Do I feel valued? A co-produced exploration of the notion of value from the perspective of a Service User or Carer participating in health and social care education in a university.

By
Alison Alexandra Morris

Masters by Research
awarded by
The University of Huddersfield

Resubmitted 12th March 2024

Copyright statement

Table of contents

List of tables

List of Appendices

Abstract

Service User and Carer (SU&C) involvement in health and social care education is an established feature in the teaching and learning of student nurses, social workers, and allied health professionals. SU&Cs have evolved from playing a minor role, primarily sharing their personal stories as a focal point in a lesson, to being actively included in student assessments, recruitment, curriculum development, and co-designing sessions with academics.

The role is evolving, and academics are learning to include, embed, and collaborate with SU&Cs. Research is shedding light on innovation in this area and encompassing the impact on students and academics. However, little is known about the SU&Cs themselves, their perspectives, and the impact this work has on them. Investigating the viewpoints of this informal workforce is essential to ascertain their needs and opinions and develop meaningful and effective involvement for all stakeholders. There is also a scarcity of research which has been designed, developed, and co-produced with SU&Cs in this field.

An interpretivist, qualitative study incorporated two groups of SU&Cs using separate methodological approaches. The SU&Cs were all active members of the Public Partnership Group (PPG) at the University of Huddersfield. A small team of four SU&Cs volunteered through self-selection to co-produce, design, and evaluate the research. This group was named the Research Design Team (RDT). A second group of ten SU&Cs volunteered through self-selection as research participants. The ten participants took part in a semi structured interview; designed by the RDT, where they were asked a series of questions relating to their notion of value in relation to their contribution to the teaching and learning at The University of Huddersfield. The interviews were then transcribed and analysed. Template Analysis was used to evaluate the findings.

This study identified that SU&Cs did feel valued for their contribution. Many reasons were attributed to this, indicating that value is experienced in various ways unique to everyone. Participants shared an increased sense of wellbeing where "being heard" was a key influence of feeling valued. The findings clearly demonstrate the motivations for involvement and how it impacts well-being. Altruism featured strongly as a motivating factor for involvement. Participants expressed conflicting feelings about their connection with the wider university, with some lacking a sense of belonging within the organisation. The RDT faced several obstacles when co-producing the research with ethical approval and the global pandemic altering the initial plans for the research study. Their role swiftly moved online, and new skills were developed, however co-production was hindered as a result.

This empirical research contributes knowledge to the emerging field of Service User and Carer Involvement pertaining to their perspectives. This research sheds light on the role of the SU&C and their notions of feeling valued for their contributions. The research provides insight into SU&C experiences in relation to how partnership working can be achieved and used in this field. It has also created knowledge of the holistic impact of involvement on the individual and demonstrated how modelling successful involvement in an educational setting is also a valuable learning tool for students. As a result of their analysis, the RDT generated a set of recommendations applicable to Higher Education Institutes (HEIs) where SU&C involvement is integrated into teaching and learning.

This research also contributes knowledge to user led research that is co-produced by SU&Cs. It has exposed issues faced with co-producing research in a Higher Education Institute (HEI) and the ethical standpoint of this research field. Additional research is needed to further develop this field in relation to best practices for successful SU&C involvement, using democratic models to carry out research and providing guidance to ethics panels in relation to working in a co-production model.

KEY WORDS

Service User, Carer, SU&C, Involvement, health & social care education, lived experience, expert by experience, co-production, shared decision making, co-design, Service User and Carer perspectives. Service User and Carer Involvement.

Acknowledgements

I would like to thank the members of the Research Design Team: Catherine, Claire, Janet and Ilyas for making this project possible, for their commitment and passion, and for collaborating with me even under unexpected circumstances. Thanks to the research participants for their honest views and commitment to this research.

I would like to thank my supervisors, firstly – Dr Christine Rhodes and Dr Christine Smith who began this journey with me and kept me going.

Immense thanks are due to my third supervisor Dr Mary Turner, who took over once Dr Rhodes retired. Thank you for turning me around and leading me in the right direction, even when my chips were down. Your gentle steer beyond my limits has helped me realise that I'm not always an imposter. Your guidance has been immeasurable, and I know that this would not be possible if you had not provided me with your wisdom, for that I am so thankful.

I would like to acknowledge the brute force of all my family and friends who have done their utmost to keep me going. All the hours of childcare, tea, pep talks and encouraging hugs have meant the world to me – Marc, Mum, Dad, Ann, Vicki, Paul, Vicci, Hayley, Emma, and my ever-patient boys Lucas and Asa. I will never forget how you picked me up. Special thanks to Rhoda for her guidance and advice.

Thank you, Christine R and Janet, for planting the seed that I could do this in the first place. Thank you all for helping me on this journey.

Chapter 1: Introduction and background

"We were not add on extras… we were not the novelty factor. We weren't the owl that they brought in at the end of a really boring Friday afternoon in school".
(Research participant June 2021)

1.1 Introduction

This chapter introduces the concept of Service User and Carer (SU&C) involvement within a Higher Education Institute (HEI) and outlines the role of the Public Partnership Group (PPG) at the University of Huddersfield School of Human and Health Sciences. The chapter also provides an understanding of how SU&C involvement correlates with health and social care education and offers background information on the history of involvement and key legislation that has developed this agenda. In so doing, I will provide a clear understanding of the setting for this research study. Additionally, the chapter introduces the concept of coproduction and explains the fundamentals of this research study.

The PPG (Public Partnership Group) at the University of Huddersfield consists of Service User and Carer (SU&C) representatives who possess extensive experience in accessing health and social care services. These individuals are invited by the university to share their personal experiences with students studying social care, nursing, and allied health professions. The involvement of PPG Members occurs within the context of professional courses that are regulated by various bodies such as the Nursing and Midwifery Council (NMC), the Health and Care Professionals Council (HCPC), and Social Work England. PPG Members engage in multiple ways to contribute to the education of students. They are involved in activities such as recruitment, curriculum development, classroom teaching, resource creation, and student assessments. Their participation ensures that the experiences and perspectives of service users and carers are integrated into the education and training of future healthcare professionals.

This involvement of SU&Cs in health and social care education is commonly known as Service User and Carer Involvement, although there are other terminologies used to describe it, 'Expert by Experience', 'Public and Patient Involvement', 'Lived Experience', 'Consumer Educator' and 'Consumer Participant' to name a few (Simmons et al., 2010;

National Survivor User Network, 2021). The PPG has a history of 50 years, influenced by nationwide survivor movements and community partnership initiatives, and its growth has been furthered by government policies and international conceptions of modern healthcare.

As this study is co-produced, the chapter introduces the concept of co-production and explains the practicalities and ethos of co-production. The chapter concludes by explaining the fundamentals of this research study and my role in it.

1.2 The history of SU&Cs – the survivor movement and key legislation

To fully understand the function and position of the PPG, it is important to learn about its history and how it achieved its role in the education of students. In 1972, the newly formed Conservative government in the UK, under Prime Minister Edward Heath, aimed to reform the National Health Service (NHS). This led to the National Health Service Reorganisation Act 1973 (Health Foundation, 2023a), which introduced Community Health Councils (CHCs) as a key initiative to acknowledge the patient voice in decision-making. CHCs were developed to represent and advocate for patients in matters such as complaints, as well as monitor and review performance (Ham, 2009).

This allowed CHCs to work collaboratively with patients involved in decision-making with managers, functioning as a pipeline between local authority and the community (Marre, 1977; UK Parliament, 2007; Parker, 2017). CHCs played an essential role in the UK healthcare system until they were abolished in England by the Labour government in 2003. However, the devolved Labour government in Wales has remained committed to CHCs and their role in collaborating with local communities (UK Parliament, 2015). The establishment of CHCs and their subsequent abolition in England demonstrates the fluctuating nature of patient involvement in the UK healthcare system. Nevertheless, their legacy lives on, and the PPG at the University of Huddersfield School of Human and Health Sciences is an example of how patients can have a role in the education of future healthcare professionals.

The Influence of emancipatory survivor movements has been a key contributor to modern legislation in the UK and beyond since the 1960s, 70s, and 80s, and this influence continues today. These movements have had a significant impact on policy and lawmakers (Beresford, 2012; Bourdieu, 1998; Brown & Zavestoski, 2004; Chassot & Mendes, 2015; McKeown et al., 2014; National Involvement Standards, 2015). In 1970, survivor movements began to grow in the UK, Europe, and beyond. These movements were primarily established by users of mental health services who felt disempowered by paternal psychiatric legislation and services (Newbigging & Ridley, 2018). During the 1970s and 80s, physically disabled people also began to organise and establish groups that represented the rights and embodiment of people with physical disabilities (Berghs et al., 2019). This happened with a heterogenous range of service user groups and socially stigmatised citizens such as: The Gay Liberation Front 1970–- 1973, The Claimants Union 1969, The Mental Patients Union 1973, Community Organisation for Psychiatric Emergencies (COPE) 1973, The Phobics Society 1970, The Scottish Union of Mental Patients 1972, The Disabled Peoples Association 1980 (DPA). In 1970, the first Women's Liberation Conference was held (The Survivors History Group, 2005; Disability Equality Northwest, 2020). This momentum called into action campaigning, raising awareness, publishing and policy making (Oliver, 2013). The passive patient directed by a paternalistic medical world was no longer tolerable (Haycock-Stuart et al., 2016).

Alf Morris MP was responsible for creating and actualising the Chronically Sick and Disabled Persons Act 1974 (Hampton, 2020). This Act instructed local authorities to provide welfare services to disabled people such as improvements to building accessibility and services to promote independence (UK Parliament, 2023). 1974 saw the Union of the Physically Impaired Against Segregation (UPIAS) and the Disability Alliance (DA) merge together and declare their ethos for an emancipatory and freedom-seeking establishment by agreeing on the first iterations of the social model of disability (Oliver, 2013). This model defined disability as:

> In our view, it is society which disables physically impaired people. Disability is something imposed on top of our impairments, by the way we are unnecessarily isolated and excluded from full participation in society. Disabled people are therefore an oppressed group in society (UPIAS & Disability Alliance meeting recording 1975, transcribed 1997, p.4).

This declaration shifted the emphasis from disability perceived as a deficit where the focus is on a cure or following a medical model, to an emancipatory and rights-based agenda (Shakespeare, 2017).

In 1978, the World Health Organisation (WHO) held its International Conference of Public Health in Alma-Ata (now known as Almaty, Kazakhstan). Following the conference, the Declaration of Alma-Ata- Health for All by 2000 (Declaration of Alma-Ata International Conference on Primary Health Care, 2004) was formed, which is now thought of as a key piece of twentieth-century legislation in public health (Cueto, 2004).

Key points include an agreed definition of health and an acknowledgement of the voice of the patient:

- The Conference strongly reaffirms that health, which is a state of complete physical, mental, and social wellbeing, and not merely the absence of disease or infirmity, is a fundamental human right.

  The people have the right and duty to participate individually and collectively in the planning and implementation of their health care.

(WHO, 1978. Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978, 2004.p. 1)

In 1983 the Government led by Prime Minister Margaret Thatcher commissioned the Griffiths Report which initiated improvements in health and social care services through improved organisational and management initiatives (Waring, 2013). This government fully embraced the concept of the patient as a consumer and considered the NHS as an industry that could be opened for tender (Mold, 2015). This rhetoric crossed over from the business world (Brindle, 2015; Sturgeon, 2018) and the move cemented the political ideology of a taxpaying health and social care consumer (Wood et al., 2015).

The consumerist model, coupled with its new management structures, was very different from the emancipatory, democratic model that the survivor movements had campaigned for in the 1960s and 70s (Beresford, 2019). A key commentator on this issue is Beresford (2002), who discusses the dichotomy between the consumerist and democratic/emancipatory models within the involvement sector of SU&Cs in health and social care. He states how each model is at opposite ends of an imaginary spectrum. The consumerist model foundation lies within the realms of the political right-wing agenda and is suited to policy makers and management (Beresford 2002). The democratic model was developed from a bottom-up approach firmly in the hands of the patient or service user (McKeown, 2014). It exists to provide a voice and agency to groups who need and want input into their care and welfare. Beresford, (2002) states that despite the definitions and polarity of the two models, there are several overlaps and blurring of lines, suggesting that the two concepts are now accepted in varying forms.

During the 1980s and 90s, John Major's Conservative government developed the Citizens Charter (UK Parliament, 1991). The Charter called for more transparency and accountability of public services. The Citizen's Charter was swiftly followed by the Patient's Charter (GMC, 2023) which was specifically linked to the NHS and outlined how it served its patients. It emphasised that the NHS belongs to the public and intended to develop positive doctor patient relationships, shoring up the rights of the patient in all aspects of their care and communication (Stocking, 1991).

On account of mounting pressure from the survivor movements, a key document for the rights of the patient/citizen/consumer was passed through parliament. The Disability Discrimination Act, 1995, (DDA) was formulated to acknowledge the issues raised for decades by the survivor movements and professionals (Lewis, 2009). Although criticised for not going far enough (Oliver, 2016), the DDA was the first piece of legislation which addressed the social model of disability and recognised how society needed to make changes to not only enable people with disabilities access to employment and education; but also make it unlawful to be discriminated against because of a disability (Waterman, 2013). The DDA (Disability Discrimination Act) has undergone several revisions since its inception. In 2010, it was incorporated into the Equality Act (2010, which legally safeguards the rights of individuals with disabilities and other protected characteristics (Malleson, 2018). Consequently, this legislation has a significant impact on policy and regulations within the health and social care sector, ensuring the rights of individuals are respected and protected. As a result, it promotes the maintenance of dignity and the practice of nonjudgmental care (SCIE, 2020).

The involvement of Service User and Carer (SU&C) representatives can illustrate how the Equality Act 2010 is implemented in the care provided to service users and carers. They can share successful examples with students, highlighting instances where the Act has been effectively enforced. Moreover, they can also address the challenges and shortcomings they have encountered, facilitating discussions on how these issues could be rectified in a supportive forum.

The new Labour government introduced the NHS Plan (Dixon & Dewar, 2000) and formalised this into the Health and Social Care Act 2001 (Legislation.gov.uk*, 2023a).* Controversially, Tony Blair fully embraced the Private Finance Initiative (PFI) and developed deeper links with private companies tendering contracts for the NHS. Private investment flooded the NHS and in 2005, A Patient Led NHS (DoH, 2005) was launched. This document set out an NHS improvement plan stating the importance of providing:

> More choice, more personalised care, real empowerment of people to improve their health……to move from a service that does things to and for its patients to one which is patient led, where the service works with them to support their health needs (DoH, 2005. p. 3).

Various legislation which strengthened the voice of the patient and service user has since followed. A White Paper titled, 'Our health, our care, our say' in 2006 (DoH 2006), emphasised the embedding of patient voices in decision-making and famously moved services for people with learning disabilities from institutions into the community (King Owen, 2020). In 2009 Lord Darzi published 'High Quality Care for All' (DoH, 2008), which was rooted in the work of the Patients Charter and focused on the importance of providing patients with more choices in their care. This was later revised as the NHS Constitution 2013 (NHS England, 2013) and the introduction of the much-awaited Care Act 2014. Subsequent governments have since continued to review and reform health and social care with various strategies and continue to put a marketised version of person-centred care (Latimer et al., 2017) at the epicentre of its motivation. Many NHS trusts and local authorities (LA's) now involve SU&Cs, patients, experts by experience, and others in planning and service delivery workstreams, including on boards and panels. For example:

> We want our services to be the best they can be for everyone who uses them and the feedback, views, and experiences of our services users, along with their families and carers, can help us develop, deliver, and improve them (Pennine Care NHS Foundation Trust, n.d. p.1).

> We believe that the best health services are ones that are planned, shaped and delivered by patients, carers and staff working together. (Central and Northwest London NHS Foundation Trust 2023 p.1).

It is widely recognised now that a patient/client has the biggest impact on services when they participate in the development, delivery, and consumption of their care (Leadbeater, 2004; Sturgeon, 2018). The evolution of survivor movements and the patient voice campaign is an acknowledged history to learn from. Policy makers recognise the value of involving people with lived experiences to the extent where their opinions count and can influence future practice.

> We worked with carers to understand more about the experience and knowledge they can bring to improve services and care. We also looked at examples of where practice is changing, and carers are being involved in service design and delivery (Churchill, 2018 p.1).

> By involving people in decisions about their health and care we will improve health and wellbeing, improve the quality of care and ensure people make informed use of available healthcare resources (NHS England, 2017, Involving people in their own health care, p. 3).

1.3 The Public Partnership Group (PPG) and the patient/carer voice in education

It is at this point where we can now place the focus on the Public Partnership Group (PPG) and its relevance. The PPG is embedded in the School of Human and Health Sciences at the University of Huddersfield, a post-1992 University. As demonstrated previously, the PPG stands on the shoulders of giants that have, for over 50 years, campaigned and lobbied for people with lived experiences of receiving treatment and care, to be recognised as valuable partners in service design and delivery. This initiative has also directly impacted the training of professionals in health and social care and therefore, education programmes must include the voice of the SU&C. The University of Huddersfield works in partnership with SU&Cs to contribute to health and social care training. The PPG is not unique in this initiative. There are various SU&C groups installed in UK Higher Education Institutes (HEIs) acting as an informal workforce (The Health Foundation, 2017), representing the Service User and Carer voice. In the UK, the involvement of SU&Cs in the training of Nurses, Health Care professionals and Social Workers is a requirement on all Health and Social Care courses. The regulators include the Nursing & Midwifery Council 2018 (NMC), Health and Care Practitioners Council 2017 (HCPC) and Social Work England 2021 (SWE).

The term 'Public and Patient Involvement' is used to describe how individuals from the public with relevant experiences in health and social care practice can contribute to the training and education of future health and social care professionals (Patient and Public Involvement in Nurse Education, 2018). This term is well used and embedded within training standards (NMC, 2018).

The involvement of SU&C perspective has a profound impact on student development, and much has been written on this subject (Bassett et al., 2006; Happel et al., 2014; McKeown et al., 2014; McSherry & Duggan 2016; Hughes, 2017; Odejimi 2020; et al. Rhodes 2012; Russo & Beresford 2015; Unwin et al., 2017a; Unwin & Rooney 2020; Smith & Dransfield 2019).

In 2012 the Willis Commission Report (Willis, 2012) which scrutinised the training of nurses, identified the importance of SU&C involvement in education, particularly in regard to SU&Cs collaborating on training programmes. (Willis, 2012). This report was a direct response to the tragic and colossal failings found in poor nursing care at the Mid Staffordshire Hospital (Campbell, 2013) and preceded the Mid Staffordshire NHS Foundation Trust Public Inquiry, also known as The Francis Report (Francis, 2013). The quality of nursing care at this Trust faced in-depth scrutiny and the report found that there were many occasions where patients, carers and staff were not listened to, resulting in neglectful treatment. A recommendation arising from the Francis Report, regarding improving standards, was aimed at HEI's to include SU&C involvement in their health and social care training programmes (Francis, 2013), and for these to be mandated by the regulatory bodies: NMC, HCPC, and SWE. As a result, SU&C involvement is now embedded in varying forms and structures at relevant HEIs. Courses are validated and their commitment to involvement is continuously scrutinised. However, the directive from regulators is vague and is open to interpretation by programme leaders. Below is an example of the regulations:

> **The Health and Care Professions Council**
>
> Evidence we expect to see. We appreciate that expectations about the level and type of service user and carer involvement will vary between professions, and that different programmes will meet the standard in different ways. You will need to explain and justify where and how service user and carer involvement takes place, as appropriate to your programme (HCPC, 2023 p.1).

> **Nursing and Midwifery Council**
>
> Approved education institutions, together with practice learning partners, must… ensure programmes are designed, developed, delivered, evaluated, and coproduced with service users and other stakeholders (NMC, 2018. p.4).

Social work and allied health care professions were also affected by the Francis Report (Francis, 2013) and subsequently, the Care Act 2014 (Legislation.gov.uk, 2023b) was created to serve the recommendations from it, amalgamating existing legislation and strengthening policy on health and social care. As a result, the Care Act 2014 included a new part which implemented gradings for care homes and hospitals (Adass, 2023). It is essential to monitor the quality of SU&C involvement within an HEI. Fears can arise that SU&C involvement is only occurring because it is a requirement (Watson et al., 2022; Webber & Robinson, 2012), or that it may be perceived as tokenism, leading to a lack of quality control (Ocloo & Matthews, 2016). Therefore, directives should state that involvement must be meaningful with the correct organisational structures in place to meet this need (Ward & Rhodes 2010). The impetus for involvement in a module predominantly originates from the academic who teaches the module (Beresford, 2020; Scammel et al., 2016). The demands of regulatory involvement and the decision to involve SU&Cs in the education of students lies with the academic to begin the process of involvement (Happell et al., 2020a). Therefore, it is essential that involvement is monitored for quality within a HEI to dispel tokenism.

Quality control monitoring could take the form of a devoted team co-ordinating involvement (Ward & Rhodes 2010) or and/or include adequate training for academics. At the University of Huddersfield, members of the PPG are involved in all aspects of teaching and learning in a myriad of ways such as: sharing their lived experiences, discussing their care, and assessing students in a module relevant to their lived experiences. PPG members are consulted on the curriculum and attend strategy and course meetings. (Haycock-Stuart, 2016; Irvine, 2015; Tritter et al., 2009; Fox 2011; Smith & Dransfield, 2019).

The instruction from regulators is intentionally broad and ambivalent leaving the 'how, why and where' down to interpretation. Rooney et al. (2019) conducted a study documenting the views of academic staff on SU&C involvement in health and social care education. The results were varied, but it was acknowledged that SU&C involvement is of great value to student learning, as it can challenge preconceptions and provide a deeper level of understanding from the SU&C perspective. Academics noted that it can be considered a complex and time-consuming exercise involving a service user but with appropriate planning, briefing, support and administration, a successful and meaningful involvement opportunity can be achieved. This research highlights the importance of effective organisational structures in a university which supports involvement in health and social care education. Ward & Rhodes (2010) discussed this also in their paper from over a decade ago, exposing many issues which for some HEI's remain likely to still be prevalent today. They discuss what a university can do to embed the 'consumer and service culture' (Ward & Rhodes, 2010) in the training of health and welfare students. It is not enough for academics to be simply passionate and encouraging about involvement. There must be designated staff to support and develop this momentum. Ward & Rhodes (2010) investigated the necessity for academics and SU&Cs to work in partnership to develop a meaningful and non-tokenistic involvement opportunity. Similarly, nearly 10 years later, Rooney et al. (2019) also found that developing, organising, and delivering involvement sessions could be complex and time consuming.

Academic staff are stretched for time (Read et al., 2020); if time is limited for developing quality involvement, then problems affecting quality may arise. Ward & Rhodes, (2010) suggest that a designated member of staff in the form of a development worker be employed to develop involvement opportunities in a university and ensure it is embedded within organisational structures and systems. Employing a development worker was considered a key component to successful involvement and participation (Ward & Rhodes, 2010). It is important to add that Ward & Rhodes were employed at the University of Huddersfield at the time of writing their paper. Their knowledge and influence are evident today by looking at organisational structures regarding SU&C involvement within the University.

1.4 This research study

In this dissertation, I will adopt a first-person perspective. This decision is based on the qualitative nature of the study, the co-production element, and my dual involvement in the research process. As well as studying for this MRes, I work at the University of Huddersfield as the Service User and Carer Involvement Coordinator. I am responsible for coordinating the PPG and other similar activities that Ward & Rhodes (2010) and Rooney et al., (2019) refer to. This university also employs a development worker, making us a team of two – SU&C Involvement Development Lead and SU&C Involvement Coordinator. Having worked in this role for five years I was keen to conduct research on, and with, PPG members, focused on the work they do. Looking at the literature regarding Service User and Carer Involvement within health and social care training in a university, the majority covered the impact of involvement on students or the role of the student and academic in teaching sessions with SU&Cs. There seemed to be a paucity of research capturing the perspectives of SU&Cs in this field; in addition to little if any research conducted with SU&Cs participating as researchers within a higher education training and teaching context. (Buckley et al., 2022).

The nucleus for this research study came from the ethos behind the motto “nothing about us, without us”. This phrase is famous within the disability rights movement referring to the inequalities and oppression that disabled people face (Charlton, 2000). It is thought to have originated from Central European politics but is also a known term for attitudes towards services and policies that should be created with the people and groups that they directly affect (Jackson & Moorley, 2021). I wanted to use this philosophy and create a research project with the PPG as its focus.

I initiated the project by inviting PPG members to join me in an informal discussion about my research. I wanted to discuss with members what they felt should be researched and draw on their perspectives to establish a research question. Seven members attended and after explaining the impetus of my research being to work with members to decide on what to research, design the research, and evaluate, a conversation ensued regarding their PPG involvement and areas they felt should be researched. The notion of value arose repeatedly, concluding that PPG members did not know if they were valued or if they themselves felt valued for their involvement work. This formed the basis of the research subject; we would investigate whether members felt valued and if so why.

1.5 Aims and objectives of this study

There were two aims of this research.

Aim 1 – To understand and document the perspective of SU&Cs, whether they feel valued and why.

Objectives:

- Develop a research study comprising of semi-structured interviews which asks SU&Cs their views and thoughts on the issue of involvement work in health and social care education, and if they feel valued.
- Apply for ethical approval.
- Conduct a template analysis on the transcripts to ascertain the results.

Aim 2 – To involve SU&Cs in all aspects of the research from inception and work collaboratively using co-production mechanisms.

Objectives:

- Initiate a conversation with SU&Cs concentrating on what they think should be researched.
- Apply for ethical approval to recruit a small number of SU&Cs to co-design the research in aim 1 (above).

- Recruit SU&Cs to participate in designing the research and analyse the results in a co-produced group of SU&Cs, named the Research Design Team (RDT).

The aims and objectives of this research study dictated that two separate groups from the PPG were involved in this research. The first group, the Research Design Team (RDT) co-produced the research. The second group, the Participant Group or Data set, comprised a different set of PPG members who chose to participate in semi structured interviews exploring their feelings of being valued.

In this chapter, I have outlined the history of the survivor movement and explained how legislation and policies have shaped this movement, from activist status to involvement in service design and development, policy input, and the involvement of people with lived experiences in health and social care education. I have demonstrated how far the survivor movement has progressed and how it is now embedded in the systems and processes which it fought against. I have explained the impetus for this research and presented the aims and objectives of the study. In the next chapter, I will discuss the process undertaken to review the relevant literature by carrying out a scoping review.

Chapter 2: Literature review

2.1 Introduction

In this chapter, I explain how I conducted a literature review on the participation of Service Users and Carers (SU&C) in involvement opportunities at Higher Education Institutes (HEIs). I will provide a detailed account of the process I used to establish the title of this review and choose the appropriate mechanisms and framework for the review. I will explain how I searched for relevant literature using specialist search engines and examined the papers for relevance using an inclusion criterion and a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram (PRISMA, 2023). I will then outline how I identified eighteen papers significant to my research field by charting the data and creating a patterning chart, which will enable me to demonstrate the themes identified in the selected literature. Finally, I will consider the position of this research study in relation to what is currently known on the subject and identify areas for further research. This literature review was originally conducted in January 2022, and since then, I have repeated the search and updated the review to include literature published between January 2022 and March 2023.

2.2 The literature search

To initiate a research project, it is essential to ascertain what is already known about a subject (Kiteley & Stogdon, 2013). Once the literature has been searched, gaps in knowledge are identified (Lingard, 2018), providing a clear picture of the research field. Aveyard & Bradbury-Jones (2019) use the analogy of a jigsaw puzzle to describe the different pieces of literature on a specific subject. Quality literature reviews instil order in a comprehensive way by offering a clear assessment and investigation of the literature on a given topic (Polit & Beck, 2013; Wyborn et al., 2018; Leenaars et al., 2021). The aim of this review was to examine what is known about SU&C perspectives of involvement in co-production within health and social care education at a university. There is an increasing body of research focused on SU&C involvement, particularly within the disciplines of mental health nursing and social work (Schreur et al., 2015; Irvine et al., 2015; Saini et al., 2022), with a particular emphasis on the impact on students or academic staff (Rhodes, 2012; Happel et al., 2014; McKeown et al., 2014; Russo & Beresford, 2015; McSherry & Duggan, 2016; Rooney et al., 2016; Unwin et al., 2017b; Unwin & Rooney, 2020). However, there is limited research centred on the experiences and impact on SU&Cs themselves (Rhodes, 2014; McKeown et al., 2012). One outcome of Rooney et al.'s (2016) research suggested that a focus on the motivations for involvement from SU&Cs was an area lacking in current research and would be beneficial to this field. This indicates that there is scope for this review to also search for co-produced research on SU&C perspectives, as it is unknown if any exists.

Driven by time limits, funding requirements and research methodologies a variety of analysis tools have been created and utilised to meet the demands of diverse research requirements.   Aveyard & Bradbury-Jones (2019) noted thirty-five different terms used to describe literature reviews, concluding that whilst there are distinct differences in approaches, there is some ambiguity with regards to definitions (Aveyard & Bradbury-Jones, 2019). The most common review approach is an integrative or narrative approach (Aveyard & Bradbury-Jones, 2019). This traditional approach is prone to accusations of bias, questioning the validity and reliability of the review (Massaro et al., 2016). In a narrative approach, literature is selected to review subjectively, which can enable a researcher to 'cherry pick' literature providing the opportunity to strengthen their argument. This puts the quality of the review in jeopardy as they have not mitigated against any possibility of bias, disregarding conflicting research and counter arguments, therefore discrediting the narrative approach (Petticrew & Roberts, 2006; Fleming, 2022).

A comprehensive, structured review is inherently more dependable due to the replicability of the methodology in which a review is conducted (Coughlan & Cronin, 2021). When beginning a structured review, steps are taken to ensure reliability such as: documenting the search terms used in databases; using a clear and justified inclusion and exclusion criteria; listing the accepted or rejected papers; and adhering to a transparent critique of the accepted literature (Massaro et al., 2016). A comprehensive approach in the form of a scoping review, for example, is considered a robust method which has clearly defined protocols (Pham et al., 2014; Munn et al., 2018). Scoping reviews provide an overview of available research on a broad subject which assesses the selection of data. (Levac, 2010; Sucharew & Macaluso, 2019). As discussed, current evidence indicates that research on

SU&C involvement using co-production and co-production approaches is an emerging field (Smith et al., 2022).

A scoping review can be used for several purposes. Arksey & O'Malley (2005), identified four main reasons for researchers using a scoping review:

1. To examine the extent, range, and nature of available research on a topic or question.
2. To determine the value of undertaking a full systematic review.
3. To summarise and disseminate research findings across a body of research evidence (e.g., that is heterogeneous and/or complex).
4. To identify research gaps in the literature to aid planning and commissioning of future research.

(p.22)

As the subject of this review potentially falls within an emerging field, it was necessary to conduct a structured literature review to thoroughly investigate what is known about this subject, employing robust and reliable strategies.

A scoping review was considered the best method to follow and is pertinent for points 1 and 4 of the above from Arksey & O'Malley's (2005) justification. Arksey and O'Malley (2005) also developed a 6-point methodological framework for conducting a scoping review effectively.

2.3 The 6-point framework

(1) Identifying the research question
(2) Identifying existing studies
(3) Selecting studies
(4) Charting the data
(5) Collating, summarising, and reporting the results
(6) An optional final step to consult with stakeholders regarding findings

By using the 6 -point framework protocols, this review did not allow for selection bias and as such presented a robust and clear perspective of what is known about this field.

Step 1: Identifying the research question

The impetus for this research has been discussed in chapter 1 p.18. Attending an informal discussion with PPG members provided insight into individuals' thoughts regarding the focus of the research. Initial discussions led to the notion of value, which served as the reference point for this review question. Subsequently, a PEO(S) framework was employed to clarify the question. Frameworks can be used to formulate a review question that determines the aim of the review and confirms which search terms to use (Elsevier Author Services, 2022).

This review utilised the PEO(S) framework, which stands for Population, Exposure, Outcome, and Study.

- Population: Service Users and Carers (SU&Cs)
- Exposure: SU&Cs participating in health and social care training
- Outcome: perspectives
- Study: qualitative/co-produced

The question which developed using the PEOS framework was:

In SU&C involvement research, what co-produced studies exist in association with SU&Cs who participate in health and social care education, focusing on the perspectives and opinions of SU&C?

The question was intentionally broad, inviting literature from any social or health care discipline and within any context of teaching, learning or research in a university. Although the focus was on perspectives of SU&Cs, the flexibility of the question could include other perspectives such as students or academics. This is a broad question which is suited to the methodology of a scoping review (Arksey and O'Malley, 2005).

The aim of this literature review was to identify if any co-produced research exists which focuses on the perspectives of SU&C's who contribute to health and social care training in a HEI.

The aim of the review was met using the following objectives:

1. Using a PEOS framework to formulate the review question.
2. Performing a scoping review with a priori protocols to retrieve the literature.
3. Recording the results on a PRISMA diagram.

4. Using a 6-point framework to analyse the findings and create a thematic analysis of the literature found.

Step 2: Identifying existing studies

Empirical research was included, while grey literature was excluded from this review. This decision was justified by the nature of the review question, which specifically focused on peer-reviewed publications. Research that was not peer-reviewed was not included in the search, as it had not undergone scrutiny by external reviewers. Hand searches were conducted on the final selection of papers to identify additional papers. The Francis Report (2013) was chosen as the starting point for the paper selection. This choice is detailed in Chapter 1 (p.15/16) due to the reports significance in requesting changes in practice and standards within health and social care education in the UK. This review included research papers from 2013 up to the date when this literature review was last updated, which was March 2023, see Table 1 for a detailed account of the inclusion and exclusion criteria for this review.

Table 1: Inclusion and Exclusion Criteria

Criterion	**Inclusion:** Studies must meet all the following criteria to be included.	**Exclusion:** Any of the following papers will not be used in this review.
Types of research studies	• Qualitative research • Peer reviewed academic articles • Original/empirical research • Published in English language	• Discussion papers • Systematic reviews • Conference papers • Quantitative research
Period	Post March 2013 to present	Pre-March 2013
Language	Published in English language	Published in all other languages
Type of participants	• Service users and carers/experts through experience/people with lived experiences of health and social care who have contributed to health and/or social care training in Higher Education.	All other populations
Context	• Co-production • Service user and carer perspectives of their involvement in HE education health and social care training • SU&C quotations included in the research.	Research that does not focus on views and opinions of service users and carer experiences regarding their involvement in health and social care training.
Knowledge discovered	• Perspectives of SU&C involvement in health and social care education. • Knowledge of co-produced research.	Perspectives populations, in other areas not specific to HE involvement in health and social care training.

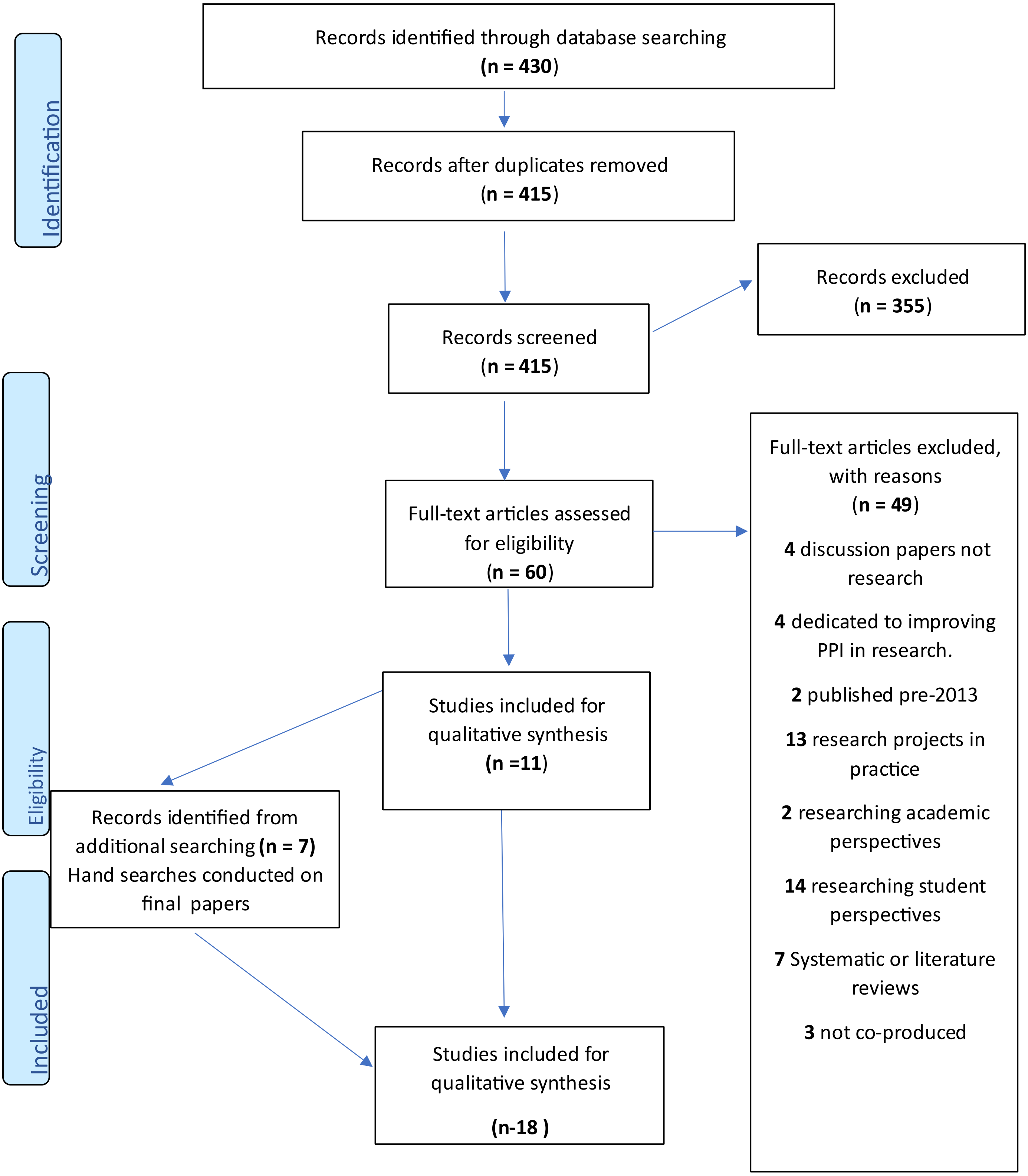
After an advisory meeting with the subject librarian, the literature was drawn from two databases known for including key peer-reviewed journals in the field of health and social care. The databases are: Cumulated Index of Nursing and Allied Health Literature, (CINAHL), which is a database of articles with a specific nursing and allied health content, and Scopus an extensive database containing over 18,500 journals from a range of subjects including health and social care. SU&C involvement is embedded within health and social care training in higher education and such databases serve this subject well. They are current and reliable databases for this field of research.

To ensure an accurate selection was made in the database searches, the Boolean operators "AND" and "OR" were used. The search terms used were "Service User and Carer" OR "expert by experience" AND "Involvement" OR "co-production" OR "perspectives" AND "health and social care education" AND "higher education" – "published from April 2013". A second literature search with the same terms was conducted to check for any recent literature published from January 2022 to March 31, 2023, to ensure the review was current.

Step 3: Study selection

A PRISMA diagram was used to record the literature search process and the number of papers included in the review (see Table 2). The PRISMA diagram (PRISMA, 2023) is a flowchart that illustrates the process of searching for papers by listing the number of papers found and accepted for review after applying the inclusion and exclusion criteria. The diagram provides a detailed account of why a paper was rejected for review. The abstracts of each paper from the search results were reviewed, which resulted in the rejection of several papers. The final selection was made after reading and further editing the papers. A hand search was then conducted on the final papers.

Table 2: PRISMA diagram



Step 4: Charting the data

A table was created to chart the main aspects of each paper under the headings: date, country, author, title, research aims, level of involvement, methods, sample, and findings. These headings provided an overview of each paper and began the first stages of analysis. The purpose of charting is to provide easy access to key information in each paper reviewed (see Table 3).

Table 3. Scoping review summary of selected papers

	Author, title, country, year	Aims	Level of involvement	Method	Sample	Findings
1	**Bocking et al., 2019. Ireland, UK, Australia, Finland, Netherlands, Norway, Iceland** *'It is meant to be heart rather than head'; International perspectives of teaching from lived experience in mental health nursing programs*	The aim of the study is to investigate the collective views of the Experts by Experience who taught the COMMUNE module and their perceived contribution to nursing student learning. MH	Consultative/ Participatory. Partnership	Interviews with SU&C participants carried out by SU&C researcher and academic. SU&C researcher and academic team in each country, assisted with data collection, analysis, and general tasks.	SU&C members who taught on the module. n+ 14	Study supports previous research indicating that incorporating first-hand lived experience teaching into nursing curricula broadens the scope of student learning. EBE's felt they offered a different source and type of knowledge and thus were a catalyst for deep learning experiences for students. 2 themes – 1 there wasn't a barrier. 2, made the human being visible.
2	**Fox, J. 2022. UK.** *Perspectives of experts-by experience: an exploration of lived experience involvement in social work education*	SU&C experts participated in a workshop to explore their lived experience of involvement in social work education	Participatory	A workshop/focus group capturing participant views, following a topic sheet. Thematic analysis co- created in the same workshop	6 SU&C members	The group explored their role as that of going beyond solely SU&C and recognised the expertise they experienced as a group, and the sense of mutuality and support each shared with the other; and how JD, the SU&C administrator, provided effective and caring support. This sense of unique cohesion and support is key to their effective involvement and strengthens their impact on students.
3	**Happell, et al., 2015a Australia,** *Exploring the Scope of Consumer Participation in Mental Health Nursing Education: Perspectives from Nurses and Consumers*	Exploration of the views and experiences of nurse academics and consumer academics (SU&C) and educators regarding the scope of consumer participation in mental health nursing education	Consultative/ Participatory for interviewees, Partnership for service user researcher.	Telephone interviews SU&Cs interviewed by SU&C researcher. "Experienced researcher who identifies as and has worked extensively from a consumer perspective". Nurse academics interviewed by an academic.	34 nurse academics across 27 universities. 12 SU&C consumers participated.	The responses of both nurse and consumer participants suggest that consumers generally played an important but quite minor role, usually limited to delivery of course content and most commonly involving the telling of their story. The responses of consumer participants suggest their involvement is frequently of short duration and nominal.
4	**Happell et al., 2015b. Australia**. *Lived experience in teaching mental health. nursing: Issues of fear and power*	Qualitative research carried out to elicit views on involvement and inclusion of SU&Cs. Research conducted with SU&Cs an academics. MH	Consultative/ Participatory for interviewees, partnership for service user researcher.	Qualitative study, conducting semi structured interviews recorded 1:1	12 participants who were lived experience practitioners and 27 participants who were academics.	A main theme was revealed – Fear and Power with 3 subthemes. Facing fear, demystifying mental illness and issues of power. Lack of autonomy and power for SU&Cs in their involvement. Poor partnership working in HE

	Author, title, Country Year	Aims	Level of involvement	Method	Sample	Findings
5	**Happell & Bennetts, 2016 Australia.** *Triumph and adversity: Exploring the complexities of consumer storytelling in mental health nursing education*	The aim was to present the views of consumer educators and academics regarding the use of story in the education of **MH nursing students.**	Consultative/ Participatory for interviewees, partnership for service user researcher.	Qualitative study, conducting semi structured interviews recorded 1:1	34 nurse participants and 12 academic or consumer educators	Story telling heavily utilised in teaching. All participants felt strongly about the uses of storytelling. The sub themes relating to the use of story that emerged from the interviews with consumer educators were the power of story; story as expectation; vulnerability, preparation, and support; and the politics of story. Involvement is increasing and storytelling can be seen as either powerful or verging on tokenistic
6	**Happell et al., 2021. Ireland, Iceland, Australia, The Netherlands, Norway, Finland.** *Something special, something unique: Perspectives of experts by experience in mental health nursing education on their contribution*	To enhance understanding of the unique knowledge and expertise experts by experience contribute to **mental health nursing education.**	Consultative/ Participatory for the interviewees and collaborative for EBE researcher **Co-production intended from the outset.**	Semi structured 1:1 interviews and thematic analysis.	14 EBEs interviewed in a range of countries.	The findings suggest the unique knowledge and expertise EBEs bring to mental health education can positively impact student learning. EBEs bring an in-depth understanding of the influence of nursing practices in areas where evidence is lacking. EBE participants described how they used their expertise to facilitate a learning environment that challenged students to critique their clinical understanding of mental health and mental health service delivery.
7	**Horgan et al., 2018. Ireland, Iceland, Australia, The Netherlands, Norway, Finland** *To be treated as a human': Using co-production to explore experts by experience involvement in mental health nursing education – 'The COMMUNE project'*	The aim of this study was to develop an understanding of the potential contribution to mental health nursing education by those with experience of mental health service use.	Consultative/ Partnership for the researcher EBE and participatory for the focus group attendees.	Co-produced research EBE researcher in each country. Focus grp for participants. Participants in each country attending.	50 service users in total participated in the focus groups. 22 female 28 male participants attending focus groups.	Two themes are presented in this paper. The first focuses on how experts by experience can enhance students' understanding of recovery by seeing the strengths inherent in the 'human' behind the diagnostic label. The second highlights the importance of communication and self-reflection on personal values, where students can explore their own thoughts and feelings about mental distress alongside those with lived experience. Interacting with experts by experience in the classroom can assist in challenging stigmatizing attitudes prior to nursing placements.
8	**Horgan et al., 2020a Ireland, Australia, Netherlands, Finland, Iceland, Norway.** Expert by experience involvement in mental health nursing education: The co-production of standards between Experts by Experience and academics in mental health nursing	The aim of this study was to co-produce standards to facilitate the genuine and meaningful involvement of EBEs in **mental health nursing education.**	Partnership/ Collaborative Yet still participatory focus groups. The research mentions participants in focus groups.	Co-produced. 2 phases- 2 focus groups. explore perceptions. 2nd focus group co-produce standards.	SU&C sample size (n = 50)	Three themes emerged in Phase one: enablers and barriers, practical and informational support, and emotional and appraisal support. These themes underpinned development of the standards, which reflect nine processes: induction and orientation, external supervision, supportive teamwork, preparation for teaching and assessing, "InterVision," mutual mentorship, pre- and post-debriefing, role clarity and equitable payment.

	Author, title, country, year	Aims	Level of involvement	Methods	Sample	Findings
9	**Horgan et al., 2020b Ireland, Iceland, Australia, The Netherlands, Norway, Finland** *Improving Service User Involvement in Mental Health Nursing Education: Suggestions from Those with Lived Experience*	The purpose of this paper is to report on service users’ views regarding potential improvements to their involvement in **mental health nursing education.**	Consultative/ Partnership/collaborative for the researcher EBE and participatory for the focus group attendees.	Co-produced research EBE researcher in each country. Focus grp for participants. Participants in each country attending.	50 service users in total participated in the focus groups. 22 female 28 male participants attending focus groups.	The findings from this research provide a better understanding of service users’ views about mental health nursing education, both in terms of improving the content, and in enhancing the involvement of service users teaching nursing students from their perspective. Two main areas were identified where service users believed more content was required; stronger focus on personal development, communication, and interpersonal skills; and understanding the socio-political context of distress.
10	**Horgan et al., 2021 Ireland, Iceland, Australia, The Netherlands, Norway, Finland** *‘Meet Me Where I Am’: Mental health service users’ perspectives on the desirable qualities of a mental health nurse*.	Research project was undertaken to inform and enhance understanding of what service users see as the desired qualities of a **mental health nurse.**	Consultative/Partnership for the researcher EBE and participatory for the focus group.	Co-produced research EBE researcher in each country. Focus grp for participants. Participants in each country attending.	50 total participated in the focus groups. 22 female 28 male participants attending focus groups.	“Being with me” was a key theme identified from this research and reflects participants’ views of the desirable qualities of a mental health nurse and included the following sub-themes: • Respect towards service users as persons • Empathy, compassion, and effective communication • Understanding service users • Knowledge of services • Foster hope and believing that recovery is possible.
11	**Lea et al., 2016. UK.** *Aims for service user involvement in training – ’Staying human’*	The aims of this study were to elicit service users,’ **clinical psychology trainees’** and staff perception of the objectives and potential outcomes of service user involvement in clinical psychology training, to inform future questionnaire development.	Consultative/Partnership for the researcher EBE and participatory for the focus group attendees.	Three separate focus groups were held to elicit the potentially different views of service users and carers, clinical psychology trainees and staff. Thematic analysis (Braun and Clarke, 2006) was used to analyse the transcripts.	International focus groups of SU&Cs 22 female 28 male participants attending focus groups. 8 SU&Cs.	The theme of “Being and staying human” appeared central in the accounts of all three groups. In terms of questionnaire development this may become a key domain of a potential questionnaire aimed at capturing self-reported impact of service user involvement in mental health training.
12	**Newman et al., 2021. UK.** *‘My Contributions Made a Significant Difference’: Young Carers’ Reflections on Their Participation in Social Work Admissions*	The aim of the study was to ascertain from YP involved in the university what the experience was like if their involvement in SW was meaningful.	***Using a coproduction approach drawing on PAR.***	1:1 interview, recorded and transcribed. Analysed using a thematic analysis.	6 SU&C young carers	The findings show that the participation of YP in SWA requires both similar and different approaches to those commonly involving adult SUCs. Close, honest, and meaningful collaboration with a partner organisation that knows and advocates for the YP is crucial to facilitate supportive, authentic partnerships (Brady and Preston, 2017) with individual YP. This enables participation that is relevant and meaningful.

	Author, title, country, year	Aims	Level of involvement	Methods	Sample	F3indings
13	**Opeyemi et al., 2021 UK.** *Optimising service users and carers involvement in nursing and social work pre-registration degrees*	The study sought to examine factors that could optimise the beneficial outcomes of involvement to all three stakeholders within a higher education setting. Specifically, it will focus on describing these factors from the perspectives of the three main stakeholders in Adult Nursing and Social Work pre-registration degrees. These are: students, academic staff, and service users/carers.	Consultative/Participatory for the interviewees. Partnership for the SU&C members of the advisory group involved in thematic analysis.	Semi-structured interviews were used to gather views, which was then thematically analysed.	A total of 38 participants took part in this study: there were 8 service users, 15 students (11 adult nursing, 4 social work) and 15 academic staff (10 adult nursing. 5 social work)	The findings of this study strongly support the value of service users and carers' involvement in social work and nursing preregistration degrees. It has provided new insight by illuminating the tripartite perspectives of the three main stakeholders involved in this dynamic learning process. Furthermore, the findings help to bridge current gaps in knowledge about service users and carers' involvement in adult nursing education, of which there have been fewer published studies, compared to other health and social care professions such as mental health nursing.
14	**Read et al., 2019. UK.** *Facilitating personal development for public involvement in health-care education and research: A co-produced pilot study in one UK higher education institute*	A pilot study introduced across a health faculty to deliberately integrate PPI. Aimed to provide an educational, focused meaningful programme to develop peoples' (SU&Cs) knowledge, skills, and confidence for their involvement in the health faculty.	Participatory/partnership	SU&C volunteers present on a steering group. 3 focus groups with PPI members and academics informed the program content. *An action research approach – the authors used Participatory Action Research Frameworks of which they state co production is a PAR process.	SU&C and Academics samples size n=32	The programme was developed in collaboration with SU&Cs who are involved with that HEI health and social care training. SU&Cs involved in the development and attending the sessions found it a very useful exercise. The academic staff found it useful but labour intensive as the duties required occurred in addition to their usual roles. Universities should invest time, effort, and resources in supporting public contributors to get the ultimate engagement from a range of volunteers and to affirm their importance to educational programmes and when conducting research.
15	**Rooney et al., 2016 UK.** *Gaining by giving? Peer research into service user and carer perceptions of inclusivity in Higher Education*	This paper reports the results of research led by the University of Worcester's SW SUAC group, 'IMPACT', into perceptions regarding the SUAC role both within the University and regarding the wider community	Consultative/Participatory for interviewees and collaborative for EBE researchers	Semi structured interviews and thematic analysis	15 SUAC members	SUAC respondents reported being given a sense of purpose, access to training/learning, personal development/increased emotional well-being, practical and material benefits, social networking, and peer support.

	Author, title, year, country	Aims	Level of involvement	Methods	Sample	Findings
16	**Rooney et al., 2021. UK** *Service user and carers' views of best practice in student selection at an English University*	This study redresses an absence in the literature, by demonstrating, for the first time, SUACs' voices in selection of students across health and social care disciplines (social work, nursing, nursing associates, occupational therapy, physiotherapy, paramedicine, and physician associates) at a single university.	Consultative/Participatory for interviewees and collaborative for SUAC researcher.	Individual semi structured interviews. Thematic analysis.	10 SUC members	Four main themes emerged: expected contributions of SUACs; perceived benefits, challenges, and suggestions for areas of improvement. Sub-themes included: perceived benefits and challenges for students, staff, and SUACs, respectively. This research is believed to be the first time SUAC-voices will be heard in such a range of student recruitment disciplines.
17	**Unwin et al., 2017. UK.** *Are perceptions of disability changed by involving service users and carers in qualifying health and social work training?*	To determine whether perceptions of disability change in H&SC students after working with SU&Cs in a university lecture. Also, to document the impact of such engagement with SU&Cs. 2 related studies	Partnership/collaborative	Student focus groups. Semi structured 1:1 interview for SU&C participants. 2 small scale qualitative studies.	22 students from a mixture of BA, MA health & Social care courses. 11 SU&Cs volunteered to participate.	Students largely view SUAC involvement as a meaningful activity with some elements of it being transformative. SU&Cs members experienced significant transformations themselves because of participation. This research makes a case that SUAC inclusion can indeed make a tangible contribution towards the promotion of positive models of disability, both in SUAC participants and in the student body.
18	**Watson et al., 2022. UK.** *Key stakeholder perspectives on expert-by experience involvement in the values-based recruitment of student mental health nurses: A coproduced qualitative study*	To understand the impact of expert-by-experience involvement in the values-based recruitment of mental health nursing students from the perspective of candidates, experts-by-experience, and academic staff.	Consultative/Participatory for interview participants and partnership for the EBE researchers. The paper uses the term co-designed.	Focus groups and an on-line survey were used to collect data, with Burnard's thematic analysis providing a framework for data analysis.	Seven academics (Response rate 64 %), 10 EBE (Response rate 71 %) and 45 students (response rate 32 %) took part.	Thematic analysis identified four themes: starting out, collaboration, rich assessment, and stakeholder gains. Whilst not without its challenges, the involvement of experts-by experience in the recruitment of mental health nursing students was identified as delivering a robust recruitment process, encompassing academic abilities alongside the personal qualities required to make a 'good nurse'. Personal benefits for experts-by experience, candidates, and academics were also reported.

An important aspect of this review is the level of involvement in which people participated in each study and if it is meaningful for the person and for the organisation. A framework was required to record the involvement according to level. Arnstein, (1969) developed the ladder of citizen participation which demonstrates the involvement of citizens from a community engagement perspective such as urban renewal or anti-poverty (Arnstein, 1969). Rhodes, (2014), has created the '*Approaches to involvement continuum'* which is specifically designed to measure SU&C involvement within a university setting and therefore conclusively appropriate for this study. The level of involvement was charted using the '*Approaches to involvement continuum'* (Rhodes 2014). Rhodes states that all levels of involvement are acceptable as it is dictated by the work required. Involvement, however, must be meaningful. Rhodes developed the continuum rating levels of involvement from tokenistic to emancipatory. The continuum would suggest the label Partnership/collaborative is the correct definition to align with co-production strategies in the context of SU&C involvement in health and social care education, leaving the other labels as self-explanatory (see Table 4).

Table 4: Approaches to involvement continuum (Rhodes, 2014)

Tokenistic	**Consultative**	**Participatory**	**Partnership/collaborative**	**Emancipatory**
Superficial involvement, ad hoc, used, not included.	Deliberation, discussion. exchange of views, 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.

Step 5: Collating, summarising, and reporting the results

The final eighteen papers were carefully scrutinised and analysed. The key aspects of each paper were read multiple times to identify relevant codes. Through sustained scrutiny, the codes were organised into clusters, resulting in the development of fourteen sub-themes that stemmed from four main themes: SU&C in education, improving SU&C involvement, level of involvement, and the real person perspective. Please refer to Table 5 for the themes and a frequency chart of each theme and sub-theme.

Table 5. Themes and frequency chart

		Papers numbered as in table 3																	
Main theme	**Sub theme**	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18
SU&C in education	SU&C impact on teaching			*	*	*				*	*	*		*					
	SU&C impact on students	*		*		*	*	*		*	*	*		*		*		*	*
	SU&C impact on SU&C		*			*	*		*	*			*		*	*	*	*	
Improving SU&C involvement	Creating		*						*	*					*				
	Consultations				*		*			*			*	*	*	*	*	*	
	Organisational factors								*	*			*		*			*	
	Meaningful								*				*		*	*	*		
Level of involvement	SU&C researcher phenomena	*		*	*	*	*	*	*	*	*	*		*		*	*	*	*
	Is it co-production?						*		*	*			*		*				
	2 Tier	*		*	*	*	*	*	*	*	*	*		*		*	*		*
The real person perspective	Enrichment/user knowledge	*					*		*					*			*	*	*
	Power and autonomy			*	*	*			*										
	Empowerment		*						*		*	*	*		*	*		*	*
	Real people	*				*					*	*	*			*		*	

Step 6: Consultation

Regrettably I have been unable to share this review with the RDT which would have been ideal given the nature of this study. Unfortunately, time constraints (due to the pandemic and the need to complete my MRes programme of study) have made it difficult to reconnect with the RDT to fulfil this optional stage of the literature review.

2.4 Results

Each of the 18 papers were scrutinised to identify cohesive aspects. Four main themes were identified with fourteen sub themes; each main theme is discussed in detail below. Studies are referenced by number, as in Table 5.

Theme 1: SU&C in education

This theme highlights the intended impact of each study, which is designed to influence either the teaching, the students, or SU&Cs. An example of this is found in study number 7 (Horgan et al., 2018). This paper explored the views of SU&Cs regarding their contribution to mental health nursing teaching. The results of this paper focus on the impact of SU&C involvement on students and how they benefit from it. Therefore, this paper has an impact on student experiences. Newman et al. (2021) (12) conducted a study that sought the opinions of young carers regarding their involvement in student recruitment. The research provided recommendations to support this user group, thus impacting SU&Cs. The impact of the research is an indicative factor regarding its intended audience. Much of the published research is intended to have an impact on students, benefiting their learning experiences. This involves consulting students on their views regarding involvement in their curriculum (18) and recognizing the influence that individuals with lived experiences can have on students (1, 3, 5, 6, 7, 9, 10, 11, 13, 17). Such involvement is considered a powerful resource (5) that can bring about transformation (7, 17). Academics have also commented on SU&C involvement in terms of its impact on teaching and their perceptions of its effectiveness (9, 7, 11, 13, 18). SU&C involvement is reported as a labour-intensive endeavour that many academics undertake in addition to their regular job requirements (14). Research is being conducted to document the impact of SU&Cs' opinions on delivering modules (1, 17). Much of this research focuses on SU&Cs' perspectives on teaching and learning among students (3, 4, 9, 10, 11, 13, 15, 17). Some studies also examine the impact on multiple populations, discussing SU&C perspectives and investigating the viewpoints of students, academics, and SU&Cs (4, 5, 11, 13, 17, 18). Additionally, certain studies explore SU&C perspectives on involvement in response to the scarcity of existing research on this topic (13, 16).

Theme 2: Improving SU&C involvement

This theme identified research that investigates the systems, processes, and infrastructure in place at a Higher Education Institution (HEI) to enable successful involvement to proceed. A small amount of research focused on the organisational and individual requirements for involvement to be successful and meaningful. This is evidenced through research that initiated training opportunities by asking SU&Cs to provide input into their training needs for successful involvement (8, 15, 14). These projects were co-created and co-delivered by academics and SU&Cs. This area of research is in its infancy, producing evidence of collaborative work. SU&Cs consult and collaborate regarding the effectiveness of the systems and procedures in place at an organisation (8, 9, 12, 13, 14, 15). This is evidenced through consultation on the SU&C perspective on recruitment processes (12, 16, 18) and in the development and delivery of standards for successful involvement (8). The role of the SU&C in education is researched with a view to improving the systems and processes in an HEI, which primarily benefits SU&Cs and, in doing so, firms up internal policies and structures (8, 12, 14, 18) to facilitate quality and meaningful engagement that will impact all stakeholders. This theme indicates a shift in the literature that encompasses the views of SU&Cs to create clear pathways and mechanisms of involvement in an organisation. There is also a paucity of research that captures the personal perspectives of SU&Cs and the impact that involvement work has on an individual (2, 4, 15, 17).

Theme 3: Level of involvement

This review intended to locate evidence of co-produced research in collaboration with SU&Cs and other stakeholders. This theme identified the level of co-produced research evident from the literature within the parameters of the review question. Much of the literature discusses adopting co-production mechanisms which largely involves a SU&C researcher as part of the research team (1,3,4,5,6,7,8,9,10,11,13,15,16,17,18). This strategy seems to be standard for co-produced projects. There is little else discussed on the role of the SU&C researcher and as such I consider this sub-theme a phenomenon which requires more information. Several studies report using co-production strategies, yet these declarations are questionable when referring to the literature (2,6,8,9,12,14). This presents the issue of the definition of co-production which varies from either co-creation (2) to consultation/participatory. Without seeing or reading the interview topic, the precise level of involvement is unknown (1,3,4,5,6,7,8,9,10,11,13,15,16,18), or Participatory Action Research (12, 14) and one paper which is verging on emancipatory and led by a SU&C researcher (15). It is clear from this evidence that definitions of such practices are 'blurry'. However, this may also be because of the two-tier process which has become apparent in many of the studies (1,3,4,5,6,7,8,9,10,11,13,15,16,18) and has manifested into projects possessing multiple involvement levels depending on the SU&Cs tasks. The advent of a SU&C researcher on a research team or steering group includes the co-production element, yet SU&Cs are also involved in the same studies on a consultative or participatory level which functioned as the data group, thus a two-tier involvement system is in place.

Theme 4: The real person perspective

This theme draws attention to many of the outcomes from the research which indicates the growing sense of appreciation for involvement as a teaching and learning tool. In doing so, this accentuates how involving lived experiences in teaching delivers the real person perspective to students and facilitators (1,4,5,7,9, 10,11,15, 17). This simplistic aspect is thought of as powerful and emotive (5,17) drawing on many important components of health and social care practice. Much of this research reports from the student perspective and the impact of involvement demonstrating how involving lived experiences in teaching allows for the real person perspectives to be heard, enriching the curriculum and considers it an essential part of the teaching (1,3,5,6.7,13,17,18). SU&C involvement creates a further dimension of learning in the form of user led knowledge (1,13,15) which signifies the presence of person-centred care (PCC) and how it is demonstrated through involvement of lived experiences thus acting as a model/demonstrator of (PCC). There is acknowledgement of limitations of power or autonomy within the involvement field (3,4). Many aspects of involvement are driven by academics in pockets or silos, where strategic leadership is sparse (4,5,14,).

The research spans various countries from the UK, Europe, and Australia, providing a global perspective on approaches to SU&C involvement in health and social care. 50% of the selected papers were based in the UK where SU&C involvement in health and social care training is mandatory (NMC, 2018; HCPC, 2017; SCIE, 2004). SU&C involvement is particularly elusive in Europe and North America and rendered more experimental (Stanley & Webber, 2022). Australia is embracing the concept of SU&C involvement, although it is not yet mandated in Australian policy (Happell 2023). It is encouraging to see a series of research papers written in collaboration with authors from other countries showcasing their passion for SU&C perspectives and their participation in research. Five of the eighteen studies are related to the COMMUNE project, spanning several countries in Europe and Australia. Comparing the literature is challenging due to the differences in collaboration practices. However, these papers demonstrate various models of collaboration that contribute to the development of literature in this field.

All the selected research includes quotes which convey the perspectives of SU&C in reference to the research project they are involved in. Several papers reported that SU&Cs have a sense of empowerment derived from their input, fostering a sense of purpose and usefulness in contributing their expertise to help train new professionals (2, 8, 10, 11, 12, 14, 15, 17, 18).

2.5 Discussion and conclusion

This scoping review demonstrates the positive reputation of involvement in health and social care education. Current research portrays a picture of SU&Cs working in collaboration at varying levels of partnership, consultative for the minority, and participatory for most of the involvement workforce.

There is a large amount of research which reports on the effectiveness of involvement as a concept (1,2,3,4,5,6,7,9,11,12,13,16,18,). However, there is evidence of developing research which investigates and develops teaching modules in partnership with SU&Cs in areas of: curriculum development, training, and standards (,8,14,15,17). Along with this impetus, there is a growth in research which encompasses an SU&C researcher (1,3,4,5,6,7,8,9,10,11,13,15,16,17,18). These developments have also enabled the SU&C voice to be recognised within the research field, enabling SU&Cs to be quoted in research and considered participants or partners in projects concerning involvement. This signifies a shift in the literature which historically has reported on fears of tokenism (McCutcheon &

Gormley, 2014; Ocloo & Matthews, 2016) and whether SU&C is a valid mechanism (Clarke & Holttum, 2013; Rooney et al,. 2019); to current day developments in training of SU&Cs and identifying the need for infrastructure to support involvement work. Research is beginning to report on this area with a wider lens by looking into SU&C infrastructure and embedding. Much of the work is still added on to academic responsibilities, rendering it a capacity issue (14). This affects the power and autonomy of the research and involvement in general (3,4,14).

Unfortunately, there is little evidence of co-production or partnership/collaborative working in the literature, except for the role of the SU&C researcher. This role is somewhat concealed when it comes to what qualifies as a SU&C researcher and how this role manifests within the research team dynamic. The SU&C researcher role was present in fifteen of the eighteen studies within the review, yet there was little, if anything, discussed about its function. For many of the studies, the inclusion of the SU&C researcher appeared to constitute tokenistic participation or, at best fell within the participatory category according to the continuum by (Rhodes 2014).

There are various descriptions for co-production used in the literature which convey the contentious arguments around its definitions and subsequently adds fuel to the fire of its many critics. Several papers use the term co-production, when in accordance with the involvement continuum in table 4, it is more suited to participatory or consultative models of involvement. However, this makes a case for the need for a standardised framework for co-production within this context and a universally recognised definition to be adhered to on an international level. The lack of clarity regarding whether co-production is occurring or not will persist until the lines are universally defined and recognised within this research field.

A limitation of this review was not including the views of the Research Design Team (RDT) in Step 6 of the 6-point framework. This would have been an important component of the review. Time constraints made it impossible to do this. Involving the RDT in step 6 of this framework would have strengthened the participatory nature of this study, enabling the RDT to gain a broader perspective of this research field. There are various possibilities regarding the outcomes of achieving this point, but if I were to predict, it is possible that a different approach might have been chosen for methodological decisions. Ideas selected from studies could have influenced the decisions made. However, these studies primarily used focus groups, questionnaires or individual interviews as their methods which does not deviate significantly from the RDT's decisions. However, learning from other projects similar to this research might have had an additional influence. As noted in the literature review, there are variations on definitions of co-production, which may have also influenced the working model of co-production used by the RDT and whether it aligns with the goals of working in a co-produced framework.

This scoping review highlights the impact of involvement on health and social care education and provides evidence of the emerging collaborative practices in this field. It emphasises the co-produced nature of the research and reveals the different levels of involvement incorporated in the studies. The literature predominantly focuses on the role of involvement in teaching and learning, exposing gaps in the understanding of SU&C experiences in this context. There is a limited body of evidence that examines involvement across disciplines, as most research is confined to a single discipline within health and social care. An under researched area is that of the perspectives of SU&Cs involved in interdisciplinary collaborations, which would contribute to the evidence base of involvement as a strategy within higher education institutions (HEIs) beyond specific fields. Furthermore, there is a lack of research that involves SU&Cs as equal contributors from the outset, working collaboratively to co-produce the research. Collaborating with SU&Cs in HEIs aligns with the principles of shared decision making, collaboration, and partnership, reflecting the philosophy of "nothing about us without us." The research study outlined in this MRes aimed to address these gaps in the literature.

In the next chapter I will discuss the philosophical positioning of the research and how the research was developed from initial discussions to ethical approval. I will explain how the Research Design Team was formed and how we designed the research, recruited participants, and provide the rationale for the methodology chosen.

Chapter 3: Methodology and methods

3.1 Introduction

In this chapter, I will present the philosophical underpinnings of this research, which determined the methodology for this study. I will provide information on the Research Design Team (RDT) with reference to its formation and explain the rationale behind the choice of methods used. I will discuss the co-production process of designing the research, the development of the interview questions, and elaborate on applying for ethical approval by stating the ethical challenges and considerations. I will conclude the chapter by explaining how we worked within a co-produced framework while navigating the research tasks amidst the Covid 19 pandemic within the constraints of studying for a qualification.

3.2 Philosophical underpinnings

In choosing a methodology for a research project, it is essential to establish the philosophical underpinnings regarding its ontological and epistemological positions (Grix, 2002). The ontological position of research concerns the nature of reality and what we need to know about it (Grix, 2002; Dunne et al., 2005; Gomm, 2008; Nasution, 2018; Sentesy, 2020). From the literature review conducted in the last chapter, the ontological position of this research study resides within the understanding of SU&C perspectives in relation to their contribution to health & social care education at a university. This research is firmly rooted in the qualitative paradigm; however, there is some debate concerning an overall definition of qualitative research and its reliable status in the research family (Ragin, 2004; Aspers & Corte, 2019; Hammersley, 2013). A standard benchmark of qualitative research is depicted through the aims of the research, which focus on feelings, descriptions, or opinions (Noble & Smith, 2015). The qualitative researcher is interested in analysing an individual's perspective (Creswell, 2018). Aspers & Corte (2019) describe this process as 'getting closer to the phenomenon studied' (p.155), which employs methods such as recording, observing, and speaking to the subjects of the research (Nickerson, 2023a).

Justifying the methodology

This study operated on two levels, co-production was at the core of the research project. Four members and I formed a Research Design Team (RDT) to discuss and agree on the methodology required for data collection in this research. Ten individuals participated in the data collection and contributed their perspectives, each with heterogenous views of their role and sense of value as participating PPG members. Each member elicited differing viewpoints, characteristic of qualitative research (Noble & Smith 2015), which collectively manifested into multiple versions of reality (Fox, 2001; Erlinsson & Brysiewicz, 2013). The interpretivist paradigm adopts a methodological understanding that an individual's perspective of truth and knowledge is subjective, and multiple realities exist, (Nickerson, 2023a), which are then analysed to reach a conclusion of what is known (Ryan, 2018). An interpretivist researcher believes that meaning can only be found in the world through studying human experience and ascertaining the meanings people express behind their experiences (Pulla & Carter, 2018).

Max Weber, 1864-1920, a German sociologist, developed the theory of interpretive sociology (Crossman, 2021). Weber believed that the meanings behind anthropological phenomena must be observed and studied to enable an understanding of a person's thoughts, actions, hopes and expressions (Crossman, 2021). Weber created the term *verstehen* which can be translated to 'understanding' (Elwell, 2005), demonstrating his viewpoint that to understand a sociological phenomenon, a researcher must understand it from within (Nickerson, 2023b). This presents the analogy of a researcher 'walking in their shoes' and encourages the researcher to assimilate with the study rather than remain observant and distanced on the sidelines (Gann, 2017; Tucker, 1965). In summary, the application of *verstehen* requires the researcher to adopt an empathetic and appreciative attitude toward the research participant (Hanemaayer, 2021). However, this theory and approach can be considered problematic regarding reliability, bias, and authenticity. Weber's theory has attracted critics who highlight the obvious complexities and concerns regarding a researcher's ability to truly 'walk in their shoes' as a research strategy. Sceptics of Weber's approach question the feasibility of *verstehen*, particularly emphasising the potential for researcher bias when the researcher possesses significantly different life experiences, such as differences in religion or culture, compared to the research area (Rane, 2022).

An interpretivist researcher must consider their position and engagement with the research when using an interpretivist paradigm to exercise reflexivity (Polit & Beck 2013). This research is dedicated to the perspectives of SU&Cs and is fundamentally qualitative. Its primary focus is to comprehend the perspectives of participants and their shared experiences, which will reveal multiple realities. Through in-depth discussions, it aims to illustrate how participants perceive and interpret their experiences as members of the PPG. This will allow the researchers to discover the meaning behind value and contributing as a PPG member. This paradigm is well suited to this research along with Weber's principles of social interpretivism and its correlation with the principles of co-production (Hickey, 2018).

Adopting an empathetic approach is tantamount to co-production (Southall et al., 2021). An interpretivist methodology underpins the ontological positioning of this research and resonates particularly from the perspective of my research study, highlighting the relationship the RDT and I have with this research. This methodology is particularly pertinent to co-production and shared decision making. An empathetic approach can be adopted invoking solidarity with the research participants and the field (Hanemaayer, 2021). The ramifications of reflexivity are discussed in the ethical considerations section in this chapter on page 52.

The interpretivist paradigm works closely with qualitative methodologies, yet it is possible to undertake a mixed methods approach (McChesney & Aldridge, 2019). However, the nature of this research and its rich data is inherently reliant on a qualitative paradigm, which is sensitive to the perspectives and attitudes of the research participants. A mixed methods approach would not be appropriate for this research as it is only concerned with qualitative data.

Interpretivism or anti-positivism as it is also known (Nickerson, 2023a), is a direct opponent of the positivist paradigm. Auguste Comte, a philosopher in the 1870s, believed that rigorous scientific methods should be employed in research to understand how society and humans behave (Corry et al., 2018). A positivist approach focuses on determining facts as truth rather than assumptions (Hasan, 2014). In doing this and using methods such as questionnaires, statistics, and replicable experimentation, the research is robust, measurable, and reliable (Irshaidat, 2019). Positivism is a quantitative methodology which takes an objectivist view (Park et al., 2020). There is one reality based upon robust research using measurable methods (Ryan, 2018). Due to the myriad of individual perspectives in the data sample presenting multiple realities, positivism is not appropriate for this research.

Epistemological position of this research

The epistemology of research is concerned with how knowledge is acquired (Gray, 2014; Oppong, 2014). An aspect of this study focused on partnership working with Service Users and Carers (SU&Cs) who are members of the Public Partnership Group (PPG) at the University of Huddersfield's School of Human and Health Sciences. This research study invited members of this group to be involved in the form of a co-produced group called the Research Design Team (RDT). By inviting members to be part of the shared decision making, key stakeholders were able to draw on their own experiences as PPG members. This provided authenticity to the research and as a result, the development of collaborative research. Co-production is an approach that enables the democratisation of research and knowledge (Lindhult & Axelsson, 2020) by applying a 'bottom up' approach to shared decision making (Bell & Pahl, 2018). Co-production is seen as being on the fringes of traditional research (Metz et al., 2019). Its categorisation continues to meander around the term's method, mode, approach, framework, and methodology (Metz et al., 201; Perry, 2022). However, Boaz (2021), Bell & Pahl, (2022) and Lindhult & Axelsson, (2020) are keen to describe co-production as epistemology. In a recent article, Boaz (2021) states, 'For coproduction in particular, the approach is not merely a set of activities, but a fundamental and epistemologically different way of working from conventional knowledge production' (p.1), strengthening the case for co-production to be seen as an epistemology.

This research study was designed, and knowledge analysed using co-production principles. The initial idea for this study was to design, with the participation of PPG members, a study focusing on the work/impact/role of PPG members. The research design and its execution were intended to be a fully collaborative effort with a group of willing PPG members. Co-production was developed in the 1970s by a team led by Elinor Ostrom, a political economist (Levine, 2011). Ostrom developed this concept from the ethos that people who use services can help improve those services (Parks et al., 1981). Working within a co-production framework provides the opportunity to work in a democratic model where decisions are achieved through discussion and debate, developing ideas democratically. (Reed et al., 2020). Co-production is rooted in the Participatory Research (PR) inquiry paradigm (Heron & Reason, 1997).

> PR engages those who are not necessarily trained in research but belong to or represent the interests of the people who are the focus of the research. (Vaughn & Jacquez, 2020, p.1).

This quote illustrates the suitability of applying participatory research methodology to this study. A small group contributed to the design of the research study through a co-produced framework. This group represented the interests of the individuals who are the focus of the research, in this case, the PPG members. They were responsible for designing and evaluating the research for their colleagues in the data collection group.

3.3 Methods for the research

Research Design Team

Recruitment for this study followed a transparent and iterative process. The initial step was an informal discussion with self-selecting members of the PPG to begin the conversation about this project. An email was sent out to all members explaining my intentions to undertake a research project with the PPG for my MRes course of study. One person had expressed interest in this research but was unable to attend the informal meeting. I communicated a date and time, and seven members voluntarily attended to join the conversation. Once ethical approval had been granted to initiate the research and establish the design team, I invited the same people to join the Research Design Team (RDT), including the person who could not initially attend. (See Appendix A).

I considered it vital that members who attended the informal discussion should be invited to maintain the momentum from our initial conversation and ensure that the research developed remained faithful to our preliminary discussions. Three people from the meeting requested to join the RDT, along with the person who could not attend the first meeting, totalling four members of the PPG, along with myself. When considering how to set up the RDT, it was essential to decide beforehand how many people to invite onto the RDT. There is no recommended number of participants for coproduction, the literature is broad in that it suggests co-production can involve stakeholders from a variety of backgrounds (Hickey, 2018; Farr, 2021). Lidwell (2015) discusses the principles of good design by committee and states: "Successful design committees are small and diverse, and equipped with the method to facilitate decision making and prevent deadlocks" (p. 77). Therefore, a small group of 4 (one male, three females) and myself would be appropriate for effective decision making. Consent forms (Appendix B) were sent out to the four volunteers.

Using a co-production framework, a series of online meetings were held to discuss the project. Following discussions, we agreed the purpose of the research, the aims, objectives, and methods. The design was co-produced with the intention of providing members with a platform to discuss their individual roles. This acknowledged the unique nature of the study, which sought individual perspectives on their roles. Research focusing on this perspective is still in its early stages as prior focus was primarily on the HEI, its students, and academics.

We agreed on the title of the research, which was:

As a Service User or Carer, do I feel that my lived experience contribution is valued by the School of Human and Health Sciences at the University of Huddersfield.

Meetings were chaired by myself in a project lead role; we discussed co-chairing or having other people chair meetings, but it was agreed that it was better suited to me as the master's student. All members contributed to the design and discussion, although some members were quieter than others. As we all knew each other, we managed to keep the meetings friendly, yet task orientated. Decisions were made as a group through discussion and consensus. All meetings were held online due to the COVID-19 pandemic restrictions.

When designing the research, there was a firm stance from all involved regarding the role of the RDT as set out in the initial discussions and research information literature. Consensus was clear that the RDT would design and analyse the data created by the participants of the data collection group.

Methods for data group

Setting and sample

Once the RDT had designed the research and obtained ethical approval, I sent out an email to the remaining PPG members, inviting them to volunteer as participants (See Appendix E). Ten members were recruited on a first-come, first-served basis, this formed a convenience sample. The RDT agreed to ten participants for the research as it was felt that interviewing ten participants would be sufficient to provide an array of data and a robust answer to the research question. Interest was expressed by a number of people from this population who were sent a detailed information sheet (Appendix F). Research participants were provided with a consent form (Appendix G), which asked for consent on holding personal data, information on the practicalities of the interview and details of how participants could withdraw if they chose to.

Data collection

The pandemic compelled us to adopt convenient data collection methods that worked within the current parameters we were faced with. Prior to the UK Covid lockdown restrictions, we had previously considered visual data collection methods such as photo elicitation and arts-based visual qualitative methods. These methods would have provided perspectives on value, identity, purpose, well-being, and personal development. This approach might have evolved into a workshop or world café style data collection method, enabling RDT members to act as facilitators and making the experience interactive for both participants and the RDT.

The ethical approval stipulated that I alone would be carrying out the participant interviews. Each participant was interviewed in an individual semi-structured interview. The rationale for this was to ensure participants answered questions from their own perspective. The limitations of working online culminated into limited data collection options such as individual interviews or focus groups. Focus groups were considered as an option because of their ability to promote discussion on the topic through group dynamics. However, research found that focus groups are a social experience where participants may be influenced by each other (Tran et al., 2021).

Over the course of several online meetings, the RDT developed six questions for the semi structured interview (see Appendix H for interview topic guide). The questions were designed with the intention of being open, transparent, and simple to understand. Each participant had the choice of a telephone or online video call interview. I was unable to offer face-to-face interviews because of the restrictions in place during the Covid-19 pandemic. Two out of the ten participants opted for a phone call, and the remaining eight were interviewed via video call. Interviews were completed within a two-week period. I recorded the interviews and transcribed them verbatim after recording. Transcripts were numbered, anonymised, and sent out in batches to the RDT.

Analysis

We discussed the Braun and Clarke (2006) thematic analysis approach and instead agreed to use the template analysis (TA) method, due to its iterative process, which assisted the RDT in learning this method in stages. TA is a style of thematic analysis used in qualitative research that adopts a hierarchical approach to coding the data (Turner et al., 2022). The process of TA involves working through the transcripts in stages and beginning to build a template that conveys the codes from the data (King, 2004). By using a TA method of analysis, we were able to learn the process over a period of time, allowing us to develop knowledge and skills of this method. The RDT recognised a skills deficit concerning carrying out a thematic analysis of the data, as only one member had carried out a thematic analysis before. This is common in research involving different stakeholders who are not familiar with jargon or research processes and can be rectified through training and guidance, along with attempts to work without jargon where possible (Barber et al., 2011).

Coding meetings

As a group, we agreed to use one a priori high-level code. An a priori code is agreed upon in advance of reading the data (Brooks et al., 2015). The a priori code related to the participant feeling valued. Since the research focused on this, we were certain this issue would be addressed in the findings. The RDT met for coding meetings to discuss each batch of transcripts. The outcome of every coding meeting was to have agreed codes from the transcripts contributing to the template. As the transcripts were worked through over the course of the coding meetings, the template was adjusted, culminating in a final template indicating high-level and low-level codes. This was an iterative process which we found appropriate to our training needs.

The RDT members individually read through the transcripts and made a note of codes and themes they found. I chaired the meetings and asked people to comment on a transcript, which then manifested in members contributing to the discussion as I wrote the notes. We found similarities in our individual coding, which made the process smoother. We all knew each other prior to this research, and as such found it easier to converse about the research and its themes. On average, three people and I attended the meetings, but most people could only attend for 1 hour. This was stressful as there was a lot to discuss. I was mindful that people were giving up their free time during a pandemic and therefore worked with people's availability. After each coding meeting online, I emailed a summary out to everyone (including the non-attenders), which covered our discussion, codes, themes identified, and date of next meeting. This would be the procedure until all transcripts were read, and themes agreed upon.

This way of working with the template analysis (TA) suited the needs of the RDT in learning a new skill. The use of an a priori code assisted in addressing the skills deficit. Our approach to TA was a two-stage process: once all transcripts were read and codes agreed upon, we began constructing the template by identifying themes. This was developed online, with me sharing my screen and scribing the template as we discussed. The expected online dynamics were present at the MS Teams meetings; some members kept quiet and were politely encouraged to input ideas by me or other RDT members, while others spoke freely. This all occurred amidst the usual technical difficulties of internet strength, microphone issues, being on mute, losing connection and general issues regarding discussions online.

3.4 Ethical considerations of the research

Throughout all stages of this research, ethical issues were considered in order to present quality research that is thorough and transparent. It is important for a researcher to reflect on and acknowledge the ethical considerations they faced in the research. Below, I have outlined the ethical considerations in the research that were reflected upon by the RDT and myself.

Reflexivity

As mentioned in the introduction of this dissertation, I have various connections with the Public Partnership Group (PPG). I am employed as the PPG coordinator, and the PPG is also the focal point for my MRes study. Qualitative research is influenced by a researcher's own subjectivity (Rees et al. 2020). Von Unger (2021) states that 'reflexivity describes an analytical practice whereby researchers take the context of the research situation into account, including the influence researchers have on the study and its results' (pp1). To prevent researcher bias, instil transparency, and ensure rigor in research, reflexivity is applied to the nuances of decision making by the researcher. (Olmos-Vega et al., 2022).Reflexivity and its application are crucial for ensuring quality research, which requires researchers to be transparent about their role (Dodgson, 2019).

As a parent of a child with an intellectual disability, I have spoken with students in sessions at The University of Huddersfield about my family. This experience provided me with some insight into the role of the PPG member, leading me to understanding my position as both an outsider and insider in this research. Insider research is conducted by a member of a group or population that the research is focused on (Yanto & Pandin, 2023; Aburn et al., 2021). Berger (2015) discusses how a researcher's insider/outsider status and shared experiences with study participants can affect the research process (p. 219). Insider researchers often face criticism due to their pre-existing knowledge of the research area and their established rapport with the participants. The implications of this can include challenges related to impartiality, subjectivity in research findings, the potential for biases to emerge, and difficulty maintaining an objective perspective (Costley et al., 2014). However, there are also reported benefits to insider research, such as the advantage of already having a rapport with participants, which can facilitate smoother data collection in semi-structured interviews, for example (Aburn et al., 2021). I found that I did have a good rapport with participants due to my relationship with them through my working role, and I did find this to be an advantage.

Co-production and reflexivity

From the beginning of the research project, I was mindful of my positioning and how it influenced my own experiences and approach to the "researcher-researched relationship" (Berger, 2015, p. 220), particularly considering my prior relationship with PPG members. I assumed the role of project leader, responsible for maintaining project momentum and task lists. Decisions were made collaboratively within the co-production group dynamic. This role allowed me to maintain a certain level of emotional distance from the project and the RDT, similar to maintaining a sense of professionalism. However, there exists a dichotomy for a researcher in my position, as boundaries are necessary in my working role but not as essential within the ethos of co-production or as a master's student. Finding a balance requires continuous self-reflection and awareness (Olmos-Vega et al., 2022). Working within a co-produced framework facilitated accountability and research validity. For instance, I was not the sole person responsible for reading and analysing the transcripts. Having a team involved in shared decision-making helps mitigate issues of bias (Dodgson, 2019).

RDT members and co-production

Setting aside my own position in this research, it was also essential to consider the perspective of the RDT regarding their experience in the research. Not only were the RDT members designing and analysing the research, but they were also doing so within a co-produced framework. This approach required thorough attention from the outset.

Purpose of the research

An informal discussion was held with PPG members prior to the commencement of the research. At this discussion, attendees discussed their opinions on areas pertinent to the PPG, which would warrant research. As stated previously, the conversation focused on PPG members' feelings of being valued in their role and became the emphasis of the research. Following ethical approval, members were then invited to become the Research Design Team (RDT). As a result, three attendees plus another PPG member went on to volunteer as RDT members. At the first formal RDT meeting, we discussed the conception of the research idea to ensure clarity of the research origin. A comprehensive information sheet (Appendix A) was sent out to explain the rationale behind the research.

As the project lead, I asked everyone to read the current guidance on co-producing a research project (NIHR 2018). This document set out the role of a researcher in a co-produced framework. Reading the guidance and discussing the research enabled RDT members to understand the research thoroughly and through discussion, adopt a clear understanding of expectations. As a group, we discussed the project and how we would approach specific tasks. We shared in a forum our reasons for volunteering on this project. This activity contributed to the transparency in the team and importantly defined how power within the team is balanced equally. The main theme from this being for PPG members in the RDT to gain insight into the role from a number of perspectives and as a result, answer the research question. The RDT were curious to know if other members felt valued for the work they do as a PPG member at the university.

The RDT role

At the first meeting, we discussed how we would work as a team. We were made up of four PPG members and myself. The knowledge that we held as a team was diverse, as some members had experience being involved in research projects before, while others had no knowledge. Additionally, some members had been a member of the PPG for several years, while others were new to the PPG. Through these dynamic strengths and differences, a sense of passion and enthusiasm emerged to find out, through the research, the perspective of the PPG members.

With reference to the guidelines (NIHR 2018), I asked the RDT if they would like to take on any specific roles and what skills they would like to develop as a result of this research. No one had any specific requests in terms of their skill development. All members were curious to discover the answer to the research question and wanted to take part in designing and analysing the research.

The requirements of the research were discussed, and we stipulated the number of tasks required to carry out the research as a team. This became a checklist for us to refer to. A number of people expressed a lack of knowledge in creating a thematic analysis of the data. We decided this aspect would be our main area of learning. As the project lead, I completed the administration for the team, such as setting up online meeting links and taking meeting notes. At every meeting, we reflected on previous discussions and decisions, and I wrote notes to capture what people said and actions. Much of my role involved gaining clarity and asking questions. By acknowledging the roles required and delegating a project lead from the outset, we fostered a democratic model towards co-producing the research, tackling any presence of uneven power relationships, and addressing our individual needs to be involved in the research. Defining roles, delegating, and understanding how power can be shared and balanced in co-production is vital for a successful project outcome and can be easily overlooked (Turnhout et al., 2020).

Shared decision making

Designing and analysing research within a co-produced framework demands decision making as a team and is a key component of working in co-production (Loughlin et al., 2019). The ethical challenges of shared decision making (SDM) are centred around communication and relationships (Anrooij et al., 2022). There must be clear communication within a team with specificity of the decisions to be made; trust is paramount when expressing opinions, along with respect (Anrooij et al., 2022), and team members should feel confident to discuss freely their opinions. Where this is not evident in a team, the SDM process will default to a tokenistic approach (Frankena et al., 2019; Pratt, 2020).

As the project developed, RDT members were mindful of shared decision-making practices. Working in this way calls for patience and good input from all stakeholders in discussion (Elwyn, 2021). This research project followed an ethical approach to SDM, and a decision was made from the start on how we would employ shared decision making in the research development and implementation. Consensus checking was agreed upon by all. A member of the RDT suggested this as a strategy that worked for them on a previous project, and RDT members agreed to follow this method. This member also acted as the facilitator when consensus checking was required in the team.

> Instead of simply voting for an item and having the majority getting their way, a consensus group is committed to finding solutions that everyone actively supports – or at least can live with. (Short Guide to Consensus Decision Making - Seeds for Change, n.d.(p1)

As mentioned in this chapter, the RDT and I already knew each other and were aware of how each person interacts and functions in their PPG roles. This was advantageous for shared decision making as members felt free to discuss their opinions in a safe and supportive environment.

By acknowledging from the commencement of the research that the RDT were very keen to find out the answer to the research question and demonstrating a common interest between us, we strengthened our relationship as a team and mutual respect developed for each other. This basis allowed for differences of opinion, which did occur (but in a somewhat mild fashion), to be discussed as a group in a considered manner. Consensus checking through thorough discussion among patient, courteous people was the preferred approach adopted when making decisions and discussing differences of opinion.

Power and ownership

Within co-produced projects, the issue of power and how it must be shared among the team is crucial to discuss. There can be discrepancies in this ethos, with power being wielded unequally (Farr, 2017). Different aspects of power are at play within co-production, and as Farr (2017) states, "They can reproduce relations of domination or be potentially emancipatory", (p.626). The quote by Farr (2017) aligns with this research, setting an emancipatory approach to co-production. The power I held in the research was merely to keep the work progressing. This was agreed upon and enabled the other members to react, design and consider the research. I did feel complicit in this, and while I had control of the pace of the research, I did not have any control over the shared decision-making components of the research. The RDT were keen to begin the research and passionate about the subject. This factor enhances the co-produced ethos.

This research presents some complexities when considering its ownership. It has been designed and analysed by the Research Design Team, yet this dissertation has not been written as a team, nor has the literature review been carried out by the team. Ownership of the data and its findings has been co-produced, and knowledge generated by the RDT; therefore, this aspect is jointly owned by the RDT as it intrinsically represents the views of the team and not an individual. The other components, such as the literature review and write-up, contribute to my own quest for a master's qualification and are therefore owned by me. I have not collaborated with any party on the writing and reviewing for this research, and these components are a solo endeavour. However, as the research is profoundly embedded within the work of the PPG and reports on the perspectives of PPG members, I consider that the research dissertation is owned by the Public Partnership Group at the University of Huddersfield.

Ethical approval application

If a research study involves human subjects, it is essential that its design and methods are evaluated and approved for the protection of its research participants (UKRI, 2023). A researcher must consider the ethical implications of their research with regard to ethics, values, rights, and dignity, and apply for ethical approval (UKRI, 2023) from a Research Ethics Committee (REC). The University of Huddersfield School of Human and Health Sciences has its own ethics panel known as The School Research Ethics and Integrity Committee (SREIC), consisting of academics who are trained and qualified to evaluate research from an ethical standpoint (UKRI, 2022).

This research involved human subjects and thus required ethical approval before any research activity could begin. My research proposal stipulated that the design and analysis of the research would be co-produced by a specific group, made up of volunteers from the PPG. I spoke informally with a researcher at the University to gain advice on how to approach ethical approval given the nature of my study and the elements of co-production and semi structured interviews. I was advised to apply for ethical approval for each stage.

Ethical approval was received on the 17th of February 2020 to set up the RDT (See Appendix C). After the formation of the RDT, we co-produced the research methods (this discussion can be found in the methods for the research project, see page 48 chapter 3.3.. Ethical approval for the second phase of the research regarding the semi-structured interview participants was granted on the 27th of April 2021 (see Appendix D).

Reflections on ethical challenges

In retrospect, I discovered that applying for ethical approval to set up the RDT conflicts with the ethos of co-production as stated in the guidelines for co-producing research set out by the NIHR. A key principle of public involvement in health research is that you do not need to get prior ethical approval to involve the public in decisions about designing and managing the research. This also applies to co-production. This difference is because those members of the public involved in, or co-producing, research are understood to be colleagues working alongside other team members. This role is different from people who are recruited to be research study participants from whom research information (data) is collected (NIHR, 2020. p.6).

It is unknown if the SREIC were aware of this fact. There are varying options which could have resulted in this conflict relating to the qualification I am undertaking. The consensus from the SREIC may have been that I will need to apply for ethics approval for the co-production aspect, as a matter of my education which supersedes the NIHR directive. However, it may be that the SREIC were not aware of this and treated my application as if it was not co-produced research. If this is the case, it provides possible insight into the attitude towards co-production and its application in a university. It is a non-traditional research process (Dodgson, 2019) and as such, the act of applying for approval to involve colleagues to co-produce cancels out the power sharing dynamic. This issue highlights the point raised previously of “breathing air into a closed system” (de Peuter & Hall, 2007, p. 110).

3.5 Conclusion

The outcome of the analysis stage was the creation of a template outlining the themes which arose from the semi-structured interviews (see Table 7). A final task for the RDT was to create a list of recommendations from the data which would be submitted to the involvement team (my paid employment). The recommendations could impact policies, training, and other HEI organisations.

In this chapter, I have presented the methodology and methods of this research study and explained how we worked in a co-productive framework. In the next chapter, I will present the findings and themes found in the data which addressed the research question and discuss the co-produced template.

Chapter 4: Findings

4.1 Introduction

In this chapter I will share the basic demographic participant information and discuss the seven main themes identified by the Research Design Team (RDT) from the template analysis of the ten semi-structured interviews conducted with the research participants. I will present the final template and discuss each main theme in turn.

4.2 The research participants

At the commencement of designing the research we discussed if including participant information would inform the findings of the study. The participant responses were anonymous in accordance with ethical approval therefore it was decided to strengthen the reliability and rigour of the research and include basic demographics of each individual. Table 6 shows the sociodemographic information from the ten participants in the study. The sample consisted of diverse age bands ranging from 25-34 to over 75. The median age range was 45 - 54, the mode was 35 – 44, and gender was reported as six females, three males and one non-binary.

I cannot provide additional sociodemographic characteristics of the research sample because the RDT decided to limit the information collected due to the study's small size of only ten participants. I do acknowledge the importance of Equality, Diversity, and Inclusion (EDI) in bolstering the research field. Despite this study's small scale and limited participant data, we gathered research data from individuals aged 25 – 75 or older, encompassing male, female, and non-binary participants.

Table 6. Participant information

Participant number	sex	Age range
1	F	65 - 74
2	F	55 - 64
3	F	45 - 54
4	M	35 - 44
5	M	35 - 44
6	F	45 - 54
7	F	35 - 44
8	Non-binary	55 - 64
9	M	25 - 34
10	F	75 or older

4.3 The template

The final template is the culmination of repeated coding meetings with the RDT to ascertain agreement on the main themes and sub themes of the research. We identified seven main themes and twenty-six sub themes. See Table 7 below for the final template and themes. Each of these themes will be presented and discussed in turn. Quotes from participants are used to illustrate each point. Participants are depicted via number at the end of each quote and the letter p.

Table 7. Final template and themes of the study

Theme 1 Routes into involvement 1.1 Referral inexperienced 1.2 Recommended experienced 1.3 Outreach
Theme 2 – Motivation to be involved. 2.1 Altruism 2.2 Needs to be done/intrinsic 2.3 Advocacy 2.4 Service improvement/promoting good practice
Theme 3 – What value is 3.1 Being listened to, asked questions, taken seriously 3.2 Feeling that you are an important part of the team 3.3 Being asked back 3.4 Remuneration 3.5 Feedback 3.6 Respect and acknowledgement for sharing emotions/ 'stories'
Theme 4 – Value is important. 4.1 Fundamental 4.2 Not as much as advocacy
Theme 5 – Personal effect of involvement 5.1 Enjoyment, enlightening 5.2 Meeting and working with students 5.3 Confidence 5.4 Purpose
Theme 6 – Perception of equality 6.1 Limited sense of belonging 6.2 Sense of belonging/awareness of role in the school 6.3 Identified staff perception
Theme 7 –Organisational responsibilities and processes 7.1 Member training 7.2 Thorough briefings post and pre - feedback 7.3 Staff training 7.4 Power over involvement topics

4.4 Themes

Theme 1: Routes into involvement

This theme identified how participants became involved in the PPG and found out about this aspect of teaching and learning in the University. We identified that most participants found out about involvement work at the University through either someone they knew who is a member of the PPG, or someone who knew about the role the PPG play in the school.

> *'I first heard about the public partnership through a friend. They were in the public partnership group'. (P6)*

This demonstrates the networking pathways and how valuable word of mouth is. Most participants were inexperienced in this work when they joined and therefore took on a steep learning curve.

Networking and friendships were key in the recruitment of members. This is not to insinuate that the PPG advocates nepotism. All members are recruited and receive training and interviews to ensure that they have the competencies and experience required. Many members have shared their PPG work through groups and networks that they attend where they share common factors such as having the same condition or access the same support groups for example.

Some participants mentioned that health and social care professionals discussed involvement work with them and shared information about it. When exploring the reasons for this, it is likely that these professionals recognized the benefits and purpose of involvement for specific individuals based on their lived experiences. In doing so, the professionals acknowledged the value of participation for those individuals.

> *'An outreach team were supporting me, and this was one of their suggestions, and you accepted me'. (P 10)*

However, most participants did join because they knew someone who was already involved. Attracting members through outreach events was also considered an important role within this theme.

> *'I got involved through the ***** group that I was attending'.* (P1)

We identified the importance of this point in ensuring that contributing to health and social care education is a known and accepted way of sharing experiences to impact future health and social care professionals. It assists with normalising this practice and spreading awareness of its existence. It is an important part of recruiting people who will not be aware of this work or the impact it can have.

Theme 2: Motivation

Participants spoke about what motivated them to get involved in this work. This theme explores the relevance of altruistic and intrinsic attitudes which, for some, brought a sense of advocacy focused on making changes in service delivery and promoting best practice. Altruism is most dominant when it comes to the reasons behind individuals participating in involvement work. Many of the participants felt that 'giving back' was a key area for their motivation. We interpreted the term 'giving back' as having a sense of duty to share an experience with students with the aim of facilitating their learning and benefiting from firsthand knowledge.

> *'I think initially it was that feeling of wanting to give back, that has really been key for me all the way through... and having an opportunity to say what you think was really good practice, say what you think was bad practice and present it in a way so that people can then learn from those'. (P3)*

Participants spoke of shaping, helping, and feeling useful. We understood from this there is a role people take on and feel a responsibility to be a part of students' experiences and training.

> *'Because I've been a student myself, health care, mental health is something that I'm passionately interested in. I can see how it helps students, whether they're learning to involve people with real lived experiences of health conditions, I think it makes it more real for them'. (P5)*

Some participants felt that involvement work in HEI's is an intrinsic component of learning and teaching for health and social care professionals, using phrases such as 'should be involved' which suggests how it is a responsibility but perhaps not just for the participant but also the organisation.

> *'Stakeholders should be involved in the development of different things…… I think that having real people with real stories and real insights, is, is important for especially for educational purposes, and research purposes'. (P7)*

Participants who were carers included discussion on advocacy in their interview, referring to this being a driver for them. They acknowledged how their work at the university was helping to make changes by developing students' perspectives in order to equip them with the knowledge of how to care for people.

> *'Sharing experience that can help people so it's kind of advocating really…. for the future, for a family member'. (P6)*

Participants spoke of fostering changes in healthcare systems and being listened to. This conveyed how involvement work is a cathartic experience which we acknowledged has enabled some participants to greatly understand their own care along with informing students of best practice.

> *'Having come to this, because of my experiences with a health condition, and my experiences as a patient, and as a carer going through various parts of the health system. I want to be able to use my experiences, but some of my experiences were quite negative. It's almost because I want to try and improve the system and to, to be listened to'. (P2)*

Theme 3: Being valued

This theme was identified through the initial a priori code and is at the heart of this research project. All participants did feel valued and when probed further, described their experiences which made them feel valued. Some participants gave multiple examples for this which demonstrated that value can be a collection of things. We found that feeling valued amounted to achievable things like kindness, respect, sense of belonging, instilling participants with a feeling of value.

> *'People checking in that everything's alright that you're happy, that you're comfortable that you feel alright with what's going on around you. That was all important'. (P7)*

This theme emphasises how participants wanted to feel that their contribution is useful and needed to draw on the responses of students or staff to acknowledge their input.

> *'I certainly felt that our views and comments were wholly taken on board and really listened to, and they really did help to develop the course it was, it was great'. (P5)*

We identified how important this is for participants as it highlights the importance of belonging. Being a team player indicates a preference for a collaborative approach to involvement work and also of being on an equal footing with colleagues.

> *'I felt very valued by the social work team. I was viewed as a member of the interview panel and wasn't treated as a separate service user category, simply as a panel member, which really did make me feel appreciated'. (P8)*

Being asked back was common for participants. This is essentially the participant receiving approval for their input by being asked to participate again. We felt this an important theme as it lays the impetus for being asked back by the institution or lecturer which shows the relationship dynamic between service user and staff member (academic).

> *'Yeah, you definitely feel valued particularly when you get invited back, you know, year on year to do it again'. (P4)*

Participants presented opposing views in response to value correlating with remuneration. A small number of participants felt that being paid a fee for their time makes them feel valued as it acknowledges the importance of their time. Most participants stated that the money was not as important. The point made about a person's situation dictating how this *affects their choice of occupation is an important issue raised.*

> *'The money does matter. It does in my situation because, I can't work very easily. So, doing this is not what I would have been doing if I wasn't in this situation. I love it, but I wouldn't have been doing it, why shouldn't I want to be paid for my time'. (P3)*

Participants highlighted the importance of receiving feedback for the sessions or events they were involved in either from academics or students, which they received via a lecturer. This affirms that the participant is still included after a session or event and the academic has not forgotten about them as soon as the event is over.

> *'The support that the students themselves gave back was just so sweet to have that validation from them, that you've done a good job and that you know, you've stood up there and delivered what you needed to deliver is really nice'. (P9)*

Respecting participants for sharing personal experiences about emotional or traumatic times in their life must be done with dignity and acknowledged by students and colleagues. It indicates the importance of emotional intelligence and its development in students.

> *'To do this work where to agree I'm opening up personal areas. I need to feel respected and valued and my time at Huddersfield University I have felt that'. (P8)*

Theme 4 – Value is important

This theme addressed another main thread of the research which stemmed from the a priori code developing the notion of value. Participants were asked directly if value was important to them. All participants said that value is important and were able to talk about the reasons why they felt this. We realised that there are many components involved which depict value which is unique to each participant. This demonstrates the complex nature of value.

Participants expressed how they felt that value and feeling valued is inherent to this work. Most participants stated that they would not be involved if they instinctively did not feel valued for their contribution.

> *'To have that acknowledgement, and to have that consideration, and to know that what I'm contributing is valued by somebody, and has been listened to, is really key'. (P2)*

A small number of participants conveyed that advocacy and the power that advocacy can have with students in a classroom setting is more important than value. This demonstrated the level of responsibility that a participant can have with regards to their attitude to this work. It is deep rooted and carries a vast amount of emotion which demonstrates a passion and responsibility for this work. This conveys that participants would be willing to bypass their own feelings of value to ensure they were able to advocate for others. This may then subconsciously, also bring with it a sense of value.

> *'I think for myself if the message is getting out there as long as people are learning and taking things. I think that you'd, I mean you do subconsciously feel valued by that happening anyway but even if I wasn't feeling valued I think that I'd still want to do it because it's important stuff that needs to be out there'. (P6)*

Theme 5 – Personal effect of involvement

Participants spoke of the impact that involvement work and being a member of the PPG has had on them. The role is varied and sporadic, it has challenges and can be nerve wracking or emotional. There is much more to involvement and participation than sharing lived experiences. The individual is affected and impacted in positive ways. Many participants spoke of the work being enjoyable and enlightening. Participants can experience learning on a personal level about themselves or regarding the course, students, or university for example.

> *'I found it interesting and enlightening really, the questions that are asked…… just seeing what people's views and opinions are'. (P6)*

Working with students was discussed by most participants and conveyed how important and interesting it is to work with students and seemed to be an integral part of involvement which many participants enjoy.

> *'It was nice to have that impact on a student and know … you've been part of that'. (P9)*

Many participants spoke of their self-confidence and the amount it had grown as a result, establishing the impact this work has on an individual. It is an important aspect that participants have shared and refers to the amount of personal development experienced by participants.

> '*It helped build my confidence and I thought, look at me I'm back'. (P10)*

Having a sense of purpose was a popular thread throughout the research and many themes are linked to this. Most participants were unable to work due to their own circumstances. The psychosocial impact that this has had on participants was expressed and we found that this work enriches and enhances a person's sense of purpose, adding meaning to their lives. Participants felt that this work made them feel valued in that it gave them or reinstated a sense of purpose and empowerment.

> *'Why do I define myself by what I can't do. Whereas I think what this particular opportunity gives you is to define yourself by something you can do'. (P1)*

Theme 6 – Perception of equality

This theme emerged from the question we asked about the University and whether the voice of PPG members is valued within it. We received varied responses to this question. While some participants felt a sense of belonging in the University, others did not. Participants were also asked about the University in a broader context, specifically regarding how involvement work is valued by the School in the University. Participants expressed a limited sense of belonging. Several factors contributed to this perception, with some participants mentioning the sporadic and irregular nature of their role, which created a divide. Visibility played a role, as participants had limited interactions with other colleagues. They primarily interacted with the academics they worked with and the staff involvement team, which restricted their perspective on how the school perceived their contribution.

> *'It's hard to say that because I don't know about the work of the school beyond what I've done with it so if you're asking me to comment on the school as a whole, I don't really know'. (P5)*

Participants conveyed opposing views on this front rendering it a subject dependent on individual experiences and knowledge along with length of time working in the University. A smaller number of participants saw their role as being valued by the school, basing their answer on their experiences and observations.

> '*We are absolutely, seen as equals with practice educators, lectures, and the student'. (P4)*

Some participants were able to identify attitudes from staff members who demonstrated a lack of understanding of the ethos around involvement by the Health and Care Professions Council (HCPC) and the Nursing and Midwifery Council (NMC), choosing instead to focus purely on the fact that involvement is mandated. One participant witnessed this and, despite thinking it was inappropriate, decided to 'laugh it off'.

> *'I've had sometimes comments about sort of, how they're here because it's a requirement, which makes me laugh and I just think ……. stop introducing me like that'. (P3)*

Theme 7 – Organisational responsibilities and processes

From discussions concerning the organisation, this theme emphasised the shortfall of knowledge that participants have concerning the organisation. Participants identified a number of areas which would improve their knowledge and experiences in the PPG and wider context. We used much of this data to formulate recommendations from the research.

We asked participants to share with us any training requirements or wishes that they felt were needed to carry out the role. Participants reported a need to develop technical skills in public speaking, teaching skills, mentoring / supervision on a regular basis and some organisational information.

> *'Public speaking or talking to groups of people, I think maybe some members might feel anxious about that I know I would'. (P5)*

The issue of feedback arose and highlights the input that a participant makes. This is important to participants and something which is also a thread throughout.
As highlighted previously in the findings some participants identified staff attitudes which did not seem conducive to the ethos of involvement. This is an area to be explored in terms of training staff members on the task, role, and impact of involvement work.

Power has been identified with regards to research and the impetus behind a piece of research coming from the academic. This can also extend to involvement in teaching and learning in the school. The impetus for this also comes from the academic which can seem to render the SU&C powerless, meaning they must wait to be invited to participate. Participants expressed a wish to input into this impetus which is an area worth exploring.

> '*Why can't I talk about what I want to talk about, when I look at what is being taught, I think well it would be great if I could talk about….'. (P3)*

4.5 Conclusion

The RDT identified seven main themes and twenty-six sub themes as a result of analysing the transcripts from ten semi-structured interviews using template analysis as a method. With reference to the research question, participants felt valued for their contribution and many nuances regarding the notion of value were expressed. These findings enable a deeper understanding of the role of the SU&C to be considered. In the next chapter, I will discuss the research and the relevance of the findings.

Chapter 5: Discussion

5.1 Introduction

In this chapter, I will discuss the key findings of the research, exploring how they relate to current research in this field and highlight the implications for policy and practice. I will then elaborate on the aspect of co-production and consider how co-production performed as a framework, focusing on its abilities as a methodology for research in a university setting. I will explain the strengths and limitations faced by the Research Design Team (RDT) in this research, as well as my own challenges studying for this qualification and working collaboratively. Finally, I will conclude the chapter by sharing the recommendations from the research as agreed upon by the RDT and discuss their application.

5.2 Key findings from the research

A key finding from this research shows that participants in this study do feel valued for their contributions to health and social care education. Their reasons for feeling valued encompass a range of emotional, practical, cathartic, purposeful, and inspirational factors, all of which are related to altruism and a sense of responsibility to give back. These findings align with research conducted by Mckeown et al. (2012), where participants were interviewed about their perception of value in relation to their volunteer role at a university. The study revealed that participants felt valued due to a "plurality of factors" tied to "altruistic self-expression" (Mckeown et al., 2012, p. 183). This corresponds with our own research, which demonstrates how SU&Cs also feel valued and highlights several reasons for this, often not reducible to a single factor. Notably, the study by McKeown et al. (2012) explores the issue of payment to examine whether it contributes to the sense of feeling valued, given that participants do not receive remuneration.

In this study, the participants receive compensation for the tasks they perform at the University, but interestingly, they still feel valued for reasons unrelated to monetary remuneration. One participant emphasised that while remuneration is important, it is not the determining factor for their involvement. Another participant expressed that the financial aspect is not significant, while the remaining eight participants did not mention the payment status at all. Despite the disparity in remuneration, both studies found that participants felt valued for their involvement, leading to similar perceptions of value.

Consequently, we can infer that remuneration does not have a significant influence on the relationship between feeling valued and SU&C participation.

Participants in this research articulated how feeling valued was attributed to respect, courtesy, and kindness. Griffiths et al. (2012) investigated SU&C opinions inquiring what the most important elements a nursing graduate should possess. Results found it to be 'a caring professional attitude'. Comparing the findings of this research study with the research from Griffiths et al., (2012), both studies report on 'caring qualities', delineating the similarities with training and practice in relation to caring, kindness and courtesy. Both studies link in with policy allowing us to step back and see the wider perspective of involvement and its impact. The Health and Social Care Act 2008: Regulations 2014, requires that health and social care providers "treat service users with dignity and respect" (CQC, 2023. p1. regulation 1), mirroring the sentiment found in this research and demonstrating a congruence between training, practice, and policy. SU&C involvement in health and social care education acts as a modelling exercise (Happell, 2022), which enables students to see successful collaboration with SU&Cs and as such provides students with a demonstration of successful partnership working.

The research findings highlight the significance of feeling part of a team, which aligns with best practices. Regulatory requirements dictate the involvement of service users, patients, and clients in their own care, ensuring their voices are heard in care planning and collaborative efforts (NICE, 2019). These requirements closely correspond to the findings of this research, emphasising the importance of teamwork and meaningful contributions, which is supported by current research (Fox, 2020). The role of teamwork in SU&C involvement is crucial in fostering a sense of value and reinforcing the need to model best practices to students. This underscores the importance of consistency in training and practice, presenting a united front in promoting excellence.

There were differing views concerning the motivations behind involvement; however, altruism and the need to 'give back' was a prominent feature in the responses. Reasons such as these are expected (Rooney et al., 2016) and is a profound and inspirational aspect of involvement work.

A surprise aspect of this research we did not anticipate were responses associated with a sense of purpose, confidence, and wellbeing which resulted in a SU&C's sense of value. This enabled further understanding of the role and the identification of a multitude of aspects that successful involvement impacts. These findings correspond with previous research reporting on the sense of value gained through feelings of purpose, inclusion, appreciation, and well-being (Rhodes & Nyawata, 2011; Rhodes et al., 2014; Rooney et al., 2016). Many participants spoke of their inability to work due to their condition or caring responsibilities and the impact this had on their confidence. Feeling valued, contributing, and being respected restore a sense of purpose and meaning to participants and demonstrate the theories associated with occupational identity. Hansson et al. (2021) write of the connection between identity and occupation stating that "occupation is a means to rebuild one's identity" (pg. 198). This concept came through in the research as participants spoke of regaining a sense of purpose, restoring confidence, and feeling useful.

One finding of this research indicates that participants have a limited sense of belonging and feel isolated in the role they undertake at the University. They have minimal contact with staff and mostly work in silos with the involvement team and a lecturer at any given time. The transition to online teaching has further increased the distance between SU&Cs, the organisation, and academics, and more recently, the students. SU&Cs do not have team meetings or receive supervision/appraisals as employees would. This issue has been acknowledged in other higher education institutions (HEIs), leading to the development of the Vancouver Statement (Towle et al., 2016). The Vancouver Statement emerged from an international conference titled 'Where's the Patient's Voice in Health Professional Education?' Towle et al. (2016) developed the Vancouver Statement as a five-year plan to enhance SU&C involvement, outlining specific actions for institutions to consider:

> To- Foster institutional, local, national, and global recognition of patient expertise that grounds this activity and makes it valued. Recognize achievement and celebrate success. (Towle et al., 2016. p.22).

This point distinguishes the role an institution plays in successful involvement and the significance of recognising and celebrating involvement. The deficit felt by participants in relation to their sense of belonging in the University can be rectified through such endeavours as described above. In doing so it acknowledges the informal workforce (The Health Foundation, 2017) and strengthens the cohesion required to embed involvement in a HEI. The relevance of this is reflected in this research.

Participants in this research reported that successful collaboration and teamwork fostered meaningful involvement and instilled empowerment. By modelling this practice and embedding it in training, the future workforce will already be accustomed to working in shared power dynamics, alleviating conflicts. Happell et al. (2023) reported on the increased involvement of service users and carers in partnership working, specifically within mental health services, as a tool for recovery-focused initiatives. Happell et al. (2023) identified a reluctance from health and social care personnel to acknowledge this power-sharing collaboration. Consequently, they found that this lack of enthusiasm conflicted with the ethos and policy directives concerning collaborative working with SU&Cs and definitive power-sharing approaches. This is also the case found by Ward (2021) regarding the role of Peer Support Workers (PSW), who are based in practice and face a multitude of challenging issues pertaining to working in multidisciplinary teams (MDTs), supervisions, and generally working in a shared power environment (Ward, 2021). PSWs reported difficulties working with colleagues who expressed a reluctance to work collaboratively. Arguably, policy, practice, and training must work in unison to demonstrate effective working in partnership with students, benefit future practitioners in their approaches, and equally benefit SU&Cs working in collaboration. Our research supports this; participants reported a sense of value from feeling like a member of the team.

5.3 Co-producing this research

This section discusses the methodology of co-production in relation to carrying out research by a student/employee in collaboration with SU&Cs embedded in the involvement agenda at the same university. I will focus on the application of co-production in this research and its effectiveness in this context.

Co-production as a concept was initially developed for the purposes of community project design and development, involving both citizen and government stakeholders (Robert et al., 2021). Ostrom (1996) describes the literal act of co-production as "a process through which inputs from individuals who are not 'in' the same organisation are transformed into goods and services" (Ostrom, 1996, p. 1073). Applying this ethos within a university research context has led to unexpected contemplation regarding ethics procedures and definitions of co-production. The intrinsic factor of this research was to maintain the co-produced ethos and shared decision-making as the mainstay element. At the end of the research process, I sent an online questionnaire to the members of the RDT, asking for their feedback on working in a co-produced team (see Appendix I). However, I only received two out of four responses, which is indicative of the sporadic, ad hoc nature that co-production can sometimes carry. Among the two responses received, the results are of interest, particularly regarding members' views on working within a co-produced team and the impact of a pandemic.

Ethical challenges

As discussed in Chapter 3, a contributary factor of the issues faced in this study regarding co-production stemmed from the ethics procedure. This occurred initially by applying for ethical approval to form the Research Design Team (RDT), which I subsequently discovered was unnecessary. The second ethical approval issue concerns the research methods and the RDT, who were not approved to carry out the semi-structured interviews. I have explained the possible reasons for this in chapter 3. However, it is necessary to discuss the implications of co-producing research in a university. Academia is established as a safe and trusted source of knowledge creation, which can react adversely to co-production and its unconventional approaches (Bell & Pahl, 2018). Research Ethics Committees (RECs) can be unresponsive to research that is coproduced. This is due to the systems within academia, which are not conducive to collaborative and democratic approaches to knowledge production (Laidlaw, 2022), which correlates with this research. Laidlaw (2022) is leading a project that will produce guidance for ethical approval to be gained for co-produced research projects. This guidance will not only be for researchers but also members of RECs who operate in isolation from each other. One REC committee may have different views from another (Laidlaw, 2022). It is also worth noting that from the scoping review carried out in Chapter 2, there was little, if any, mention of ethical considerations in any of the papers selected, other than ethical approval was received.

Positionality/reflexivity/insider research

My connection with members of the PPG in this research, as mentioned on page 18, could categorise me as an insider researcher. This necessitated self-reflection to consider my approach. I have experiences that somewhat align with those of a PPG member because I have shared my lived experience with students, discussing my son who has an intellectual disability. Through my role at the University of Huddersfield, I have developed a working relationship with all PPG members involved in this study. As a coordinator, I am very familiar with how the PPG operates in the context of the university. This connection allowed me to comprehend how my contributions could personally affect me and enabled me to approach the research with empathy. It is an intrinsic part of the researcher's role to engage in self-reflection and maintain objectivity throughout the research. My position in this research required me to objectively listen to the voices of the participants and remain impartial. By participating in the RDT, I could contribute to the discussions with my own opinions while also maintaining objectivity during the interviewing and data analysis process. Maintaining this position does require continual self-awareness. The motivation for this research and any subsequent research must remain integral and be successfully achieved. During the semi structured interviews, I remained conscious of reflexivity and made efforts to ensure a consistent experience for the participants. While there were instances where the conversation deviated from the topic, I quickly redirected it back on track. Reflexivity should be applied from the beginning of a research project and maintained throughout (Dodgson, 2019).

Definitions of co-production

The National Institute for Health Research (NIHR) has provided a set of principles as a guiding steer to successfully co-produce research:

1. Sharing of power – the research is jointly owned, and people work together to achieve a joint understanding.
2. Including all perspectives and skills – make sure the research team includes all those who can contribute.
3. Respecting and valuing the knowledge of all those working together on the research – everyone is of equal importance.
4. Reciprocity – everybody benefits from working together.
5. Building and maintaining relationships – an emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential.

(NIHR, 2018. Pg. 4)

All five principles were employed in this research, yet there were inconsistencies that rendered certain areas of the research unable to be fully co-produced. It would be disingenuous to report that co-production practices were ineffective in this research. Instead, it is more appropriate to acknowledge that co-production principles were only able to be applied partially in certain aspects of this research. Farr et al. (2021) discuss the challenges faced when working within a co-production framework, stating that the reality can often differ from the principles outlined in guidance. Therefore, it is unrealistic to create a single definition of co-production, but rather to use the principles and level of involvement as parameters for determining co-production (Co-Production Collective, 2020).

Definitions or variants of co-production have become a common criticism or subject of commentary in participatory approaches (Vargas et al., 2022). In the scoping review conducted in chapter 2, the term "co-production" encompassed various interpretations, ranging from co-creation to using a co-production approach drawing on Participatory Action Research (PAR) (Newman et al., 2022). Facer & Enright (2016) assert that "co-production" has become an umbrella term for any type of collaborative research (pg. 87) and discuss how researchers are labelling any form of collaborative or participatory research as coproduction.

Throughout this research process, we have operated within a co-produced framework, adhering to the boundaries set by ethical approval. However, unlike the papers examined in the literature review (chapter 2), we cannot label the members of the Research Design Team (RDT) as SU&C researchers since they did not assume the roles described in the literature. This discrepancy is likely due to the qualification I was pursuing, rather than a decision by the School Research Ethics and Integrity Committee (SREIC). Conducting this research within a university setting has inevitably posed challenges to the co-production ethos, raising questions about its effectiveness in a Higher Education Institution (HEI). In future research involving SU&Cs, it may be more appropriate to consider a Participatory Action Research (PAR) approach, which can facilitate a democratic process (Percy Smith, 2019).

Beresford (2020) discusses the longstanding issue of the consumerist philosophy towards public involvement being for the SU&C voice to:

> be heard in public policy, but not have a seat on the board.
>
> (Beresford, 2020)

This sentiment is acutely demonstrated in this research study and in the literature review, with research procedures and protocols revealing the challenges in striving for a completely democratic model. This can potentially relegate the participatory/co-produced element to an additional consideration (Beresford 2020). This raises questions about the issues of power and its imbalance in SU&C research and involvement, which tends to favour the consumerist model. Beresford (2021) points out how power can be balanced in a state of equilibrium when it is distributed equally, highlighting the need for further research addressing power imbalances within the field of public involvement.

Although this research was designed within a co-production framework, we did not employ any tools to monitor or evaluate the quality and effectiveness of co-production. The literature highlights this as an area of uncertainty and calls for greater attention to be given to assessing co-production in future research (Verschuere et al., 2018).

5.4 Strengths of this research

A strong point of this research is its originality, as it exclusively focuses on the role of SU&C involvement in a HEI, specifically examining their perspectives on feeling valued. This study solely investigated SU&C perspectives by asking questions that inherently had subjective answers. In contrast to most of the current research, this study covered all health and social care courses offered at the HEI because the PPG is involved in all courses, including nursing, social work, and allied health. In a recent study, Rooney & Unwin (2021) discussed the perspectives of SU&Cs who participate in the recruitment and selection of students at an English university. They conducted research with SU&Cs involved in a range of interviews based within social work and allied health. When discussing their research, they stated that "SU&C voices are little heard; this study addresses this knowledge gap for the first time" (p.1). Our research study follows in the footsteps of Rooney & Unwin (2021) by addressing and developing knowledge in this emerging field. What sets our research apart is that we researched SU&C perspectives who have participated in all involvement work across the school, including recruitment, assessment, resource creation, classroom delivery, and attending meetings or focus groups relating to all courses.

There is strength in the outcomes of the research, as they have revealed several areas that require further discussion. Both this study and the selected studies in the literature review indicate the importance of coordination to ensure the successful implementation of research. In this study, I personally carried out the necessary administration and coordination to ensure the project was completed. However, it remains unclear how coordination was handled in the selected studies, whether it was the responsibility of an academic or a coordinator. Investigating this aspect would provide valuable insights into the roles of development workers or coordinators in SU&C involvement, which is an important factor and a strength of this research.

A strength of this research lies in the extensive knowledge and skills I have acquired throughout the project. What initially started as a small research endeavour on the topic of involvement with SU&Cs has transformed into a comprehensive exploration of research processes, methods, protocols, methodologies, and assuming the role of project lead in a coproduced team. I have gained valuable insights into the intricacies of ethics applications and the nuances of conducting a scoping review. These newfound abilities will enhance my role as a Service User and Carer Involvement Coordinator, ultimately improving the quality of involvement for SU&Cs and the impact on students. I will be better equipped to engage with researchers in meaningful discussions regarding Public and Patient Involvement (PPI) and feel confident in doing so. Additionally, this research has bolstered my self-assurance and provided a sense of accomplishment in carrying out this study.

5.5 Limitations of this research

A limitation of this research study is the time it has taken to complete. It began just before the Covid-19 pandemic in the Autumn of 2019 and had to be significantly delayed on account of Covid-19 limitations and personal circumstances. However, despite the delays, this research remains current and relevant in the field of SU&C involvement.

The impact of the pandemic affected most of the processes of the research. The original concept was to meet in person on a regular basis to discuss various creative qualitative methods, as described in the research proposal. I intended to thoroughly address any skills deficit, which may have arisen by providing training to members of the RDT and using the training as an exercise to determine which methods we preferred. This would have been relevant when deciding on a thematic analysis approach for example. The Covid 19 pandemic diminished our ability to meet in person and took a dramatic effect on everyone's lives. As a result, the RDT were forced to meet online via MS Teams, bringing with it a new set of challenges concerning IT equipment and a request for people's time in a stressful and unprecedented situation.

Positive and negative outcomes of the research process

A positive aspect of this research study was the formation of the Research Design Team and the commitment everyone had to carry out the research. Despite the limitations, we worked collaboratively and were interested in seeing the research develop. The semi-structured interviews went well, and participants expressed a commitment to the research and the area it was investigating.

Working online was an unexpected element of this research. We had initially envisioned numerous in person meetings to discuss, hypothesize and explore different methodological approaches to agree on the research design. However, as the research had to be conducted online, a new set of challenges emerged. The RDT had to adapt to new methods for online collaboration and discussed the most convenient approaches to analysis, considering our circumstances and the need for training in these new methods. To mitigate this, we chose the analysis tool, Template Analysis (TA), which allowed us to learn the process iteratively. It proved to be a fitting and reliable method for this research, enabling the RDT to acquire a new skill and effectively meet the research needs.

One aspect I would change if I were to start the research again would be to not apply for ethical approval to set up the RDT. In the initial stages of the research, I would work closely with the RDT to establish clear boundaries between my role as a student and the role of the research. This would create defined definitions for the roles and tasks of the research, allowing the RDT to conduct the semi-structured interviews and contribute more significantly to the co-production of the research. Additionally, I would involve the RDT in step 6 of the scoping review and seek their commentary relevant to their involvement. These actions would enhance the integrity of the co-produced research.

5.6 Recommendations from the Research Design Team

Below are the recommendations agreed upon by the RDT as an outcome of this research. I have organised the recommendations into three groups: practice, policy, and research. I have also added my own recommendations which sit independently from those developed by the RDT. We offer these recommendations to all institutions that include SU&C involvement in their training courses.

Practice

1. **Administrative infrastructure with clearly defined systems and processes –** A robust administrative infrastructure with clearly defined systems and processes is essential to facilitate involvement work. This infrastructure should include systems for staff requests SU&C bookings, payments, registration, induction, and evaluation processes. These processes should be transparent and serve as evidence of good practice in involvement work.

2. **Curriculum overview** – Providing SU&Cs with an overview of the entire module or curriculum when planning events is crucial. This ensures that SU&Cs have a broader perspective of their contributions.

3. **Staff training and development** – Training should be co-produced and co-delivered by SU&Cs and staff. It should cover the mechanisms of involvement, collaborative working and provide practical examples.

4. **Feedback and impact** - PPG members should receive feedback and acknowledgement from academics. Students should be asked for feedback regarding the impact of SU&C involvement on their learning.

5. **Induction and managing expectations –** SU&Cs should undergo a comprehensive induction covering all aspects of involvement, including role clarity, expectations, conduct skills and organisational structures.

Policy

1. **Internal strategy/policies/mapping** – Embedding SU&C involvement in curriculum planning, recruitment, course validation, course evaluation should be a part of internal strategies and policies. These strategies should be demonstrable through clear mapping.

2. **Refining national guidance to develop meaningful high, standards of involvement in external policies.** National guidance should be refined to develop high standards of meaningful involvement in external policies. The NMC, HCPC and SWE, while not overly prescriptive, should emphasise the importance of quality and meaningful involvement while discouraging tokenism. Policy guidance should also address the need for dedicated staff or protected time for academics to coordinate and manage successful involvement.

Research

1. **Streamlined research opportunities –**
    - Create streamlined research opportunities for SU&Cs by providing information on research special interest groups and research centres at the HEI.
    - Encourage partnerships at the research design level with relevant SU&Cs and researchers.
    - Develop accessible and transparent systems for this purpose and provide training packages to facilitate it.

2. **Further research on SU&C perspectives** – Further research on SU&C perspectives within Higher Education Institutes is essential to expand knowledge in this field. Areas warranting additional research include well-being as an impact of

involvement, collaborative involvement methods, operational factors affecting involvement and successful involvement practices.

I have made the following recommendations as an individual.

1. **Systematic review of involvement standards.** Conduct a systematic review of published involvement standards in HEIs and affiliated organisations such as the National Institute of Health Research (NIHR). The aim of this being to identify common themes or conflicts which results in a reputable assessment of the literature.
2. **Co-produced research on involvement standards as an outcome of the systematic review** - (see above).
3. **Further co-produced research -**Promote further co-produced research within HEIs to address power dynamics, ethics procedures, and develop a standard model of working in a co-produced framework.

These recommendations predominantly focus on practical service improvement suggestions that emerged from the comments made by participants in the semi-structured interviews. They primarily apply to internal systems, processes, and policies within the University of Huddersfield. However, they can be adapted and applied to any HEI where involvement is a critical component of health and social care training. The RDT has carefully considered the opinions expressed by the study participants and has formulated recommendations for enhancing service delivery and improvement. This aligns with the RDT's knowledge base, as all members, except me, are part of the PPG, making the recommendations relevant to enhancing this role.

5.7 Conclusion

In this chapter, I have considered the key findings of this research study in relation to other literature and discussed some of the policies and practices implicated through this research. I have discussed co-production as a methodology and explored the issues faced regarding ethical approval from a university. I concluded by discussing the strengths and limitations of the research and sharing the recommendations made by the Research Design Team. In the next chapter, I will conclude the research study and discuss how the research contributes to the literature and what we have learned from this study.

Chapter 6: Conclusion

6.1 Introduction

In this final chapter, I will briefly consider the impact of this research on Service User and Carer Involvement (SU&CI), and provide my perspectives on future research, furthering knowledge in this field.

6.2 The impact of this research study

This research study has achieved an in-depth understanding of Service Users and Carers perspectives regarding their involvement in health and social care education at a university. The focus of the study was specifically whether participants felt valued by the Higher Education Institute (HEI) for their involvement. The study was ambitiously co-produced with SU&Cs embedded in the involvement agenda at the same HEI. Despite institutional challenges and the global health emergency of the pandemic, the four members of the research design team and I designed, analysed, and concluded this research while maintaining the co-produced element.

We have learned from this study that participants feel valued for their contributions, experiencing a multi-layered impact that includes being respected, treated as team players, being listened to, feeling a sense of giving back, gaining confidence in collaborative roles, and fostering positive relationships with students and staff. This highlights the significant impact of their involvement, and for some participants, it even helped them discover a sense of purpose related to their occupational identity. The research has emphasised the importance of feeling valued, as it is intrinsic to engagement and participation.

The diverse sample, encompassing various age ranges and experiences of involvement, resolutely reported feeling respected and listened to, reflecting a commitment to equality and diversity by staff at the HEI. Colleagues new to involvement can benefit from this research as it establishes standards that can guide their involvement training. Additionally, we have learned about the importance of measuring the level of involvement to assess the effectiveness of participants' contributions and the competencies of the academic.

This research study covers all areas of involvement in a HEI, exploring different applications of Service User and Carer Involvement (SUCI) across various disciplines. This comprehensive approach makes our research unique and contributes to filling a knowledge gap regarding SU&C perspectives in all aspects of teaching and learning. By encouraging SU&Cs to share their personal experiences in a myriad of ways, we bring a fresh perspective to this area of knowledge. The principles of this research can be applied to all areas of involvement in education, practice, and research. As a result, the literature is evolving, and further research can advance this knowledge.

The results of this research provide a comprehensive view of involvement at the University of Huddersfield School of Human and Health Sciences. Participants felt strongly valued for their involvement, and the research highlights why this is crucial. Ensuring the voice of SU&Cs is heard and documented in this field is a critical component of involvement, partnership working, and collaboration, which all health and social care providers and educators should aspire to. This research presents a path to meaningful involvement that, in turn, impacts involvement across an institution, whether in practice, education, or policymaking.

The principles of this study can also be applicable within a research context to enhance the quality of Patient and Public Involvement (PPI) in research. This research showcases the fundamental elements of meaningful involvement and offers strategies for designing meaningful involvement for PPI researchers, thereby increasing the likelihood of securing research bids, and enhancing the overall strength of research endeavour's.

6.3 Further developments following this research

This research has conducted a practical test of the co-production principles within a university student project, revealing the encountered challenges and identifying areas that warrant further investigation in relation to the co-production approach.

As a result of this research, the RDT (Research and Development Team) expressed a sense of fulfilment from their collaboration in this study and expressed a desire to continue their involvement. Sustaining this endeavour on a relevant project beyond this foundational study would be a positive step for both the research field and the involvement agenda at the University of Huddersfield.

Having established what factors contribute to the sense of value felt by SU&Cs and having explored their motivations, we can now build upon this foundation and conduct research that specifically focuses on projects promoting successful involvement. For instance, we can explore the co-production of modules, schemes of work, or classroom sessions that incorporate involvement, draw on user knowledge, and utilise teaching tools beyond storytelling.

This research also highlights the crucial aspect of including the voice of SU&Cs in the research process, whether through a consultative, participatory, or partnership approach. Demonstrating a high level of respect for the voice of SU&Cs in relevant research and a commitment to their inclusion should be considered indicative of good practice and quality. It embodies person-centered practice and reflects the researcher team's attitudes towards involvement. Incorporating the perspectives of service users, patients, carers, and experts by experience is an essential component of research in this field, and we must always adhere to the universal principle of "nothing about us without us."

References

Adass. (2023). *Briefing 1: Short summary of the Care Bill.* Carers trust. Adass.ork.uk. Carers Trust Care Bill Short Briefing 1.pdf (adass.org.uk)

Anrooij, K. V., Frankena, T. K., Van Der Cruijsen, A., Jansen, H. M., Naaldenberg, J., & Bevelander, K. E. (2022). Shared decision making in inclusive research: Reflections from an inclusive research team. *British Journal of Learning Disabilities*, *50*(4), 554–563. https://doi.org/10.1111/bld.12450

Arksey, H., & O'Malley, L. (2005). Scoping studies: towards a methodological framework. *International Journal of Social Research Methodology*, *8*(1), 19–32. https://doi.org/10.1080/1364557032000119616

Arnstein, S. R. (1969). A Ladder Of Citizen Participation, Journal of the American Institute of Planners, 35:4, 216-224, A Ladder Of Citizen Participation: Journal of the American Institute of Planners: Vol 35, No 4 (tandfonline.com)

Aspers, P., & Corte, U. (2019). What is Qualitative in Qualitative Research. *Qualitative Sociology*, *42*(2), 139–160. https://doi.org/10.1007/s11133-019-9413-7

Aburn, G., Gott, M., & Hoare, K. (2021). Experiences of an insider researcher – interviewing your own colleagues. *Nurse Researcher*, *29*(3), 22–28. https://doi.org/10.7748/nr.2021.e1794

Aveyard, H., & Bradbury-Jones, C. (2019). An analysis of current practices in undertaking literature reviews in nursing: findings from a focused mapping review and synthesis. *BMC Medical Research Methodology*, *19*(1). https://doi.org/10.1186/s12874-019-0751-7

Barber, R., Beresford, P., Boote, J., Cooper, C., & Faulkner, A. (2011). Evaluating the impact of service user involvement on research: a prospective case study. *International Journal of Consumer Studies*, *35*(6), 609–615. https://doi.org/10.1111/j.1470-6431.2011.01017.x

Basset, T., Campbell, P. J., & Anderson, J. T. (2006). Service User/Survivor Involvement in Mental Health Training and Education: Overcoming the Barriers. *Social Work Education*, *25*(4), 393–402. https://doi.org/10.1080/02615470600593675

Bell, D., & Pahl, K. (2018). *Co-production: towards a utopian approach. International Journal of Social Research Methodology*, 21(1), 105–117. https://doi.org/10.1080/13645579.2017.1348581

Beresford, P. (2002). Thinking about "mental health": Towards a social model. *Journal of Mental Health*, *11*(6), 581–584. https://doi.org/10.1080/09638230020023921

Beresford, P. (2012). Psychiatric system survivors: an emerging movement. In *Routledge Handbook of Disability Studies* (1st Edition). Routledge. https://doi.org/10.4324/9780203144114-19

Beresford, P. (2020). PPI Or User Involvement: Taking stock from a service user perspective in the twenty first century. *Research Involvement and Engagement*, *6*(1). https://doi.org/10.1186/s40900-020-00211-8
Beresford, P. (2019). Public Participation in Health and Social Care: Exploring the Co production of Knowledge. *Frontiers in Sociology*, *3*.https://doi.org/10.3389/fsoc.2018.00041

Berger, R. (2015). Now I see it, now I don't: researcher's position and reflexivity in qualitative research. *Qualitative Research*, *15*(2), 219–234. https://doi.org/10.1177/1468794112468475

Berghs, M., Atkin, K., Hatton, C., & Thomas, C. (2019). Do disabled people need a stronger social model: a social model of human rights? *Disability & Society*, *34*(7–8), 1034–1039. https://doi.org/10.1080/09687599.2019.1619239

Boaz, A., *(2021). Lost in co-production: To enable true collaboration we need to nurture different academic identities.* (2021, June 30). Impact of Social Sciences. https://blogs.lse.ac.uk/impactofsocialsciences/2021/06/25/lost-in-co-production-to-enabletrue-collaboration-we-need-to-nurture-different-academic-identities/

Bocking, J., Happell, B., Scholz, B., Horgan, A., Goodwin, J., Lahti, M., Platania-Phung, C., MacGabhann, L., Greaney, S., Granerud, A., Griffin, M., Russell, S., Bjornsson, E., Van Der Vaart, K. J., Ellilä, H., Hals, E., Doody, R., Vatula, A., Pulli, J., . . . Biering, P. (2019). 'It is meant to be heart rather than head'; International perspectives of teaching from lived experience in mental health nursing programs. *International Journal of Mental Health Nursing*, *28*(6), 1288–1295. https://doi.org/10.1111/inm.12635

Bourdieu, P., & Johnson, R. (1998). *Practical Reason: On the Theory of Action* (1st ed.). Stanford University Press.

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brindle, D. (2015, October 13). A quiet revolution: looking back at 20 years of social services reform. *The Guardian*. A quiet revolution: looking back at 20 years of social services reform | Social Care Network | The Guardian

Brooks, J., McCluskey, S., Turley, E. L., & King, N. (2015). The Utility of Template Analysis in Qualitative Psychology Research. *Qualitative Research in Psychology*, *12*(2), 202–222. https://doi.org/10.1080/14780887.2014.955224

Brown, P., & Zavestoski, S. (2004). Social movements in health: an introduction. *Sociology of Health and Illness*, *26*(6), 679–694. https://doi.org/10.1111/j.0141-9889.2004.00413.x

Buckley, B. J. R., Newton, J., Knox, S., Noonan, B., Smith, M., & Watson, P. M. (2022). Multi-stakeholder perspectives on co-production: Five key recommendations following the Liverpool Co-PARS project. *Qualitative Research in Sport, Exercise and Health*, 1–15. https://doi.org/10.1080/2159676x.2022.2152085

Campbell, D. (2013). *Mid Staffs hospital scandal: the essential guide.* (The Guardian). https://www.theguardian.com/society/2013/feb/06/mid-staffs-hospital-scandal-guide

CQC. (2023). *Regulation 10: Dignity and respect - Care Quality Commission*. Regulation 10: Dignity and respect - Care Quality Commission (cqc.org.uk)

Central and Northwest London NHS Foundation Trust. (2023). *Support and involvement organisations* . Patient, Carer and Public Involvement Team :: Central and North West London NHS Foundation Trust (cnwl.nhs.uk)

Charlton, J. I. (2000). *Nothing About Us Without Us: Disability Oppression and Empowerment*. University of California Press.

Chassot, C. S., & Mendes, F. R. P. (2015). The experience of mental distress and recovery among people involved with the service user/survivor movement. *Health*. https://doi.org/10.1177/1363459314554313

Churchill, M. (2018). *NHS England » Improving healthcare by involving carers*. https://www.england.nhs.uk/blog/improving-healthcare-by-involving-carers/

Clarke, S., & Holttum, S. (2013). Staff Perspectives of Service User Involvement on Two Clinical Psychology Training Courses. *Psychology, Learning and Teaching*, *12*(1), 32–43. https://doi.org/10.2304/plat.2013.12.1.32

Co-Production Collective. (2020). Co-Pro Stories: Exploring lived experiences of coproduction. London: University College London;. assets.website-files.com/5ffee76a01a63b6b7213780c/602e8d10d2437c983f6d3e0f_Co-Pro-Stories-ShortFinal.pdf

Corry, M., Porter, S., & McKenna, H. (2018). The redundancy of positivism as a paradigm for nursing research. *Nursing Philosophy*, *20*(1), e12230. https://doi.org/10.1111/nup.12230

Costley, C., Elliott, G., & Gibbs, P. (2014). Key concepts for the Insider-Researcher. In *SAGE Publications Ltd eBooks* (pp. 1–7). https://doi.org/10.4135/9781446287880.n1

Coughlan, M. P., & Cronin, P. (2021). Doing a literature review in nursing, health and social care. 3rd edition. SAGE.

Creswell, J. W. (2018). *Educational research: Planning, conducting, and evaluating quantitative and qualitative research*. Pearson Education.

Crossman, A. (2021). How to Understand Interpretive Sociology. ThoughtCo. Definition of Interpretive Sociology (thoughtco.com)

Cueto, M. (2004). The ORIGINS of Primary Health Care and SELECTIVE Primary Health Care. *American Journal of Public Health*, *94*(11), 1864–1874. https://doi.org/10.2105/ajph.94.11.1864

Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6–12 September 1978. (2004). *Development*, *47*(2), 159–161. https://doi.org/10.1057/palgrave.development.1100047

DoH. (2005). *Creating a Patient-led NHS is available on the Department of Health (265602).* DH Publications. Creating a Patient-led NHS (plymouth.ac.uk)

DoH. (2006) *Our health, our care, our say: a new direction for community services. (HM Government* Cm 6737). HMSO. Our health, our care, our say: a new direction for communityservicesJanuary 2006 CM 6737 (publishing.service.gov.uk)

DoH, (2008). *High* Quality Care For All, NHS Next Stage Review Final Report. (CM 7432). Crown copyright. High Quality Care For All NHS Next Stage Review Final Report CM 7432 (publishing.service.gov.uk)

Disability Equality Northwest. (2020). *Timeline History of the Disabled People's Movement.* DENW-UKDHM-timeline-November-2020.pdf (disability-equality.org.uk)

Disability Discrimination Act, 1995. Disability Discrimination Act 1995 (legislation.gov.uk)

Dixon, J., & Dewar, S. (2000). The NHS plan. *BMJ*, *321*(7257), 315–316. https://doi.org/10.1136/bmj.321.7257.315

Dodgson, J. E. (2019). Reflexivity in Qualitative Research. *Journal of Human Lactation*, *35*(2), 220–222. https://doi.org/10.1177/0890334419830990

Dunne, M., Pryor, J., & Yates, P. (2005). *Becoming a Researcher*. McGraw-Hill Education.

Elsevier Author Services. (2022, August 8). *Clinical Questions: PICO and PEO Research Author Services Blog*. Elsevier Author Services - Articles. https://scientificpublishing.webshop.elsevier.com/research-process/clinical-questionspicoand-peo-research/

Elwell, F. (2005). Verstehen: The Sociology of Max Weber. http://www.faculty.rsu.edu/users/f/felwell/www/Theorists/Weber/Whome2.htm

Erlinsson, C, & Brysiewicz, P. (2013). Orientation among multiple truths: An introduction to qualitative research. African journal of emergency medicine, 3(2), 92- 99. https://doi.org/10.1016/j.afjem.2012.04.005

Equality Act 2010. (2023) Equality Act 2010 (legislation.gov.uk)

Facer, K & Enright, B. (2016). *Creating Living Knowledge: The Connected Communities Programme, community-university partnerships, and the participatory turn in the production of knowledge.* Arts and Humanities Research Council. FINAL_FINAL_CC_Creating_Living_Knowledge_Report.pdf (bris.ac.uk)

Farr, M., Davies, P., Andrews, H., Bagnall, D. M., Brangan, E., & Davies, R. (2021). Coproducing knowledge in health and social care research: reflections on the challenges and ways to enable more equal relationships. *Humanities & Social Sciences Communications*, *8*(1). https://doi.org/10.1057/s41599-021-00782-1

Fleming, S. (2022). *3 reasons why we're breaking up with narrative reviews (and you should too) - Traverse Science*. Traverse Science. https://traversescience.com/review/best-style-of-review/

Fox, R. (2001). Constructivism Examined. *Oxford Review of Education*, *27*(1), 23–35. https://doi.org/10.1080/03054980125310

Fox, J. (2011). 'The view from inside': understanding service user involvement in health and social care education. *Disability & Society*, *26*(2), 169–177. https://doi.org/10.1080/09687599.2011.544057

Fox, J. (2020). Perspectives of experts-by-experience: an exploration of lived experience involvement in social work education. *Social Work Education*, *41*(4), 587–604. https://doi.org/10.1080/02615479.2020.1861244

Francis, R. (2013). *Report of the mid Staffordshire NHS Foundation Trust Public Inquiry*. London: The Stationery Office. http://www.midstaffspublicinquiry.com/report

Frankena, T. K., Van Schrojenstein Lantman De Valk, H., Cardol, M., Van Der Cruijsen, A., Jansen, H. M., Leusink, G. L., & Naaldenberg, J. (2019). Contributing to Inclusive Research Policy and Practice: A synthesis of four inclusive (Health) research projects. *Journal of Policy and Practice in Intellectual Disabilities*, *16*(4), 352–360. https://doi.org/10.1111/jppi.12293

GMC. (2023) *Charter for patients, relatives and carers*. https://www.gmcuk.org/about/what-we-do-and-why/charter-for-patients-relatives-and-carers

Gann, P. (2017). *An Explication and Application of Max Weber's Theoretical Construct of Verstehen.* Journal of Social Work Values & Ethics, Fall 2017, Vol. 14, No. 2 - pp 31 – 34.Fall2017-Vol-14-No-2-Full-issue-FINAL-revised.pdf (jswve.org)

Gomm. (2008). *Social research methodology: a critical introduction* (2nd ed.). Palgrave Macmillan.

Gray, D. E. (2014). *Doing research in the real world*. London: Sage

Griffiths, J., Speed, S., Horne, M., & Keeley, P. (2012). 'A caring professional attitude': What service users and carers seek in graduate nurses and the challenge for educators. Nurse Education Today, 32(2), 121–127. https://doi.org/10.1016/j.nedt.2011.06.005

Grix, J. (2002). Introducing Students to the Generic Terminology of Social Research. *Politics*, *22*(3), 175–186.https://doi-org.libaccess.hud.ac.uk/10.1111/14679256.00173

Ham, C. (2009). *Health Policy in Britain (Public Policy and Politics)* (6th ed. 2009). Springer.

Hammersley, Martyn. (2013). *What is qualitative research?* Bloomsbury Publishing.

Hampton, J. (2020). The 1970 chronically sick and disabled persons act – fifty years on. *Disability &Amp; Society*, *35*(5), 831–836. https://doi.org/10.1080/09687599.2020.1751080

Hanemaayer, A. (2021). The Ethic of Responsibility: Max Weber's Verstehen and Shared Decision-Making in Patient-Centred Care. The Journal of Medical Humanities. https://doi.org/10.1007/s10912-019-09577-7

Hansson, S., Carlstedt, A., & Morville, A. (2021). Occupational identity in occupational therapy: A concept analysis. *Scandinavian Journal of Occupational Therapy*, *29*(3), 198–209. https://doi.org/10.1080/11038128.2021.1948608

Happell, B., Byrne, L., Platania-Phung, C., Harris, S., Bradshaw, J., & Davies, J. I. (2014). Lived-experience participation in nurse education: Reducing stigma and enhancing popularity. *International Journal of Mental Health Nursing*, *23*(5), 427–434. https://doi.org/10.1111/inm.12077

Happell, B., Bennetts, W., Harris, S., Platania-Phung, C., Tohotoa, J., Byrne, L., & Wynaden, D. (2015). Lived experience in teaching mental health nursing: Issues of fear and power. *International Journal of Mental Health Nursing*, *24*(1), 19–27. https://doi.org/10.1111/inm.12091

Happell, B., & Bennetts, W. (2016). Triumph and adversity: Exploring the complexities of consumer storytelling in mental health nursing education. *International Journal of Mental Health Nursing*, *25*(6), 546–553. https://doi.org/10.1111/inm.12244

Happell, B., Bennetts, W., Platania-Phung, C., & Tohotoa, J. (2016). Exploring the Scope of Consumer Participation in Mental Health Nursing Education: Perspectives From Nurses and Consumers. *Perspectives in Psychiatric Care*, *52*(3), 169–177. https://doi.org/10.1111/ppc.12113

Happell, B., Horgan, A., Manning, F., Doody, R., Greaney, S., Goodwin, J., Bocking, J., Waks, S., Hals, E., Griffin, M., Scholz, B., Granerud, A., Platania-Phung, C., Russell, S., MacGabhann, L., Pulli, J., Vatula, A., Van Der Vaart, K. J., Allon, J., Biering, P. (2020a). Experts by experience in mental health nursing education: What have we learned from the commune project? *Journal of Psychiatric and Mental Health Nursing*, *27*(6), 675–677. https://doi.org/10.1111/jpm.12635

Happell, B., Bocking, J., Scholz, B., & Platania-Phung, C. (2020). The tyranny of difference: exploring attitudes to the role of the consumer academic in teaching students of mental health nursing. *Journal of Mental Health*, *29*(3), 263–269. Https://doi.org/10.1080/09638237.2019.1581344

Happell, B., Warner, T., Waks, S., Horgan, A., Manning, F., Doody, R., Greaney, S., Goodwin, J., Hals, E., Griffin, M., Scholz, B., Granerud, A., Platania-Phung, C., Russell, S., MacGabhann, L., Pulli, J., Vatula, A., Van Der Vaart, K. J., Allon, J., . . . Biering, P. (2022). Something special, something unique: Perspectives of experts by experience in mental health nursing education on their contribution. *Journal of Psychiatric and Mental Health Nursing*, *29*(2), 346–358. https://doi.org/10.1111/jpm.12773

Happell, B., Gordon, S., Sharrock, J., Horgan, A., Kenny, N., & Warner, T. (2023). There is something about oppression: Allies' perspectives on challenges in relationships with experts by experience. *International Journal of Mental Health Nursing*. https://doi.org/10.1111/inm.13117

Hasan, M. N. (2014). Positivism: to what extent does it aid our understanding of the contemporary social world? *Quality &Amp; Quantity*, *50*(1), 317- 325. https://doi.org/10.1007/s11135-014-0150-4

Haycock-Stuart, E., Donaghy, E., & Darbyshire, C. (2016). Involving users and carers in the assessment of preregistration nursing students' clinical nursing practice: a strategy for patient empowerment and quality improvement? *Journal of Clinical Nursing*, *25*(13–14), 2052–2065. https://doi.org/10.1111/jocn.13279

HCPC, (2017). *Standards of education and training.* HCPC. Standards of education and training | (hcpc-uk.org).

HCPC, (2023) *Service user and carer involvement*. https://www.hcpc-uk.org/education/resources/education-standards/service-user-and-carerinvolvement/

Heron, J., & Reason, P. (1997). A participatory inquiry paradigm. *Qualitative Inquiry*, *3*(3), 274–294. https://doi.org/10.1177/107780049700300302

Hickey, G. (2018, October 3). *Co-production from proposal to paper*. Nature. https://www.nature.com/articles/d41586018068619?error=cookies_not_supported&codee188059-4323-4658-9e23-fbed0563d0be

Horgan, A., Manning, F., Bocking, J., Happell, B., Lahti, M., Doody, R., Griffin, M., Bradley, S. P., Russell, S., Bjornsson, E., O'Donovan, M., MacGabhann, L., Savage, E., Pulli, J., Goodwin, J., Van Der Vaart, K. J., O'Sullivan, H., Dorrity, C., Ellilä, H., . . . Biering, P. (2018). 'To be treated as a human': Using co-production to explore experts by experience involvement in mental health nursing education – The COMMUNE project. *International Journal of Mental Health Nursing*, *27*(4), 1282–1291. https://doi.org/10.1111/inm.12435

Horgan, A., Manning, F., Donovan, M. O., Doody, R., Savage, E., Bradley, S. P., Dorrity, C., O'Sullivan, H., Goodwin, J., Greaney, S., Biering, P., Bjornsson, E., Bocking, J., Russell, S., MacGabhann, L., Griffin, M., Van Der Vaart, K. J., Allon, J., Granerud, A., . . . Happell, B. (2020). Expert by experience involvement in mental health nursing education: The coproduction of standards between Experts by Experience and academics in mental health nursing. *Journal of Psychiatric and Mental Health Nursing*, *27*(5), 553–562. https://doi.org/10.1111/jpm.12605

Hughes, M. (2017). What difference does it make? Findings of an impact study of service user and carer involvement on social work students' subsequent practice. *Social Work Education*, *36*(2), 203–216. https://doi.org/10.1080/02615479.2016.1274725

Irshaidat, R. (2019). Interpretivism vs. Positivism in Political Marketing Research. *Journal of Political Marketing*, *21*(2), 126–160. https://doi.org/10.1080/15377857.2019.1624286

Irvine, J., Molyneux, J., & Gillman, M. (2015). '*Providing a Link with the Real World*': Learning from the Student Experience of Service User and Carer Involvement in Social Work Education. *Social Work Educ*

Jackson, D., & Moorley, C. (2021). 'Nothing *about us without us'*: embedding participation in peer review processes. *Journal of Advanced Nursing*, *78*(5). https://doi.org/10.1111/jan.15122

King, N. (2004). Using templates in the thematic analysis of texts. In C. Cassell & G. Symon (Eds.), *Essential guide to qualitative methods in organizational research* (pp. 256–270). London: Sage Publications.

King-Owen, J. (2020). *Service User Involvement in Social Work Education. A case study. (Citizens Network).* Service User Involvement in Social Work Education (citizen-network.org)

Kiteley, R., & Stogdon, C. (2013). *Literature Reviews in Social Work*. SAGE.

Laidlaw, L. (2022). *Ethical research: "a state of being, not a state of doing"? | Co-Production Collective*https://www.coproductioncollective.co.uk/news/ethical-research-a-state-ofbeing-not-a-state-of-doing

Latimer, T., Roscamp, J., & Papanikitas, A. (2017). Patient-centredness and consumerism in healthcare: an ideological mess. *Journal of the Royal Society of Medicine*, *110*(11), 425–427. https://doi.org/10.1177/0141076817731905

Leadbeater, C. W. (2004). *Personalisation Through Participation: A New Script for Public Services*. https://www.amazon.com/Personalisation-Through-Participation-ScriptServices/dp/1841801224

Lea, L., Holttum, S., Cooke, A., & Riley, L. L. (2016). Aims for service user involvement in mental health training: staying human. *The Journal of Mental Health Training, Education and Practice*, *11*(4), 208–219. https://doi.org/10.1108/jmhtep-01-2016-0008

Leenaars, C. H. C., Tsaioun, K., Stafleu, F. A., Rooney, K., Meijboom, F. L. B., Ritskes-Hoitinga, M., & Bleich, A. (2021). Reviewing the animal literature: how to describe and choose between different types of literature reviews. *Laboratory Animals*, *55*(2), 129–141. https://doi.org/10.1177/0023677220968599

Legislation.gov.uk. *(2023a). The Health and Social Care Act 2001* *https://www.legislation.gov.uk/ukpga/2001/15/contents*

Legislation.gov.uk. (2023b) *The Care Act 2014.* Care Act 2014 (legislation.gov.uk)

Levac, D., Colquhoun, H., & O'Brien, K. K. (2010). Scoping studies: advancing the methodology. *Implementation Science*, *5*(1). https://doi.org/10.1186/1748-5908-5-69

Lewis, L. (2009). Mental health and human rights: a common agenda for service user/survivor and women's groups? *Policy and Politics*, *37*(1), 75–92. https://doi.org/10.1332/030557308x364187

Levine, P. (2011). Seeing Like a Citizen: The contributions of Elinor Ostrom to "Civic Studies." *The Good Society*, *20*(1), 3–14. https://doi.org/10.1353/gso.2011.0010

Lidwell, W. (2015). *The pocket universal principles of design : 150 essential tools for architects, artists, designers, developers, engineers, inventors, and makers*. Quarto Publishing Group USA.

Lindhult, E., & Axelsson, K. (2021). The logic and integration of productive research approaches. *International Journal of Managing Projects in Business*, *14*(1), 13–35. https://doi.org/10.1108/ijmpb-07-2020-0215

Lingard L. (2018). Writing an effective literature review: Part I: Mapping the gap. *Perspectives on medical education*, *7*(1), 47–49. https://doi.org/10.1007/s40037-0170401-x

Malleson, K. (2018) Equality Law and the Protected Characteristics. *Modern Law Review*, *81*(4), 598–621. https://doi.org/10.1111/1468-2230.12353

Marre L. (1977). Community health councils – a personal view. Community Health, 8 (3),164 -167.. Community Health Councils — a personal view on JSTOR

Massaro, M., Dumay, J., & Guthrie, J. (2016). On the shoulders of giants: undertaking a structured literature review in accounting. *Accounting, Auditing & Accountability*, *29*(5), 767–801. https://doi.org/10.1108/aaaj-01-2015-1939

McChesney, K., & Aldridge, J. M. (2019). Weaving an interpretivist stance throughout mixed methods research. *International Journal of Research & Method in Education*, *42*(3), 225–238. https://doi.org/10.1080/1743727x.2019.1590811

McKeown, M., Malihi-Shoja, L., Hogarth, R., Jones, F., Holt, K., Sullivan, P., Lunt, J., Vella, J., Hough, G. G., Rawcliffe, L., & Mather, M. L. (2012). The value of involvement from the perspective of service users and carers engaged in practitioner education: Not just a cash nexus. *Nurse Education Today*, *32*(2), 178–184. https://doi.org/10.1016/j.nedt.2011.07.012

McKeown, M., Dix, J. A., Jones, F., Carter, B., Malihi-Shoja, L., Mallen, E., & Harrison, N. A. (2014). Service user involvement in practitioner education: Movement politics and transformative change. *Nurse Education Today*, *34*(8), 1175–1178. https://doi.org/10.1016/j.nedt.2014.03.016

McSherry, R., & Duggan, S. (2016). Involving carers in the teaching, learning and assessment of masters students. *Nurse Education in Practice*, *16*(1), 156–159. https://doi.org/10.1016/j.nepr.2015.08.015

McCutcheon, K., & Gormley, K. (2014). Service-user involvement in nurse education: partnership or tokenism? *British Journal of Nursing*, *23*(22), 1196–1199. https://doi.org/10.12968/bjon.2014.23.22.1196

Metz, A., Boaz, A., & Robert, G. (2019). Co-creative approaches to knowledge production: what next for bridging the research to practice gap?, *Evidence & Policy*, *15*(3), 331-337. https://bristoluniversitypressdigital.com/view/journals/evp/15/3/article-p331.xml

Mold, A. (2015). *Making the patient-consumer: Patient organisations and health consumerism in Britain* (1st ed.). Manchester University Press.
Molyneux, J., & Irvine, J. (2004). Service user and carer involvement in social work training: a long and winding road? *Social Work Education*, *23*(3), 293–308. https://doi.org/10.1080/0261547042000224047

Munn, Z., Peters, M. D. J., Stern, C., Tufanaru, C., McArthur, A., & Aromataris, E. (2018). Systematic review or scoping review? Guidance for authors when choosing between a systematic or scoping review approach. *BMC Medical Research Methodology*, *18*(1). https://doi.org/10.1186/s12874-018-0611-x

NHS England. (2013). *NHS England » Updated NHS Constitution published*. https://www.england.nhs.uk/2013/03/nhs-constitution/

NHS England (2017). *NHS England » Involving people in their own health and care: statutory guidance for clinical commissioning groups and NHS England*.
NHS England » Involving people in their own health and care: statutory guidance for clinicalcommissioning groups and NHS England

NICE, (2019). *Quality statement 1: Empathy, dignity, and respect | Patient experience in adult NHS services | Quality standards | NICE*.
https://www.nice.org.uk/guidance/qs15/chapter/quality-statement-1-empathy-dignity-andrespect

NIHR, (2018). *Guidance on Co-producing a research project.* NIHR Involve.
Copro_Guidance_Feb19.pdf (invo.org.uk)

NIHR, (2020). *A map of resources for co-producing research in health and social care.* Map-of-resources-Web-version-v1.2.pdf (nihr.ac.uk)

Nasution, M. A. (2018). Ontology. *Journal of Physics*, *1116*, 022030.
https://doi.org/10.1088/1742-6596/1116/2/022030

National Involvement Standards. (2015). *Involvement for influence.*
https://www.nationalvoices.org.uk/sites/default/files/public/4pinationalinvolvementstandrdsfullreport20152.pdf

National Survivor User Network. (2021). *Lived Experience Leadership. Mapping the Lived Experience Landscape in Mental Health*.
https://www.nsun.org.uk/resource/lived-experience-leadership/

Newbigging, K., & Ridley, J. (2018). Epistemic struggles: The role of advocacy in promoting epistemic justice and rights in mental health. *Social Science & Medicine*, *219*, 36–44.
https://doi.org/10.1016/j.socscimed.2018.10.003

Newman, A. K., Carey, B., & Kinney, M. (2021). 'My Contributions Made a Significant Difference': Young Carers' Reflections on Their Participation in Social Work Admissions. *British Journal of Social Work*, *52*(5), 2931–2948. https://doi.org/10.1093/bjsw/bcab187

Nickerson, C. (2023a) *Interpretivism Paradigm & Research Philosophy.* Simply Sociology.
https://simplysociology.com/interpretivism-paradigm.html

Nickerson, C. (2023b). *Verstehen In Sociology: Empathetic Understanding.* Simply Sociology.
Verstehen in Sociology: Empathetic Understanding (simplysociology.com)

Noble, H., & Smith, J. (2015). Issues of validity and reliability in qualitative research. *Evidence-Based Nursing*, *18*(2), 34–35. https://doi.org/10.1136/eb-2015-102054

NMC. (2018). *Realising professionalism: Standards for education and training.* NMC.
education-framework.pdf (nmc.org.uk)

Ocloo, J., & Matthews, R. (2016). From tokenism to empowerment: progressing patient and public involvement in healthcare improvement. *BMJ Quality & Safety*, *25*(8), 626–632. https://doi.org/10.1136/bmjqs-2015-004839

Odejimi, O., Lang, L., & Serrant, L. (2021). Optimising service users and carers involvement in nursing and social work pre-registration degrees. *Nurse Education Today*, *107*, 105128. https://doi.org/10.1016/j.nedt.2021.105128

Oliver, M. (2013). The social model of disability: thirty years on. *Disability & Society*, *28*(7), 1024–1026. https://doi.org/10.1080/09687599.2013.818773

Oliver, M. (2016). Rewriting history: the case of the Disability Discrimination Act 1995. *Disability & Society*. https://doi.org/10.1080/09687599.2016.1213054

Olmos-Vega, F. M., Stalmeijer, R. E., Varpio, L., & Kahlke, R. (2022). A practical guide to reflexivity in qualitative research: AMEE Guide No. 149. *Medical Teacher*, 1–11. https://doi.org/10.1080/0142159x.2022.2057287

Oppong, S. (2014). A Critique of the Philosophical Underpinnings. *Academicus,* (10), 242254. https://doi.org/10.7336/academicus.2014.10.17

Ostrom, E. (1996). Crossing the great divide: Coproduction, synergy, and development. *World Development*, *24*(6), 1073–1087. https://doi.org/10.1016/0305-750x(96)00023-x Padgett, D, (2017 *Qualitative methods in social work research*. SAGE.

Park, Y. S., Konge, L., & Artino, A. R. (2020). The Positivism Paradigm of Research. *Academic Medicine*, *95*(5), 690–694. https://doi.org/10.1097/acm.0000000000003093

Parks, R. B., Baker, P., Kiser, L. L., Oakerson, R. J., Ostrom, E., Ostrom, V., Percy, S. L., Vandivort, M. B., Whitaker, G. P., & Wilson, R. K. (1981). CONSUMERS AS COPRODUCERS OF PUBLIC SERVICES: SOME ECONOMIC AND INSTITUTIONAL CONSIDERATIONS. *Policy Studies Journal*, *9*(7), 1001–1011. https://doi.org/10.1111/j.1541-0072.1981.tb01208.x

Parker, S. (2017, September 21). *The row over the abolition of community health councils rages on*. The Guardian. https://www.theguardian.com/society/2001/jan/08/localgovernment.nhs2000

Patient and public involvement in nurse education. (2018, May 31). Health Education England. https://www.hee.nhs.uk/our-work/patient-public-involvement-nurse-education#skip-link

Pennine Care NHS Foundation Trust. (n.d.). *Service user and carer involvement and Engagement.* https://www.penninecare.nhs.uk/involvement

Percy-Smith, B., Cuconato, M., Reutlinger, C., & Thomas, N. (2019). Action research with young people: possibilities and 'messy realities.' *Journal of Childhood and Adolescence Research*. https://doi.org/10.3224/diskurs.v14i3.02

Perry, B. (2022). Co-production as praxis: Critique and engagement from within the university. Methodological Innovations, 15(3), 341–352. https://doi.org/10.1177/20597991221129773Perry

Petticrew, M., & Roberts, H. (2006). Systematic reviews in the social sciences: a practical guide. *John Wiley.*

de Peuter, G., & Hall, S. (2007). Universities, intellectuals, and multitudes: An interview with Stuart Hall. In M. Coté, R. F. J. Day, & G. de Peuter (Eds.), *Utopian pedagogy: Radical experiments against neoliberal globalization* (pp. 108–128). Toronto: University of Toronto Press.

Pham, M. T., Rajić, A., Greig, J., Sargeant, J. M., Papadopoulos, A., & McEwen, S. A. (2014). A scoping review of scoping reviews: advancing the approach and enhancing the consistency. *Research Synthesis Methods*, *5*(4), 371–385. https://doi.org/10.1002/jrsm.1123

Polit, D. F., & Beck, C. T. (2013). *Study Guide for Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. Lippincott Williams &Wilkins.

Polit, D. F., & Beck, C. T. (2018). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice*. LWW.

Pratt, B. (2020). What constitutes fair shared decision-making in global health research collaborations? Bioethics, 34(9), 984–993. https://doi.org/10.1111/bioe.12793

PRISMA. (2023). http://www.prisma-statement.org/Extensions/ScopingReviews

Pulla, V., & Carter, E. (2018). *Employing Interpretivism in Social Work Research. International Journal of Social Work and Human Services Practice*. Horizon Research Publishing Vol.6. No.1, pp. 9-14. IJRH2-1929047620200504-61084-3v3zjb-libre.pdf(d1wqtxts1xzle7.cloudfront.net)

Ragin, C. (2004). Introduction to session 1: Defining qualitative research. In *Workshop on Scientific Foundations of Qualitative Research*, 22, ed. Charles C. Ragin, Joane Nagel, Patricia White. http://www.nsf.gov/pubs/2004/nsf04219/nsf04219.pdf

Rane, I. (2022). Verstehen -Types, Examples, Characteristics, Criticism. *Sociology Group: Welcome to Social Sciences Blog*. Verstehen -Types, Examples, Characteristics, Criticism (sociologygroup.com)

Read, S., Aries, A. M., Ashby, S., Bambrick, V., Blackburn, S., Clifford, H., Rhodes, C., Thirlwall, S., & Watkins, C. A. (2020). Facilitating personal development for public involvement in health-care education and research: A co-produced pilot study in one UK higher education institute. *Health Expectations*, *23*(5), 1191–1201. https://doi.org/10.1111/hex.13097

Reed, H., Couturiaux, D., Davis, M., Edwards, A. K., Janes, E., Kim, H. J., Melendez-Torres, G. J., Murphy, S., Rotevatn, T. A., Smith, J. S., & Evans, R. (2021). Co-production as an

Emerging Methodology for Developing School-Based Health Interventions with Students Aged 11–16: Systematic Review of Intervention Types, Theories and Processes and Thematic Synthesis of Stakeholders' Experiences. *Prevention Science*, *22*(4), 475–491. https://doi.org/10.1007/s11121-020-01182-8

Rees, C. E., Crampton, P., & Monrouxe, L. V. (2020). Re-visioning academic medicine through a constructionist lens. *Academic Medicine*, *95*(6), 846–850. https://doi.org/10.1097/acm.0000000000003109

Rhodes, C., & Nyawata, I. D. (2011). Service user and carer involvement in student nurse selection: Key stakeholder perspectives. *Nurse Education Today*, *31*(5), 439–443. https://doi.org/10.1016/j.nedt.2010.10.005

Rhodes, C. (2012). User involvement in health and social care education: A concept analysis. *Nurse Education Today*, *32*(2), 185–189. https://doi.org/10.1016/j.nedt.2011.11.012

Rhodes, C, A. (2014) The agency of service user and carer engagement in health and social care education. Doctoral thesis, University of Huddersfield. https://eprints.hud.ac.uk/id/eprint/23682/

Rhodes, C., Hardy, J., Padgett, K., Symons, J., Tate, J., & Thornton, S. (2014). 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. https://doi.org/10.11120/pblh.2013.00025

Robert, G., Williams, O., Lindenfalk, B., Mendel, P., Davis, L. M., Turner, S., Farmer, C., & Branch, C. (2021). Applying Elinor Ostrom's Design Principles to Guide Co-Design in Health(care) Improvement: A Case Study with Citizens Returning to the Community from Jail in Los Angeles County. *International Journal of Integrated Car*, *21*(1). https://doi.org/10.5334/ijic.5569

Rooney, J. M., Unwin, P., & Osborne, N. D. (2016). Gaining by giving? Peer research into service user and carer perceptions of inclusivity in Higher Education. *Social Work Education*, *35*(8), 945–959. https://doi.org/10.1080/02615479.2016.1227314

Rooney, J. M., Unwin, P., & Shah, P. (2019). Keeping us grounded: academic staff perceptions of service user and carer involvement in health and social work training. *Journal of Further and Higher Education*, *43*(7), 929–941. https://doi.org/10.1080/0309877x.2018.1429581

Rooney, J. M., & Unwin, P. (2021). Service user and carers' views of best practice in student selection at an English University. *Journal of Further and Higher Education*, *45*(5), 641–653. https://doi.org/10.1080/0309877x.2020.1804539

Russo, J., & Beresford, P. (2015). Between exclusion and colonisation: seeking a place for mad people’s knowledge in academia. *Disability & Society*, *30*(1), 153–157. https://doi.org/10.1080/09687599.2014.957925

Ryan, G. (2018). Introduction to positivism, interpretivism and critical theory. *Nurse Researcher*, *25*(4), 14–20. https://doi.org/10.7748/nr.2018.e1466

Saini, P., Roks, H., Sambrook, L., Balmer, A., McIntyre, J. C., Martin, A. P., Tait, J., Ashley Mudie, P., Shetty, A., & Nathan, R. (2022). A Qualitative Study Exploring the Experiences of Carers of Service Users with Complex Mental Health Needs. *British Journal of Psychiatry Open*, *8*(S1), S70. https://doi.org/10.1192/bjo.2022.240

Scammell, J., Heaslip, V., & Crowley, E. J. (2016). Service user involvement in preregistration general nurse education: a systematic review. *Journal of Clinical Nursing*, *25*(1–2), 53–69. https://doi.org/10.1111/jocn.13068

Schreur, Fides K., Lea, L. and Goodbody, L. (2015) Learning from service user and carer involvement in clinical psychology training. Journal of Mental Health Training, Education and Practice, 10 (3). pp. 137-149. https://www.emerald.com/insight/content/doi/10.1108/JMHTEP-02-2015-0009/full/html

SCIE. (2004). *Involving Service Users and Carers in Social Work Education.* Soxial Care Institute for Excellence. Involving service users and carers in social work education (scie.org.uk)

SCIE. (2020). *Equality Act 2010 - overview for social care*. Social Care Institute for Excellence. Equality Act 2010 | Overview for social care | SCIE

Sentesy, M. (2020). *Aristotle’s Ontology of Change (Rereading Ancient Philosophy)*. Northwestern University Press.

Shakespeare, T. (2017). *Disability: The Basics* (1st ed.). Routledge.

Short guide to consensus decision making - Seeds for Change. (n.d.). Seeds for Change. https://www.seedsforchange.org.uk/shortconsensus#process

Simmons, P., Hawley, C. J., Gale, T. M., & Sivakumaran, T. (2010). Service user, patient, client, user or survivor: describing recipients of mental health services. *The Psychiatrist*, *34*(1), 20–23. https://doi.org/10.1192/pb.bp.109.025247

Smith, J., & Dransfield, A. (2019). Patient and carer involvement in healthcare education, service delivery and research: avoiding tokenism. *Evidence-Based Nursing*. https://doi.org/10.1136/ebnurs-2019-103105

Smith, B., Williams, O., Bone, L., & Collective, T. M. S. W. C. (2022). Co-production: A resource to guide co-producing research in the sport, exercise, and health sciences.

Qualitative Research in Sport, Exercise and Health, 1–29. https://doi.org/10.1080/2159676x.2022.2052946

Southall, A. E., Gardner, F., & Baxter, L. P. (2021). Educator perspectives on teaching students from traumatic backgrounds and the potential for reflective circles. *Australian Educational Researcher*, *49*(4), 675–689. https://doi.org/10.1007/s13384-021-00455-7

Stanley, S., & Webber, M. (2022). Systematic Review of service user and carer involvement in qualifying Social Work Education: A Decade in Retrospect. *The British Journal of Social Work*, *52*(8), 4871–4893. https://doi.org/10.1093/bjsw/bcac080

Stocking, B. (1991). Patient's charter. *BMJ*, *303*(6811), 1148–1149. https://doi.org/10.1136/bmj.303.6811.1148

Sturgeon, D. (2018). The advantages and disadvantages of encouraging consumerist notions of health care at two minor injury units. *British Journal of Nursing*, *27*(6), 308–313. https://doi.org/10.12968/bjon.2018.27.6.308

Sucharew, H., & Macaluso, M. (2019). Methods for Research Evidence Synthesis: The Scoping Review Approach. *Journal of Hospital Medicine*, *14*(7), 416. https://doi.org/10.12788/jhm.3248

The Health Foundation. (2017). Empowering people and communities *The Health Foundation*. https://www.health.org.uk/blogs/empowering-people-and-communities-theroleofnationalbodies

The Health Foundation. (2023a). *National Health Service Reorganisation Act 1973*. NHS Reorganisation Act 1973 | Policy Navigator (health.org.uk)

The Survivors History Group. (2005). *Mental Health Survivors Movements and context.* Mental Health and Survivors Movements (studymore.org.uk)

Towle, A., Farrell, C., Gaines, M. E., Godolphin, W., John, G., Kline, C., Lown, B. A., Morris, P. A., Symons, J., & Thistlethwaite, J. (2016). The patient ' s voice in health and social care professional education. *International Journal of Health Governance*, *21*(1), 18–25. https://doi.org/10.1108/ijhg-01-2016-0003

Tran, B., Rafinejad-Farahani, B., Moodie, S., O'Hagan, R., & Glista, D. (2021). A Scoping Review of Virtual Focus Group Methods Used in Rehabilitation Sciences. *International Journal of Qualitative Methods*, *20*, 160940692110422. https://doi.org/10.1177/16094069211042227

Tritter, J. (2009). Revolution or evolution: the challenges of conceptualizing patient and public involvement in a consumerist world. *Health Expectations*, *12*(3), 275–287. https://doi.org/10.1111/j.1369-7625.2009.00564.x

Tucker, W. T. (1965). Max Weber's "Verstehen." *The Sociological Quarterly*, *6*(2), 157–165. http://www.jstor.org/stable/4105245

Turner et al., (2022). Coding for broader impact: leveraging coding skills for stakeholder communication. *Frontiers in Ecology and Environment, 20 (4), 201-268.* Coding for broader impact: leveraging coding skills for stakeholder communication (iecolab.org)

Turnhout, E., Metze, T., Wyborn, C., Klenk, N., & Louder, E. (2020). The politics of co-production: participation, power, and transformation. *Current Opinion in Environmental Sustainability*, *42*, 15–21. https://doi.org/10.1016/j.cosust.2019.11.009

UK Parliament (1991) *The Citizens charter*
House of Commons - Public Administration - Twelfth Report (parliament.uk)

UK Parliament (2007). *House of Commons Select Committee on Health Third Report.* https://publications.parliament.uk/pa/cm200607/cmselect/cmhealth/278/27806.htm

UK Parliament (2015). *The Community Health Councils*. https://www.legislation.gov.uk/wsi/2015/507/contents/made

UK Parliament, (2023). *Chronically Sick and Disabled Persons Act 1970*. https://www.legislation.gov.uk/ukpga/1970/44

UKRI, (2022). *Research organisations and research ethics committees.* https://www.ukri.org/councils/esrc/guidance-for-applicants/research-ethicsguidance/research-organisations-and-research-ethics-committees-our-principles-researchethics-committees/

UKRI, (2023). *Understanding health research. Ethical approval – UKRI*

UPIAS and The Disability Alliance. (1975, transcribed 1997). *Fundamental principles of disability a discussion*. fundamental principles.PDF (leeds.ac.uk)

Unwin, P., Rooney, J. M., & Cole, C. (2017a). Service user and carer involvement in students' classroom learning in higher education. Journal of Further and Higher Education, 42(3), 377 388. https://doi.org/10.1080/0309877x.2017.1281886

Unwin, P., Rooney, J. M., Osborne, N. D., & Cole, C. (2017b). Are perceptions of disability changed by involving service users and carers in qualifying health and social work training? *Disability & Society*, *32*(9), 1387–1399. https://doi.org/10.1080/09687599.2017.1322498

Unwin, P., & Rooney, J. M. (2020). The 'nuts and bolts' of including service users and carers in the recruitment of health and social work students in an English university—An interdisciplinary critique. *Health Expectations*, *23*(6), 1523–1532. https://doi.org/10.1111/hex.13137

Vargas, C. R., Whelan, J., Brimblecombe, J., & Allender, S. (2022). Co-creation, co-design, coproduction for public health – a perspective on definition and distinctions. *Public Health Research & Practice*, *32*(2). https://doi.org/10.17061/phrp3222211

Vaughn, L. M., & Jacquez, F. (2020). Participatory Research methods – choice points in the research process. *Journal of Participatory Research Methods*, *1*(1). https://doi.org/10.35844/001c.13244

Verschuere, B., Vanleene, D., Steen, T., & Brandsen, T. (2018). Democratic Co-Production. *Routledge eBooks* (pp. 243–251). https://doi.org/10.4324/9781315204956-38

Von Unger, H. (2021). *Historical Social Research / Historische Sozialforschung*, Vol. 46, No. 2, Special Issue: Reflexivity Between Science and Society pp. 186-204. https://www.jstor.org/stable/27032978

Ward, E. (2021). *No longer fledglings but struggling to fly: Peer Support Workers' experiences of forming an occupational identity within an urban NHS trust:* An Interpretative phenomenological Analysis. Doctoral thesis, London Metropolitan University. https://repository.londonmet.ac.uk/6934/

Ward, L. J., & Rhodes, C. (2010). Embedding consumer culture in health and social care education - a university office's perspective. *International Journal of Consumer Studies*, *34*(5), 596–602. https://doi.org/10.1111/j.1470-6431.2010.00911.x

Waring, J. (2013). Looking back (and forwards) at General Management: 30 years on from the Griffiths Report. *Journal of Health Services Research & Policy*. https://doi.org/10.1177/1355819613503632

Waterman, I. R. (2013). Disabled Access to Facilities. *Routledge EBooks*. https://doi.org/10.4324/9781315001647

Watson, F., Glascott, M., Eke, A., Hedgecock, L., Kelly, M. M., Saint, P., Singh, J., Small, V., Tasker, F., & Walker, G. (2022). Key stakeholder perspectives on expert-by-experience involvement in the values-based recruitment of student mental health nurses: A co-produced qualitative study. *Nurse Education Today*, *118*, 105513. https://doi.org/10.1016/j.nedt.2022.105513

Webber, M., & Robinson, K. A. (2012). The Meaningful Involvement of Service Users and Carers in Advanced-Level Post-Qualifying Social Work Education: A Qualitative Study. *British Journal of Social Work*, *42*(7), 1256–1274. https://doi.org/10.1093/bjsw/bcr141

WHO. (1978). *Declaration of Alma-Ata International Conference on Primary Health Care, Alma-Ata, USSR, 6-12 September 1978.* Microsoft Word - almaata_declaration_en.doc (who.int).

Willis, G. P. (2012) Raising the bar, shape of caring review. (Health education England). 2348Shape-of-caring-review-FINAL.pdf (hee.nhs.uk).

Wood S, Collins A & Taylor A (2015) *Is the NHS Becoming More Person Centred?* The Health Foundation. https://www.health.org.uk/sites/default/files/IsTheNHSBecomingMorePersonCentred.pdf

Wyborn, C., Louder, E., Harrison, J. J. E. K., Montambault, J., Montana, J., Ryan, M., Bednarek, A. T., Nesshöver, C., Pullin, A. S., Reed, M., Dellecker, E., Kramer, J. K., Boyd, J., Dellecker, A., & Hutton, J. (2018). Understanding the Impacts of Research Synthesis. *Environmental Science & Policy*, *86*, 72–84. https://doi.org/10.1016/j.envsci.2018.04.013

Yanto, E. S., & Pandin, M. G. R. (2023). The Position of Insider (EMIC) and Outsider (ETIC): A review of Deborah Court and Randa Khair Abbas' Insider-Outsider Research in Qualitative Inquiry: New Perspectives on Method and Meaning. *The Qualitative Report*. https://doi.org/10.46743/2160-3715/2023.6190

APPENDIX A

University of HUDDERSFIELD
Inspiring global professionals

Research design team participants required for a co-produced study.

I am studying a Masters by Research qualification here at the University and I am looking for people to join me in my research study. The question I would like to explore is:

Do I feel valued? A co-produced exploration into the notion of value from the perspective of a service user or carer participating in a university health and social care education setting?

Are you interested in research? Are you interested in designing a research study? Are you interested in working on a co-produced project?

Co–produced = A project that is co-produced is one in which researchers, practitioners and the public together share power and responsibility for the work throughout. *Gary Hickey. (2018). Senior public-involvement manager at INVOLVE, a UK health-research advisory group.*

Rationale:

I held a very informal discussion with some members of the Public Partnership Group a few months ago and the theme of value continually came up. There is a lot that we can learn from why and if people feel valued regarding the input they make. Because the research will explore the feelings of value that service users or carers feel when they participate in aspects of health or social care education. It feels only natural to me, that this piece of work should be co designed with service users and carers who have their own perspective of participating in health and social care education

I would like people to join me in making the decisions about how we do the research and analyse the data we gather. The findings from this research will hopefully develop into a series of recommendations to the School of Human and Health Sciences and therefore I feel it is essential that this work is co-produced and able to robustly reflect the thoughts and viewpoints of all involved from the very foundations of the research.

Stage one:

The first thing I need is to get a group of people together who are interested in designing the research. This will be called the research design group. Here we will work together to design how we are going to find out the answers to the question, how we are going to ask people, what resources we need, what we are going to ask them and then how we look at the results. These are all the methods, and everyone should have a say in how we do it.

What you will do:

I imagine that we will need about 3 maybe 4 meetings together to design the research and agree on how we carry it out. The meetings can either be on the university campus or using an online meeting system. The dates and times of the meetings will be agreed by everyone in the research design group.

Once we have done this first part then the research will need to be carried out. You can facilitate on the dates when we are gathering data. This will be with me (I will nominate myself to be involved with the data gathering groups stages as this is my research degree). when we have more details, a schedule of facilitators can be drawn up.

Stage two:

I imagine we will need to meet regularly throughout stage two of the study so that we can touch base on what data we have and discuss the findings and analysis. We may need to meet 3 or 4 times throughout the study or more. Again, this will be discussed at the initial set up meeting.

Once we have all the data then I will write up the findings (it is my MSc and so I am required to submit the work) I would also like to invite all the research design group to present the findings with me at a presentation? This will be at the end of the study and at a time and place that we are all in agreement with.

How the experience might benefit you:

I am hoping that the experience will be of great value to everyone involved. We will learn new skills and learn more about research and how we do it, particularly in a co-productive way. It is important that we work at developing working relationships with each other. I hope that we can work informally on things.

If you are interested, I'm really excited about this research and am really looking forward to hearing from you.

I can offer you your travel expenses reimbursed plus a possible parking space and of course refreshments and lunches if needed. I can also offer you a fun experience and one that I hope you will really value.

Let me know if you think this is for you or want to chat

further. Alison Morris u172283@hud.ac.uk 01484473491

You can also contact my supervisors for any further information. My supervisors will act as my advisors throughout the whole of my research degree and can also answer any queries you may have regarding this study.
My two supervisors are:

Dr Christine Rhodes

Dr Christine Smith

GDPR information:

- The University of Huddersfield is responsible for the secure management of the data i.e. the 'data controller'
- The legal basis for the collection of the data is usually 'a task in the public interest'.
- The researcher or research team (including transcribers) is the recipient of the data i.e. 'the data processor'.
- The data subject should contact the University Solicitor (as the Data Protection Officer) if they wish to complain about the management of their data. If they are not satisfied, they may take their complaint to the Information Commissioner's Office (ICO).
- You are also required to detail precisely how your data will be safely stored, and when
  it will be destroyed (i.e. as soon as it is no longer needed). You will also need to detail the additional safeguards you will put in place if the data will be transferred outside Europe.

APPENDIX B

Research design group - Consent form

Research title:

As a Service User or Carer, do I feel that my lived experience contribution is valued by the School of Human and Health Sciences at the University of Huddersfield.

I agree to be a member of the research design group for the above study.

My contact details are:

-

I agree to meeting for a possible 3 or 4 meetings during the initial stages of designing the research (dates listed below). After the design period we will meet to discuss the progress and actions of the research and data gathering activities. The dates, venues and times for these meetings have been agreed as:

Design meetings:

Meeting 1 3.3.20

Meeting 2 18.3.20

Meeting 3____

Meeting 4____

Progress meeting dates x 4

____

(Please tick)

I have received a copy of the INVOLVE guidelines on **co-producing research**

☐

I have received information on how I can reimburse my travel

☐

I have had the opportunity to ask questions ☐

If you require further information, you can contact - Alison Morris (the researcher) or the Supervisors - details available at the bottom of this document.

I am aware of how to contact the supervisors and the researcher. It has been explained to me what support services are available to me within the university and throughout this research project.

☐

We have agreed on a role descriptor for the research design group which is attached.

Do you wish to be anonymous or cited in the report/ writing up of the research?

I give/do not give consent to be cited /quoted in the write up of this research and in any publications which may follow. I will be able to read the documents before submission publication for approval. (Delete as appropriate)

Reasonable adjustments:

____

Individual research goal/ specific training needs identified:

GDPR

- As part of your legal obligations to research participants, prior to embarking on any research study that involves the handling of personal (i.e. identifying) data, I (the student research) are required to inform them of the following:
- The University of Huddersfield is responsible for the secure management of the data i.e. the 'data controller'
- The legal basis for the collection of the data is usually 'a task in the public interest'.
- The researcher or research team (including transcribers) is the recipient of the data i.e. 'the data processor'.
- The data subject should contact the University Solicitor (as the Data Protection Officer) if they wish to complain about the management of their data. If they are not satisfied, they may take their complaint to the Information Commissioner's Office (ICO).
- You are also required to detail precisely how your data will be safely stored, and when it will be destroyed (i.e. as soon as it is no longer needed). You will also need to detail the additional safeguards you will put in place if the data will be transferred outside Europe.

Signed:

____

Date:

____

Research Student

____date________________________

Supervisors:
Dr Christine Rhodes: c.a.rhodes@hud.ac.uk

Dr Christine Smith: c.smith4@hud.ac.uk

APPENDIX C

THE UNIVERSITY OF HUDDERSFIELD

School of Human and Health Sciences – School Research Ethics and Integrity Committee

APPLICATION FORM

Please complete and return via email to:
Kirsty Thomson SREIC Administrator: hhs_srep@hud.ac.uk

Name of applicant: Alison Morris

Title of study:

Do I feel Valued? Using co – production to discover the notions of value from the perspective of service users and carers involved in health and social care education.

Department: Human and Health Sciences Date sent:

Please provide sufficient detail below for SREIC to assess the ethical conduct of your research. You should consult the guidance on filling out this form and applying to SREIC at https://research.hud.ac.uk/strategy/concordat-research-integrity/hhs-ethics/

Researcher(s) details	Alison Morris. A.morris2@hud.ac.uk ex 3491. Member of staff undertaking MSc by research.
Supervisor(s) details	Dr Christine Rhodes, C.A.Rhodes@hud.ac.uk Dr Christine Smith c.smith4@hud.ac.uk
All documentation has been read by supervisor (where applicable)	**YES /** **See email attached from Dr Christine Rhodes and Dr Christine Smith.**

Aim / objectives	After seeking advice on how to apply for ethical approval on a co-produced piece of research, this research study will require ethics approval in two stages. This is due to the study being co-produced. The first stage of the ethics application will be concerned with establishing a research design group to develop the research design and agree upon the methods used. The research design group will develop a study involving thoughts and opinions of service users and carers which will answer the question: *Do I feel valued? A co-produced exploration into the notion of value from the perspective of a service user or carer participating in a university health and social care education setting.* The intention is to attract participants to the research design group who are themselves Service Users and carers. As the study intends to ask what the service user or carer thinks and feels about being valued then it is intrinsic that the design and the development of the study be designed and developed with Service User or Carer input. The design group will be made up of members explicitly tasked for their role and they will not participate in any data gathering activities. *A project that is co-produced is one in which researchers, practitioners and the public together share power and responsibility for the work throughout* (Hickey 2018). The overall aim of the study is to design and develop a research project about the thoughts and opinions of service users and carers. In addition to the outcome and findings of the research study, the research will have been designed by service users and carers. The second stage of the study will be to discover the voice of the Service User and Carer with reference to the research study question. It is anticipated that the mode of communication for this to happen will be through a series of interviews and focus groups with Service Users and Carers who are involved with the teaching and learning of student's, nurses, and health care professionals. As mentioned, the methods have yet to be decided until approval for the first ethics application has been granted. The objective of this stage 1 ethics approval application is: 1. Establish a research design group. 2. Co-produce the methods used and overall design of the research to answer the question.

Brief overview of research methods	The intention is to arrive at a research design through discussion and learning about process, role descriptions, methods and analysis. This kind of research is naturally embedded within the qualitative paradigm as interpretivist data regarding the study of people and their thoughts along with the process of the research is qualitative in nature. *'Patients and the public have the right to be more than just participants in research, and their involvement can lead to better outcomes'. (Hickley2018).* Co – production has gained popularity with researchers and this, co -production means different things to different people. *' is meant by co-produced evidence isn't always clear: co-production still means many things to many people'*. (Coutts 2019) Co-production is a process which is increasingly employed particularly in relation to service improvement and service design. Working within a power sharing environment amongst all stakeholders is a radical process which has led the way in bringing the user voice into research planning and not just limiting research to participating. *'A transformative model of co-production involves service users in all aspects of a service from planning to delivery, transferring power and resources from organisations to people who use services and carers.* (SCIE, 2015) This model however can often fall into the trap of tokenism or revert to less democratic consultative methods under the name of co-production. Co-produced research can only be effective if the key principles are addressed. There has been much written about quality and meaningful co-production. The key principles to adopt which produce a robust co-produced piece of research are: **Power sharing**- By explaining this principle and the reasons why we must all work with equal powers in the group and foster a **sense of shared ownership** of the research, we can develop power sharing techniques. Examples of this could be in decision making, using a democratic vote or reaching consensus through discussion. However, by working in an equal project, this does not mean all doing the same. It must be acknowledged that all **members will have different skills and knowledge.** This is to be **respected and valued**. After some discussion the group will identify the specific skills each member possesses, and this will formulate into individual role descriptions for the group. Along with contributing knowledge and skills it is also key that **members gain something from the experience**. I as the student feel it is in keeping with the coproduction ethos if everyone gains from the experience. Examples of this could be that members have affiliate status and attend training pertinent to the research such as NVIVO, endnote or other training opportunities. On the consent form a list of goals or training needs can be added by the individual. The final and yet most important principle to be addressed is the importance of **developing relationships with everyone in the research design group**. This is through effective communication, mutual respect,

	understanding of the groups and each member's role and responsibilities. These principles have been advised through the guidance published by (*INVOLVE 2019).* As this piece of research sets out to be co-produced it is difficult for me (the student) to set out the methods we will use for the process in stage one. The initial meeting cannot be co-produced, but I can nominate myself as a facilitator and draw from guidance on how best to proceed. I have created an agenda which encompasses the key principles in the literature. First meeting agenda: About the project Getting to know you Ground rules Joint ownership- what it is and how we maintain it Our skills Our roles in the research project Goals/aims/challenges How we work together and develop a working relationship Actions for meeting 2 I must also think about my role and the best way I can act as a member of the research design group and also as the student who will be writing up the project as my thesis. I must consider how to democratise my role and yet still maintain ownership all be it shared. I will discuss this with the research design group. The research design group will develop the research design, individual role descriptors incorporating continuous reflection of the project.
Project start date	*September 2019*
Project completion date	September 2021

Permissions for study	I will be approaching members of the University of Huddersfield Public Partnership Group (PPG), to ask if members would like to consider participating. I have written permission from the service user and carer development lead (Mr Chris Essen), in the School of Human Health sciences who has granted me permission to approach PPG members. See attachment. At present I have held a couple of brief discussions with some members. I have indicated that I am looking for people to participate in the research and other people to participate in designing the research. This has attracted interest from four individuals specifically for the research design group. The individuals are aware that further engagement with this study will be subject to ethical approval and subsequently no further discussions have taken place.

Access to participants	Once ethical approval has been granted. A formal invitation to individuals will be sent out via letter and email. This letter will only set out the needs of the research design group. The invitation will outline the level of commitment required to participate in the research design group. See consent form attached. Once ethical approval has been granted for stage one: • Send out information letters on the project to PPG members, (Info sheet attached) • Be available for any informal meetings with any interested members before the first meetings. This is to answer any questions about the research or participation. • Invite all members who are interested in being involved in the research design group to a meeting approximately 2 – 3 weeks after the info letter was sent. • Hold the first research design group meeting following the agenda set out above. • Discuss the consent form with each member at the meeting and complete the sections. (Consent form attached) • Give each member 2 weeks to consider their involvement, commitment etc in the research group. Ask for the signed consent forms to be returned to me within 2 weeks of meeting 1. • Be available to members in the 2-week window to answer any questions each possible member of the research design group may have. • After consent forms are returned and the group are at least 3 or more members (excluding myself) commence the research project. Apply for stage 2 ethical approval. Each meeting for the research design group, will last no longer than 2 – 3 hours (regular breaks, refreshments etc provided). The length of meetings and the dates they occur will be agreed with all participants of the research design group. Once the entire study is complete, I will invite the research design group to present the findings with me at a presentation to the Public Partnership community and t other relevant personnel. This commitment will be clearly outlined. Everyone will be asked to identify any reasonable adjustments that they may require in order to participate. The letter will provide a period for the individual to consider their availability before notifying me of their decision. I have applied for funding via HHS Research, which will enable me to provide the research design group with any travel expenses that they may incur. It is also possible that members of the research design group may wish to assist the researcher (me) during the data gathering meetings with the study participants in stage 2. This will be ascertained during discussions. Once the research study has been discussed and research methods decided upon, I will apply for ethical approval for the second stage of the study. The second stage of the study encompasses gathering data from participants (the data group) in what is likely to be interviews or focus groups.

Confidentiality	It is not anticipated that any information discussed will be of a sensitive nature however guidelines will be in place throughout which protects individuals. Before the commencement of the project ground rules will be discussed and agreed. This will cover, confidentiality, conduct, commitment and data protection. Meetings will either be in private rooms with doors that can ensure privacy and confidentiality. Or online meeting spaces using webcams will be offered and discussed as a possible meeting tool. The implications of using this resource will be fully explained with specific emphasis on the usage of the software in private and public spaces. All files and information shared with the research design group will be password protected and all other documents or information will be confidential.
Anonymity	Participants of the research design group can choose if they wish for their identity to be public or anonymous. The co-produced nature of the study means that the members of the research design group can be listed in any future publications as an author and thus cited. This will be explained to all research design group participants. Their preferences around anonymity will be respected.
Right to withdraw	All participants of the research design group will be aware of their right to withdraw from the study at any time. No data is to be collected from this group and therefore their input into the group will cease at the time of withdrawal and no further input will be made. They can choose if they wish to remain cited as a former member of the research design group or be removed from the study literature completely.
Data Storage	All electronic data will be password protected. If disseminated during the study, only the research design group will be aware of the password. Any other information will be kept in a locked drawer. It is not anticipated that data will need to be stored during transit however if this does occur then the data will be kept within a laptop in an electronic folder which is password protected. The data produced will be kept for 10 years as recommended by the university. I will act as the custodian of the data.

Psychological support for participants	It is not anticipated that support for the participants will be required for stage 1 however it is good practice to build this into the study. All participants in the research design group will receive peer support from each other. Along with designing a research study together this group will rely heavily on building relationships with each other. An emphasis on relationships is key to sharing power. There needs to be joint understanding and consensus and clarity over roles and responsibilities. It is also important to value people and unlock their potential. (Involve 2018). In addition to this I will act as support worker to members and provide signposting to any services which may be required. The University does offer welfare and support to its students and this is extended to affiliates and staff members.

Researcher safety / support (attach completed University Risk Analysis and Management form)	No risk at stage one has been identified.
Information sheet	See attachment
Consent form	See attachment
Letters / posters / flyers	n/a
Questionnaire / Interview guide	n/a
Debrief (if appropriate)	
Dissemination of results	The results will be disseminated to all participants involved in the study.
Identify any potential conflicts of interest	None identified

Does the research involve accessing data or visiting websites that could constitute a legal and/or reputational risk to yourself or the University if misconstrued? Please state Yes/No If Yes, please explain how you will minimise this risk	NO

The next four questions in the grey boxes relate to Security Sensitive Information – please read the following guidance before completing these questions: http://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2012/oversight-of-security-sensitiveresearch-material.pdf	
Is the research commissioned by, or on behalf of the military or the intelligence services? Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data	NO

Is the research commissioned under an EU security call Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data	NO
Does the research involve the acquisition of security clearances? Please state Yes/No If Yes, please outline how your data collection and storages complies with the requirements of these clearances	NO

Does the research concern terrorist or extreme groups? Please state Yes/No If Yes, please complete a Security Sensitive Information Declaration Form	NO

Does the research involve covert information gathering or active deception? Please state Yes/No	no
Does the research involve children under 18 or participants who may be unable to give fully informed consent? Please state Yes/No	no
Does the research involve prisoners or others in custodial care (e.g. young offenders)? Please state Yes/No	No

Does the research involve significantly increased danger of physical or psychological harm or risk of significant discomfort for the researcher(s) and/or the participant(s), either from the research process or from the publication of findings? Please state Yes/No	no
Does the research involve risk of unplanned disclosure of information you would be obliged to act on? Please state Yes/No	No
Other issues	
Where application is to be made to NHS Research Ethics Committee / External Agencies	
Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy	

All documentation must be submitted to the SREIC Administrator. All proposals will be reviewed by two members of SREP. If you have any queries relating to the completion of this form or any other queries relating to SREIC's consideration of this proposal, please contact the SREIC Administrator (Kirsty Thomson) in the first instance – hhs_srep@hud.ac.uk References

Hickey, G. 2018. Share power in five ways. Nature. Vol 562. Pg. 29.

Coutts, P. 2019. The many shades of co-produced evidence. Carnegie trust. Pg. 3.

INVOLVE. 2018. *Guidance on co-producing a research project*. Pg. 4

SCIE 2015. Co-production in social care: What it is and how to do it, Guide 51. https://www.scie.org.uk/publications/guides/guide51/

APPENDIX D

THE UNIVERSITY OF HUDDERSFIELD
School of Human and Health Sciences – School Research Ethics and Integrity Committee

APPLICATION FORM
Please complete and return via email to:
SREIC Administrator: hhs_srep@hud.ac.uk

Name of Applicant: Alison Morris

Title of study: : As a Service User or Carer, do I feel that my lived experience contribution is valued by the School of Human and Health Sciences at the University of Huddersfield.
Department: Human and Health Sciences Date sent:

Please provide sufficient detail below for SREIC to assess the ethical conduct of your research. You should consult the guidance on filling out this form and applying to SREIC at https://research.hud.ac.uk/strategy/concordat-research-integrity/hhsethics/

Researcher(s) details	Alison Morris. A.morris2@hud.ac.uk ex 3491. Member of staff undertaking MSc by research.
Supervisor(s) details	Dr Mary Turner - M.Turner@hud.ac.uk Dr Christine Rhodes, C.A.Rhodes@hud.ac.uk Dr Christine Smith c.smith4@hud.ac.uk
All documentation has been read by supervisor (where applicable) and Supervisor Report Form attached	YES / NO / NOT APPLICABLE This proposal will not be considered unless the supervisor has submitted a report confirming that (s)he has read all documents and supports their submission to SREIC

Aim / objectives	After seeking advice on how to apply for ethical approval on a co-produced piece of research, this research study will require ethics approval in two stages. The first stage of the study and ethics application will be concerned with establishing a research design group to develop the research design and agree upon the methods used. Ethical approval for stage 1 was granted in Feb 2020. The second stage of the study and ethics application will involve, recruiting and listening to participants perspectives who have agreed to be asked a series of co-produced questions. *A project that is co-produced is one in which researchers, practitioners and the public together share power and responsibility for the work throughout* (Hickey 2018). The overall aim of the study is to design and develop and carry out a research project about the thoughts and opinions of service users and carers to answer the question – As a Service User or Carer, do I feel that my lived experience contribution is valued by the School of Human and Health Sciences at the University of Huddersfield. The objective of this stage 2 ethics approval application is: 1, Send out invite to participants to be interviewed. 2, Recruit participants. 3, Ask a set of co-produced questions to participants on a 1-1 basis.

Brief overview of research methods	This kind of research is naturally embedded within the qualitative paradigm as interpretivist data regarding the study of people and their thoughts along with the process of the research is qualitative in nature. The methods will be in interview format. Each participant will have a 1:1 interview with the interviewer. The original concept for this would have been face to face where possible. However, the research design team have agreed to offer various options to each participant considering the global pandemic and the affect this will have upon this research project. Option 1 - a recorded online interview on Microsoft Teams with participant and interviewer/ researcher. Option 2 - a recorded telephone interview with participant and interviewer/ researcher. Option 3 – a socially distanced Covid secure meeting in either a room approved by the University of Huddersfield Health and safety staff, or an external location on the university campus that meets socially distanced regulations. The latter will most likely be an external bench. Option 3 will also be a recorded interview 1:1 wit participant and interviewer/researcher. The purpose of introducing 3 options to each participant for the interview is to address inclusivity, accessibility, and reasonable adjustments if applicable.
Project start date	September 2019
Project completion date	May 2022 (disruption of studies application granted due to Covid 19 pandemic)
Permissions for study	I will be approaching members of the University of Huddersfield Public Partnership Group (PPG), to ask if members would like to consider participating. I have written permission from the service user and carer development lead (Mr Chris Essen), in the School of Human Health sciences who has granted me Permission to approach PPG members.

Access to participants	The research question focuses explicitly on the role of the Service User and Carer (PPG member) within the School of Human and Health at the University of Huddersfield, therefore to answer the question I can only approach participants that meet that criteria. I am the coordinator for the PPG, which focuses on Service User and Carer involvement and as such my role works with individuals who are service users and carers who contribute to the involvement work in the school for teaching, learning and research. Once ethical approval has been granted for stage one: • Send out information leaflet / invitation about the project to PPG members mailing list (email attached) • Be available for any informal meetings with any interested members before any interviews commence. This is to answer any questions about the research or participation. • Respond to all interested participants providing a thorough description of what they are being asked to do. Be available for questions. Make it clear this is a student research study and there is no payment. Provide a consent form to read and return (attached). • Allow each participant a period of 2 weeks or more to return the form along with providing participants wit opportunities to ask questions. • After consent form received, discuss with participant their preferred mode of interview and make arrangements regarding times and dates to interview. • Post interviews provide participants with the opportunity to view and consider their recording. Reiterate the issue of consent and if they are happy for their interview contribution to be analysed as part of the research. • Discuss anonymity (all participants will be anonymous) and any other questions the participant may have. • Once research has been completed and written up, send a copy to each participant and invite comments. • Ensure again each participant is happy to proceed and for the research to be submitted. Ensure there is opportunity for questions.

Confidentiality	It is not anticipated that any information discussed will be of a sensitive nature however guidelines will be in place throughout which protects individuals. Before the commencement of the interviews, ground rules will be discussed and agreed. This will cover, confidentiality, conduct, and data protection. As an introduction the interviewer will remind participants that the interview is recorded, if the participant discloses anything of a confidential nature which may put them or another person at harm, then the interviewer must inform the participant that they will need to act upon the information and follow safeguarding procedures as a student at the university. I will ensure each participant is aware that the video recording will only be viewed by the interviewer however a transcript will be available should the design team need to view their interview. The transcript will be made anonymous. As discussed in the methods section. The interviews will be carried out on a 1:1 basis. If a participant chooses to be interviewed via Microsoft Teams, then the interviewer will suggest that the participant chooses a quiet place where they are alone, or they use headphones to prevent being overheard. This will also be the case if a participant selects a telephone interview. If a participant selects a socially distanced location in the university, then confidentiality will be ensured through a room with a closed door, but windows open to ensure adequate ventilation or if the location is external then the location will be chosen to ensure that the issue of being overheard is at a bare minimum. The issue of being overheard will be discussed beforehand with participants in whichever mode of interview they choose. All recording files will be kept within my university Microsoft Streams account which is secure. A back up of MP4 or MP3, recording files will be kept on a memory stick which I the researcher will be in possession of. All other files such as consent forms and contact details will be kept in my files held in the University one drive location. During analysis, participants names on transcripts etc will be anonymised. Participants post interview and transcription will be known as a participant number. Members of the research design team will not know the identity of any participant. information shared with the research design team will be password protected and all other documents or information will be confidential.
Anonymity	All participants for the data group will be anonymised. This will be explained to participants from the outset.
Right to withdraw	All participants of the data group will be aware of their right to withdraw from the study at any time. Any interviews and data they have created. will be discounted from the study. They will be given the option of whether they wish to receive the recording and files that they created. I the researcher will destroy any documents or recordings once they tell me they wish to withdraw.

Data Storage	All electronic data will be password protected. If disseminated during the study, only the research design team will be aware of the password. The only files anticipated to be disseminated would be with the research design team regarding thematic analysis of the interviews as a whole or any anonymised transcriptions. Any other information will be kept in a secure online file within my university one drive account. It is possible that a participant may request a social distanced interview, this will require me to use a Dictaphone or similar device. The data from this will be uploaded onto a laptop when I am at an indoor location which is likely to be my place f of dwelling. All data for this study will be kept until it is no longer required for the benefit of this study. I will act as the custodian and destroy the data at this time or within a time period of no longer than 10 years.
Psychological support for participants	It is not anticipated that support for the participants will be required for stage 2 however it is good practice to build this into the study. All participants will be provided with signposting of relevant networks where professional support is offered. I will ensure that participants can contact the PPG development lead if they feel it necessary. I will also provide all participants with the email addresses of my supervisors should they need to discuss anything further with them.
Researcher safety / support (attach completed University Risk Analysis and Management form)	Other than the possibility of a socially distanced interview being requested and the following of COVID 19 regulations set out by the UK Government, no risk at stage two has been identified. I have emailed the university health and safety officer to check if socially distanced interviews of this nature can be carried out at ether and external or internal location on campus. I am waiting for a reply. All PGR students were asked to make any requests regarding their research on campus to the Health and Safety team.
Information sheet	See attachment
Consent form	See attachment
Letters / posters / flyers	See attachment
Questionnaire / Interview guide	See attachment
Debrief (if appropriate)	Identified as no relevant
Dissemination of results	Participants will be sent a copy of the research once written up at the end of the project.

Identify any potential conflicts of interest	Some participants may feel conflicted to discuss their thoughts with me the interviewer s I am also the coordinator for the PPG.

Does the research involve accessing data or visiting websites that could constitute a legal and/or reputational risk to yourself or the University if misconstrued? Please state Yes/No If Yes, please explain how you will minimise this risk	No
The next four questions in the grey boxes relate to Security Sensitive Information – please read the following guidance before completing these questions: https://www.universitiesuk.ac.uk/policy-and-analysis/reports/Documents/2019/Oversight-securitysensitive-research-material-guidance-3.pdf	
Is the research commissioned by, or on behalf of the military or the intelligence services? Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data	No

Is the research commissioned under an EU security call Please state Yes/No If Yes, please outline the requirements from the funding body regarding the collection and storage of Security Sensitive Data	No

Does the research involve the acquisition of security clearances? Please state Yes/No If Yes, please outline how your data collection and storages complies with the requirements of these clearances	No
Does the research concern terrorist or extreme groups? Please state Yes/No If Yes, please complete a Security Sensitive Information Declaration Form	No
Does the research involve covert information gathering or active deception? Please state Yes/No	No

Does the research involve children under 18 or participants who may be unable to give fully informed consent? Please state Yes/No	No
Does the research involve prisoners or others in custodial care (e.g. young offenders)? Please state Yes/No	No

Does the research involve significantly increased danger of physical or psychological harm or risk of significant discomfort for the researcher(s) and/or the participant(s), either from the research process or from the publication of findings? Please state Yes/No	No
Does the research involve risk of unplanned disclosure of information you would be obliged to act on? Please state Yes/No	No

Will your research involve NHS patients? Please state Yes*/No *If Yes, please follow the HRA Decision Algorithm (http://www.hradecisiontools.org.uk/ethics/) and indicate the outcome. If the algorithm indicates that an application will be required through the IRAS system please append your draft IRAS application and all accompanying documents to this form. NB: Do not submit your IRAS Application until full approval has been granted at School level.	No

Will your research involve NHS staff? Please state Yes*/No *If Yes, please follow the HRA Decision Algorithm (http://www.hradecisiontools.org.uk/ethics/) and indicate the outcome. If the algorithm indicates that an application will be required through the IRAS system please append your draft IRAS application and all accompanying documents to this form. NB: Do not submit your IRAS Application until full approval has been granted at School level.	No
Where application is to be made to any other External Agencies	No
Other issues	no
Please supply copies of all relevant supporting documentation electronically. If this is not available electronically, please provide explanation and supply hard copy	

All documentation must be submitted to the SREIC Administrator. All proposals will be reviewed by two members of SREIC.
If you have any queries relating to the completion of this form or any other queries relating to SREIC's consideration of this proposal, please contact the SREIC Administrator in the first instance – hhs_srep@hud.ac.uk

APPENDIX E

University of
HUDDERSFIELD
Inspiring global professionals

Participants wanted.

Do you want to help with a research project about the work you do in the Public Partnership Group?

Research Study title:

Do I feel valued? A co-produced exploration of the notion of value from the perspective of a Service User or Carer participating in health and social care education in a university.

Introduction to the research

My name is Alison, and I am studying for or a Masters by Research. The title of my research is above. I would like to invite you to be interviewed for my research about your experiences and the work you have done for the Public Partnership Group. (PPG) This is a voluntary opportunity.

What do I have to do?

This involves one interview lasting around 30 minutes. Interviews can be either through the internet on Microsoft Teams, via the telephone or a socially distanced meet up on the University of Huddersfield campus. You can say where you prefer to be interviewed

Why get involved.

This research will get the views of the PPG members regarding if they feel valued. As a result of the research, I will be able to make recommendations to the School of Human and Health sciences which means this research will have an impact.

You will remain anonymous throughout the study. This is a voluntary opportunity and therefore no funding is available.

Please contact me if you have any questions.

Alison.Morris@hud.ac.uk

APPENDIX F

Participant Information Sheet.

Study title:

Do I feel valued? A co-produced exploration of the notion of value from the perspective of a Service User or Carer participating in health and social care education in a university.

Researcher: Alison Morris

You are being invited to take part in this study because it is about the thoughts and opinions of people who are members of the Public Partnership Group (PPG) and who have taken part in one or more projects in the school. As you are a member of the PPG and have participated in one or more projects you are invited to volunteer to take part in this study. Before you decide to take part, it is important that you understand why the research is being done, what it will involve and what will happen to data you provide.

Please take time to read the following information carefully and discuss it further with me if you wish. Please do not hesitate to ask if there is anything that is not clear or if you would like more information.

What is the purpose of the study?

The purpose of this study is to find out from PPG members if they feel valued for the involvement work that they participate in. A short interview will be conducted with each participant to ask questions on this issue. It is also intended that from the research a list of recommendations is developed which informs the school on future best practice.

This is also a research study about co-production as a process. About 12 months ago, I held a discussion with some PPG members and asked them for their thoughts and ideas of what they would like to be researched. The issue of value came up a lot. I then formed the research design team for this study where we worked co productively on the themes generated from the discussion and came up with the research title:

As a Service User or Carer, do I feel that my lived experience contribution is valued by the School of Human and Health Sciences at the University of Huddersfield.

Who is the target audience?

The audiences of whom this completed research will be of interest to are: PPG members and its immediate staff, service users and carers with an interest in this subject area, academic staff in the university who work alongside the PPG, researchers with an interest in service user and carer involvement, university teaching and learning managers, other institutions who involve service users and carers in similar course curriculum opportunities, national and international co-production networks, national and international service user and carer involvement networks, regulatory bodies such as the Nursing and Midwifery Council, the Health Care Practitioners Council, Social Work England and any other national or international organisation with a special interest in Involvement, participation, co-production and collaboration with service users and carers in health and social care education.

What will I need to do?

You will be asked to participate in 1 recorded interview. You can decide if you want to be interviewed using Microsoft Teams online, via the telephone or at a venue on the university campus which adheres to the regulations surrounding COVID-19. Before interviewing, you will be provided with a consent form and the opportunity to ask questions. Once you agree to be interviewed, sign the consent form, and confirm how you would like to be interviewed, we will agree on a date and time. I will record the interview either online or using a Dictaphone. I will ask you some questions regarding your experiences which will take approximately 30 minutes. The questions have been co designed by the research design team. After the interview has finished your recording will be transcribed and made anonymous for analysis. You will be sent a copy of the research when it is completed. You will be anonymous in this study.

Do I have to take part?

You decide if you wish to take part. If you decide to participate, you will be asked to sign a consent form. A decision not to take part will not affect you in any way. You can withdraw your data any time prior to the interview and 2 weeks after you have been interviewed without giving a reason. Once you have completed the interview, you will have 2 weeks to consider if you wish to continue with the research study. If you decide to withdraw within that time your data will be destroyed. After the 2-week period the research data wil be analysed and it will not be possible to withdraw. A decision to withdraw will not affect you in any way.

Who is conducting the research?

My name is Alison, and I am studying for or a Masters by Research qualification here at the university. I am also working with 4 PPG members, and we have been working together to co-produce the research design. These members are the research design team and will not be participating in these interviews with me.

Who will have access to the data?

I will be the only person conducting the interview. I will be the only person with access to your interview recording. I will transcribe your interview into a written format. This will be anonymised so that your name and any identifiable phrases are removed.

I will make every effort to remove all participant identifiers from the transcript. Examples of this are people's names and names of events that will identify a participant. However, it may not be possible to remove subtle identifiers. There is a small possibility that something you said at the interview could identify you to a member of the research design team who are also PPG members. However, every attempt will be made by me for this to not happen.

All anonymised transcriptions will be sent to the research design team, where overall analysis will begin.

I will be the only person with access to your consent form for the research study. Nobody outside the research team will have access to any of the data collected.

What will happen to the data collected?

Personal data shared by participants in this research will be held confidentially by the University of Huddersfield in accordance with the requirements of the General Data Protection Regulation (GDPR) and Data Protection Act 2018.

The University is the Data Controller and is responsible for its secure management. The research team and transcribers are the data processors.

No information provided will be shared in a way that would allow participants to be personally identified [*except where legal obligations would necessitate disclosure by the researchers to appropriate personnel*].

The data will be securely stored for 10 years, it will then be safely destroyed.

Quotes used in any resulting book/article/report or other publication will be anonymised.

The interviews will be recorded and either an audio or visual recording will be made to aid accuracy of the research and enable a transcription. These recordings will be retained by the University for a period of 10 years.

The data will not be transferred outside the European Union.

The University of Huddersfield is the Data Controller. Complaints should be addressed to the University Solicitor (the Data Protection Officer)

Appeals can be made to the Information Commissioner's Office if a participant is not satisfied with the response from the University.

Ethical approval

This research project has obtained ethical approval form the School of Human and Health Sciences Research Ethics Committee at the University of Huddersfield.

Will I be reimbursed for taking part?

No. This research project is being carried out in my own time. I would be asking for you to generously volunteer your time.

You may not wish to participate because of a conflict of interest.

Whilst I the researcher, would make every effort to be open, honest, impartial approachable and non-judgemental with every participant, it may be an issue that because I am also the PPG coordinator, you may not wish to discuss if you feel valued with someone who you know is a member of staff. If this is the case, then you may want to consider whether participating in this study is the right thing for you.

How many participants are required and how will people be selected?

I am looking for 10 people to participate in this research study. If you decide you wish to participate and contact me to volunteer, this does not automatically mean you will be selected. Members will have 2 weeks to contact me if they wish to volunteer. Once this period has ended then 10 names will be randomly selected. You will be notified immediately if you have or have not been selected for this research study. Because of the time constraints it is only possible to conduct the research with 10 participants.

During the analysis stage of the research each participant's age range, gender, and length of time in the PPG will be recorded for demographic analysis. No other information about each participant will be requested.

What do I do if I wish to participate?

You can send me an email to express your interest in this study. The deadline to express interest is 2 weeks from now which is: *ADD DATE* After this date, volunteers will be randomly selected.

You can contact me at any time to ask me any questions, my contact details are:

- Alison Morris - Alison.Morris@hud.ac.uk
- You can contact my supervisors if you require any further information regarding this study or to make a complaint. Please add my name to the email subject heading.
  My supervisors for this study are:

  Dr Mary Turner: M.Turner@hud.ac.uk

  Dr Christine Rhodes: c.a.rhodes@hud.ac.uk

  Dr Christine Smith: christine.smith@nihr.ac.uk

- If you wish to discuss any specific PPG details with an impartial PPG member of staff, then please contact - Chris Essen: c.s.essen@hud.ac.uk

APPENDIX G

Participant Consent Form

Research title:

Do I feel valued? A co-produced exploration of the notion of value from the perspective of a Service User or Carer participating in health and social care education in a university.

Researcher – Alison Morris

Thank you for your interest in this project. Before agreeing to participate, please read the information sheet. If you have any questions, please ask the researcher (Alison Morris). You will be given a copy of this consent form, and one will be retained by the researcher.

I agree that.

I have read the information sheet and understand the purpose of the research.	(Please tick)
I have had the opportunity to ask questions and have had these answered satisfactorily.	
I understand that should I wish to withdraw my contribution I can contact Alison Morris – Alison.Morris@hud.ac.uk before the cut-off point of 2 weeks after my interview without giving a reason.	
I understand that my personal information will be processed only for the purposes of this research. I understand that such information will be treated as confidential, except where legal obligations require information to be shared with relevant personnel and handled in accordance with the provisions of the General Data Protection Regulation (GDPR) and UK Data Protection Act 2018.	
I understand that the information I share, including anonymised direct quotes, may be included in any resulting report.	
I consent to the research team having access to any results derived from this study for any subsequent analyses or publications in the future. I understand that any identifying information would be kept confidential (except where legal obligations require information to be shared with	
relevant personnel), and access limited strictly to the original study team and database team.	
I understand that my participation will be video, or audio recorded for accuracy	
I understand that the video or audio recordings will be transcribed only by Alison Morris the researcher	

I understand that the information I provide will be retained for 10 years and destroyed securely after this time.	
I agree that the project named above has been explained to me to my satisfaction and I agree to take part in this research.	
I have read and understood the institution's Privacy Statement and consent to the researchers processing my personal data accordingly.	

Name of participant

Date

Signature

Researcher signature

Date

APPENDIX H

Interview topic guide

Research question

As a Service User or Carer, do I feel that my lived experience contribution is valued by the School of Human and Health Sciences at the University of Huddersfield.

Researcher- Alison Morris Pre-interview:

Introduce yourself, thank the participant for coming, discuss that the interview will be recorded and ask if the participant is still happy to proceed, remind the participant that they can stop at any time.

Interview:

The following questions are the main questions and prompts, which have been devised to cover all areas of the research question.

1. **how did you hear about the Public Partnership Group?**

2. **What motivated you to participate?**

3. **Can you tell me about any involvement that you have participated in and how the experience was for you?**
    - Please tell me if you felt valued or not for that experience?
    - What happened to make you feel that way?
    - How important is feeling valued to you for the work you do?

4, Do you feel the voice of the PPG member is equally valued in the school?

- Why?

5, Do you feel that you have received the right support to enable you to carry out your role?

- What support did you receive and what other support do you feel you would benefit from?

1. Is there anything else you would like to add?

End of interview

Thank the participant, end recording, check if the participant needs to talk about anything discussed and have a de brief if. Explain that participant now has 2 weeks to notify me if they wish to be withdrawn from the study. Provide exact date and mode of contact.

APPENDIX I

RDT AFTER THOUGHTS

When you began this research project did you feel you understood how you would be involved and what you were doing? Please explain?	Member 1 Yes I did feel I understood. We had done some co-production in ither projects, so it was not entirely new. I also understood that things would not be predictable - they might change and grow depending on what the group talked about and agreed. Member 2 Yes, I did fully understand what was involved in this research. This is because as a member of PPG, I had had the opportunity to hear Alison share on this topic with us and I also thought that it was a valuable and relevant topic. Secondly the introduction and invitation documents that Alison had prepared were very clear and easy to follow.
How did you contribute to the research?	Member 1 Joined in with the sessions, responded to emails and requests for input, read through drafts of the template. Member 2 I contributed to all the main stages of the research as this piece of work was co-production oriented. The group left off for Alison to put together the document together after we did the findings and recommendations.
What does Coproduction mean to you?	Member 1 Working together with a group of people to achieve something - where the group may all have different, but relevant experience and skills to offer. Member 2 To me it means working cooperatively on a piece of work or project as a group with every member contributing to the best of their ability in every level from the beginning to the end of the project as happened in this case. completed.
Do you think this research study was coproduced?	Member 1 As far as it could be Alison facilitated very well & her commitment to co production kept it on track, but two factors inevitably limited this. Firstly, this was a piece of assessed course work so there were constraints beyond Alison's control such as the overall scope of coursework, and the timescales. Secondly lockdown meant that the quality of face-to-face reaction we had hoped for was not possible. We cannot know what difference this might have made to the way we each contributed. Member 2 Yes, I do and believe so.

Do you think it is important to coproduce research?	Member 1 Not always, but in this instance yes. Member 2 I think so. I believe it is essential that research especially health research is co-produced because the results are more likely to be more reflective and relevant than if it was done by just one individual.
Was the research study what you expected? please explain your answer.	Member 1 Yes, I knew what to expect and it achieved that Member 2 The research was what I expected. As a long-time member of PPG, this was an important aspect of the Service user and carer aspect that I thought was important to explore. Was what Service Users did really value by those who commission it? Did the Service user feel that that they were valued?
What did you enjoy and not enjoy about participating in this research?	Member 1 Enjoyed being part of the group, contributing, interaction with the others seeing Alison's ideas developing. Less enjoyed not being able to meet & not being able to continue to be involved later in the work - I do not mean that I expected to be involved - I know Alison had to reach a point where she got on with writing up, I just missed being involved:) Member 2 I enjoyed every bit. It was just such a shame that Covid interrupted, and we had to do the research on zoom. The gaps and the zoom disrupted the smooth flow of emotions that needed to be expressed.
Are there any aspects of this research study that you would change about it? This could be things like your input, other people's input, the role you had, the research and how it was carried out, the process in which the research was done for example.	Member 1 I don't think so - we could have gone down different routes, and that might have radically changed the study, but the path we followed seemed to work & I cannot say anything else would have been better- just different. Member 2 No. Not really. I felt that all the other members had their heart and mind in this project which allowed for progress after each stage was completed.

Please feel free to add any other comments.	Member 1 Doing such an unpredictable methodology must have been stressful for Alison at times - but the experience was important, not just for the authenticity of what she wanted to achieve, but also longer-term skills. I hope it has been fruitful. Member 2 Just to add that I know the members who co-produced this research were there because they wanted to be there, and they wanted the project to succeed for the benefit of improving PPG as well as the future of Service user development in general.