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**THE AGENCY OF SERVICE USER AND CARER ENGAGEMENT IN HEALTH
AND SOCIAL CARE EDUCATION**

CHRISTINE A RHODES

**A THESIS SUBMITTED IN PARTIAL FULFILMENT OF THE REQUIREMENTS
FOR THE DEGREE OF DOCTOR OF PHILOSOPHY**

UNIVERSITY OF HUDDERSFIELD

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“Service user involvement brings something that you cannot learn in a text book, that you cannot learn in a lecture, you learn from the person who has dealt with it day in day out, real people, with a real situation in real life”

Student

“Being involved helped me learn about myself, put things in perspective, gave me a sense of purpose and belonging, has enhanced my life and given me more than I could have ever imagined”

Service user

Abstract

Service user and carer involvement in health and social care education in the UK has gained momentum over the last two decades, largely driven by consumerist and democratic ideologies. This is reinforced by the health and social care regulatory bodies such as the Nursing and Midwifery Council (NMC) and the Health and Care Professions Council (HCPC).

This thesis presents a series of eight peer reviewed papers that have focussed on the agency of service user and carer involvement in health and social care education. The accompanying commentary draws the papers together and locates them within an overarching theoretical framework, 'The Ladder of involvement'. This portfolio of evidence demonstrates a coherent approach that draws on underlying philosophies and theoretical underpinnings and displays contribution to knowledge in five distinct sections: Contribution to the literature with new findings, location of the findings within the current literature, location of the findings within the theoretical framework, contribution to the refinement and development of theory and contribution to dialogue and debate.

The key message from the studies undertaken as part of this portfolio of evidence is that service user and care involvement in health and social care education enhances student learning and influences their future practice. However, there must be a well-developed infrastructure within higher education institutions that recognises the complexities of user involvement for the key stakeholders. There is a pressing need for additional research to further substantiate the benefit of user involvement for all parties concerned, in order for user involvement to take its place as a core component of health and social care education.

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Glossary of Terms

ALG	Action Learning Group
CAIPE	Centre for the Advancement of Interprofessional Education
DH	Department of Health
DoE	Department of Education
GP	General Practitioner
HCPC	Health and Care Professions Council
HEE	Health Education England
HEI	Higher Education Institution
IPE	Interprofessional Education
LETB	Local Education and Training Board
LINKs	Local Involvement Networks
MaD	Making a Difference
NHS	National Health Service
NMC	Nursing and Midwifery Council
OECD	Organisation for Economic Co-operation and Development
PAR	Participatory Action Research
PINE	Participation in nurse education
QAA	Quality Assurance Agency
SHA	Strategic health Authority
UK	United Kingdom
UKCC	United Kingdom Central Council

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Paper 3	Ward, L., and Rhodes, C. (2010). Embedding a Consumer Culture in Health and Social Care Education – a university office's perspective. <i>International Journal of Consumer Studies</i> , 34, 596-602	93
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Chapter one

Introduction

This portfolio presents a series of eight peer reviewed papers (2008 – 2013) that have focussed on the agency of service user and carer involvement in health and social care education in the United Kingdom (UK). The accompanying commentary draws the papers together and locates them within an overarching theoretical framework. This chapter presents an overview of the body of work undertaken as part of this PhD by portfolio including the published papers, the context and rationale for the body of work and the thesis aim and objectives. In addition my perspective as the researcher and service user and carer involvement definitions are outlined. Finally, an overview of the chapters in the portfolio is included.

Table 1 The published papers

Paper 1	Balen, R., Rhodes, C., and Ward, L. (2010). The Power of Stories: Using narrative for Interdisciplinary Learning in Health and Social Care. <i>Social Work Education</i> , 29 (4), 416-426
Paper 2	Dearnley, C., Coulby, C., Rhodes, C., Taylor, J and Coates, C. (2011). Service users and carers: preparing to be involved in work-based practice assessment. <i>Innovations in Education and Teaching International</i> , 48 (2), 213-222
Paper 3	Ward, L., and Rhodes, C. (2010). Embedding a Consumer Culture in Health and Social Care Education – a university office's perspective. <i>International Journal of Consumer Studies</i> , 34, 596-602
Paper 4	Rhodes, C., and Nyawata, I. (2010). Service User and Carer Involvement in Student Nurse Selection; Key Stakeholder Perspectives. <i>Nurse Education Today</i> , 31, 439 -443
Paper 5	Padgett, K., Rhodes, C., Lumb, M., Morris, P., Sherwin, S., Symons, J., Tate, J., and Townend, K. (2012). What matters to users of services? An explorative study to promote shared decision making in health care. <i>Health Expectations</i> , DOI: 10.1111/j.1369-7625.2012.00767.x
Paper 6	Rhodes, C.A. (2012). User involvement in health and social care education: A concept analysis. <i>Nurse Education Today</i> , 32 (2), 185-189
Paper 7	Rhodes, C., Hardy, J., Padgett, K., Symons, J., Tate, J., Thornton, S. (2013). The Health and Well-being of Service User and Carer Educators: A Narrative Enquiry into the impact of Involvement in Healthcare Education. <i>International Journal of Practice-based Learning in Health and Social Care</i> . DOI: 10.11120/pbh.2013.00025
Paper 8	Rhodes, C. (2013). Service User Involvement in Pre-registration Children's Nursing Education the Impact and Influence on Practice: A case study on the student perspective. <i>Issues in Comprehensive Pediatric Nursing</i> . DOI: 10.3109/01460862.2013.830161

I was lead author in five of these papers because I initiated and led these projects. Through collaborative work I have also participated in several projects, where I was not the principal investigator or lead author. Authorship declarations indicating the percentage contribution have been recorded and included with each collaborative paper. The full articles are included in Appendix 1. Web analytics and relevant metrics are included in Appendix 2.

The supporting commentary will demonstrate the coherence of the work as a critique and analysis of service user and carer involvement in health and social care education. The published papers are located within the commentary and are highlighted as bold text or through footnotes.

1.1 The context and rationale

Service user and carer involvement in health and social care, and health and social care education, is at the forefront of health and social care policy, legislation and practice in the UK. Recommendations from the Francis enquiry (2013), the Berwick Report (2013) and the Keogh Report (2013) call for a much stronger patient voice at all levels of health and social care and health professional education in order to gain a richer understanding of peoples' experiences and improve service delivery. Service user and carer involvement is not only a UK phenomenon. For example, government policy directives exist in Australia (Happell and Roper, 2009), Canada (Romanow, 2002) and the Netherlands (Vos, 2002, cited in Tritter, 2009, p 280), with varying degrees of development. The work presented here is located within the UK and the National Health Service (NHS) and social care services and therefore specific to the UK context.

The requirement for service user and carer involvement in health and social care education has led to an expansion of literature, particularly in the evaluation of the experiences of higher education institutions (HEI's) (McKeown et al., 2010). Literature reviews conducted on service user and carer involvement in health and social care education (Morgan and Jones, 2009; Repper and Breeze, 2007; Rhodes, 2006), identify that although a number of qualitative studies have been published that investigate students and users perspectives of involvement activities, there are gaps in the literature and the need for further research exploring the experience and its effectiveness. Findings from these reviews provided the rationale for the studies presented within the portfolio.

Service user and carer involvement in health and social care education includes a range of key stakeholders requiring interaction with a number of different types of people; service users and carers, students, academics and practice partners. A decision was therefore made to approach the topic through the presentation of a series of papers exploring topics related to the key stakeholders. The papers are embedded in practice based enquiry to meet the objectives of the study whilst also contributing to the emerging literature and knowledge base.

1.2 Aims and objectives

The aim of this body of work was to explore the agency of service user and carer involvement in health and social care education in the UK from a range of perspectives.

The specific objectives were to:

- Undertake an in depth critique of user involvement in health and social care education;
- Critically evaluate the theoretical underpinnings of service user and carer involvement and service user and carer involvement in health and social care education;
- Investigate key stakeholder perspectives of service user and carer involvement in health and social care education.

1.3 The researcher

The body of work presented in this portfolio is from the viewpoint of an academic working in nurse education, attempting to offer a collaborative approach to the education of nurses and allied healthcare professionals, with an overarching aim of improving care delivery. As the researcher reflexivity is acknowledged as I am immersed in the area of enquiry and therefore located and positioned within the work. It would have been impossible and inappropriate to attempt to bracket or suspend my beliefs; in order to manage this, self- critique and self- appraisal has been undertaken throughout supported by supervision (Finlay, 2002; Finlay and Gough, 2008). I planned to present a thoughtful, systematic critique of the agency of service user and carer involvement in healthcare education in the UK. Service user

and carer involvement has been a key focus of my practice for a number of years, initially as a health care practitioner, then lecturer and currently as someone who now holds a leadership role in relation to curriculum development. Chapter 7 and Appendix 2 presents a reflexive critique and career profile in relation to user involvement respectively.

Undertaking this body of work represents a significant period of transition in my professional career in terms of my intellectual, academic and personal development. It has included a journey of self-exploration as well as an in depth enquiry into user involvement in health and social care education. I have reflected on my role as an academic and identified the approach that I have adopted is that of a critically engaged academic as described by Creswell and Spandler (2013). The relationship that has developed with service users and carers represents deep engagement and has demanded reflexivity and the giving of self with critical agency. Inevitably as an academic I have both an ‘insider’ (within) and ‘outsider’ (about it) views. Critically, success has been dependent upon ‘working with’ service user and carers rather than ‘taking from’, remaining true to their experience (Cresswell and Spandler, 2013).

1.4 Service user and carer involvement definitions.

Service user and carer involvement is a complex, multi- faceted phenomenon, not least in regard to the range of terms, definitions and theoretical underpinnings. An array of terminology is used to describe the people who use health and social care services ranging from consumer, patient, public, service user and carer. Exploration of definitions are highlighted within the published literature (Beresford, 2005;

McKeown et al., 2010; **Rhodes** et al., 2013). For the purposes of this commentary the broad term ‘user’ will be adopted. The following definition of user involvement will be used. This was derived from a concept analysis undertaken and presented in the portfolio:

‘A process whereby the user’s lived experience is utilised in teaching and learning for students undertaking health and social care courses. Involvement can occur at a number of levels, as identified on the ladder of involvement (Tew, Gell and Foster, 2004) from design and development of the course, recruitment, direct teaching, assessment and research’ (**Rhodes, 2012**).¹

1.5 Portfolio overview

The portfolio is presented in the following chapters.

- Chapter 1 provides an outline to the portfolio and presented the published papers, the context and rationale, aims and objectives, details of the researcher and service user and carer definitions.
- Chapter 2 outlines the background of health policy in relation to involvement in health and social care with discussion of the expansion into health and social care education. A synopsis of the key literature is also included.
- Chapter 3 examines the underpinning concepts, theories and theoretical framework. The concepts of agency and social capital are critically discussed, followed by exploration of the theoretical underpinnings of user involvement and the theories associated with health and social care education. The identified theoretical framework is presented and justified.

¹ Paper 6 is the only currently published concept analysis on service user and carer involvement in health and social care education, with clarification on meaning and defining attributes.

- Chapter 4 covers methodology and the research paradigm is identified and a plan of work is presented. The research methods used across papers are discussed along with a critique of each published paper. The assimilation of the theoretical framework underpinning each study is included.
- Chapter five presents the contribution to knowledge in five distinct areas; contribution to the literature with new findings; location of the findings within the current literature that reinforces and extends the evidence base; location of the findings within the theoretical framework; and contribution to dialogue and debate.
- Chapter 6 summarises the body of work and discusses the implications of user involvement in health and social care education. The aims and objectives of the thesis are reviewed and the findings are drawn together to offer suggestions depicted from the key implications derived from the publications and supporting commentary. Recommendations are made on future user involvement and research. The theoretical framework is critiqued and an alternative model ‘The Approaches to Involvement Continuum’ offered for consideration.
- Chapter 7 provides a reflexive critique where the intellectual journey is articulated that acknowledges the personal insight gained, the knowledge and understanding acquired and the motivation this has instilled for future work in this field.
- Chapter 8 presents a conclusion that sums up the body of work produced that represents a coherent approach with critical and original contribution to knowledge that is timely in this growing field of inquiry.

Chapter Two

Background

This chapter is presented in three distinct sections. First, it will explore how health policy in relation to user involvement in health and social care in the UK has developed over the last 20 years. Second, the expansion of policy requirements into health and social care education will be discussed. Finally, a synopsis of the key literature reviewed is outlined.

2.1 Health policy background

The ideology of user involvement is embedded in health and social care policy (McKeown et al., 2010). There has been successive and developed legislation relating to the inclusion of users in health service policy and delivery, which has had a political context in addition to social drivers (Barnes and Cotterell, 2012). The political context is represented by two models of involvement; first a consumerist approach, broadly associated with market interests of efficiency, economy and effectiveness and essentially this is top down and managerially led. Second, a democratic approach primarily concerned with people having more say in services that impact upon them (Beresford, 2002). Social drivers embody movements and organisations of health and social care users, that tend to follow an empowerment model with freedom to make choices and accept responsibility (Barnes and Cotterell, 2012).

2.1.1 Policy development

Early policy, for example, ‘Working for Patients’ (DH, 1989) and ‘The Patients Charter’ (DH, 1991), emphasised consumerist choice. The proliferation of subsequent policy documents embedded this consumerist approach, reflecting the ethos of the then conservative government with neoliberal ideologies (Gibson, Britten and Lynch, 2012). Following the election of the labour government in 1997 a social democratic approach, in keeping with the philosophy of the Labour Party, with an increased emphasis on improving quality rather than efficiency was adopted (Barnes and Cotterell, 2012; Tritter, 2009). The shift in philosophy was reflected in ‘Patient and Public Involvement in the new NHS’ (DH, 1999a) and ‘The NHS Plan’ (DH, 2000). Public and patient involvement became a duty manifested in ‘Shifting the Balance of Power’ (DH, 2001) and section 11 of the 2001, ‘Health and Social Care Act’ (DH, 2003), which placed a duty on health care planners to involve patients and the public in the planning, delivery, and evaluation of care affected how services operate. The new labour government was influenced by the ‘third way’ ideology (Giddens, 1998), a combination of capitalism and socialism with social justice, equality of opportunity and the advent of citizenship. Citizenship engenders individual responsibility and ‘no rights without responsibilities’ and the notion of civil society (Rose, 2000 cited in Cowan, Banks, Crawshaw and Clifton, 2011).

Organisational change of public involvement structures accompanied the legislative dictates, with the abolition of Community Health Councils in 2003 (Barnes and Cotterell, 2012). Established since 1974, their function was to provide a voice for patients and the public in the NHS. Public and Patient Involvement Forums were introduced with a remit of improving public engagement in NHS organisations.

However, these in turn were abolished in 2008 and Local Involvement Networks (LINKs) were introduced, with a view to improving engagement with more local community and voluntary organisations (Barnes & Cotterell, 2012; Bradshaw, 2008; Gibson, et al., 2012; Tritter, 2009). Political commentators viewed this constant rearranging as a search for ways of involving the patient and public in the complex healthcare system (Barnes and Cotterell, 2010). However, a more contrasting viewpoint suggested this was a way of maintaining control and preventing the development of a democratic approach (Tritter, 2009).

At this juncture the overarching principle of user involvement is high on the agenda in multiple arenas in health and social care and health across the world (OECD, 2005; National Institute of Health, (US) 2011). The latest white paper, Equity and Excellence: Liberating the NHS has the testimony 'nothing about me without me' (DH, 2010) and endorses a quasi-market approach with GP commissioning consortia and the premise of the public exerting choice from a range of competing service providers. The element of choice is however questionable as it will, most likely be notional, limited by local monopoly positions due to economies of scale determined by the rationed, centrally financed and controlled healthcare system in the UK (Bradshaw, 2008; Cowan et al., 2011). LINKs are to be replaced by HealthWatch charged with representing patients, improving choice and information, assisting people with complaints and recommending inspections of services indicating a shift towards a consumerist approach to user involvement by the Coalition government elected in May 2010 (Gibson et al., 2012).

2.2 Social movements

Internationally service user organisations have been evolving since the 1960's and 70's, with personal development and empowerment emerging as social movements with the aim of influencing social and political change (Campbell and Oliver, 1996; Cowan et al., 2011). Traditional social movements tended to be condition specific for example Arthritis UK, Diabetes UK, Mencap and Mind, and are criticised as being divisive with fragmentation and segregation (Beresford and Branfield, 2012). Disability movements recognised the need for inclusivity and diversity in the 1980's; leading to the forging of alliances between groups with The British Council of Organisations of Disabled People becoming the umbrella organisation. Alliances were created with excluded groups such as gay, lesbian, bisexual and transgendered disabled people. Despite these alliances the narrow interpretation of disability continued to exclude a number of people, for example, mental health service users, people with a learning difficulty and older people (Shakespeare, 2006; Thomas, 2007).

The Patient's Association, an established healthcare charity, is possibly one of the most well-known social movements within the UK and their motto is 'Listening to Patients and Speaking up for Change'. The Patient's Association gather patient opinions on health and social care issues nationally and links with a number of health and social care charities to form a network that campaign on common issues targeting Parliament, the media and professional bodies. Significantly, Robert Francis QC, author of The Francis Inquiry is to take up the post of President at the Association. This has been viewed as an opportunity to drive forward NHS reform to

ensure patients are treated in a safe, dignified and caring way (The Patient's Association, 2013).

Further development of social movements has occurred with the emergence of new social movements with a focus on social identity and humans rights, seeking active participation and equality achieved through liberation and a democratic approach (Todd and Taylor, 2004). New social movements are portrayed as less formal, with direct democracy and membership from a wide social base built on relationships and friendships (Wiewiorka, 2005). Shaping Our Lives a national service user controlled organisation and network is an example of a new social movement. Shaping Our lives works across a wide range of service users including those considered to be 'hard to reach' or 'seldom heard', for example people who have problems with drugs and alcohol, homeless people, travellers and those with experience of prison. This more inclusive working has been found to strengthen solidarity with the ability to challenge prejudices and discriminations (Beresford and Branfield, 2012).

In summary, user involvement has political and social drivers and is becoming embedded within the health and social care system. However, lack of coherence across policies from successive governments over the last two decades has resulted in a fragmented approach to user involvement regarded by some commentators as disarray (Bradshaw, 2008). Whatever the purpose of the frequent rearranging of systems is, either as a search for improvement or due to changing political ideals, in reality user involvement has been controlled by the salaried professionals (Gibson et al., 2012). Control is retained due to the fear that democratic decision making would lead to unworkable populism. Moreover, there would appear to be a conflict of

ideology between coalition government policy and new social movements (Cowan et al., 2011). Despite these opposing views there is recognition that user involvement has the potential to change the culture of healthcare services. There is however acknowledgement that any change will require investment and time in order to operate from a position of equality, representative of a democratic approach, that allows real influence on decision making in order to achieve open and transparent communication with the potential of health gain for all (Gibson et al., 2012; Tritter, 2009). Policy surrounding user involvement has subsequently expanded to health and social care education and is discussed in the following section.

2.3 Policy in relation to user involvement in health and social care education

User involvement in health and social care was central to Lord Darzi's review of health care delivery and the subsequent report 'High Quality Care for all' (DH 2008a). The report emphasised the dual agenda calling for a range of patient involvement, including patient choice together with partnership working and high quality care at its core. Additionally, 'Real Involvement: working with people to improve health services' (DH, 2008b), led to policy dictate on involvement in health and social care education. The subsequent Department of Health Education Commissioning for Quality document represented a significant shift in emphasis with the additional inclusion of guidance on user involvement in the design and delivery of healthcare education (DH, 2009).

Healthcare education is now under the remit of Health Education England (HEE).

The establishment and development of HEE was set out in 'Liberating the NHS: Developing the Healthcare Workforce, From Design and Delivery' (DH, 2012), as

part of the coalition government healthcare reforms. Health Education England has the responsibility to provide leadership and allocation of resources for the new education and training system supported by Local Education and Training Boards (LETBs) who commission education and training to support the current and future workforce. Health Education England and LETBs acknowledge the need for local and national partnerships with key bodies and stakeholders that includes patient groups (DH, 2012).

User involvement in higher education institutions (HEI's) where health and social care professionals receive education and training has predictably evolved to emulate what is perceived to be happening in practice (Lathlean et al., 2006; McKeown et al., 2010). As a result, good practice guidelines for user involvement in education have been developed (Levin, 2004; Tew et al., 2004). The development of user involvement in health professional education has been further influenced by increasing professional body requirements (HCPC, 2013; NMC, 2010).

2.3.1 Professional body requirements

Professional Statutory Regulatory Bodies now require HEI's to demonstrate user involvement. For example, the Nursing and Midwifery Council, Standards for pre-registration nursing education require HEI's to demonstrate how service users and carers contribute to programme design, delivery and assessment (NMC, 2010). Additionally, the Health and Care Professions Council have amended the standards of education and training to include a new standard which states that service users and carers must be involved in the programme (HCPC, 2013).

2.3.2 Public inquiries

The Mid Staffordshire NHS Foundation Trust public inquiry, initiated in 2010 following an independent inquiry into the care provided at the Trust, has resulted in a further emphasis on care and compassion with patient-centred care. The subsequent ‘Francis Report’ identified care failure and made 290 recommendations in relation to healthcare practice and the education of health care professionals with an emphasis on the principle of ‘putting other’s needs before your own’ (Francis, 2013). The follow up Berwick Report (2013) was charged with identifying reasons for care failures at mid Staffordshire, and to specify the changes needed to meet the recommendations in the Francis Report. Berwick (2013) states that the patient voice should be heard during the training of healthcare personnel and promotes ‘practice partnering with patients’.

Funding 2.3.3

Despite the requirement for user involvement in HEI’s there is no universal central funding. Social work education has, been supported by the education support grant since 2003, which included up to £7,400 a year per HEI for user involvement. The education support grant is however currently under review with a consultation exercise that completed in December 2013, with the outcome as yet pending (DH, 2013). The lack of specific funding for health professional education has resulted in a wide variation in user involvement activities in HEI’s dependent on the individual institutions interpretation and implementation of policy. Some universities meet minimum requirements representing a consumerist top down, academically led model often reliant on individual enthusiasts with limited or short term funding (Beresford, 2005; McKeown et al., 2010; Ward and Rhodes, 2010). Other

universities are pioneers, striving to achieve collaborative models analogous to a democratic approach to user involvement, this has required significant investment from individual HEI's with the recommendation for ring-fenced funding (Downe et al., 2007; McKeown et al., 2012; Simons et al., 2006; Stickley et al., 2009).

In summary, user involvement in health and social care education in the UK is now a requirement and as a result is gaining importance and becoming an accepted part of the education of health and social care practitioners. The policy and professional body drivers offer the incentive for user involvement. The lack of specific funding is however problematic and the interpretation and implementation of user involvement is disparate resulting in a wide variation in the amount and types of user involvement with fluctuating levels of investment.

2.4 Synopsis of the key literature reviewed

For the purposes of the portfolio the relevant literature is reprised and critically discussed here. In addition distinct and pertinent sections of prior literature and research have been discussed within each of the studies undertaken and included in each paper within the portfolio.

The growing impetus for user involvement in health and social care education has led to an expansion of published literature on this topic. Published work, including the papers presented as part of this portfolio, has added to the evidence base for user involvement in health and social care education in the UK. Publications range from good practice guidelines, position papers, and reports of evaluative, qualitative and participatory action research (Gibson et al., 2012; McKeown et al., 2010;

McKeown et al., 2012; Morgan and Jones, 2009; Repper and Breeze, 2007;

Rhodes, 2012; Towle et al., 2010).

The majority of the UK published papers have been either evaluation (Balen, **Rhodes** and Ward, **2010**; Barnes, Carpenter and Dickenson, 2006; Costello and Horne, 2001; Simons et al., 2006) or qualitative research (Bailey, 2005; Dearnley, Coulby, **Rhodes**, Taylor and Coates, **2011**; Jones, 2006; **Rhodes, 2013; Rhodes et al., 2013**; Shah, Savage and Kapadia, 2005) that investigated students and users perspectives of involvement activities. A majority of the publications are in the field of mental health and social work education (Morgan and Jones, 2009), with a limited number of comparative studies (Forrest, Risk, Masters and Brown, 2000; Wood and Wilson Barnett, 1999). Despite methodological differences, findings from the studies suggest that user involvement has a positive influence on student learning, and practice and affords benefits to users themselves, whilst also identifying a number of barriers and challenges (Balen, **Rhodes** and Ward, **2010**; Dearnley, Coulby, **Rhodes**, Taylor and Coates, **2011**; Minogue et al., 2009; Morgan and Jones, 2009; **Rhodes, 2012; Rhodes, 2013; Rhodes et al., 2013**). Literature reviews undertaken on service user and carer involvement identify the need for further research exploring the experience and its effectiveness on student learning and practice to strengthen the evidence base (Morgan and Jones, 2009; Repper and Breeze, 2007; Rhodes, 2006). A concept analysis of user involvement in health and social care education, undertaken as part of this portfolio, contributed towards clarification of the meaning of user involvement in this context, and provided a definition along with defining attributes (**Rhodes, 2012**).

Participatory action research (PAR) approaches, which emphasise participation of key stakeholders and are associated with empowerment are increasingly being undertaken. A number of PAR studies adopt a longitudinal approach, with recognition of the need to carry out large studies that observe the evolution of user involvement over a period of time (Downe et al., 2007; McKeown et al., 2012; Stickley et al., 2009). An example of a PAR study is the Comensus initiative with a modified participatory action study comprising of iterative meta-cycles or phases from 2004 to date. The focus of the study is the development of service user and carer involvement in a university setting and has included the setting up, establishment and maturation of a community involvement team (Downe et al., 2007; McKeown et al., 2012). Similarly, the Participation in Nurse Education (PINE) project was a three year participatory action research project designed to fully involve service users in the design and development and implementation of teaching sessions for mental health nursing students. The service users developed the qualitative research questions, undertook the research, and analysed the results (Stickley et al., 2009). Participatory action research is closely aligned to critical and feminist research with an emphasis on collaboration between researchers and participants typically with a group or community that are vulnerable or oppressed. Participatory action research aims to generate community solidarity with empowerment and emancipatory ideals through the use of knowledge with action and consciousness raising (Polit and Beck, 2008). Participatory action research and has a clear alignment to the underpinning theory discussed in chapter 4 and consistent with a democratic approach.

Despite growing evidence base about user involvement the literature has been criticised as being largely optimistic and does not offer a balanced view (Speed, Griffiths, Horne and Keeley, 2012). Additionally, there is a gap in the literature reporting on quantitative approaches. Staniszewska et al. (2011) reviewed the evidence base of public and patient involvement in research and suggest that quantitative approaches can offer multiple questions to address a different aspect of the same underlying construct, in this case, to measure the impact of user involvement in research. They argue that this would complement qualitative approaches, identify causal relationships to support policy implementation and strengthen the evidence base. Realistic evaluation, developed by Pawson and Tilley (1997) that explores contextual factors to investigate effectiveness, focusing on context, mechanisms and outcomes is suggested as an appropriate approach (Staniszewska et al., 2011).

The existing literature acknowledges both consumerist (Cleminson and Moseby, 2013; Happell and Roper, 2009; Repper and Breeze, 2007; Ward and **Rhodes, 2010**) and democratic approaches (Simons, 2006; McKeown et al., 2012; **Rhodes** et al., 2013; Tritter and McCallum, 2006). Regardless of the approach there is recognition that for user involvement to be successful it requires a partnership approach with mutual support and quality relationships (Downe et al., 2007; Minogue et al., 2007; Morgan and Jones, 2009; **Rhodes, 2012**). For effective partnerships to develop, a range of contextual and process factors need to be in place, for example the right environment, atmosphere and attitude. Consideration needs to be given to funding, roles, training and the time that this will take (**Rhodes** and Nyawata, 2011; **Rhodes, 2012**; Rush, 2008). Process factors for involvement in health and social

care research have been referred to as the ‘architecture of involvement, where having the right infrastructures and landscape in place is paramount to successful involvement (Brett et al., 2009). In order to achieve this there is a need for commitment from the highest level at the institution (Downe et al., 2007; **Rhodes, 2012**; Ward and **Rhodes, 2010**). To argue the case for the resources required a substantive evidence base as to the value of user involvement is required.

In summary, the body of literature contributing to the knowledge, understanding and evidence base of user involvement in health and social care education is expanding with increasing evidence that demonstrates the benefits and added value that user involvement brings. There is acknowledgement of both consumerist and democratic approaches with an overarching view that regardless of the approach, partnerships and networks are critical to success with the implication that a democratic approach is the ideal.

The papers included in this portfolio that have arisen out of an in depth critique and investigation of the agency of user involvement from a variety of key stakeholder perspectives, has significantly contributed to knowledge, and expanded the literature in an interprofessional context (Chapter 5). Nevertheless, further research exploring the experience and effectiveness of user involvement in health and social care education utilising a variety of research methods and approaches is required.

Adopting a particular emphasis on the influence user involvement has on transformative learning, health care professional practice, and subsequent care delivery, would support the continued development of user involvement within HEI’s and espousal of more inclusive approaches (**Rhodes, 2012**).

Chapter Three

Underpinning concepts, theories and theoretical framework

The underpinning concepts and theories associated with user involvement in health and social care, and health and social care education in conjunction with the chosen theoretical framework will be outlined in this chapter. First, the concepts of agency and social capital will be critically discussed and related to the key stakeholders of user involvement in health and social care education; users, students, academics and practice partners. Second, the theoretical underpinnings of user involvement and thirdly the theories associated with health and social care education will be presented. Finally, the theoretical framework 'The Ladder of Involvement' (Tew et al., 2004), chosen, in an attempt to achieve theoretical assimilation will be justified.

3.1 Underpinning concepts of user involvement

3.1.1 Agency

Within sociological theory, it is argued that agency is a causal relationship between personal experience and on-going process of events (Giddens, 1993). Emirbayer and Mische (1998) define agency as 'the temporally constructed engagement by actors of different structural environments' (p 970). This definition was informed by the dimensions of iteration, which affect what action is taken in a given situation. The dimensions of iteration are described as reactivation of past thought and action; a projective element, with possible future action and a practical-evaluative element, with the actual action taken to the present situation (Emirbayer and Mische, 1998).

The characteristics of agency are purposefulness, intentionality, historical embeddedness (judgements based on experiences) and intersubjectivity (the sharing of subjective states by two or more individuals) (Emirbayer and Mische,

1998). A social behaviourist approach to user involvement suggests that agency is exercised differently by individuals due to socially patterned selves that interact within bounded situations and social structures. A theoretical model with four analytical types of agency is offered; existential ('free will'), identity (ability to innovate), pragmatic (capacity to act) and life course (retrospective analysis of decision) which overlaps with social psychological theory related to 'self' (Hitlin and Elder, 2007).

The 'agents', in relation to user involvement are seen primarily as service users and carers, but can also be students, academics and practitioners. Each agent will have their own characteristics and social influences (Emirbayer and Mische, 1998; Hitlin and Elder, 2007). It seems reasonable to suggest that the achievement of effective involvement will be determined by the ability of the agents to work in partnership, for example whether they understand each others roles and are able to collectively participate to achieve a common goal, or whether they oppose and dismiss one another's intentions and ideas (Markwell, Watson, Speller, Platt and Younger, 2003; National Coordinating Centre for Public Engagement, 2013). The need for effective partnerships implies that a consumerist approach, that is managerially led, has the potential to adversely affect the relationship of the agents and hinder a wholly successful outcome. A democratic approach, with collaboration and partnerships, would positively enhance relationships and facilitate the opportunity of a positive outcome for all concerned (Beresford, 2002, Beresford, 2013).

3.1.2 Social capital

Social capital, though a contested concept is frequently associated with user involvement (Laverack, 2013). Referred to as the ‘glue’ that holds a community together (Hancock, 2001), it enables a collective, rather than individual approach, a bringing together of agents, often resulting in more purposeful action. Putnam (2000) defines social capital as a social organisation with connections among individuals, social networks and the norms of reciprocity and trustworthiness that arise from them. This is echoed by Hsieh (2008) who defines three attributes for social capital these being trust, networks and reciprocity. Furthermore, three types of social capital have been identified: bonding, where there are common identities or ties among people similar to one another, participation within a community; bridging, with diversity or ties among people who differ from one another, participation across communities and linking, which relates to power or ties with those in authority, participation between communities and organisations (Improvement and Development Agency, 2011).

The strong ties and networks identified by the theorists of social capital are important. However, these networks have been criticised for disregarding issues such as power and inequity, with the potential for destruction when people move on and the possibility of becoming insular (Jarley, 2005). Jarley (2005) in his work on unions as social capital offers solutions by involving internal and external relationships, with a collective approach that strengthens and expands social capital. The collective in user involvement aims to include all key stakeholders on an equal

footing in order to create alliances with the potential for bringing about purposeful action.²

3. 2 Underpinning theories of user involvement.

After taking into consideration the political and social drivers associated with user involvement, critical evaluation of the current literature, and undertaking several studies investigating the agency of user involvement in health and social care education,³ I have arrived at a position of advocating the adoption of a democratic approach to user involvement.

This philosophy of user involvement is based on Marxist principles for transformative social change and relates to critical social theory that aims to liberate individuals, freeing conscious and unconscious constraints that interfere with participation and enable social interactions, free from domination (Freire, 2000). The influential work of Jurgen Habermas is of particular relevance. His early work from the Frankfurt school, ‘The Structural Transformation of the Public Sphere’, with theories of democratisation and political participation (Habermas, 1989), was followed by a shift to ‘The Theory of Communicative Action’; a consensual form of social co-ordination with language and communication, orientated to understanding and interpretation, as a basis for societal democratisation. Habermas (1987) describes the need for respectful acknowledgement of difference and equalised power differentials with reciprocity, equal domination and an emphasis on rationality in order to achieve deliberative democracy. Habermas’ view is that in order to communicate you need to use speech with mutual understanding, communicative competence and critical

² The literature on user involvement in health and social care, including the papers presented here, identify that networks and the collective partnerships with active participation are crucial to its success.

³ (Balen et al., 2010; Dearnley et al., 2011; Padgett et al., 2012; Rhodes and Nyawata, 2011; Rhodes, 2012; Rhodes et al., 2013; Rhodes, 2013; Ward and Rhodes, 2010)

reflection. Self reflection is seen as integral to move beyond explanation to achieve empowerment to change. Critiques of Habermas contend that his stance on communicative competence, specifically his exclusion of non verbal speech is seen to obscure the complexity of communication and acts against the principles of a democratic approach that would result in the exclusion of a number of people with various disabilities. This viewpoint is reportedly influenced by Habermas' negative experiences encountered as a child with a cleft palate that meant other people did not understand him resulting in a lack of reciprocity (Clifford, 2009). Clifford (2009) further suggests the expansion of verbal exchange to 'embodied participation', with multiple ways of transmitting and understanding meaning that recognises shared vulnerability and inter-dependence, as a way of fulfilling the democratic norms of inclusivity and reimagining deliberative democracy.

Habermas' (1984) 'Theory of Communicative Action' divides the social world into the 'system'; the state or government driven by instrumental rationality and the 'lifeworld'; the everyday lives of citizens grounded by communicative rationality. Reproduction of the 'lifeworld' is achieved through communicative action. It is argued that user involvement in health and social care education is an example when the 'system' and 'lifeworld' are brought together. The university has the possibility of providing a critical social space for dialogue and alliances to flourish; this is dependent upon the correct infrastructures being in place to facilitate effective collaboration and partnerships.

The acknowledgement that the democratisation of user involvement can be problematic affords exploration of alternative theories in relation to power

relationships. Power-over, whereby one party is made to do what another wants them to, and the work of Michel Foucault (1979), that explores the nature of power, and how it functions, is particularly relevant to the health and social care environment. Foucault (1979) describes hegemonic power that is taken for granted in our everyday lives, as it is ‘invisible’. Here the bourgeois use implicit power processes to maintain control over the social classes by propagating a belief in their ideologies, through regimes of truth that enforces sub ordination. Hegemonic power is associated to health professionals who impose their own ideas without listening to what is important to others (Laverack, 2013). The work of Pierre Bourdieu (1990) and the dynamics of power relationships is also worthy of consideration. Bourdieu suggests in the social structures of society there are struggles and conflicts to appropriate rare social goods or forms of capital. These are categorised as economic, cultural, social and symbolic capital in industrialised capitalist societies (Bourdieu, 1986). Capital is not evenly distributed amongst social classes, leading to the struggles from the agents to take advantage of the capital that they own. Within healthcare, professionals have cultural capital based on professional qualifications that gives them power- over service users who may be seen as having little or no capital (Gibson et al., 2012). This links with the work of Fraser (1997) with weak to strong publics, suggesting public is formed when private individuals come together to discuss issues publicly. She argues that there is a plurality of publics due to differing viewpoints that lead to potential conflict. ‘Subaltern counterpublics’, for example, disability groups, can develop and offer alternative conceptions from their perspective, to influence decision making. Fraser acknowledges there are differences in the ability to influence, with strong publics who are able to influence decision making and weak publics with no influence at all. She proposes a concept

of 'participatory parity' where economic and status inequalities are dealt with first to attempt to eliminate or reduce social inequity and create a more equal platform (Fraser, 1997).

In summary, the concepts of agency and social capital are commensurate with a democratic approach to user involvement in health and social care and can be aligned to the theoretical underpinnings of critical social theory. Operationalisation of a democratic approach is however endangered by the complexities of achieving reciprocity compounded by the bureaucratic, hegemonic model of the UK health and social care delivery with the risk of tokenism.

3. 3 The theories of health and social care education.

As the focus of this portfolio is the education of health and social care professionals, the underpinning educational theories that relate to user involvement have also been explored. The shift away from apprenticeship models of health professional education, with training schools attached to hospitals, has dislocated training from practice with education now taking place in the university setting. Nursing in particular was criticised for the so called theory practice gap with critics claiming there was an emphasis on theory at the expense of developing competence in clinical skills (While et al., 1995; Macleod-Clark et al., 1996). Consequently policy documents initiated changes to nursing curricula (DoE, 1998; DH, 1999b). In addition, the Fitness for Practice report (UKCC, 1999) set out recommendations and resulted in the 'Making a Difference' (MaD) curricula (DH, 1999c) with an emphasis on practice. It is argued that the theory practice gap has the potential to be reduced through the involvement of service users and carers in education (Hislop, Inglis, Cope, Stoddart and McIntosh, 1996). Moreover, the shift in health policy that challenges the traditional positivist approaches to health and social care education, as discussed in the following sections, heightens the need for service users and carers to infiltrate the university and the curriculum.

3.3.1 Transition to Higher Education and Graduate Status

Traditionally approaches to health and social care professional education were influenced by bio-medical models with a scientific approach to knowledge that was acquired and then implemented (Roberts, 2000; Sweeney, 2006). This was positioned within the positivist paradigm and utilised a behavioural approach with an emphasis on factual recall. Despite the gradual shift of all health and social care

education into higher education and the move to graduate status, where there is more emphasis on student centred learning and constructivist approaches (Purdy, 1997a, 1997b), and these programmes remain different to traditional degree programmes. Health and social care programmes are outcome driven with tensions around prescribed content in order to meet professional, statutory and regulatory body requirements in terms of competence along with critical thinking skills and the ability to be caring and compassionate (Cowan, Norman and Coopamah, 2005; Eraut, 2005; HCPC, 2012; NMC, 2010). Students have the dual task of completing a degree and eligibility to apply for a professional qualification resulting in a crammed curriculum with a high workload for all involved. Dalley, Candela and Benzel-Lindley (2008), identified that student centred learning is inhibited by increasing content and argues for a de-crowding of the curriculum.

3.3.2 Educational Approaches

Contemporary health and social care education adopts a biopsychosocial approach and utilises a range of learning theories, and teaching and learning strategies, depending on the subject matter (Dalley et al., 2008). There has been an increased recognition of the need for transferable skills and interprofessional working facilitated by teamwork and interprofessional education (IPE) (Begley, 2009). The Centre for the Advancement of Interprofessional Education [CAIPE] (2012), suggests that the contribution from service users and carers complements perspectives from teachers and practice supervisors with the recommendation that ‘service users and carers are involved as teachers and mentors in IPE after preparation followed by on-going support’ (pg 16). Interprofessional education particularly lends itself to user involvement and facilitates a shift of focus from the professional to the patient or

client. Interprofessional education occurs when two or more professionals learn with, from and about each other, to improve collaboration and the quality of care (CAIPE, 2012). Evidence suggests that effective collaborative practice is enabled by IPE, which in turn improves health outcomes (World Health Organization, 2010). Interprofessional education is increasingly a requirement (DH, 2004; NMC, 2010) or recommendation (QAA, 2006; HCPC, 2012) of pre- registration professional education.

3.3.3 Educational Theory

The involvement of service users and carers in the education of health and social care professionals has an affinity to the philosophical perspectives of Dewey (1966) utilising a humanistic, student centred approach with reflective and experiential learning together with problem solving and critical thinking objectives. These philosophical ideologies are combined with the theoretical underpinnings of Habermas' (1971; 1984) acquisition, development and consideration of knowledge with the aim of liberation with reflection on action and communicative learning that involves feelings, intentions, values and moral issues. The work of Freire (2000), who endorsed education based on liberation, with empowerment of individuals through critical reflection, referred to as conscientiation, is perhaps the most valid. Here the student and teacher are co-learners with a dialogical education with teaching and learning occurring for both teacher and student simultaneously (Freire 2000).

3.3.4 Learning Theory

A range of learning theories support humanistic education principles affiliated to andragogical or adult learning theories that adopt a constructivist approach with a view to experiential, reflective and transformational learning. For example, Bandura (1977, 1997), Benner (1984), Freire (1994), Knowles (1990), Kolb (1984), Mezirow (1990, 2000) and Schon (1987,1991). Complexity theory (Morrison, 2008) developed from chaos theory (Doll, 2008) is increasingly advocated as an alternative to traditional educational approaches and is consistent with student centred learning. Complexity theory has similarities to Dewey and Habermas with openness and recognition of relationships, connections and networks that are relevant to the complexities of user involvement and the multiple agents involved (Doll, 2008; Morrison, 2008; Santanus, 2006).

The learning theories outlined correspond with the theoretical underpinnings of critical social theory, and a democratic approach to user involvement, with a partnership approach, with collaboration and active participation, further justifying the use of the ladder of involvement (Tew et al., 2004) as a theoretical framework discussed in the following section.

In summary, contemporary health and social care education corresponds with the theoretical underpinnings of a democratic approach to user involvement. It is imperative that user involvement is an integral component and not simply added on to what is already a crammed curriculum.

3.4 Theoretical framework

Theoretical frameworks provided a rationale and conceptual integration to explore user involvement (Polit & Beck 2008). This is reflected in the multiple concepts that informed this PhD, namely ‘agency; the service users and carers, students, academics and practitioners being the agents, concomitant within the underpinning theories of ‘involvement’ and ‘education’.

Drawing these concepts and theories together led to postulating that collaboration and partnership are essential for effective user involvement (Downe et al., 2007; Minogue et al., 2009; Morgan and Jones, 2009; **Rhodes, 2012; Ward and Rhodes, 2010**). Various attempts were made to identify stages or hierarchies of user involvement to identify inclusive approaches. This included Arnsteins ‘Ladder of Citizen Participation’ (1969), introduced as a scale of participation to identify social capital and social cohesion and refers to power relationships from citizen control at the top, through to informing, therapy and manipulation at the bottom. Arnsteins (1969) ladder has been used to identify progress in user involvement in health and social care education (Happell and Roper 2002; Gutteridge and Dobbins, 2010; Simons et al., 2007). A further adaptation of a hierarchical model used to determine the level of user involvement in education, in terms of the level of collaboration and partnerships, is the ‘Ladder of Involvement’, see Table 2 (Tew et al., 2004). The ladder is an adaptation of a framework developed by Goss and Miller (1995) designed to rate the progress of user involvement in health and social care education, with the principle that advancement up the ladder equates to meaningful involvement (Tew et al., 2004). The ladder of involvement is frequently referred to in the literature (Cleminson and Moseby, 2013; McKeown et al., 2010; McKeown et al.,

2012; Molyneux and Irvine, 2004; Towle, 2010; Townsend et al., 2008). The application of Tew et al's. (2004) adapted ladder of involvement was explored in the concept analysis, (**Rhodes, 2012**), and led to the decision to utilise this tool conceptually within this portfolio. The intention was to tentatively apply the ladder to each aspect of user involvement in education explored; to locate the level of involvement, and attempt to ascertain whether the level of involvement had influenced the outcome. The level of involvement is identified and included in the critique of each paper presented in Chapter 4. Tew et al's. (2004) framework was used with the acknowledgement that such hierarchical frameworks are not without criticism mainly that they fail to capture the complexity of involvement (Tritter and McCallum, 2006). It was however anticipated that the ladder would be flexible enough to correspond to the multiple agents or key stakeholders. The subsequent research undertaken has led me to reconsider Tew et al's. (2004) ladder, discussed in Chapter 6, section 6.4.

3.5 Summary

To summarise, the concepts and theoretical underpinnings of the agency of user involvement in health and social care and health and social care professional education are multiple and complex. After critical evaluation a democratic approach to user involvement is advocated. When a democratic approach is adopted there is an affiliation to the concept of social capital and the work of Putnam (2000), with social organisation, networks and connections with partnerships and active participation. This is associated with the philosophical perspectives of Dewey (1966), Habermas (1971, 1984, 1989, and 1998) and Freire (1994), and critical social theory and inter-subjective relations. Adopting a democratic approach can however be

challenging due to the inherent power differentials in UK health and social care and health and social care education.

In health and social care education multiple learning theories that relate to humanistic approaches apply concomitant to the relatively new concept of complexity theory (Sweeney, 2006) again with recognition of networks relationships and connectedness. The ladder of involvement (Tew et al., 2004) was identified and used as a theoretical framework to investigate the underlying principles of user involvement in health and social care education in an attempt to offer theoretical assimilation.

Table 2: The Ladder of involvement (Tew, Gell and Foster 2004 pg 54).

Level 1: No involvement	The curriculum is planned and delivered with no consultation or involvement of service users or carers
Level 2 : Limited involvement	Outreach and liaison with local service user and carer groups. Service users/carers invited in to 'tell their story' in a designated slot, and /or be consulted ('when invited') in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offered for their time. No opportunity to participate in shaping the course as a whole.
Level 3: Growing involvement	Service users/carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. Payment for teaching activities at normal visiting lecture rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users/carers are not represented. Some support available to contributors before and after sessions but no consistent programmes of training and supervision offered. No discrimination against service users and carers accessing programmes as students.
Level 4 Collaboration	Service users/carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. A statement of values and aspirations underpins this. Payment for teaching activities at normal visiting lecturer rate. Service users/ carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users/carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.
Level 5 Partnership	Service users, carers and teaching staff work together systematically and strategically across all areas- and an explicit statement of partnership values underpins this. All key decisions made jointly. Service users and carers involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users to join in as participants in learning sessions even if they are not (yet) in a position to achieve qualifications.

Chapter four

Methodology

This chapter will discuss the research paradigm that underpinned the studies included in this portfolio. The research paradigm will be related to relevant approaches and associated to the work undertaken through a critique of the published papers presented. Table 3 provides an overview of the dissertation plan. Finally the assimilation of each study to the theoretical framework, the ladder of involvement will be included.

4.1 The research paradigm

User involvement lends itself to exploratory enquiry and lies within epistemological and ontological relativism that is situated within a naturalistic or constructivist paradigm with multiple interpretations of reality (David & Sutton, 2011; Gray, 2009; Guba and Lincoln, 1994; Liamputong, 2010). The terms social constructionism and constructivism are often used interchangeably: Constructionism refers to interactions and interpretations made by human actors (agents). The social world is built on shared meanings and co-ordinated actions of rational actors. Constructivism refers to the view that social order is constructed and these structures shape individual actions with multiple truths and subjectivity (Grey, 2009). Reality is interpreted with mental construction by individuals in time and place and reconstructed through communication (Guba and Lincoln, 1994). Constructivists seek to explore the complexity of views in order to make sense of meanings of others, with recognition that ones own background will shape the interpretation (Creswell, 2014). The underpinning theory is located within the ontology of critical inquiry with critique of

existing social structures, collaboration, enlightenment and transformation. In addition, feminist theory, with a focus on social movements, structures and policies is drawn on. Researchers utilising a feminist approach develop collaborative relationships with informants and often negotiate meaning of results with participants (Gray, 2009; Polit and Beck, 2008).

4.2 The research plan

Reflection on the epistemology and ontology of exploratory enquiry led to the decision to adopt a collaborative approach to the exploration of the highly complex and multi-faceted nature of user involvement. Exploration was undertaken through a series of studies from a variety of stakeholder perspectives outlined in this portfolio of evidence. A range of research methodologies were utilised including a concept analysis, two mixed methods studies and three qualitative studies (Table 3). The two final studies adopted a narrative inquiry approach that investigated the impact of user involvement in health and social care education on service users and carers and students. The decision to adopt a narrative inquiry approach was based on the principle that communicative power is seen as the main strength of narrative research, enabling a personal account of people's motives, experience and actions with insight into the way they assign meaning and interpretation (Holloway and Freshwater, 2007).

Table 3: The plan of work

Research Plan	Process and Outcome ⁴
To conduct a critical review of the literature that builds upon prior synthesis.	Continuous appraisal of the literature with a distinct review of the pertinent literature for each study. Networking and engagement with the involvement community on a local, regional and national basis will be maintained to keep informed of the grey literature.
To undertake evaluation of current user involvement in order to explore and build knowledge and understanding of the subject of enquiry	Evaluation of user involvement in interdisciplinary narrative workshops. Outcome – Paper 1: Balen, Rhodes & Ward (2010) A qualitative evaluative study on proposed user involvement in practice assessment. Outcome – Paper 2: Dearnley, Coates, Coulby, Rhodes & Taylor (2011) Exploration of how to embed user involvement in a Higher Education Institution through a case study and reflection. Outcome – Paper 3: Ward, & Rhodes (2010)
To identify and test research theory and methods.	A mixed methods study exploring user involvement in student selection. Outcome Paper 4: Rhodes & Nyawata (2011) A mixed methods study investigating user involvement in shared care and decision making. Outcome- Paper 5: Padgett, Rhodes , Sherwin, Symons, Tate & Townend (2012)
To identify key concepts of user involvement in health and social care education and inform future research.	A concept analysis of user involvement in health and social care education. Outcome Paper 6: Rhodes (2012)
To undertake research in relation to the impact of user involvement.	Narrative research on the impact of involvement on service users and carers. Outcome Paper 7: Rhodes , Hardy, Padgett, Symons, Tate & Thornton (2013) Narrative research on the impact of involvement on students. Outcome Paper 8: Rhodes (2013)
To provide an overview of the body of work undertaken in order to illustrate cohesion.	The supporting commentary will demonstrate the coherence of the work as a critique and analysis of service user and carer involvement in health and social care education. The commentary will also convey the overall contribution to knowledge with recommendations for the future.

⁴ See Appendix 1 for details of the percentage contribution to each paper verified by copies of co-author agreements.

4.3 The methods used and critique of the published papers

The following section will discuss the research methods used and provide a critique of the published papers.

4.3.1 Concept analysis

Concept analysis is a method that is used to search for common use and meaning of the concept being explored (Morse, 2000). Concept analysis has been defined as 'a process of dissecting an idea or phenomenon to understand better and optimise its use' (Holcomb, Hoffart and Fox, 2002). There are a variety of methods, from Wilsons (1963) naturalistic, relativist; context bound approach with transformation of meaning and reconstruction to Walker and Avant's (2005) essentialist, realist method of analysis that seeks accurate representation of an independently existing reality (Smith and Hodkinson). Walker and Avant's (2005) method is the most common method used within the sphere of nursing (Duncan, Coulter and Bailey, 2007).

A concept analysis was carried out after a preliminary scoping review of studies that explored user involvement suggested a need to clarify and illuminate the meaning of user involvement in healthcare education to inform future work, resulting in the following publication.

Paper 5: **Rhodes, C.** (2012) Service User and Carer Involvement in Health and Social Care Education: A Concept Analysis. *Nurse Education Today*, 32, pp185-189.

In summary, paper 5 was an evaluative discussion of the literature presenting the findings of a concept analysis undertaken to explore user involvement in the context of health and social care education in the UK.

Walker and Avant's (2005) eight step framework for concept analysis was used to clarify and elucidate the meaning and nature of user involvement in health and social care education. This method was chosen as despite an increasing body of literature, user involvement in health and social care education was vague with a lack of a clear definition. The framework provided a clear and systematic method with results presented in a meaningful format. The analysis identified the defining attributes, a model case and antecedents and consequences. The ladder of involvement (Tew et al., 2004) was also critiqued and found to be an empirical referent, as it related to the defining attributes delineated from the literature and provided a way of measuring or determining the existence of user involvement. This led to the decision to use the ladder of involvement as a tool for defining involvement within the body of work.

The decision to use Walker and Avant's (2005) method was coherent with empirically based abstractions of reality that transcend the contextual experience (Penrod and Hupcey, 2005), as opposed to Wilsons (1963) contextually bound relativist concepts, has presented a concept analysis with a particular view that could be contested as too rigid (Duncan et al., 2007). On reflection should a concept analysis be undertaken again, a relativist approach would be adopted, for example, Rogers (1989) evolutionary method of concept analysis. The evolutionary approach searches for common use and meanings whilst acknowledging it is dynamic and context bound.

This model case within paper 5 was equated to Level 4 on the ladder of involvement (Tew et al., 2004). Service users and carers are involved in the team in a variety of teaching and learning activities, decision making, planning and evaluation. They have affiliate lecturer status, access to staff development and are members of a service user and carer group, a network of service users and carers.

4.3.2 Qualitative research

The focus of this portfolio of evidence, user involvement, lent itself to qualitative research in that it followed a naturalistic approach that sought to understand a phenomenon in context. In particular qualitative research methods that facilitate individuals to articulate how they make sense of their experiences in their world is offered an approach that would consider key stakeholder perspectives (David & Sutton, 2011; Liamputpong, 2010). Reflexivity, whereby there is acknowledgement of personal values, experiences and beliefs and how these impacted on decision, processes and procedures when planning and undertaking the studies reported, was a central aspect as the researcher became immersed in this area of work (Dowling, 2006, Gavin, 2008). Three of the studies within the portfolio adopted a qualitative approach, reported on in papers 2, 7 and 8.

Paper 2 reports a qualitative study that was based on a collaborative workshop with key stakeholders in user involvement, service users and carers, students and practice educators. The purpose of the workshop was to gather feedback on the acceptability and feasibility of service user and carer involvement in practice assessment.

Paper 2: Dearnley, C., Coates, C., Coulby, C., Rhodes, C., & Taylor, J. (2011). Service users and carers: preparing to be involved in work based practice assessment. *Innovations in Education and Teaching International*. 48 (2), pp 213-222.

The article describes the participant recruitment strategy as a convenience sample. On reflection the sample would have been more accurately described as purposive as the participants were selected because they had experience of involvement or experience of assessment in practice (Polit and Beck, 2008). Data was collected using a focus group that was audio recorded. Ethical approval for the study was obtained and ethical issues were considered in relation to confidentiality and consent. Data analysis was undertaken using thematic analysis, which aims to detect patterns and themes across participant accounts as well as differences (Polit and Beck, 2008). Key issues in relation to the ethics, reliability and validity of service user and carer involvement in the assessment of practice were identified. Paper 2 equates to Level 2, limited involvement on the ladder of involvement (Tew et al., 2004), as the study was designed and undertaken by academics. The key stakeholders were consulted on their opinion by invitation. Payment was offered to service users and carers who participated.

Paper 7 presents findings from a collaborative study that adopted a narrative inquiry approach, which investigated the impact of service user and carer involvement on the health and wellbeing of service users, and carers involved in health care education in the UK. The aim of the research was to give a clearer and stronger

voice to service users and carers by valuing their experience and embedding their views within health and social care education.

Paper 7: **Rhodes, C.**, Hardy, J., Padgett, K., Symons, J., Tate, J., Thornton, S. (2013). The Health and Well-being of Service User and Carer Educators: a Narrative enquiry into the Impact of Involvement in Healthcare Education. *International Journal of Practice-based Learning in Health and Social Care*, 2 (1), 51-68. DOI: 10.11120/pblh.2013.00025

A non-probability purposive sample was used to recruit participants. Ethical approval was obtained and written consent was gained at the outset followed by further process consent at key stages of the study. Narratives were collected from five service users and carers who had extensive experience of involvement in health education via small group interviews. Service users and carers were facilitated to tell their individual story and the discussions were digitally recorded. Content analysis of the data followed a naturalistic perspective with a focus on the individual narrative to ensure the final story was a re-representation of the narrator's experience. The content was then translated into a story or poem that was further developed into a digital story. The digital stories were openly available on the web. In addition, a cross sectional approach was employed that identified common defining categories arising out of the individual narratives. The defining categories that emerged from the data related to three overarching questions:

- What made you get involved? With the category: 'The patient learning journeys'.

- What has helped or hindered? With the categories; support, bureaucracy, lack of support, knocking of confidence, negative feedback or no feedback.
- What effect has involvement had on your health and well-being? With the categories; confidence, better health, a sense of purpose, self-worth, value and respect.

Study findings equated to Level 5, partnership on the ladder of involvement (Tew et al., 2004). The research was service user and carer led from the topic of enquiry, collection and analysis of the data and presentation of the results.

Paper 8 reports on a single case study that followed a narrative inquiry approach to investigate the impact of user involvement on student learning and subsequent influence on practice as a qualified nurse.

Paper 8: **Rhodes, C.** (2013). Service User Involvement in Pre-registration Children's Nursing Education the Impact and Influence on Practice: A case study on the student perspective. *Issues in comprehensive Pediatric Nursing*
 DOI: 10.3109/01460862.2013.830161

Purposive sampling was used with narratives collected from a children's nursing student on completion of her three year training programme and again after practising as a qualified children's nurse for one year. Ethical approval was obtained and informed consent was obtained from the participant. Data was collected from in depth narrative interviews that were digitally recorded. The data analysis followed a feminist, interpretive approach utilising 'The Listening Guide' (Doucet & Mauthner,

2008), with the researcher's interpretation of how the experience was conveyed with clear acknowledgement of reflexivity.

Taking part in the research enabled the participant to consider and reflect on her experience of user involvement in her education and training. The findings identified the following central themes; authenticity, knowledge of self, resilience and coping, professional relationships, personalisation of care, and influence on practice. Paper 8 equated to Level 2, limited involvement on the ladder of involvement (Tew et al., 2004). The user involvement that had the most impact was from a service user who was invited in to tell her story in a designated slot. Payment for involvement was offered.

4.3.3 Mixed Methods

There is a growing and emerging trend for adopting a mixed methods approach with the integration of qualitative and quantitative data, for example data obtained from observations or interviews and surveys (Cresswell, 2014). The advantages of a mixed method approach is that it allows complementary data collection to be undertaken with the opportunity of triangulating methods to test the interpretation of the data and increase the confidence in the credibility of the results (Cresswell, 2014; Polit and Beck, 2008). Two studies adopted a mixed methods approach, reported on in papers 4 and 5, to facilitate exploration of the agency of involvement from varied perspectives.

Paper 4 reports on a mixed methods study undertaken to evaluate an innovation where service users and carers were involved in the recruitment of child and adult nursing students.

Paper 4: **Rhodes, C. & Nyawata, I.** (2011). Service User and Carer Involvement in Student Nurse Selection; Key Stakeholder Perspectives. *Nurse Education Today*, 31, pp 439 - 443.

The study comprised of a convenience sample of seventy candidates, being interviewed for a nursing course, and a purposive sample of four service users and carers and six academics, involved in the selection process. Data was collected via a questionnaire administered to the nursing candidates interviewed and two semi structured group interviews, one with the service users and carers and another with the academics involved in the selection process. Ethical approval was obtained and ethical issues were considered in relation to maintaining anonymity of the candidates and written consent was obtained from the participants in the group interviews.

Data analysis of the questionnaire was undertaken using thematic analysis, to detect patterns and regularities as well as inconsistencies in order to identify substantive themes (Polit and Beck, 2008). Data analysis of the group interviews was undertaken through content analysis where categories were identified then condensed into broader themes. The findings from the thematic analysis generated two main themes, one that user involvement helped the candidates to understand what would be expected of them in clinical practice and secondly that the candidates looked at the selection process from the service user perspective. Data from the

service user group interview identified that service users felt they had the right to be involved because of their experience, they wanted to give the candidates a sense of reality, felt valued with increased confidence and the development of new skills however, they would have liked better preparation. The academics were initially concerned about relinquishing power and concerned about user involvement in decisions about offering candidates a place on the course. However, agreement between service users and academics in who should be selected quality assured the process and had a positive impact on students. Their reservations were around cost, sustainability and ensuring the quality of the service users involved. Paper 4 equated to Level 3, growing involvement on the ladder of involvement (Tew et al., 2004), representing the involvement of service users and carers in student selection.

Payment for involvement was offered.

Paper 5 reports on a mixed methods study that included a collaborative inquiry approach with action learning groups (ALGs) and an iterative process, followed by a modified Delphi survey exercise.

Paper 5: Padgett, K., **Rhodes, C.**, Sherwin, S., Symons, J., Tate, J., & Townend, K. (2012). What matters to US (Users of Services)? An explorative study to promote shared decision making in health care. *Health Expectations* DOI:10.1111/j.1369-7625.2012.00767.x

Participants for the action learning groups were drawn from an existing service user and carer network including people with a wide range of health care experiences. The survey was posted to sixty students, sixty academics and thirty service users

from twenty different health and social care professions, spanning four Universities. Ethical approval was obtained and written consent was obtained for the service users and carers in the (ALGs). Analysis of the ALG data identified four broad categories; attention, environment, knowledge diversity and attitude. After further iteration a number of statements were formatted for the Delphi survey. Analysis of the survey identified there was general agreement as to what is most important for service users and carers when using health and social care services with full agreement about the top three. There was a consensus on the attributes and behaviours of health and social care workers in helping service users and carers contribute to own care. These were being open and honest, showing respect, listening, giving time and being up to date. Paper 5 equated to Level 4, collaboration on the ladder of involvement (Tew et al., 2004), as the service users and carers that participated in the action learning groups were from the service uses network and reported that they felt to be full members of the team. They identified that they valued the process and found it to be beneficial to themselves.

4.3.4 Evaluation research

Evaluation research, used to determine the effectiveness of an intervention (Polit and Beck, 2008) has an important place in user involvement. Two papers were based on evaluative approaches to review particular aspects of user involvement and inform future interventions. Papers 1 and 3 adopted an evaluation approach.

Paper 1 discusses the evaluation of an interdisciplinary workshop held for undergraduate students from social work, mental health nursing, adult nursing,

midwifery and occupational therapy courses. The workshops used service user narratives that focused on mental health issues.

Paper 1: Balen. R., **Rhodes, C.**, & Ward, L. (2010). The Power of Stories: Using Narrative for Interdisciplinary Learning in Health and Social Care. *Social Work Education*, 29 (4), pp 416 – 426

Data was collected via a feedback sheet that asked students specific questions in relation to what had been learnt and what would be taken away to use in practice. The data was both quantitative, through the use of a likert scale and qualitative by inviting students to make comments. Data analysis of the qualitative comments was undertaken through content analysis identifying themes and patterns. The results identified that the students felt the content was relevant to the curriculum that they were engaged in; allowed them to interact with and explore the perspectives of different professional groups; assisted them in understanding the lived experience of mental health difficulties and offered them the opportunity to consider implications for practice. Paper 1 equated to Level 2, limited involvement to Level 3, growing involvement on the Ladder of involvement (Tew et al., 2004), as the day was planned, organised and delivered by two academics and a service user. However the additional service user group that were involved were invited to tell their story in a designated slot. Payment was offered to the service users involved.

Paper 3 outlines strategies that the university sector can adopt to embed the consumer culture within the education of health and social care professionals. The

study reported on a combined case study with the reflective views of the two authors supported by a literature review.

Paper 3: Ward, L. & **Rhodes, C.** (2010). Embedding a Consumer Culture in Health and Social Care Education – a university office's perspective. *International Journal of Consumer Studies*, 34, pp 596-602

The article outlines how a user involvement development office could establish and support effective user involvement in health and social care course in higher education. Paper 3 equated to Level 3, growing involvement on the ladder of involvement (Tew et al., 2004). This is justified by the paper advocating user involvement in a variety of ways, supported by an infrastructure and a partnership approach. The paper discusses a consumer approach as opposed to a democratic approach to involvement that prevents it from being equated to a higher level of involvement.

4.4 Summary

The complex nature of user involvement in health and social care education necessitated the exploration of key stakeholder perspectives that required the adoption of a range of research methods, primarily derived from the naturalistic paradigm, with an emphasis on the lived experience. Consequently, a variety of approaches were adopted to develop the work presented in the portfolio that used a range of approaches. The variety of approaches provided the opportunity to engage in and review different research theories and methods equipping me with the knowledge and skills to undertake further research. However, the overall goal was to

add to, and strengthen the evidence base so as to enhance our understanding, share best practice and strengthen user involvement in health and social care education.

Chapter Five

Contribution to knowledge

The body of work presented includes a series of papers that have been published in peer reviewed journals. Topics are explored in relation to the key stakeholders of involvement in health and social care education; service users and carers, student's academics and practitioners. The included papers contain findings from a range of studies, utilising multiple methodologies which have been selected according to the subject of enquiry, which demonstrates significant original contribution to knowledge and the developing evidence base. The contribution to knowledge is presented in five distinct areas.

5.1 Contribution to the literature with new findings.

Paper 1, Balen, **Rhodes** and Ward (**2010**), proposes a template for interdisciplinary learning that incorporates user involvement in health and social care education.

Paper 2, Dearnley (**Rhodes**) et al., (2011), offers the unique perspectives of service user and carers, students and practice assessors, obtained via shared workshops, on the potential involvement of service users and carers in the practice assessment of health and social care students. Paper 3, Ward and **Rhodes** (**2010**), explores a model for an effective development office to support user involvement in a university setting. Paper 4, **Rhodes** and Nyawata (**2011**), offers original perspectives from candidates, service users and carers and academics on involvement in student selection for nursing programmes. Paper 5, Padgett (**Rhodes**) et al., (2012), offers an example of a collaborative approach to research with original perspectives on

user involvement in shared care and decision making from users, health and social care students and academics. Paper 6, **Rhodes (2012)**, is the first concept analysis on user involvement in the published literature. This is recognised as a robust method of enquiry (Hupcey & Penrod, 2005) and contributes to the clarification of meaning with defining attributes, a definition of, and a model case for involvement in health and social care education. Papers 7, **Rhodes et al., (2013)** and 8, **Rhodes (2013)**, report on studies that followed a narrative inquiry approach to illuminate and illustrate the impact of involvement on service users and carers and students learning and practice. The results from paper 8, (**Rhodes, 2013**), which identifies transformative learning and positive implications for practice is strengthened by its longitudinal nature.

5.2 Location of the findings within the current literature that reinforces and extends the evidence base.

For each of the studies undertaken the current relevant literature was reviewed at the outset and the outcomes were appraised against the findings. It has therefore been possible to relate the findings from this body of published work to the current published work thereby strengthening, developing and confirming the tentative evidence base.

Paper 1, Balen, **Rhodes** and Ward (**2010**) corroborates with the literature on the improved joint working practices that interprofessional education can bring about for professionals and service users and carers (CAIPE, 2002). Paper 2, Dearnley

(**Rhodes**) et al., (2011) supports and extends the limited literature on the involvement of service users and carers in the assessment of health and social care students (Bailey, 2005; Duxbury and Ramsdale, 2007; Gee, Ager and Haddow, 2009; Speers, 2008; Stickley et al., 2010). Paper 3, Ward and **Rhodes (2010)** identifies with the literature on what infrastructures are required to facilitate user involvement in health and social care education (Downe et al., 2007; DUCIE, 2009; Levin, 2004; Morris, Dalton, McGoverin and Symons, 2009; NHS Trent SHA, 2005; Tew et al., 2004). The findings from paper 4, **Rhodes** and Nyawata (2011) largely mirrors the findings of the only two previous studies identified in the literature that explored the involvement of service users in the selection process for health and social care courses (Matka, River, Littlechild and Powell, 2009; Vandrevala, Heywood, Willis and John, 2007). The study does however offer a new perspective from the viewpoint of a nursing course.

The implications from paper 5, Padgett (**Rhodes**) et al., (2012) resonate with previous studies that have explored the design and conduct of student assessments by service users (Crisp, Lister and Dutton, 2006; Masters and Forrest, 2010; Speers, 2008; Stickley et al., 2010). Moreover, the findings link with previous studies in reporting that the process of being involved resulted in significant personal development and increased capacity for partnership for both users and professionals (Davies and Lunn, 2009; Elliott, Frazer and Garrard, 2005; Stickley et al., 2009). Paper 6, **Rhodes (2012)**, a concept analysis, undertaken in light of my work to this date with appreciation that a clearer understanding of the concept of user involvement was needed, delineated the current literature. The concept analysis identified that the ladder of involvement (Tew et al., 2004), related to the defining

attributes of involvement and proposed this as a useful tool for defining involvement. Paper 7, **Rhodes et al. (2013)** presents findings that relate very closely to the findings of McKeown et al's. (2012) emergent findings from their participatory action research study on the value of user involvement for service users and carers. Paper 8, **Rhodes (2013)** confirms findings from previous studies that have identified user involvement in education has brought about transformative learning in students and ideas for practice (O'Donnell and Gormley, 2012; Rush, 2008; Stickley et al., 2009).

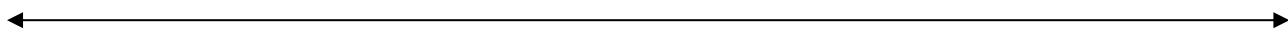
5.3 Location of the findings within the theoretical framework

The use of the ladder of involvement (Tew et al., 2004) as a theoretical framework has enabled a review and critique of this as a useful tool which will be discussed in further detail in the following chapter. The ladder was useful in identifying what type of user involvement was being undertaken and it was possible to achieve theoretical assimilation at the higher levels. The limitations, however (INVOLVE, 2012; Tritter and McCallum, 2006), namely its hierarchical nature that fails to capture the complexities of user involvement, resulted in the conclusion that it is not an ideal theoretical framework for future use.

The Approaches to Involvement Continuum (Figure 1), is offered as an alternative model to the ladder of involvement, to enable clarification of what is expected from the stakeholders. The model has the potential for multiple uses; it could be used in health and social care to identify the approach to user involvement, either to identify the approach being taken, or the desired approach to be taken with a service user or

carer. This may be with service users and carers themselves, by service planners or in quality assurance. The model could be similarly used in health and social care education to identify the type of involvement being proposed or undertaken and match this to the approach, again with service users and carers, or in the planning, evaluation or quality assurance of user involvement. The continuum of involvement represents a more dynamic process and can be used to clarify the roles and responsibilities expected to facilitate shared understanding and achievement of the identified goal for the given situation. The model acknowledges both consumerist and democratic approaches, with consumerism represented as a consultative approach and a democratic approach characterised by the participatory and partnership/collaborative approach.

Figure 1: The Approaches to Involvement Continuum



Tokenistic	Consultative	Participatory	Partnership/collaborative	Emancipatory
Superficial involvement, ad hoc, used, not included	Deliberation, discussion. Exchange of views and opinions. Gaining information	Contribution to planning and decisions. Sharing and taking part.	Equal status, joint working. Team –working as equal partners.	Service user and carer led. Freedom from restrictions.

5.4 Contribution to the refinement and development of the theory of user involvement in health and social care education.

The political drivers, underlying concepts and theories of user involvement in health and social care education have been explored with the acknowledgement that these

are multiple and complex. It is not possible to identify one theory that adequately captures the essence of user involvement in health and social care education, though it is possible to offer a range of concepts and theories related to the broad concepts of critical social theory.

The two models of user involvement, consumerist and democratic represent opposing ideologies whilst both offering the opportunity for engagement. A consumerist approach affords limited opportunity for equality due to being economically motivated concerned with economy and efficiency. Power remains with the professionals however individuals are encouraged to take responsibility for their own lives (Beresford, 2002; Cowan et al., 2011; Gibson et al., 2012).

Notwithstanding these criticisms it has to be acknowledged that a consumer approach has a role and purpose due to the intransigence of UK health and social care systems. Nevertheless, through undertaking the body of work presented in this portfolio my thinking has developed and a democratic approach that represents equal relationships with partnerships is advocated as the ideal in health and social care education due to offering genuine equality and respect (Barnes and Cotterell, 2012; Beresford, 2002; Gibson et al., 2012). This approach affords the opportunity to generate a network with solidarity and support with the potential for tangible influence on the education of health and social care professionals.

5.5 Contribution to dialogue and debate

The body of work presented is collaborative, fundamental to the ethos of the subject of inquiry; nevertheless, there has been considerable author contribution to validate the claim of a personal award. However the on-going contribution to dialogue and debate through engagement with local, regional and national networks has been essential to the progress of this area of work and affords recognition. Examples include the Patient Partnership Group at my own institution, The Patient Voice Group hosted by Leeds University, The Higher Education Academy Lived Experience Network and the Memorandum of Understanding held between my institution and The Patients Association. National networking has been vital to progress and resulted in a number of conference presentations, detailed in Appendix 3.

The collaboration with colleagues from a wide variety of health and social care professional backgrounds and service user and carers with diverse experiences has enabled a wider viewpoint. Collaborative relationships have also allowed me to offer the underrepresented perspective of my own professional background, child nursing and health visiting. Further details of my professional background are included in Appendix 2.

The strength of evidence presented resulted in opportunity to become a member of the local and national user involvement in health and social care education community. The intellectual and personal development acquired, by undertaking this

body of work has equipped me with the underpinning knowledge and understanding to make a significant contribution in the future.

5.6 Summary

To summarise, the work presented in this portfolio is located in a growing body of literature on user involvement in health and social care education. The papers presented reinforce and extend the existing evidence base with original contribution to the knowledge and understanding of this very pertinent topic. Moreover, the body of work represents significant individual growth, with development of knowledge and understanding that will inform future progress in this field of enquiry.

Chapter Six

Summary and Implications

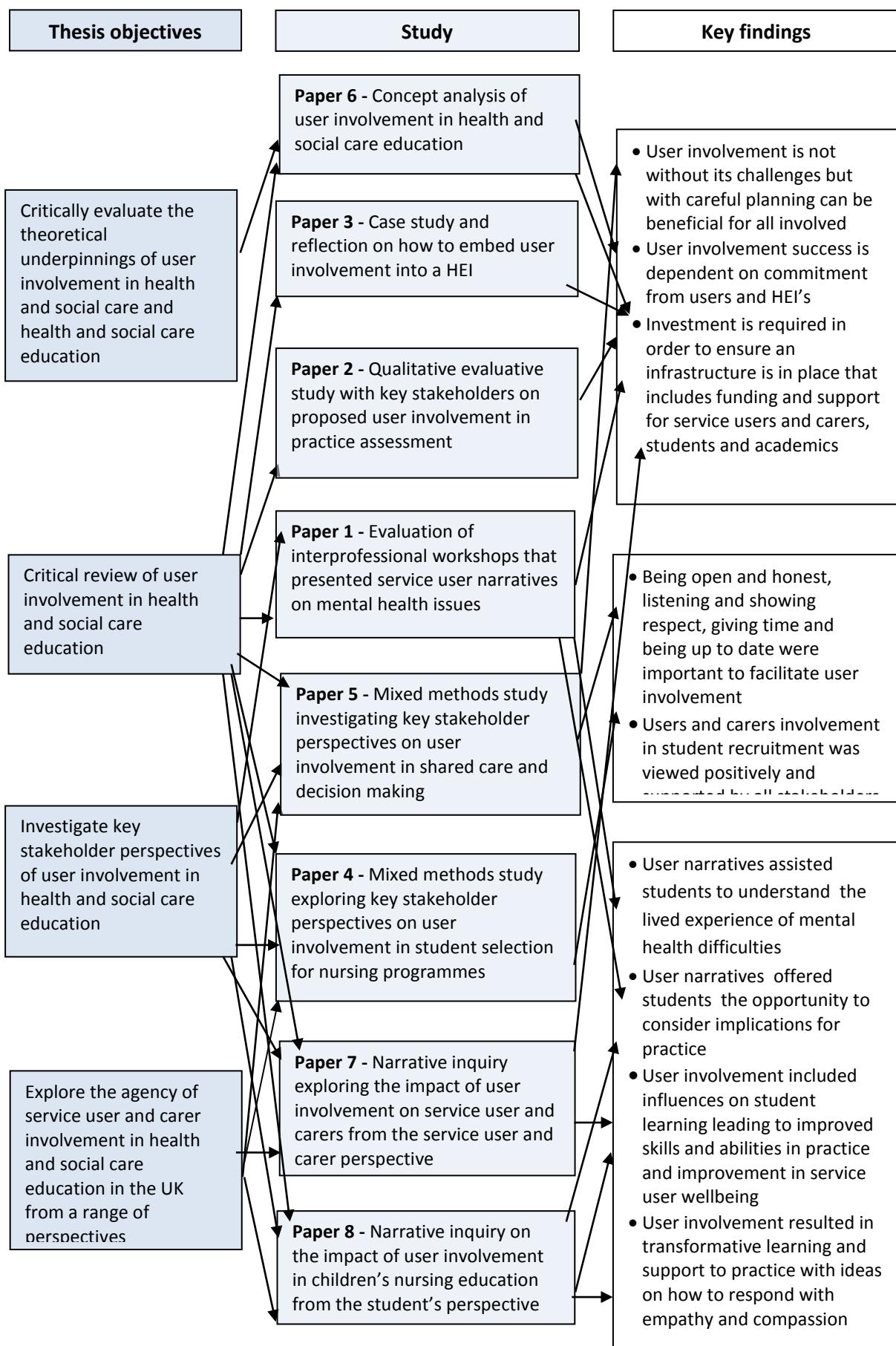
In order to demonstrate the cohesiveness of the work undertaken this chapter will review the aims and objectives of the portfolio. The findings will then be drawn together identifying the main purpose of user involvement and the current state of user involvement. The theoretical framework will be reprised and an alternative model offered for consideration. Finally the future of user involvement is considered with recommendations for practice.

6.1 Aims and objectives

The portfolio of evidence has explored the agency of service user and carer involvement in health and social care education in the UK from a range of perspectives. The specific objectives are presented on page 4.

The aim and objectives have been achieved through the presentation of the papers included and the supporting commentary. The relationship between the studies undertaken and the papers reported within the portfolio of evidence, which used a range of methods, and the key findings are presented in Figure 2. In addition the overall findings and implications for user involvement are discussed.

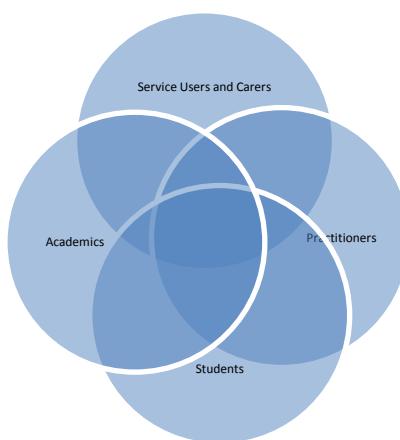
Figure 2: Relationship between objectives, studies undertaken and key findings



6.2 The main purpose of user involvement

The major focus of user involvement in health and social care education is the preparation of future health and social care professionals, ensuring that students are prepared for their role on qualification. The primary objective is to equip health and social care professionals with the insight and skills to involve service users, patients or clients in decisions about their care, with the ultimate aim of improvement in service delivery. The inclusion of user perspectives also has the potential to improve the universities relationship with the community and bring about wider community engagement (McKeown et al., 2010). Contemporary health and social care education follows a student centred approach with critical reflection and experiential learning supported by humanistic educational theories, particularly the work of Freire (2000). Learning is a joint endeavour (Figure 3) and involves students themselves along with significant others who have a contribution to make to their development of appropriate knowledge, skills and abilities. This includes academics, practitioners and service users and carers. It is, therefore, imperative that regardless of the approach, the key stakeholders work in partnership together with a clear understanding of one another's role, purpose and common goal.

Figure 3: Learning is a joint endeavour.



Consideration must be given to the rights and needs of those involved; in university settings cognisance is given to the mechanisms that need to be in place in order to protect and support students, academics and practitioners. Service users and carers involved must also be afforded the same level of consideration based on sound ethical principles. The ethical principles of the respect for autonomy, non-maleficence, beneficence and justice (Beauchamp and Childress, 2013) can be upheld by ensuring the ‘architecture of involvement’ (Brett et al., 2009) is in place with an infrastructure in terms of training, supervision and support (Ward and **Rhodes, 2010**).

The ideology of user involvement is influenced by political and social drivers that follow consumerist and democratic approaches (Barnes and Cotterell, 2012; Beresford, 2002; McKeown et al., 2010; **Rhodes, 2012**). Conversely the theoretical underpinnings of user involvement are multiple and complex however the imperative for a partnership approach has an affiliation to critical social theory and the work of Jurgen Habermas (1984, 1987, and 1989). Additional theories in relation to power relationships are also important (Foucault, 1979; Bourdieu, 1990; Fraser, 1997) due to the inherent power differentials that exist in health and social care services worldwide.

6.3 The current state of user involvement

The emerging literature, that includes the papers presented here is building the evidence base and informing the progress of future developments. There is growing, though tentative, evidence that user involvement does positively influence student learning and practice (Balen, **Rhodes** and Ward, **2010**; **Rhodes, 2013**; Rush, 2008;

Simpson, Reynolds, Light and Attenborough, 2008; Stickley et al., 2009; Tew, Holley and Caplen, 2012).

For service users and carers working in collaboration with a team approach, a sense of belonging and purpose with networks and reciprocity is crucial and can lead to positive effects on their health and well-being (Bailey, 2005; Jones, 2006; McKeown et al., 2012; Minogue et al., 2008; Padgett (**Rhodes**) et al., 2012; **Rhodes, 2012; Rhodes et al., 2013**). Conversely negative effects have also been reported (Dogra, Anderson, Edwards and Cavendish, 2008; Felton and Stickley, 2004; Minogue et al., 2009; Morgan and Jones, 2009; **Rhodes et al., 2013**). Academics and practitioners can see the value of user involvement, however, they are the most likely to identify the challenges that involvement presents, not least the perennial issue of funding and payment (Dearnley (**Rhodes**) et al., 2010; **Rhodes** and Nyawata, 2011; Speed et al., 2012; Towle et al., 2010).

6.4 The theoretical framework

The ladder of involvement (Tew et al., 2004) was identified as a framework that is commonly used to determine the level of user involvement in health and social care education (Cleminson and Moseby, 2013; McKeown et al., 2010; McKeown et al., 2012; Molyneux and Irvine, 2004; Towle, 2010; Townsend et al., 2008). The ladder was tentatively applied to each aspect of user involvement explored, locating the level of involvement and whether this had influenced the outcome.

The use of the ladder of involvement (Tew et al., 2004) as a theoretical framework was useful as regards to being able to easily locate the type of user involvement undertaken. It was possible to achieve theoretical assimilation at the higher levels of the ladder. For example, paper 7 where the service users and carers and university staff were equal partners with joint decision making and co-production equating to level 5, partnership, the highest level of involvement on the ladder.

The ladder however falls short at the lower levels where it fails to acknowledge that meaningful user involvement can occur. For example, paper 8, the narrative inquiry approach with a student, in this instance the user involvement that was most meaningful to the student was from a service user who was engaged at level 2, limited involvement, with the service user invited to come in and tell her story. This does not demonstrate the impact this user involvement had on the student and the subsequent influence on practice (**Rhodes, 2013**). The limitations of the ladder relates to its hierarchical nature, suggesting levels of involvement with success achieved only at the higher levels. This over simplification does not capture the complexities of involvement. The difficulties associated with hierarchical frameworks that conflate the means and ends, with failure to recognise the diversity of involvement and the variety of agents that interplay is identified in the literature (Tritter and McCallum, 2006). The ladder was designed to enable HEI's to judge the service user or carers level of involvement in the curriculum and it does not easily relate to all the key stakeholders. The conclusion, therefore, is that the ladder of involvement has not been found to be an effective tool for identifying whether the level of involvement has influenced the outcome. The ladder has however been useful in extending my understanding, with recognition of the need for a subtle

change in terminology to ‘approaches’ to involvement, as opposed to ‘levels’, this has led to the development of an alternative tool discussed in the following section. As such the ladder has been an invaluable tool and therefore an appropriate theoretical framework for this body of work.

6.5 Approaches to involvement

During the period of this work INVOLVE (2012), have shifted from the term ‘levels’ to ‘approaches’ with their three identified terms consultation, collaboration and user controlled approaches, due to recognition that there is meaningful contribution at all points with unclear boundaries. The use of the word ‘approach’ allows for recognition that there are a wide range of user involvement activities in health and social care education. Additionally, consideration has to be given to the fact that service users and carers, as individual agents, want to be involved in different ways. It is apparent that one size does not fit all, and it would be presumptuous to suggest that for user involvement to be successful it always has to be at the level of collaboration or partnership. What matters is that the most relevant approach is adopted taking into consideration the key stakeholder’s perspectives. Importantly, the infrastructure or ‘architecture’ needs to be in place, to facilitate the most appropriate approach (Brett et al., 2009; Ward and Rhodes, 2010).

6.6 Alternative frameworks

There have been suggestions for alternative frameworks to The Ladder of involvement for example, a matrix and a model of involvement (Tritter, 2009) and a four dimensional framework for analysing the nature of public and patient

involvement (Gibson et al., 2013). However, these frameworks are complex and difficult to apply, therefore I have proposed a linear framework based on a continuum that relates to approaches to involvement. Lathlean et al. (2006) developed a continuum of participation that simply demonstrates the following stages; user led initiatives, users as collaborators, users consulted, users as recipients. Similarly the family centred care continuum developed by Smith, Coleman and Bradshaw (2002) shifts from nurse led care with no family involvement, to nurse led care with family involvement and participation, followed by equal status with a partnership approach and finally parent led care. Having used the ladder of involvement (Tew et al., 2004), with reflection on its effectiveness and consideration the other literature (Gibson, et al.2013; Lathlean et al. 2006; Tritter, 2009), the ‘Approaches to Involvement Continuum’ (Figure 1), has been developed. Though simple, the continuum would provide clarity on the type of user involvement being proposed or undertaken and the expected roles and responsibilities of those involved, allowing for discussion and negotiation between the stakeholders.

It is possible to relate each of the studies undertaken to the continuum. Paper 2 aligning to a consultative approach, papers 1, 3, 4 and 8 a participatory approach and papers 5, 6 and 7 a partnership/collaborative approach.

6.7 The future of user involvement

Exploring the agency of user involvement from the key stakeholder perspectives has encouraged a more balanced analysis of user involvement in health and social care education. The complexities of user involvement are acknowledged with a call for a

more radical approach with the suggestion of a shift to a ‘post engagement’ state in pursuit of a democratic approach that promotes a true partnership approach with genuine equality and respect for all the agents, with collective participation (Figure 4). The emerging co-production model of involvement is advocated whereby all team members work as a collaborative partnership, acknowledging each other’s expertise with inclusion and active contribution (Farr, 2012).

Figure 4: Effective user involvement



6.8 Summary

The primary objective of user involvement in health and social care education is to prepare future health and social care professionals to work effectively with service users and carers. In order for this to be successful user involvement in health and social care education is reliant upon effective partnerships between the key stakeholders; service users and carers, students, academics and practitioners. The literature, that includes the papers presented here, identifies that provided the correct infrastructures are in place there are benefits to the health and well-being of service users and carers and positive influences on student learning and practice.

Attempts have been made to achieve theoretical assimilation through the use of the ladder of involvement. The multiplicity and complexity of involvement makes this inherently difficult. A new model is offered 'The Approaches to Involvement Continuum' (Figure 1) with the suggestion that it is utilised to identify the type of involvement being proposed or undertaken in order to identify the roles and responsibilities expected to facilitate shared understanding and achievement of the identified goal. Recommendations are made on the future of user involvement with a true partnership approach with equality and respect where co-production is seen as the gold standard.

Chapter Seven

Reflexive critique

Undertaking this work incorporated critical reflection on my personal and professional pathway that has rejected the paternalistic, bureaucratic systems of working in acute health care settings to adopt a more personalised, client centred approach to care in the community. Appendix 3 details my career narrative.

My own agency has been shaped and influenced by these personal and professional experiences. Significantly, being brought up in a single parent household, with two older sisters and a younger brother with a complex learning disability, reliant on state benefits and all the negatives connotations that this attracted influenced my dimensions of iterations and subsequent actions. This experience influenced my decision to pursue a career in nursing. After working in acute and community settings for a number of years I came to realise that as an individual or member of a small team the circle of influence and ability to make a difference was limited. Whilst this was significant, important and rewarding, it became frustrating due to the negative encounters that the service users and I experienced on a regular basis, when in contact with health and social care practitioners and led to a desire to influence a wider circle.

On-going reflection led me to a role in health and social care professional education that is within a hugely complex and bureaucratic setting with a number of competing and conflicting agendas. Initially this left me feeling powerless with a yearning to return to practice where I felt I had autonomy and an established network with service users and voluntary and statutory organisations. The most enjoyable aspect of the academic role was the relationship with the students, enabling them to grow and develop, preparing them for complex roles in the ever changing health and

social care environment, whilst instilling the core values of dignity and respect. I began to recognise that I was incorporating the same approaches to education as I had to the latter years of my practice, in short practicing the values of my profession. Adopting the role of 'facilitator of learning' rather than 'teacher', preferring student centred approaches to teaching and learning with the aim of empowerment.

The Assessment and Learning in Practice Settings (ALPS) secondment (Appendix 2) offered a serendipitous opportunity to meet a wide range of academics and service users and carers significant to my development. The secondment also provided 'ring fenced time' to begin to explore my ideas and develop my research skills.

Conducting this work has allowed me to explore my own values and beliefs, gaining insight and a developing understanding of underlying philosophies and theoretical underpinnings. Reflexivity has been vital, as I am clearly located and situated within the studies undertaken. It would have been impossible to 'bracket' my beliefs and would have been detrimental to the underpinning philosophies associated with user involvement. The rapport between the participants and researcher has facilitated the collaborative approach to the inquiry. The inter-subjective dynamics has resulted in co-construction between me as the researcher and the participants that mirrors the partnership approach that is identified for meaningful user involvement to occur.

Critical reflection and self- appraisal has raised my consciousness and enabled me to better understand why I have adopted the approaches I have, in my work as a practitioner and an academic. Whilst I understood that I had an affiliation to humanistic approaches, I am better able to articulate that this is underpinned by critical social theory and espousal of emancipatory methods with the realisation that I am actually an academic activist and a critically engaged academic.

Undertaking and presenting this portfolio has suited the way I work and enabled me to adopt a pragmatic approach that has been productive. It has facilitated the development of a body of work whilst maintaining a collaborative approach essential to the nature of the topic of enquiry. I have explored a number of research methodologies and consider that this process has equipped me with the knowledge and skills to take a lead contribution in future research that will further inform the development of user involvement in education. The issue of authorship and the need to obtain signed authorship declarations for the collaborative papers included in the portfolio presented a contradiction to the ethos of the user involvement advocated within this work. Higher academic institutions require academics to claim authorship and raised a contentious issue that had the potential to be damaging to relationships. Fortunately, due to the well established nature of the relationship with the service users and carers who participated, and their understanding of university systems this was not at issue.

I am left with a determination to strive for user involvement in education undertaken in a meaningful way for the benefit of all concerned; service users and carers, students and academics. Ultimately pursuing my quest to influence health and social care professionals to adopt the right values and attitudes towards everyone they meet. This is something that I simply cannot and would not want to achieve on my own.

Chapter Eight

Conclusion

The body of work presented in the portfolio of evidence presents a coherent approach to the investigation of user involvement in health and social care education. The studies undertaken with the key findings reported on in the publications (Figure 2) and the supporting commentary are a critical and original contribution to knowledge that is timely in this growing field of inquiry. User involvement is an increasingly important domain within health and social care policy, largely due to the consumerist, democratic and patient centred approaches to health and social care today. With the revelations from the Francis Report (2013), the recommendations from the Berwick (2013) and Keogh (2013) reports, there is unanimous agreement that a partnership approach to health and social care and health and social care education is required and the spotlight is on the fundamental values for practice that recognise and follow ethical principles.

The complexity of user involvement in health and social care education is identified in the expanding body of knowledge. The agency of user involvement and the agentic orientation of the key stakeholders, service users and carers, students, academics and practitioners, is tantamount to its success. One size does not fit all and multiple models and approaches are required that consider the key stakeholder perspectives and facilitate a participatory approach with reciprocity. Importantly, my contribution to the evidence base identifies the benefits of involvement in relation to student learning and professional practice along with benefits for service users and carers. Ultimately the progression of user involvement in health and social care

education is dependent upon investment; there is a need for the correct ‘architecture’ in terms of the right environment and resources. A united approach is required, with joined up action and collaboration, in order to strive for recognition and to achieve a step-change where the goal of a deliberative democratic approach is not a step too far.

Future recommendations for research

To strengthen the argument for investment in user involvement in health and social care education there is a pressing need for additional research to further substantiate the benefit of involvement for all parties concerned. Future research undertaken could adopt a range of approaches including collaborative and participatory approaches to give voice to the complex phenomenon from a variety of perspectives. In order to develop an understanding of peoples experiences we need to redefine what we value as knowledge, only then will user involvement in health and social care education be considered equal to other teaching and learning strategies employed allowing it to become a core component of the curriculum.

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Appendices

Appendix 1

The published work

Paper 1: Balen, R., **Rhodes, C.**, and Ward, L. (2010). The Power of Stories: Using narrative for Interdisciplinary Learning in Health and Social Care. *Social Work Education*, 29 (4), 416-426.

Author contribution: 30%

This comprised of participation in the design, development and delivery of the workshops. Involvement in the thematic analysis of the qualitative comments obtained from students. Contribution to the writing of the paper, particularly the sections on process, participant evaluation, interdisciplinary learning and conclusion.

Paper 2: Dearnley, C., Coulby, C., **Rhodes, C.**, Taylor, J and Coates, C. (2011). Service users and carers: preparing to be involved in work-based practice assessment. *Innovations in Education and Teaching International*, 48 (2), 213-222.

Author contribution: 20% due to the collaborative nature of the work.

This included participation in the workshop by acting as a facilitator. Undertaking the literature review and writing the section on service user and carer involvement in practice based assessment. Contribution to the discussion and recommendations made.

Paper 3: Ward, L., and **Rhodes, C.** (2010). Embedding a Consumer Culture in Health and Social Care Education – a university office's perspective. *International Journal of Consumer Studies* , 34, 596-602.

Author contribution 50%

This included the sections on the literature, introduction, and background, case for involvement, challenges, findings; academic perspective and employing a development worker, benefits and conclusion.

Paper 4: **Rhodes, C.**, and Nyawata, I. (2011). Service User and Carer Involvement in Student Nurse Selection; Key Stakeholder Perspectives. *Nurse Education Today*, 31, 439 - 443.

Author contribution 70%

The comprised of the design and planning of the mixed methods study that included questionnaire design, the semi structured interview plan and ethics application. The lead role on the semi structured interviews and the content analysis (Burnard, 1991) of the transcriptions. Substantial contribution to the writing of the paper.

Paper 5: Padgett, K., **Rhodes, C.**, Lumb, M., Morris, P., Sherwin, S., Symons, J., Tate, J., and Townend, K. (2012). What matters to users of services? An explorative study to promote shared decision making in health care. *Health Expectations*, DOI: 10.1111/j.1369-7625.2012.00767.x

Author contribution 20%, due to the collaborative nature of the work.

This included contribution to the bid for funding to the Assessment and Learning in Practice Settings (ALPS) programme. Participation in the research design, development, implementation and evaluation. Completion of the ethics application to undertake the research with participants from the University of Huddersfield. Specific contribution to the Delphi element of the research that included analysis of qualitative data. Contribution to the writing of the paper.

Paper 6: **Rhodes, CA.** (2012). User involvement in health and social care education: A concept analysis. *Nurse Education Today*, 32 (2), 185-189.

Paper 7: **Rhodes, C.**, Hardy, J., Padgett, K., Symons, J., Tate, J., Thornton, S. (2013). The Health and Well-being of Service User and Carer Educators: A Narrative Enquiry into the impact of Involvement in Healthcare Education. *International Journal of Practice-based Learning in Health and Social Care*. DOI: 10.11120/pblh.2013.00025.

Author contribution 50%

This included contribution to the bid for funding to the Assessment and Learning in Practice Settings (ALPS) programme. Involvement in the collection and analysis of the narrative material obtained from the service users and carers. Work with the service users and carers to distil the stories into artefacts. Writing of the paper.

Paper 8: **Rhodes, C.** (2013). Service User Involvement in Pre-registration Children's Nursing Education the Impact and Influence on Practice: A case study on the student perspective. *Issues in Comprehensive Pediatric Nursing*. DOI: 10.3109/01460862.2013.830161.

Appendix 2

Citations

Christine Rhodes

	All	Since 2009
Citations	39	39
h-index	5	5
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<input type="checkbox"/>	Health Expectations The Health and Well-being of Service User and Carer Educators: a Narrative Enquiry into the Impact of Involvement in Healthcare Education C Rhodes, J Hardy, K Padgett, J Symons, J Tate, S Thornton International Journal of Practice-based Learning in Health and Social Care 2 ...	1
<input type="checkbox"/>	What Matters to US (Users of Services) P Morris, J Symonds, C Essen, S Samociuk, C Plews, J Priestly, M Bush, ... Assessment and Learning in Practice settings Research Capacity Final Report	1
<input type="checkbox"/>		
<input type="checkbox"/>	Service user involvement in pre-registration children's nursing education: the impact and influence on practice: a case study on the student perspective CA Rhodes Issues in comprehensive pediatric nursing 36 (4), 291-308	

Appendix 3

Career narrative of engagement with service user and carers.

Initially I worked as a nurse and midwife in a variety of hospital settings. I then trained as a health visitor and in 1990 began working in the community health care environment. At this point I became aware of a totally different relationship with the people that I was in contact with. They became 'clients' as opposed to 'patients' with a significant shift in the balance of power, I was a visitor in their home, rather than them being a visitor to my domain. In order to establish effective professional relationships it was imperative to work alongside and in partnership with clients and voluntary and statutory services.

I worked with a team of health visitors and district nurses out of a house converted into a clinic in the middle of a large council estate, in the most deprived electoral ward in the area. The team adopted a community development approach, which was pioneering at the time. We built up a relationship with the community and statutory and voluntary agencies in the area. Whilst in this post I was seconded to undertake a health needs analysis, this included interviews with key stakeholders from statutory and voluntary organisations within the community and the production of a report for the Health Authority to inform service planning.

This strong community collaboration led to the development of a community initiative that became a revolutionary, award-winning partnership between the community, elected members, public services, agencies and business aimed at improving local services, community facilities and the overall environment in an effort to improve the quality of life for all residents living in the area. The intention was to tackle the range of issues that were spoiling the quality of life for local residents and preventing new people from moving into the area. Since 1997 the Initiative has achieved a huge range of improvements and led to significant development and change.

Within my health visiting role I took on the responsibility of visiting people who were housed in temporary accommodation and in 2000 I took up a post as a specialist nurse working with the homeless, asylum seekers and refugees. Again a large part of this work was working in partnership with the client group and a number of statutory and voluntary agencies. This included a close working relationship with the Primary Care Trust Healthy Living Initiative and involvement in the appointment, supervision and mentoring of peer workers; members of the community employed to facilitate engagement with these seldom heard groups. It was during this time that I began to appreciate how badly treated this client group were by health professionals.

This led me to an academic post in 2004 with the modest ambition of improving service provision. My mission was to contribute to the development of health care practitioners who would treat everyone in society with the dignity and respect that they deserve. I was not long in post when I realised that the best people to influence this were the people themselves. I could use examples from my practice to illustrate situations; this received positive feedback from students, however I felt that to take this a step further involvement from people themselves would be more meaningful. In order to explore this further in 2006 I completed a literature review of service user and care involvement in healthcare education as part of my MSc in health professional education. Alongside this I made links with colleagues in mental health and social work that already had some service user and carer involvement in their courses.

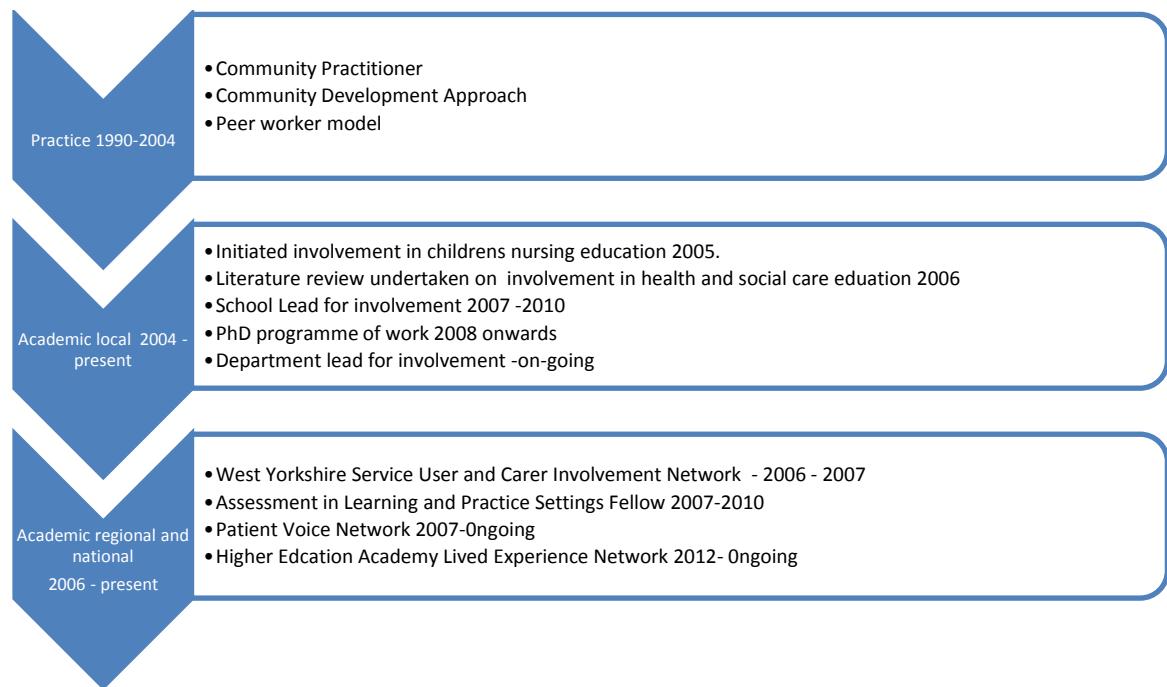
This led me to involvement with the West Yorkshire Service User and Carer Involvement Network collaboration and participation in a number of initiatives that included the 'Patient Learning Journey Workshops', an induction and training programme for service user and carers interested in engagement with Higher Education Institutions with partner universities and development of a web based resource 'Six simple steps to involvement' (see Appendix 3).

I then applied for and was appointed to a secondment opportunity, two days a week as the Schools Service User and Carer Involvement lead from 2007 – 2010. This was linked to the Assessment in Learning in Practice Setting (ALPS) Centre for Excellence in Teaching and Learning (CETL) that aimed to ensure that students graduating from courses in health and social care are fully equipped to perform confidently and competently at the start of their professional careers so improving standards of care (<http://www.alps-cetl.ac.uk>). The ALPS programme had a specific service user and carer involvement stream. This included work with a range of partners from 16 professions at 5 local Universities, alongside service users and carers. The secondment enabled significant progress with service users and carer involvement within the school. Additionally, I professionally represented the school, taking a prominent role regionally and nationally, presenting at a number of conferences. As a result of this I am an active participant in on-going collaborative research projects with Leeds Institute of Medical Education and the Patient and Carer Voice Collaborative Network. Our collaborative work in this area resulted in us being shortlisted for the Times Higher Education Awards 2011 in the outstanding contribution to the local community category.

Alongside this I have held various academic roles as a senior lecturer and subsequently course leader for child nursing. I then progressed to a principal lecturer as a divisional lead, followed by a lead role in the design and development of the all graduate nursing curriculum. This programme was commended by the Nursing and Midwifery Council at validation for the active engagement of service users in all elements of the course development and delivery.

To date I hold a leadership role as head of pre-registration nursing and am the departments lead representative for involvement and actively engaged in involvement activities within the school that includes contribution to the delivery of the school involvement strategy. Further strengthening of national collaboration is currently being achieved through membership of the developing Higher Education Academy Lived Experience Network.

Trajectory of involvement



Appendix 4

Conference Presentations

- Rhodes, C (2013) 'The lecturer experience of impact on a student's learning and practice from involving patients and carers in the delivery of the curriculum'. In: *The Role of Professional Regulatory Bodies in Patient, Carer and Public Involvement, 12th February 2013*, Leeds, UK
- Rhodes, C., Hardy, J., Thornton, S. (2012) The impact of Involvement on Service Users and Carers. In: *Authenticity to Action : Service User and Carer Involvement in Hard Times 7th November 2012*. Westleigh Conference Centre, UCLAN, Preston UK
- Rhodes, C (2012) 'The impact of service user and carer involvement in health and social care education'. In: *Celebration of the memorandum of understanding between the patients association and the University of Huddersfield, February 2012*, University of Huddersfield
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- Rhodes, C and Dew, N. (2011) A collaborative approach to curriculum development. In *RCN Joint Education Forums 3rd International Conference*. Belfast June 2011
- Rhodes, C., Ward, L., Lyons, S., Symons, J., Plews, C., Priestley, J., Sherwin, S., Young, M., Boaz, M. and McNicholl, L. (2010) 'The Service User and Carer Working Group's Journey Through the ALPS Programme'. In: *Assessment and Learning in Practice Settings - Work Based Learning and Assessment for the Next Decade, March 2010*, Weetwood Hall, Leeds, UK
- Ward, L., Rhodes, C. and Balen, R. (2009) 'Innovative, Service User led approaches to teaching and learning through interdisciplinary workshops in health and social care'. In: *Authenticity to Action - Involving Service Users and Carers in Higher Education Conference 2009, 4th - 6th November 2009*, Grange-Over-Sands, UK
- Rhodes, C., Laxton, J. and Plews, C. (2009) 'Assessment and learning in practice settings: opportunities and challenges for involvement'. In: *Authenticity to Action - Involving Service Users and Carers in Higher Education Conference 2009, 4th - 6th November 2009*, Grange-Over-Sands, UK
- Rhodes, C., Bush, M., Essen, C., Morris, P., Padgett, K., Plews, C., Priestley, J., Samociuk, S., Sherwin, S. and Symons, J. (2009) 'What matters to US (Users of Services) in shared care and decision making'. In: *Authenticity to Action - Involving Service Users and Carers in Higher Education Conference 2009, 4th - 6th November 2009*, Grange-Over-Sands, UK
- Ward, L. and Rhodes, C. (2009) 'The trials and tribulations of setting up a development worker post at the University of Huddersfield'. In: *Authenticity to Action - Involving Service Users and Carers in Higher Education Conference 2009, 4th - 6th November 2009*, Grange-Over-Sands, UK
- Rhodes, C (2009) 'Service user involvement in the selection of students'. In: *Authenticity to Action - Involving Service Users and Carers in Higher Education Conference 2009, 4th - 6th November 2009*, Grange-Over-Sands, UK
- Rhodes, C. and Smith, S. (2009) 'Digital Storytelling'. In: *School of Human and health Sciences Festival of Learning, 1st May 2009*, University of Huddersfield, Huddersfield, UK
- Rhodes, C., Essen, C., Padgett, K. and Symons, J. 'What Matters to US (users of services) in Shared Care and Decision Making'. In: *Detecting the Evidence, 6th April 2009*, University of Northampton, UK.
- Rhodes, C. and Padgett, K. (2009) 'What Matters to US (Users of Services) in Shared Care and Decision Making'. In: *School of Human and Health Sciences Research Open Day, 27th March 2009*, University of Huddersfield, Huddersfield, UK
- Rhodes, C. and Powell, E. (2009) 'Service User Involvement in the Selection of Students'. In: *School of Human and Health Sciences Research Open Day, 27th March 2009*, University of Huddersfield, Huddersfield, UK

Reports

- Rhodes, C., Plews, C., Boaz, M., Bush, M., Essen, C., McNichol, L., Noda, B., Samociuk, S., Sherwin, S., Symons, J., Young, M. (2010) The ALPS Service User and Carer Working Group Report. August 2010.
- Rhodes, C. (2010) The Business Case for a Service User and Carer (SU&C) Development Office in the School of Human and Health Sciences – March 2010

Web based Resources

- Assessment in Practice and Learning Settings Working group (2009). Guidelines for the Involvement of Service Users and Carers in ALPS and Beyond. <http://www.alps-cetl.ac.uk/essen/player.html>
- Assessment in Practice and Learning Settings Working group (2009). Guidelines for the Involvement of Service Users and Carers in ALPS and Beyond. <http://www.alps-cetl.ac.uk/essen/player.html>