – you want an end result – you want the feedback from individuals' ... (project coordinator)*

*'[...] there's one more other thing that I pick up about myself though strong. And that was my language skills [...] 'cause I'm a qualified interpreter' (carer)*

*'I felt a little bit like I was, I was on stage with an audience. And I was getting through to them, you know'... (service user)*

Existing skills were also cited as one of the factors that helped both SUCEPs to successfully participate in the PIM pilot:

*'[...] because of the way my communication skills have been, erm, I'd actually gone out and got the research that you obviously needed, by having to give a lot more of my personal experiences at times' (carer)*

*'I think one of the reasons why I got so many people – feedback from most people was me old technique of the way that I approached them. 'Cause I always try to approach people with a smile and a... and a bit of banter'... (service user)*

From the NHS manager's viewpoint, it is unquestionable that participating SUCEPs have gained valuable skills which make them ideal candidates for future involvement opportunities:

*'I think it's erm, helped them in a sense of being part of something, being part of a team, to understand that being part of a team – what it can lead to, so I think it's given them a mixture of, sort of, sort of basic skills in some areas, but in some others, very good skills. As I say, working with people, 'cause working with people on a daily basis can be difficult; it's not dead easy to be able to speak to complete strangers about sometimes difficult subjects. So I do think it's probably given them some exposure and experience of how to do that.' (NHS manager)*

Thus all involved in the PIM pilot agreed that participation has given them in some cases, or re-enforced in other cases skills that will enable SUCEPs to not only participate in involvement opportunities, but to take on more challenging roles, should they wish to do so.

#### 5.4.4 Social relations/democratic

Although the PIM pilot unfolded over only a few weeks, the SUCEPs and the PC had the opportunity to encounter ‘institutions’ – such as the NHS on one side, they have also had the opportunity to deal with the public or other service users of the health centre, called evaluation respondents (ERs) for the purpose of this study.

As regards the relationships between the SUCEPs and ERs, they differed to a large extent. One of the SUCEPs felt that it was important to maintain a professional distance from ERs in order to deliver what was required, and not to disclose the fact that he was a SU:

*‘[...] there was actually no real reason [for not disclosing the SU status], I just felt as though, if I’d have said that I was just a, erm, patient of one of the doctors there, [...] I think it would have... lowered me position’ (service user)*

Conversely, the other SUCEP reported using her status of carer as helping her to fulfil her task, and forming a common front with the ERs as being conducive to getting rich data:

*‘[...] in order to get their personal experiences, I’ve had to give them my personal experiences, and that how I fed that back was important. I could have easily just put two words on a piece of paper, and not gone back and said anything, but the fact that I’ve come back and feed back to Karen, and you know, we had chats and conversations as well, the type of things that we were comfortable, not comfortable with, and the type of things that people wanted changing, is a big thing. So these group chats and everything, is something that I’ve given back, and, you know, it means a lot.’ (carer)*

Also, she felt that her language skills enabled her to be truly inclusive and develop good relations with the ERs. This is why, she argues, she obtained feedback from some ERs who would have otherwise been unable to provide feedback:

*‘[...] because my mother tongue’s helping, [...] I was on the same level as her, I weren’t somebody who was out there, who was speaking unless you were speaking Punjabi. I’m on the same level as her, I’m asking her how her day is and if she wanted to carry on communicating with me, and after that she did, and that really did work for me as well [...] It made me feel strong, to be honest with you, [...] it made me feel good, that you know, just because I’m professional doesn’t mean I’m not human. [...] and it made me feel good that I could balance both things, and that was a very good thing for me to do. To – just recognising and identifying – when you recognise and identify need, and then try and adapt that, it’s brilliant sort of skill in itself. Just realising, ‘cause I didn’t want that lady to feel as though why am I asking everybody else and not her?... [...] I didn’t want her to feel singled out. So it was all about inclusion. That worked really really well. It’s all about equal opportunities, isn’t it? So we gave everybody an equal chance, [...] ...and that really worked.’ (carer)*

In this way, the carer brings up issues of inclusivity and equal right to participate, regardless of language barrier. Furthermore, she makes a point of facilitating the ER's contribution to the survey, therefore underlining her democratic stance on the opportunity to contribute. There were discrepancies in views as far as the relations with the staff from the health centre were concerned. Interviews uncovered two very different accounts:

*'I think, I didn't feel very comfortable to be honest with you [with how the staff at the health centre viewed the SUCEPs], at times [...] ...when we were moving from, erm, department to department where we were surveying. It's like some woman made me feel as though we're not wanted there, or we might be a bother and a nuisance to their service users... [...] Because of the fact that, you know, as soon as somebody sees somebody with a clipboard, someone who's gonna ask questions, you think oh my God, are they gonna start annoying our patients?'* (carer)

Opposed to this view, the service user saw the relations with the staff in a completely different light:

*'The staff were very obliging and said yeah, you may continue, you know, carry on. [...]I sort of like, moved in quite quickly and... but they were a very nice – they were all nice people the staff anyway. The staff, there wasn't once a single person that said, you know, can you come back, can you do this later, can you, you know, or we'd rather you're not do it. They were all... everyone obliged and said 'Oh, yes, certainly, carry on.'* (service user)

It would be true to say that in the world of employment, employees perceived the world of work in different ways, which could make the disagreement between the two SUCEPs characteristic. The following chapter of this study will look carefully at and attempt to explain the differences between SUCEPs experiences of participating.

## Chapter 6: DISCUSSION

The aim of this study was to investigate the experience of the SU and C participating in research, that is to say, a formal and professional environment for the SUCEPs who took part in the PIM pilot. As detailed in the findings chapter, three main, overarching themes came through from the interviews with the SUCEPs and other participants. These were: *'work/occupation'*, *'personal identity/sense of self'* and *'purpose.'* This chapter discusses the interpretation of the interviews and considers it in light of existing knowledge. Thus, this chapter aims to make sense of the SUCEPs experience of participating in research and identify their perceived barriers to meaningful involvement.

### 6.1 Work/occupation

The data gathered suggests that there is a general consensus over the benefit of work, from two different perspectives:

- From the SUCEPs viewpoint: work is rewarding, enabling them to build on skills previously acquired and to develop new skills
- From the NHS manager perspective: it is valuable to get the input of people who have used services to engage with the public and patients at the health centre on a peer to peer basis

Previous studies have acknowledged the importance of SUs and Cs of being able to carry out work, in a paid or unpaid capacity (Breeze & Repper, 2007; McKeown et al, 2010) and the importance of user and carer involvement in health care education (Matka et al, 2010; Turnbull & Weeley, 2013). The findings of this study show that it is important to consider the fact that SUs and Cs are complex, with complex backgrounds. The first hand experience of using health services or caring for someone who uses services was most valued by the academic and the NHS manager. For the individuals involved, however, doing the job well was also at stake in this study. This leads to a complex territory where professionalism and a valued subjectivity are mixed together. In addition, it is important to factor in that SU's and C's previous life experience can include experience of doing professional jobs, or the capacity to do so. The following section of the study will consider complexities of SU and C involvement in a working/occupation capacity.

Benefits to the individual include a more positive sense of self and social and relational benefits (McKeown et al, 2012); empowerment of users, at individual and collective level (Barnes and Shardlow, 1997) and potential for transformation, at individual and collective level (Hutchinson and Lovell, 2013). Moreover, service users involved in work activities report increased self-esteem and ability to manage their own illness (Grove and Membrey, 2005 : 5). Benefits of user involvement in research to organisations include enriched data interpretation and more comprehensive analysis (Caldon et al, 2010). Provencher et al (2002) point to the role of work for SUs in the recovery process. This was recognised by one of the participants and clearly illustrated in their views of the impact of being involved:

*'[...] because I do have mental health problems, it does help me immensely, you know, to... I'm not, erm, I haven't got a problem with mental health on a, like a daily basis, where I don't like getting out of bed in the mornings, [...] but it does help me to... you know, these sort of things, it helps me to cope with meself as well as helping other people, really'* (service user)

The PC differentiated between involvement in a project that will make a lasting change and a box ticking exercise. She suspected the latter would be the likely longer-term outcome of the service evaluation. This is acknowledged as problematic, in a context where SU and C involvement is mandated, but it remains largely symbolic (Horrocks et al, 2010). As regards meaningful support, it can be argued that for SUCEPs, the involvement in the PIM pilot was very task-oriented; the SUCEPs were in charge mainly with interacting with ERs, themselves users of services at the health centre. Support was on hand in the form of the PC who was present at the health centre at every session and available to offer support to SUCEPs. The task of the SUCEPs was to gather the information from the ERs, namely, to assist ERs with completing the questionnaire.

Arguably, if the SUCEPs would have been involved in devising the questionnaires, or analysing the data, they might have felt that more support would have been required. In the case of the PIM pilot, their personalities and existing communication skills were sufficient for them to successfully complete the task. It can be argued that for the SUCEPs, involvement in the form of having to complete clearly defined tasks was an appropriate approach and thoughtful delegation on the part of the PC; concentrating on a task meant minimising the risk of failure. The outcome would always be success if the task is completed successfully. This, in itself is likely to increase confidence and self-esteem in SUCEPs.

Lack of experience of working with SUs and Cs can sometimes drive perceptions that SUs and Cs might be unreliable and less productive in the workplace. The SUCEPs turned up on time, on the allotted day and completed the task to the required standard. The PIM pilot has shown that, given the appropriate structure and support, as in this case, SUs and Cs can counter negative perceptions.

As mentioned above, involvement did take place in a work context. As reported in the interviews, in the case of the PIM pilot work, involvement was conducive to intra- team experience transfer and peer learning. The concept of peer learning has been part of the debate, with some arguing that such interaction will be empowering and encouraging for SUs and Cs, and can help them challenge the 'unequal user – professional power dynamic' (Williams et al, 2012 : 95). Moreover, the value of diversity of experience for meaningful input in instances such as carers sitting in board structures is seen by some as being self evident (Wedgbury, 2007).

The benefits of being involved in a work context were clearly articulated by SUCEPs, and further commentary to support this was provided by the academic and the NHS manager involved in the PIM pilot. It must be noted that likely problematic areas identified in the literature review such as tokenism, power differential or meaningful support as previously identified by Bradshaw (2008) or McKeown et al (2010) did not come across as overt problematic areas in the SUCEPs interviews. Tokenism is a term with negative connotations, often invoked by SUs and Cs. Tokenism refers to involvement where no adequate prior preparation or training is provided in order for the input to be meaningful (Beresford, 2005; Ockwell, 2007). As far as the SUCEPs were concerned, tokenism was not raised as having concerned them, or as having been a barrier to involvement. In their narrative there was a clear emphasis on the opportunity of involvement in the professional environment and the positive experience that resulted from involvement.

Although the issue of power differential was not brought to fore in the interviews *per se*, it can, however, be argued, that SUCEPs attitudes towards professionalism were acting instinctively to minimise any power differential that might have been perceived. The power differential, also referred to as power relations, is the variance between roles. In the case of SU and C involvement, power differential refers to the relation between SUs and Cs and healthcare professionals. Seeking a professional identity is understandable in this context. SUs and Cs who feel empowered are likely to see the power differential as minimal. A minimal power differential is likely to be conducive to meaningful involvement and to

positive contributions from SUs (McLaughlin, 2009), as well as to democratic models of SU involvement (Butler & Greenhalgh, 2010). As regards the relationship between the SUCEPs and the healthcare professionals at the health centre, interviews revealed the fact that the SUCEPs experienced the relationships differently. This, however, is entirely congruent with most peoples' experience of the world of work, and the social relations of workplaces. Different sensitivities are often influenced or conditioned by differences in gender, age or race.

As in other accounts of SU and C involvement, the overall experience of participating was a positive one for the SUCEPs, with a powerful effect and substantial impact reported by the individuals (Masters et al, 2002). The involvement opportunity offered by the PIM pilot was reported by SUCEPs as having given them the confidence to undertake similar work again. A note of caution is, however, provided by Felton and Stickley (2004) who found that some academics consider SUs who become used to the education system as 'distanced from their experience' (Felton and Stickley, 2004) and therefore less valuable in teaching. This links in with concerns of the risk of professionalization of the lay worker as articulated by Butler and Greenhalgh (2010). Professionalised lay workers are those who, according to the authors, start as regular service users or carers, but end up gradually acquiring specific knowledge that renders them as allegedly 'uniquely qualified' to provide input in service development. The authors raise the question of their effectiveness once they become familiar and comfortable with the healthcare system: a particular form of co-option.

Conversely, South and colleagues (2013) explain the benefit of lay workers, or as in the case of this study, the SUCEPs, helping to reduce communication barriers, as they have the ability to communicate with members of the public in ways that professionals are unable to (South et al, 2013). Further, they go on to suggest the idea that a 'community-workforce' could be complementary to the professional workforce by increasing capability to deliver services, or freeing up time for professionals to undertake high-level skills. To illustrate this, they cite the example of the community-based childhood obesity programme Watch-It which relies on lay workers trained to support young adults and children to achieve weight-loss.

In the case of the PIM pilot, SUCEPs did not provide clear indications that they aspire to become 'experts by experience', or professionalised users and carers. Also, the study focused on their experience of participating in research via the PIM pilot rather than on what participants' aspirations may be. Reflection on the part of participants and reported

understanding of personal abilities might, for some proponents of professionalization as a negative characteristic, provide early clues to the process of conversion from SU or C to 'professionalised' SU or C.

A notable aspect mentioned by SUCEPs in the interviews was competition. Although it was presented as a light-hearted way to help rapport between the SUCEPs, this information was volunteered by both participants with no prompt from the interviewer. This suggests that the competition or the outcomes of the competition had particular meaning for the individuals. This can be discussed in light of SUCEPs' perception that competitiveness might result in inclusion on a professional level as an equal. The power differential between SUs and Cs and healthcare professionals has been documented as highlighted above. Competitiveness among SUs, however, is not something that was found in the literature. Competitiveness can often be seen as a drawback. The SUCEPs described competitiveness as being motivating and inspiring, and helping with rapport building. It is difficult to ascertain if this may be specific to the SUCEPs involved in the PIM pilot or if it is widespread in SU and C organisations.

Competitiveness as described by the SUCEPs was not adversarial, or wrapped up with pecuniary advantage. In actual fact, as explained throughout the interviews, the competitive relationship was laced with humour and banter, aiding cooperation. It helped motivating and driving team-work to get the best job done in completing questionnaires, as tasked. At the same time, the SUCEPs were concerned to build good relations with the ERs and other users of the health centre. It can thus, be argued that that the relationship between the SUCEPs was one of interdependence which fostered a sense of 'constructive competition', or 'co-operative competition' as the outcomes of the competitive behaviour were positive for the SUCEPs individually and as a team.

In this context, it is pertinent to propose that a 'John Lewis' style of SU and C involvement model might have an overt co-operative dimension built in, to take into consideration and encourage interdependent and co-operative relations between SUs and Cs. As it was the case of the SUCEPs experience in the PIM pilot, a 'John Lewis' style of involvement, similar to the John Lewis partnership, which emphasises the constructive relations between the employees (and partners) (John Lewis, 2013) would encourage SUs and Cs to work toward a common goal.

Professionalism was by far the most pervasive theme that came out from the SUCEPs' interviews. Many references were made to professionalism as the attitude they displayed and as a desire of how they would like to be viewed.

There are some accounts of professionalization in the published literature (Felton & Stickley, 2004; Rees, Knight & Wilkinson, 2007). Butler and Greenhalgh (2010) see professionalisation as the formalisation of the SU and C. As described above, professionalization is also associated with, or seen as a result of tokenism and unrepresentativeness (El Enany, Currie & Lockett, 2013). In the context of the PIM pilot, however, professionalism as perceived and enacted by the SUCEPs is unlike the concept of professionalization as presented in the literature.

Professionalism as described by the SUCEPs speaks of a personal need for others to recognise ability and capability. There is no indication that they intend to formalise their role as SUCEPs, or that they consider undertaking similar involvement activities *ad infinitum*. The professionalism they talk about is more akin to the lay equivalent of the 'new professionalism' professed by Scott (2008). Scott holds that neo-liberal attitudes in nurses meant that their approach is shifting from one where professional authority is paramount, to an approach where responsiveness to community aspirations is very important, as there is ever growing demand for partnership work between the health care professionals and the public.

In the case of the SUCEPs, their approach has changed from a situation where the power differential dictates that they are vulnerable users (or carers) and the health care professionals are the experts, to a new predicament where they have the skills, preparedness and ability to undertake a survey and they represent other service users and carers. In fact, by embracing the concept of 'professionalism', they willingly distance themselves from being users of services. This was made explicit by the SU participant in the PIM pilot who supposed that disclosure of the fact that he was a user of services would have diminished his position of lay researcher:

*'I just felt as though, if I'd have said that I was just a, erm, patient of one of the doctors there, [...] I think it would have... lowered me position [...] yeah, diminish me... that's right'* (service user)

There is a possibility that SUCEPs equate 'professionalism' with notions of status in society. By '*being professional*', which was emphasised by both SUCEPs in the interviews, they

might have been aspiring to the different status conferred by '*being professional*'. SUCEPs may in fact be aiming at inclusion on a professional level by professionals, as equals. Arguably, this is driven by the organisational and societal culture. Individuals, including SUs and Cs, are subject to a culture which increases personal status within a society which defines people within a classification that identifies professionals as higher class citizens. The trend of class versus hierarchy and the emergence of the 'professional society' have been discussed at length (Perkin, 2002), as has the 'professionalism' conferred by the healthcare system, where 'the unqualified' is excluded (Newton, 2003 : 116). Inherently, as well as notions of status, the theme of professionalism also links to notions of identity and self-esteem.

The Work/Occupation section discussed how SUCEPs were concerned with not only doing good, professional work, but also being seen as professional people. The sense of self, and the personal identity which came equally strong from the interviews will be discussed further in the following section

## **6.2 Personal identity and the sense of self**

As mentioned in Chapter 5, it has been difficult at times to assign sub-themes to overarching themes. The duality of role was emphasised throughout the interviews. This is not entirely unrelated to the concept of professionalism, in that professionalism was a part of what the SUCEPs aspired to be, or an *aspired to* identity. The following section will consider perceptions of personal identities. For the purpose of this study, the discussion on personal identity and role duality will focus on being a SUCEP, and temporarily a professional researcher.

Participation as service evaluators in the PIM pilot was conditioned by having used (mental) health services, and respectively, having been a carer. This implies the automatic existence of at least two separate identities for the SUCEPs: firstly, *members of communities*, be they users, carers or the wider community, and secondly, being an *individual* service user, or carer. McLaughlin (2010) sanctions the right to having multiple identities for service users in the same way as anyone else, and points that the term 'service user' '[...] identifies these individuals by their dependency on a service rather than any other aspect of their lives' (McLaughlin, 2010). Likewise, Hutchinson and Lovell (2013) are concerned with SUs' identities not being investigated. In their article, Hutchinson and Lovell note the 'lost

identities' - which are the professions or vocations participants in their study had prior to becoming service users.

The SUCEPs chose not to emphasise their SU and C identity in the interviews. That is to say, the SUCEPs felt that they were entrusted to carry out a 'professional' task, which required their 'professional' abilities to come to the fore. Their main concern seemed to be that they were viewed and treated as 'professional' individuals or on equal terms by the health care professionals. The experience in this pilot stands against previous views and findings which suggest that service users want to be appreciated for being service users (Brownhill, 2006). For those involved, the opportunity of personal development was of great significance, which is a finding reported in other involvement studies (Barnes, Carpenter and Bailey, 2000). Subsequent to the personal development opportunity, there was a dimension of self-discovery and introspection. The PIM pilot and subsequent interviews seemed to encourage the SUCEPs to take stock of their abilities and think of possibilities first and foremost.

However, while this may have remained tacit, it is clear that the SUCEPs did have a common identity, a shared language and a shared understanding of being at the receiving end of health services. The shared language might be honesty and clarity in everyday language (Sweeney and Morgan, 2009), language being one of the main cultural barriers between identities (Karban & Smith, 2010). The shared understanding comes from a shared experience of health services.

The SUCEPs appeared to have heightened self-awareness, or how they came across to other users of the health centre. This can be linked to their desire to deliver a good, professional service. Indications of belonging to other groups, however, did appear throughout the interviews. For instance, one of the SUCEPs noted the realisation of representing two different groups (with perhaps different interests) at the same time:

*'I felt as though, like, a bit of an imbalance. Sometimes like more towards the service users, and sometimes I was more towards the PCT [...]. So I found it a bit of a... sometimes I found it difficult to realise where was it that I was?' (carer)*

Such conflicting feelings suggest that despite the yearning to advance, or to be accepted as 'professional', intrinsic loyalty to a particular group is present. That is, belonging to the two groups (professionals and SUs and Cs) is not necessarily mutually exclusive, but may generate a conflict of interests.

Self-awareness can be seen to be linked to reflexivity. There is little evidence of discussion of reflexivity as a concept in the SU and C involvement literature located by the searches for the present study. Reflexive practice for nurses and other healthcare professionals is now mainstream and well documented in the literature (Jasper, 2003; Atwal & Jones, 2009; Bulman & Schutz, 2013). Taylor (2010) distinguishes between three types of reflection common for healthcare practitioners: technical reflection, which refers to application of scientific methods, practical reflection with results in improved communication of healthcare staff with other people at work, and finally, emancipatory reflection, which includes a questioning process on the part of the individual and leads to transformative action. If using Taylor's (2010) taxonomy, the category most suited to the reflexivity demonstrated by the SUCEPs would be the emancipatory reflection, which allows individuals to '[...] interpret themselves politically in terms of their roles and social obligations' (Taylor, 2006 ; 103).

Throughout the interviews, the SU and C identity was mostly tacit, unimportant. Participants were keen to present how positive and beneficial it has been for them as individuals to participate, not least because the health centre evaluation meant working with the PC and being treated as professionals. Wright et al (2007) propose the concept of *reclaiming humanity* in the case of people with personality disorder (PD). In the context of treatment and recovery, the authors argue that '[...] the very concept of 'recovery' encompasses the process whereby an individual can reclaim his/hers self-esteem, pride, choice, dignity, and meaning' (Wright et al, 2007). It would be true to say that the experience of being involved in the PIM pilot presented SUCEPs with the opportunity to experience all the features mentioned by Wright et al. This was made plain by SUCEPs throughout the interviews.

Arguably, by taking part in the service evaluation at the health centre, the SUCEPs reclaimed, or discovered the professional identity and a new sense of self. Alongside the newly discovered professional identity, the following section of this study will discuss Purpose, as the final overarching theme drawn from interviews with the SUCEPs.

### 6.3 Purpose

'Purpose' can be defined in different ways, but meanings converge to concepts of having an objective, reason, or aim. In the context of this study, purpose is seen as a sense of mission for the SUCEPs that stems from self-awareness developed throughout the PIM pilot. In this section purpose will be considered alongside concepts of esteem factors and reward. The SUCEPs involved in this study reported esteem factors highly motivating and rewarding, and contributing to the sense of purpose associated with their involvement.

The literature search employed for this study revealed no academic papers which considered the specific context of a sense of purpose reported by SUs and Cs involved in research activities. This is why, for this section, the author will draw on existing literature with transferable features that reflect the findings of this study. This approach to developing associations that explain what motivates and drives SU and C involvement in research and other work activities forms part of the unique contribution of this study. This section will consider the soft skills as an asset that SUCEPs have and that healthcare professionals could draw on. Then, factors such as esteem and sense of reward associated with successful involvement will be discussed to frame the concept of purpose to involvement.

Medical care on its own does not hold all the answers to all patients; medical schools emphasise the importance of the doctor-patient relationship, with some schools 'emphasising humanistic dimensions of medical care' (Couser, 1997 : 34). There is, therefore acknowledgement of the need for softer engagement skills for professionals in the healthcare system. The PIM pilot demonstrated, through the use of the SUCEPs, that such soft skills exist within the SU and C pool, and within communities. This was evidenced by the very low numbers of members of the public at the health centre who chose not to fill in a questionnaire. SUCEPs ability to employ soft skills and communicate with members of the public goes back to the argument of 'shared language' as discussed in the *Personal identity and the sense of self* section. In this case, SUCEPs' soft skills are an integral part of the whole that represents purpose for them.

Participants in the PIM pilot reported a deep sense of esteem and reward from helping others as being the motivating and driving factors behind their involvement. Morrow et al support this, arguing that carers become involved in research in order to help people with health problems, or in the hope of improving health services for those using health services

(Morrow et al, 2011). It has been argued that for SUs specifically, involvement increases sense of esteem helps fight stigma associated with mental illness (Green, 2009).

The PC recognised the value of participating for the SUCEPs as developmental activity, but at the same time, emphasised her own motivation for involvement which was to improve health services for others, and be responsive to issues raised by ERs. In the interview she suggested that for her personally, reward would come if services would be changed to better as a result of the evaluation at the health centre.

The PC's concern is one of the findings articulated by Ridley and Jones (2002) who argue that 'engagement' does not necessarily equate to 'meaningful involvement' if health professionals continue to make decisions without taking into account SUs' and Cs' views (p. 9). This was an issue raised by the PC, but not by the SUCEPs. This may be attributed to the fact that the PC had previously contributed to similar engagement exercises within or on behalf of large organisations. The SUCEPs identified the sense of purpose and reward felt from being involved in the research, but did not consider subsequent outcomes of the research. This could be explained by the difference in experience of involvement in research or evaluations between the PC and the SUCEPs.

The sense of purpose in involvement was reported by the SUCEPs to have been enhanced by personal reward gained from involvement. Some authors talk about good practice as regards financial reward for SU and C involvement (Green, 2007; Faulkner, 2009). Conversely, Kara (2012) talks about the perils of payments for SUs which, she argues, could lead to involvement motivated only by the financial reward. There are also pragmatic aspects of payment for SUs' involvement, namely, mechanisms to facilitate organisations being able to pay, as exemplified by Rickard and Purtell (2011) who argue that paying SU is made very difficult by ambiguous and ever changing governmental policy.

For the SUCEPs, however, the issue of payment appeared to be of no importance whatsoever. Although they were remunerated for the time and work at the health centre, at no point in the interview this was mentioned by either of them explicitly or implicitly. This leads to the conclusion that reward was of an intrinsic nature and not in monetary terms. This is in tune with McKeown et al (2010, 2012), who report that the sense of reward from involvement comes from a more positive sense of self, social and relational benefits and altruism. All of these aspects were mentioned by SUCEPs as having impacted on their experience of involvement in research. There is further evidence that SUs find participation in research

particularly rewarding provided by Leiba (2010). Leiba also points to the benefits to the individual from partaking in a rewarding activity (2010).

One of the participants remarked how using the insider's knowledge and serving a community, while at the same time being given the responsibility to represent the community and the authority to be 'a professional' gives meaning in life. This further reinforces sociological concepts concerned with the positive dimensions of the worker role (Lucas & Diener, 2003). In the case of the PIM pilot, the experience of work has been reported by participants as a positive and rewarding experience. There is, however, the possibility of the experience of work being negative and that runs the risk of alienation. Negative or positive experiences of work can depend on the extent to which workers are in control of their work, the quality of social relations with fellow workers, and feelings that the work done benefits others (family by bringing wages home, or perhaps more profoundly, benefiting others who you do not even know, or service users of public services). Thus, the concept of 'purpose' in this case refers to the SUCEPs having done work which was of benefit to themselves, but also, to a wider community of health service users.

This section detailed how for the individuals involved the PIM pilot feelings of reward and esteem contributed to an overall sense of purpose, which was a driving force behind their involvement.

## Conclusions

This study aimed to consider the experiences of service users and carers involved in research, and more specifically, in the PIM pilot. Interviews with SUCEPs, the PC, an academic and NHS manager helped in gathering valuable insights which shed light on the results and informed the wider discussion.

Three broad themes emerged following the interviews: Work or occupation, Personal identity and the sense of self and Purpose. The Discussion chapter brought to the fore several issues which highlight the fact that involvement from the viewpoint of service users and carers is far more complex and diverse than the current literature suggests. Firstly, the benefits of involvement in the form of work were acknowledged by SUCEPs, and this is in accordance with findings of previous studies and existing knowledge. For the SUCEPs the professional environment they had the opportunity to work in was a very important added dimension to their involvement.

It is important to point out the difference between the SUCEPs' 'professional' attitude and aspirations, which referred to a different status in society, from the 'professionalised' status, which is often mentioned by academics and refers to those who move from being 'ordinary' patients to becoming uniquely qualified to provide input for specific areas, and may as a consequence risk losing touch with an authentic service user/carer consciousness in the process. In the case of the SUCEPs, the former applied. This is to say that SUCEPs desire recognition for skills and abilities they have and a higher status, rather than aiming to develop a career out of similar involvement.

Under the Work theme, a perhaps unexpected emerging concept was Competitiveness. Competitiveness in the context of working mainly as a pair was seen as motivating and inspiring. It added a new dimension to a working relationship which included acknowledged intra-team experience transfer in a way that was both constructive and enjoyable. Competition as interdependence and team-work to complete tasks successfully and to the benefit of all participants is in tune with social enterprise models such as the John Lewis Partnership. In light of the policy direction which encourages commissioning out services to social enterprises and third sector organisations, the findings of this study suggest that attitudes of service users and carers who are likely to make up such enterprises favour co-operative and collegiate work, in tune with the ethos of social enterprises.

The personal identity and sense of self category emphasised the SUCEPs awareness to involvement in the PIM pilot as a valuable personal development opportunity. It also included unexpected findings. Reflexivity on the part of service users and carers involved in research is something that the literature does not offer much insight to. While there is extensive literature considering reflexivity for healthcare professionals available, consideration to the meaning of reflexivity for service users and carers is an important point to be made and to be explored further.

It is conceivable that the current academic debate and Government directed involvement policy focuses on too narrow terms when considering what service users' and carers' reasons for involvement are. The complexities of personhood, personal motivations and background when participating in research are such that involvement in research or other professional activities warrant further research. The present study was on a very small scale; it did, nevertheless bring new insights over what the experience of being involved in research means to service users and carers and over the professional and academic perspective on involvement.

The findings of this study suggest openness to means of service user and carer involvement in health and social care services that allow for more nuanced, democratic involvement would be welcome. Furthermore, the social relations of involvement work reflected on in this thesis suggest some similarities and common ground with the position of the workforce in general, especially in health and social care contexts. Equally welcome would be attention to how rewarding and productive relations at work could be facilitated and supported to experience fulfilling work that makes a positive difference for others.

# Appendices

## Appendix A: Ethics approval



10<sup>th</sup> may 2012

Mick McKeown & Grete Smith  
School of Health  
University of Central Lancashire

Dear Mick & Grete

**Re: BuSH Ethics Committee Application**  
**Unique Reference Number: BuSH 063**

The BuSH ethics committee has granted approval of your proposal application 'A qualitative study to investigate service user experience of participation in research'.

Please note that approval is granted up to the end of project date or for 5 years, whichever is the longer. This is on the assumption that the project does not significantly change, in which case, you should check whether further ethical clearance is required

We shall e-mail you a copy of the end-of-project report form to complete within a month of the anticipated date of project completion you specified on your application form. This should be completed, within 3 months, to complete the ethics governance procedures or, alternatively, an amended end-of-project date forwarded to [roffice@uclan.ac.uk](mailto:roffice@uclan.ac.uk) quoting your unique reference number.

Yours sincerely

Gill Thomson  
Vice Chair  
**BuSH Ethics Committee**

## Appendix B: Participant Information Sheet

Participant Information SheetV.2

### A qualitative study to investigate service user experience of participation in research

#### Information Sheet for Interview – Participants in the service evaluation pilot



Following participation in the service evaluation pilot at the Barbara Castle Way Health Centre, you are invited to take part in an interview. This is for the Masters by Research project referred to during the service evaluation pilot.

Before you decide to take part it is important for you to understand why the study is being done and what it will involve. Please take time to read the following information carefully and discuss it with friends, relatives and key workers from services you receive if you wish. Take time to decide whether you wish to take part. If there is anything that is not clear, or you would like more information, please ask us. If you do decide to take part you will be asked for your consent. To help you in your decision to be involved in the study, some common questions and their answers are listed below. Thank you for reading this and we hope you find the following information helpful.

#### **What is the purpose of the study?**

This study is drawing on the service evaluation pilot. The researcher, Grete Smith, is undertaking a Masters by Research. The study will examine service users' experience of participating in a service evaluation pilot run with service users.

This involves listening and understanding to the thoughts and experience of service users and carers on their experience of being involved in the service evaluation pilot.

#### **Why have I been chosen?**

As a participant of the service evaluation pilot, you indicated that you could be contacted for a follow-up interview. Whilst you have been approached for a follow-up interview, it is entirely your decision whether you take part.

#### **What will happen if I take part?**

If you agree to take part in a follow-up interview, any involvement you may have as a service user or carer with health or social care services will not alter in any way. Grete Smith, the Masters by Research student, will contact you to ask if you would like to take part in an interview. A face-to-face interview would take place on one of the UCLAN campuses, either in Preston or in Blackburn. Grete will want to record your conversation and will ask your permission before doing this. She will ask that you sign a consent form to indicate and record your agreement to be involved in the study. The appointment will be at a time convenient to you. It is anticipated that Grete's discussion with you about involvement in the service evaluation pilot will last approximately 45 – 60 minutes.

So that you can confirm who she is, Grete Smith will carry a University identity card.

#### **Do I have to take part?**

It is up to you whether you decide to take part. You can confirm verbally to Grete Smith that you would like to take part in interviews for the Masters by Research when meeting to discuss the pilot service evaluation at Barbara Castle Way Health Centre. If you do decide to take part please keep this information sheet for reference. If taking part, you will be asked to give written or

## A qualitative study to investigate service user experience of participation in research

### Information Sheet for Interview – Participants in the service evaluation pilot

verbal consent to show your agreement, but if you change your mind at a later date you will still be free to withdraw and without giving a reason. This will in no way affect any current involvement you may have arranged with health or social care services.

#### What sort of questions will be asked during the interview?

You will be asked to:

- Describe your experience of participating in the service evaluation pilot
- Describe what you found rewarding about the work
- Describe what was less rewarding about the work
- Describe how you see yourself in the role of user-worker
- Describe how do you think other see you in the role of user-worker
- Describe your thoughts on the value of similar involvement in future for self and others

#### Will my taking part in the evaluation be kept confidential?

All information you provide during the course of the study will be kept strictly confidential. Your name and contact details will be stored separately from details of the interview. With your permission, Grete Smith will record the discussion with you in order to make best use of the information shared. The recordings will be transcribed. The recordings will only be stored on UCLAN computers and will be destroyed after the thesis will be examined. All names will be removed for data protection and anonymity. Only members of the Masters by Research supervisory team will have access to the interview transcripts and these will be stored in a locked University cabinet for a 5 year period, after which they will be shredded.

#### What if I change my mind?

You have the right to change your mind about taking part in the research at any time, by contacting Grete Smith (details below).

#### If something was to go wrong

If you want to make a complaint about your participation in research, you can contact Nigel Harrison, the Head of School of Health at the University of Central Lancashire on tel: 01772 893700.

#### What will happen to the results of the study?

The Masters dissertation will be available by October 2013. You will be offered a summary of the findings by Grete Smith. On the consent form you can chose to receive the summary of the results by email or by post. Results from the study may also be published in appropriate peer reviewed journals.

#### Who has reviewed this research proposal?

The Faculty of Health Ethics Committee at the University of Central Lancashire has reviewed this proposal.

#### Thank you for your interest in this study.

To find out more about the study please contact;

Grete Smith

Tel: 01254 282197

Email: [GSmith2@uclan.ac.uk](mailto:GSmith2@uclan.ac.uk)

For further information about the SERV-USER Project, please contact; Michelle Lyons, Commissioner and Blackburn with Darwen Teaching Care Trust Plus – tel. 01254 282180, or Mick McKeown, Principal Lecturer at University of Central Lancashire – Tel. 01772 893884

# Appendix C: Participant Consent Form

Participant Consent Form V.2

## CONSENT FORM

### Title of Project:

*A qualitative study to investigate service user experience of participation in research*

Name of Researcher: Grete Smith  
Mick McKeown

Please read the following statements and initial in the box provided to confirm agreement.

1. I confirm that I have read and understand the information sheet dated 4<sup>th</sup> May 2012 (Version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that participation is anonymous and any details that might identify me/my practice will not be included in reports or other publications produced.
4. I agree to the discussions with the researcher being recorded.
5. I agree to take part in the above study and the data to be used for the Masters degree being undertaken by the researcher, Grete Smith. This includes publication of the study results in appropriate peer reviewed journals.
6. I would like to receive a summary of the findings of this study

By email (Email address: \_\_\_\_\_ )

By post (Delivery address: \_\_\_\_\_ )



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Telephone: 01254 282197  
email: [GSmith2@uclan.ac.uk](mailto:GSmith2@uclan.ac.uk)  
[www.uclan.ac.uk](http://www.uclan.ac.uk)

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Researcher

\_\_\_\_\_  
Date

\_\_\_\_\_  
Signature

1 for participant: 1 for researcher

## Appendix D: NHS Letter



### The Pan Lancashire Cluster member organisations

NHS Blackburn with Darwen Care Trust Plus,  
NHS Blackpool,  
NHS Central Lancashire,  
NHS East Lancashire  
NHS North Lancashire

Dr J Gardner  
Medical Director  
Moor Lane Mills  
Moor Lane  
Lancaster  
LA1 1GF

### Head of Research & Innovation

**Rosalind Way**  
Tel: 01524 519320  
Mobile: 07766725119  
[rosalind.way@northlancs.nhs.uk](mailto:rosalind.way@northlancs.nhs.uk)

### RM&G Contact

**Nicky Dooley**  
CLRN RM&G Coordinator  
Tel: 01772 524946  
[Nicola.Dooley@lthtr.nhs.uk](mailto:Nicola.Dooley@lthtr.nhs.uk)

Ref: HL/ND/SE.gs

15<sup>th</sup> March 2012

Grete Smith  
KTP Associate  
Guide Business School Centre  
School Lane  
Blackburn  
Lancashire  
BB1 2QH

Dear Grete

### Re: *SERV-USER: Service user and carer involvement for the future?*

Thank you for contacting the R&D Department regarding your MSc project, which you will be undertaking using data already collected from the above study.

We have reviewed the consent process which was used as part of the original study and the consent forms clearly indicate that the data will be used for your MSc study, we are therefore happy for your study to go ahead without any further submission to the Research Ethics Committee.

Please contact us if you require any further guidance or information on any matter mentioned above.

We wish you every success in your research.

Yours sincerely

A handwritten signature in black ink, appearing to be "Helen Lowey", written over a horizontal line.

Dr Helen Lowey  
**Associate Director of Public Health**

NHS Blackburn with Darwen  
Helen Lowey

NHS Central Lancashire  
Shirley Waters

NHS East Lancashire  
Paula Cooper

NHS North Lancashire  
Rosalind Way

## **Appendix E: Interview schedule**

### Interview schedule

1. Broad experience of participating in the service evaluation
2. What was rewarding about the work?
3. What was less rewarding about the work?
4. How do you see yourself in the role of service user evaluating a service?
5. How do you think others see you?
6. Reflections on the value of similar involvement in future for yourself and others

## Appendix F: Literature search results

### 1. 'service users and carers involvement' AND 'health and social care services'

CINAHL: 8 results

No.	Year	Authors	Title	Journal
1.	2012	Webber, M. and Robinson, K.	The Meaningful Involvement of Service Users and Carers in Advanced-Level Post-Qualifying Social Work Education: A Qualitative Study.	British Journal of Social Work
2.	2011	Benbow, S.M. et al	Design, Delivery and Evaluation of Teaching by Service Users and Carers.	Educational Gerontology
3.	2001	Abbott, S. et al	Participation in arranging continuing health care packages: experiences and aspirations of service users	Journal of Nursing Management
4.	2006	Hall, JE	Professionalizing action research – a meaningful strategy for modernizing services?	Journal of Nursing Management
5.	1999	Rummery, K	The way forward for joint working? Involving primary care in the commissioning of social care services	Journal of Interprofessional Care
6.	2002	Peck, E et al	Information, consultation or control: user involvement in mental health services in England at the turn of the century	Journal of Mental Health
7.	2001	Chesterman, J et al	Satisfaction with the care-managed support of older people: an empirical analysis	Health and Social Care in the Community
8.	1999	Tierney, AJ and Vallis, J	<u>Multidisciplinary teamworking in the care of elderly patients with hip fracture</u>	Journal of Interprofessional Care

Medline: 12 results

No.	Year	Authors	Title	Journal
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1.	2011	Transkanen et al	Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study	BioMedCentral
2.	2010	Ridley et al	Partners in care?: views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003	Health and Social Care in the Community
3.	2006	Rapaport et al	Carers and confidentiality in mental health care: considering the role of the carer's assessment: a study of service users', carers' and practitioners' views	Health and Social Care in the Community
4.	2011	Robotham et al	Social validity of randomised controlled trials in health services research and intellectual disabilities: a qualitative exploration of stakeholder views	Trials Journal
5.	2007	Downe, S. et al	The UCLan community engagement and <b>service</b> user support (Comensus) project: valuing authenticity, making space for emergence	Health Expectations
6.	2008	Jones et al	Engaging service users in the development of stroke services: an action research study	Journal of Clinical Nursing
7.	2011	Wilson and Clissett	Involving older people in research: practical considerations when using the authenticity criteria in constructivist inquiry	Journal of Advanced Nursing
8.	2001	Chesterman et al	Satisfaction with the care-managed support of older people: an empirical analysis.	Health and Social Care in the Community
9.	2001	Abbott et al	Participation in arranging continuing health care packages: experiences and aspirations of service users	Journal of Nursing Management
10.	2006	Hall, JE	Professionalizing action research – a meaningful strategy for modernizing services?	Journal of Nursing Management
11.	2003	Tritter et al	Divided care and the Third Way: user involvement in statutory and voluntary sector cancer services	Sociology of Health and Illness
12.	2008	Wilkinson and McAndrews	'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings	International Journal of Mental Health Nursing

Pubmed: 23 results

No.	Year	Authors	Title	Journal
1.	2014	Cooke and Campbell	Comparing patient and professional views of expected treatment outcomes for chronic obstructive pulmonary disease: a Delphi study	Journal of Clinical Nursing

			identifies possibilities for change in service delivery in England, UK	
2.	2013	Bird et al	Why collaborate with children in health research: an analysis of the risks and benefits of collaboration with children	Archives of disease in childhood. Education and practice edition.
3.	2012	Sinclair et al	Looking after children and young people: Ensuring their voices are heard in the pre-registration nursing curriculum	Nurse Education in Practice
4.	2012	Netten et al	Outcomes of social care for adults: developing a preference weighted measure	Health Technology Assessment
5.	2012	Lloyd and Carson	Critical conversations: Developing a methodology for service user involvement in mental health nursing	Nurse Education Today
6.	2011	Transkanen et al	Service user and carer experiences of seeking help for a first episode of psychosis: a UK qualitative study	BioMedCentral
7.	2012	McKeown et al	The value of involvement from the perspective of service users and carers engaged in practitioner education: not just a cash nexus	Nurse Education Today
8.	2011	Robotham et al	Social validity of randomised controlled trials in health services research and intellectual disabilities: a qualitative exploration of stakeholder views	Trials Journal
9.	2011	Hitchen et al	Lone voices have an emotional content: focussing on mental health service user and carer involvement	International Journal of Healthcare Quality Assurance
10.	2010	Ridley et al	Partners in care?: views and experiences of carers from a cohort study of the early implementation of the Mental Health (Care & Treatment) (Scotland) Act 2003	Health and Social Care in the Community
11.	2009	Jones et al	Illness careers and continuity of care in mental health services: a qualitative study of service users and carers	Social Science and Medicine
12.	2008	Wilkinson and McAndrews	'I'm not an outsider, I'm his mother!' A phenomenological enquiry into carer experiences of exclusion from acute psychiatric settings	International Journal of Mental Health Nursing
13.	2008	Jones et al	Engaging service users in the development of stroke services: an action research study	Journal of Clinical Nursing
14.	2008	Allen and Rixson	How has the impact of 'care pathway technologies' on service integration in stroke care been measured and what is the strength of the evidence to support their effectiveness in this respect?	International Journal of Evidence Based Healthcare
15.	2007	Grocott et al	A model of user engagement in medical device development	International Journal of Healthcare Quality Assurance
16.	2007	Downe, S. et al	The UCLan community engagement and service user support (Comensus) project:	Health Expectations

			valuing authenticity, making space for emergence	
17.	2006	Rapaport et al	Carers and confidentiality in mental health care: considering the role of the carer's assessment: a study of service users', carers' and practitioners' views	Health and Social Care in the Community
18.	2006	Hall, JE	Professionalizing action research – a meaningful strategy for modernizing services?	Journal of Nursing Management
19.	2003	Tritter et al	Divided care and the Third Way: user involvement in statutory and voluntary sector cancer services	Sociology of Health and Illness
20.	2001	Abbott, S. et al	Participation in arranging continuing health care packages: experiences and aspirations of service users	Journal of Nursing Management
21.	2001	Chesterman et al	Satisfaction with the care-managed support of older people: an empirical analysis.	Health and Social Care in the Community
22.	1999	Martin et al	Developing community mental health services: an evaluation of Glasgow's mental health resource centres.	Health and Social Care in the Community
23.	1994	Powell et al	Involving consumers in assessing service quality: benefits of using a qualitative approach	Quality in Health Care

## 2. 'service user and carer involvement' AND 'phenomenology'

CINAHL: 5 results

No.	Year	Authors	Title	Journal
1.	2013	Kroese et al	Mental Health Services for Adults with Intellectual Disabilities - What Do Service Users and Staff Think of Them?	Journal of Applied Research in Intellectual Disabilities
2.	2010	Donner et al	Mainstream in-patient mental health care for people with intellectual disabilities: service user, carer and provider experiences.	Journal of Applied Research in Intellectual Disabilities
3.	2012	Tasker et al	Head, heart and hands: creating mindful dialogues in community-based physiotherapy	New Zealand Journal of Physiotherapy
4.	2002	Watts & Priebe	A phenomenological account of users' experiences of assertive community treatment	Bioethics
5.	2005	Galvin et al	The intimate mediator: a carer's experience of Alzheimer's.	Scandinavian Journal of Caring Sciences

Medline: 0 results found

Pubmed: 0 results found

3. 'Service users and carers' AND 'as researchers'

CINAHL: 7 results

No.	Year	Authors	Title	Journal
1.	2004	Allam et al	Commentaries. Our experience of collaborative research: service users, carers and researchers work together to evaluate an assertive outreach service	Journal of Psychiatric and Mental Health Nursing
2.	2010	Wilson et al	A potential model for the first all Wales mental health service user and carer-led research group	Journal of Psychiatric and Mental Health Nursing
3.	2009	Martindale et al	Clinical psychology service users' experiences of confidentiality and informed consent: a qualitative analysis	Psychology & Psychotherapy: Theory, Research and Practice
4.	2005	Magnusson and Hanson	Supporting frail older people and their family carers at home using information and communication technology: cost analysis	Journal of Advanced Nursing
5.	2006	Wright et al	How to involve cancer patients at the end of life as co-researchers	Palliative Medicine
6.	2005	Smith EM	Telephone interviewing in healthcare research: a summary of the evidence	Nurse Researcher
7.	2001	Rees et al	Psychometric properties of the Community Mental Health Team Effectiveness Questionnaire (CMHTEQ).	Journal of Mental Health

Medline: 4 results

No.	Year	Authors	Title	Journal
1.	2011	Robotham et al	Social validity of randomised controlled trials in health services research and intellectual disabilities: a qualitative exploration of stakeholder views	Trials Journal
2.	2010	Wilson et al	A potential model for the first all Wales mental health service user and carer-led research group	Journal of Psychiatric and Mental Health Nursing
3.	2011	Wilson and Clissett	Involving older people in research: practical considerations when using the authenticity criteria in constructivist inquiry	Journal of Advanced Nursing
4.	2006	Wright et al	How to involve cancer patients at the end of life as co-researchers	Palliative Medicine

Pubmed: 11 results

No.	Year	Authors	Title	Journal
1.	2012	Clement et al	Filmed v. live social contact interventions to reduce stigma: randomised controlled trial	British Journal of Psychiatry
2.	2012	Young et al	Support for self-management of cardiovascular disease by people with learning disabilities	International Journal for Research in Primary Care
3.	2004	National Collaborating Centre for Mental Health UK	Self-Harm: The Short-Term Physical and Psychological Management and Secondary Prevention of Self-Harm in Primary and Secondary Care	
4.	2011	Robotham et al	Social validity of randomised controlled trials in health services research and intellectual disabilities: a qualitative exploration of stakeholder views	Trials Journal
5.	2011	Petersen et al	Lessons from case studies of integrating mental health into primary health care in South Africa and Uganda	Journal of Mental Health Systems
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