A Qualitative Exploration of the Experiences of Service Users and Carers Involved in Health and Social Care Education

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ABSTRACT

Over the last 30 years, there have been advancements in service user and carer involvement in health and social care pedagogy. This has resulted from social movements, government policies, regulatory bodies, and professional associations calling for service users and carers to be placed at the heart of developing, delivering, and evaluating services and education in the United Kingdom (UK). However, empirical evidence in the field has traditionally looked at the impact and outcomes of involvement from the student's perspective, with fewer studies seeking to understand involvement from service users' and carers' perspectives.

This qualitative research explores service users' and carers' experiences in health and social care education at a Higher Education Institution (HEI) in the UK. Through semi-structured interviews, 10 service users and carers recruited from a Service User Reference Group (SURG) shared their experiences. Participants' narratives were analysed using a thematic analysis approach, which revealed five key themes that expressed their experience of this phenomenon. The study gained rich insights into the areas of involvement that service users and carers experienced as empowering and the practices within academia that rendered them powerless. Service users and carers also provided explicit recommendations for what they would like involvement to look like in the future. Furthermore, the study elucidated the complexities of involvement and the importance of power relations within academic institutions to be scrutinised and challenged to ensure that involvement is not tokenistic but collaborative and meaningful for all stakeholders. Finally, it also revealed the institutional practices in operation and the infrastructures that perpetuate the power inequalities favouring theoretical knowledge over lived experience knowledge.

These findings contribute to the knowledge base that seeks to understand power, empowerment, and powerlessness within involvement. It is relevant to service users and carers, policymakers, the National Health Service (NHS) and academic institutions that have established involvement initiatives or are seeking to introduce the involvement of service users and carers into their programmes. This will ensure involvement moves beyond mere rhetoric and is meaningful and empowering.

LIST OF ABBREVIATION

BPS	British Psychological Society
CCG	Clinical Commissioning Group
CQC	Care Quality Commission
DH	Department of Health
GSCC	General Social Care Council
HCPC	Health and Care Professions Council
HEI	Higher Education Institution
NHS	National Health Service
NIHR	National Institute for Health Research
NMC	Nursing and Midwifery Council
PE	Psychological Empowerment
RNC	Royal College of Nursing
SCIE	Social Care Institution of Excellence
SURG	Service User Reference Group
UK	United Kingdom

CHAPTER 1. INTRODUCTION

THESIS OVERVIEW

This thesis explores service user and carer involvement in health and social care education. Research in the area often focuses on how students experience this phenomenon, and thus this research will focus solely on service users' and carers' perspectives as it considers the following questions:

1. How do service users and carers experience their involvement in health and social care education?
2. How do service users and carers report their own experiences of power and how it operates and impacts on their involvement?
3. What are the recommendations for improving involvement in health and social care education?

Chapter 1 provides the historical background of involvement in the United Kingdom (UK) and outlines the evolution of service user and carer involvement in pedagogical practices. The theoretical underpinning of this thesis is also outlined. This chapter reports on the literature review that was conducted to explore the existing literature in the field. This highlighted the gaps in the literature and provided the rationale for this study and its aims.

Chapter 2 describes the methodology used to answer the research questions and outlines the approach utilised. The sampling method, participants inclusion and exclusion criteria, and the recruitment methods, are then outlined. Finally, a detailed account elucidates how data was collected and analysed. In addition, ethical consideration; issues of trustworthiness and rigour are also explored.

Chapter 3 presents the study findings. It summarises participants' demographic information, their duration of involvement at the institution, and the involvement activities they have participated in during their journeys. The themes and sub-themes developed from the data are then presented to provide insights into how participants experience their involvement in health and social care education.

Chapter 4 further explains the findings in relation to the existing literature explored in chapter 1. It elucidates the study methodological tensions and strengths before providing further research and the study’s clinical implications. Finally, the researcher provides reflections of her research journey before providing the conclusions.

CHAPTER OVERVIEW

This chapter will introduce service user and carer involvement in health and social care pedagogy. Firstly, the chapter will begin by outlining the historical background of involvement in the United Kingdom (UK) and the political context the movement was born out of. The importance of language utilised when defining service users and carer involvement will then be discussed, looking at the inequality terminology perpetuates. Due to a lack of consistency in the phraseology used, the researcher will delineate the research study's definition of service user and carer involvement and the rationale before examining the impact of involvement on service users and carers and the involvement models. The chapter will then look more specifically at empowerment, how power operates in involvement, and the research will summarise the relevant theories. Lastly, a literature review will be conducted to appraise the existing body of qualitative research that explores the experiences of service users and carers in health and social care education in the UK and internationally, highlighting the gap within the literature that this study aims to investigate further.

BACKGROUND

In the UK, the Department of Health (DH) has patient and public involvement securely embedded into the policies (Department of Health 2000; 2001; 2005; 2008a; 2008b). It promotes patient-centred healthcare and the participation of service users and carers in the development, delivery and evaluation of services and education (Tremayne et al., 2014). The policies have driven the prominence and advancements in embedding service user and carer involvement in health and social care pedagogy and across various disciplines in the UK and internationally (Towle et al., 2010). This has subsequently led to increasing requirements being placed on Higher Education Institutions (HEI) to involve service users and carers in the education, training, recruitment and assessment of students that will later go on to be professionals in the health and social care sector (Rhodes, 2012). In 1999, the National Service Framework for Mental Health distinctly set out that "SUAC should be involved in planning, providing and evaluating education and training" (Department of Health, 1999, p.109). Shortly after, in 2002, social care too mandated the involvement of service users (SU) in all aspects of qualifying (Department of Health, 2002) and post-qualifying (General Social Care Council, 2005) social work education (Levin, 2004). Different factions have been instrumental in the movement. In addition to the political exposure, SU and user-led organisations have also played a pertinent role in campaigning to have their voices heard in services (Campbell, 1999; Turnbull & Weeley, 2013) and within education (Lathlean et al., 2006).

Social movements such as the Disability Rights movement has spearheaded the incorporation of involvement in the political arena since the 1970s (Curran et al., 2015). It has contested oppressive ideologies and the traditional medical model of disability that often focuses on diagnosing conditions. The medical discourse posits that disability is an individual's problem caused by their impairments, resulting in dependency. However, the rise of the social model of disability provided an alternative viewpoint. It transferred the blame conventionally placed on the individual onto society, thus repositioning disabled individuals (Siminski, 2003). It emphasised that societal structures are barriers that render individuals disabled as they try and navigate an inaccessible society (Oliver, 2013). Through tireless campaigning and lobbying over many years, the movement has fought for disabled people's rights and policies that advocated for inclusivity, prohibiting unfair treatment and involvement (Fawcett et al., 2018). The movement defines involvement as "Individuals and groups participating fully in decision-making processes and exercising autonomy and self-determination" (Fawcett et al., 2018, p.8). Nevertheless, a lack of agreement on the term involvement has been problematic as it has come to have various meanings.

Involvement also has roots in the human rights movement, as outlined by Lewis (2009). Core human rights principles centred on promoting fairness, respect, equality, dignity and autonomy (FREDA) are firmly embedded in the healthcare framework and ensures that organisational values and practices meet such standards. This seeks to disrupt the paternalistic approach to health care where decisions are made by professionals positioned as specialists, which invariably places SU in a submissive role. The pushback has since advocated that SU should take up a more active role in influencing and shaping their care based on partnership with care professionals (Towle et al., 2016; Levin, 2004) as they have valuable expertise. Croft and Beresford's (1992) paper explored the politics of participation and referenced the transition within welfare from service-led provisions to user-centred services. This was facilitated by hearing SU voices through involvement that address practices that disqualified and marginalised them. Beresford (2003) postulated that the foundational principles of involvement align with social care's core values that promote individuals who use such services are empowered, respected, have complete autonomy, and anti-discriminatory procedures are challenged. Thus, service users and carers have become integral and placed at the centre of the care they receive, and their lived experience knowledge is valued as they provide a distinctive and unique perspective on health and social care (Warren, 2007). This mirrors the discourse within policy, the health and social care profession, and academia, which aligns with the equality agenda (Anghel & Ramon, 2009). Radical health and social care professionals and professional associations such as the Royal College of Nursing (RCN) have also been pivotal in advocating for the recognition of service users and carers (Mcphail, 2008). In addition to all of these drivers, regulatory and statutory bodies such as the General Social Care Council (GSCC), Nursing and Midwifery Council (NMC), and the Health and Care Professions Council (HCPC) also request that institutions evidence how service users and carers are involved in their programmes. These different sectors have worked together to drive forward service user and carer involvement in services, research, policy and education. Despite the advancements, concerns have been raised about the importance of meaningful and not tokenistic involvement (Robinson & Webber, 2013). However, there is a lack of understanding of what constitutes meaningful involvement (Webber & Robinson, 2012). This lack of clarity is an area that requires further development in academia.

In response to more individualised, person-centred care, there has also been a need to ensure that trainee healthcare professionals embraced these values. Giving rise to academic institutions introducing service user and carer involvement into their undergraduate to postgraduate training (Heaslip et al., 2018; Towle et al., 2016). Capital is also provided by regulatory bodies to support this endeavour, which has significantly increased involvement in education over the past 20 years. This commenced in medicine, nursing, and then social work, and these disciplines have vastly contributed to the research (Rhodes, 2012). Involvement is now an integral component of courses across various disciplines with other health care professions such as occupational therapy, physiotherapy, dentistry, and pharmacy, also incorporating involvement into the education of their health care professionals (Towle et al., 2016). During this time, service users and carers have been involved in various activities such as in the classroom (Bennett & Baikie, 2003), curriculum development (Le Var, 2002), assessments (Frisby, 2001) and recruitment of students (Tew et al., 2004). Despite this, involvement is patchy and ad hoc as there are no guidelines provided on how service users and carers ought to be involved, nor are there any specifications on how HEIs should spend allocated funds. Neither is the involvement of service users stipulated in the philosophy underpinning social work (Beresford & Boxall, 2012) and health education. So irrespective of the political and historical foundations of service user involvement, it is still unsystematic within education. Anghel and Ramon (2009) also postulated that far less has occurred with carer involvement.

With regards to funding, involvement initiatives within educational institutions have historically been supported by the Educational Support Grant, that provides up to £7,400 per annum. In 2013, this went under review and it was agreed that the funding would continue. It is important to note that there is not just one funding stream available to institutions as there is also scope to apply for grants, and obtain funds from regulatory bodies when they evidence their involvement in their programmes.

Furthermore, policies that have promulgated the equality and empowerment of service users and carers through involvement have been criticised for maintaining inequalities between service users and carers and professionals (Lewis, 2009). Research by Cameron et al. (2019) similarly found that service users do not always experience emancipatory practices and their involvement is experienced as insincere and a function that meets regulatory and policy obligations as found in the institutions' strategic jargon. Such involvement enables institutions to meet their agenda under the guise of collaboration and change but can equally be disempowering, oppressive and undermine the principles it set out to challenge. This illuminates a policy and operationalisation discrepancy. Stickley (2006) argued that collaborative, meaningful and empowering involvement is not easily achieved, primarily when the power inequalities are not acknowledged nor tackled.

TERMINOLOGY

In addition to thinking about the historical context, it is equally important to reflect on the terminology used when describing people that have used or are currently using health and social care services. This is often controversial and highlights the complexities around discussing such vital issues. The discussion exploring the terminology used over the years reflects the evolution of the service user identity and the shift from a traditionally oppressed to a liberated position within services, research and academic institutions. Historically, this conversation in itself would have been redundant as service users' and carers' voices were rarely recognised and seldomly respected (Lewis, 2009), but they are now valued and central to processes as there has been a strive for equality.

McKeown et al. (2010) noted the influence language used serves to act out inherent power inequalities by perpetuating the prevailing narrative that aims to inhibit and, in some instances, completely discard any contending ideas in involvement initiatives from their inception (Fewcett et al., 2018). This continues to position service users and carers in passive versus active roles (Towle et al., 2010). Looking closely at the different language used over many years', expressions such as 'patient', 'consumer', 'service users', 'clients', 'survivors', 'customers' and 'expert by experience' are utilised but have equally been disputed. The appellation 'patient' is embedded in the medical profession. It represents an individual with a medical problem needing care from a medical expert (McKeown et al., 2010). The term also connotes passivity and an acceptance of an inherent power imbalance where help is sought from experts. Foucault's work in 1979 and 1981 challenged this position. He critiqued "the implied passivity of the 'patient', the processes by which individuals become 'docile bodies', and the legitimising knowledge and power regimes of the expert" (Fawcett et al., 2018, p.3) The move towards using terms such as 'consumer' and 'client' was an attempt to challenge medical ideologies. However, they were guided by faulty consumerism rhetoric that the Conservative government backed in the 1980 and 1990s and was endorsed by the New Labour Government in their 1997 agenda (Harris, 2003). There was a strong push towards the branding of services as 'needs led' not 'service led', which placed significance on the individual's power to influence and decide on their support. However, this approach did not achieve its desired effect as it failed to acknowledge that individuals would only have the ability to exercise power to choose the service they received if they had the means to pay for it. Even though the terms are commonly regarded as neutral, they are still redolent of a power differential between the person seeking support and the professionals providing it (Fawcett et al., 2018).

More recently, the term 'service user' is an umbrella term more commonly used over terms such as client. It is more widely used in the UK and internationally to describe individuals who have used or are currently using healthcare (Townend et al., 2008), welfare or social care services. Conversely, as with other terms, it is disagreed upon, seen as derogatory and problematic by service providers, health and social care professionals, SU and academics. The literature suggests that when used, it fails to acknowledge people's uniqueness as they are positioned as users of services, which may not be the way they wish to describe themselves (Beresford, 2000). Again, it also places them in the position of subservient receiver of services (Beresford, 2005). Despite the criticisms of the term, the term service user is used by Wright and Rowe's (2005) to situate service users as taking up an active position in the egalitarian relationship with professionals within academia. It is also a term endorsed by many others, such as Shaping Our Lives (Disabled Person User Led Organisation) and by some service users to describe themselves.

In addition to thinking about service users, carers' voices are also of significance. The term 'carer' is a broad phrase, that has been challenged as many individuals in the roles do not always identify with the term. A carer is a paid, unpaid, family member, informal friend or partner who cares for another individual. However, the term fails to effectively describe the nature of the relationship that exists between the two individuals (McPhail, 2008). In the literature, there is often little to no distinctions made between the experiences of SU and that of carers, with findings reported as if they are a homogeneous group. A consultation conducted by the Health and Care Professions Council (HCPC) in 2012 with stakeholders regarding the involvement of service users and carers in the education of health and social care professionals, concluded that stakeholders recognised the difference between service users' and carers' unique experiences and this should be valued separately. They also outlined that SU and carers are independent entities and heterogeneous groups in policies and legislation. However, varying views on the matter have led to this being organised differently by institutions and organisations.

Along with defining service users and carers, it is also important to delineate how service users and carers partake in services and academia. There are terms used to explicate the interactions and relationships between service users and carers and health and social care professionals. These terms include collaboration, co-production, engagement, involvement and participation (Cahill, 1996). Such terms come in and out of vogue and are easily misunderstood, which can be contentious (Croft & Beresford, 1992). The terms collaboration, co-production and partnership signify the joint working between professionals and service users based on equality. On the other hand, involvement, engagement, and participation denotes service users and carers partaking in assigned activities (Cahill, 1996) and can preserve the power disparity. Therefore, the authority that service users and carers have in making decisions is the distinction that sets the different terms apart (Thompson, 2007).

Dzombic and Urbanc (2008) detailed how the idea of involvement in itself can be problematic. This raises an important question, if people in a position of power decide the individuals they wish to include, do they then maintain the power over such people? This question illuminates the power differential that exists in hierarchical structures within health and welfare institutions. The academics are placed in a position of power with all the knowledge, and service users and carers are not always recognised for their unique lived experience knowledge. Therefore, it is seen as contradictory when service users and carers are involved in academia under the guise of empowerment and emancipation; but the power disparities are neither acknowledged nor changed. Despite various terms utilised in very different ways, what is not always clear is what service users' and carers' roles look like on the ground and the level of power-sharing and autonomy they have to make decisions within institutions.

Due to no one term agreed upon in the literature, it was integral to this study to clarify the terminology used and the rationale to avoid further confusion. Therefore, the terminology used was agreed upon by the individuals who shared their stories and experiences as a means of respecting their voices. At the start of their interviews, each individual was asked, and they agreed that the terms service users and carer were satisfactory appellations. The term 'service user' is defined as an individual who currently uses or has used health and social care services. This term will not encompass the broader public. 'Carer' refers to someone that is or has provided care to a partner, friend, family member or neighbour that is unwell (Social Care Institute for Excellence. n.d.) in an informal or formal capacity. The term involvement is utilised in this study and best encapsulates service users' and carers' roles at the university. This is defined by Rhodes (2012) as:

> A process whereby the user's lived experience is utilised in teaching and learning for students undertaking health and social care courses. Involvement can occur at several levels… from design and development of the course, recruitment, direct teaching, assessment and research. (p.8).

The full-term service user and carer involvement will therefore be used throughout this study.

WHY INVOLVEMENT MATTERS

Now let us turn our attention to why involvement matters. As outlined above, involvement is a means of incorporating service users' and carers' voices in the designing, delivery and evaluation of health and social care services, research (Hanley, 2005) and pedagogical practices (Crawford et al., 2002; Repper & Breeze, 2007). It seeks to improve the quality of care provided by service providers (Francis, 2013) and address the power imbalance between professionals and individuals as they are placed at the heart of organisational processes. This has led to growing recognition and value placed upon lived experience and the critical contribution service users and carers make to academia (Perry et al., 2013) is now nationally and internationally recognised. However, despite the prevalence of involvement in health and social care programmes, there is no clear consensus about how service users and carers should be involved, thus compromising the standards of involvement (Happell et al., 2014; Mckeown et al., 2010).

Empirical evidence suggests that the level of involvement is inconsistent across institutions ranging anything from tokenism to collaboration. Thus, indicative of a vast involvement landscape, with varying degrees in the roles service users and carers have and the involvement tasks they engage in across different institutions and disciplines. In addition, many complexities and challenges still exist (Anderson et al., 2009). Beresford and Boxall's (2012) work critically appraised the involvement of service users in social work education. It asserted the problematic nature of involvement, using the criticisms of disability research proposed by Hunt's (1981) paper that found fault with the research conducted by Miller and Gwynne (1972) and concluded that they exploited service users with disability. The literature also highlights the importance of involvement being a meaningful endeavour for all stakeholders - the academic institutions, service users and carers, staff and students. When conducted in a tokenistic manner where service users' and carers' voices are subjugated, involvement runs the risk of being harmful and oppressive as their contribution is not respected, and they are left feeling exploited and powerless by their lack of influence (Curran, 1997).

Health and social care professionals' identities that individuals working within the sector wish to maintain also serves as a barrier. As historically the professional identity does not lend itself to the philosophy of equality and power-sharing in the relationship between SU, their carers and health care professionals (O'Flynn & Britten, 2006). Involvement is therefore important to ensure that future professionals meet with service users and carers within their educational journey. As outlined by Levin (2004), the involvement of service users and carers:

> …in the design and delivery of social work degree offers a major opportunity for a new generation of social workers to gain a thorough grounding in service users' and carers' experiences and expectations from the very start of their training and careers. (p. 2).

Nevertheless, despite this being a desired outcome, there is sparse evidence in the literature to show the impact of involvement on students' clinical work post qualification (Towle, 2016). Rhodes (2012) has called for more research in this area.

Despite the progress made in service user and carer involvement in health and social care education, the literature has equally ignored factors that impact some disenfranchised groups' propensity to be involved. This is reflected in the lack of diversity in the voices heard. An example being the underrepresentation of Black, Asian and Minority Ethnic (BAME) as outlined in Begum's (2006) report. It is important to note that the term BAME is problematic as it seeks to group together all individuals that are not white. In doing so, this socio-politically constructed term used to categorise individuals, fails to capture the individuality between and within the different subgroups in question. As with service users and carers, ethnic groups are not homogenous irrespective of what the label tries to portray for convenience. Begum's (2006) report elucidates that there are groups further marginalised and their voices and experiences are seldomly heard nor respected. The report subsequently explicates that there has been no evidence to suggest that ethnic groups do not wish to be involved and recommends that matters of race must be continuously thought about and appropriately managed.

Along with race, other marginalised groups that continue to experience systemic oppression and social injustice due to their sexuality, gender, age, religious beliefs and other protected characteristic are further socially excluded and underrepresented in involvement literature. In order to progress the theory, there needs to be a desire and commitment by institutions to engage more disenfranchised groups as their voices are of equal significance. An intersectional approach is required, so in addition to examining single-axis discrimination, there is also a need to understand groups categorised by manifold disadvantages (Gazard et al., 2018).

IMPACT OF SERVICE USER AND CARER INVOLVEMENT

The impact of involvement on students, staff members and service users and carers in health and social care pedagogy is evidenced in the literature (Agnew & Duffy, 2010; Gutteridge & Dobbins, 2010; Simpson et al., 2008). A review conducted by Morgan and Jones (2009) explored the perceptions of service user and carer involvement in healthcare education and its impact on students' knowledge and practice. It identified that students found involvement beneficial. They reported that it improved their communication with patients, enhanced their need to improve services for future recipients and improved their confidence to work with such client groups. Students also conveyed gaining a deeper understanding of SU lived experiences, which has also been supported by Bornarova (2009), Happell et al. (2014), and Stickley et al. (2009). However, there is a paucity of research evidencing the impact of involvement on the care received by future patients (Carey, 2009; Rummery, 2009).

Service users and carers equally described their involvement in education as rewarding. They valued their voices being heard and recognised that they provided students with unique insights they would not traditionally obtain from academia when their teaching is based on theory-based knowledge. This is in accordance with the findings outlined by Keenan and Hodgson (2014), McGarry and Thom (2004), and Robinson and Webber (2013). Conversely, research has also illustrated the complexities of involvement, with service users and carers feeling that their contribution is not always respected. They experienced their involvement in education as tokenistic and highlighted remuneration issues (Higgins et al., 2011; Rhodes, 2012; Wykurz & Kelly, 2002). The literature review later in this chapter will further discuss the impact of involvement from the service users' and carers' perspectives.

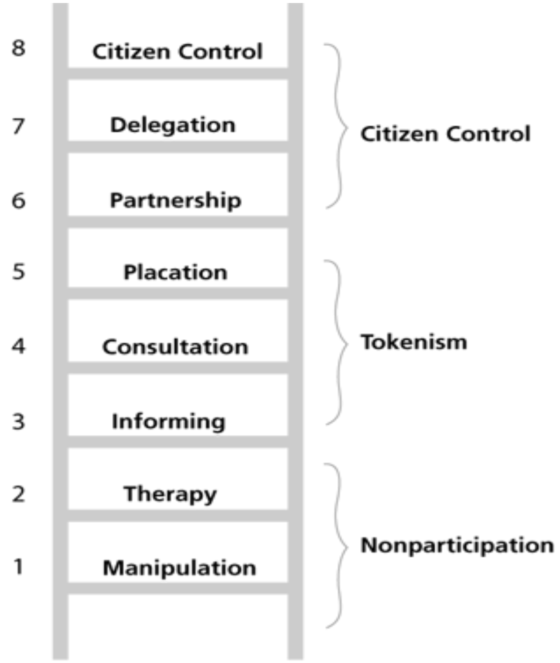
It is also important to note that despite the growing body of empirical research in this field, studies all too often focus on the outcomes and processes from the students' perspective. A dearth of evidence exploring service users' and carers' perspectives has resulted in their views and voices being underrepresented in the literature (Happell et al., 2014). Hence, there is a limited understanding of how they experience their contribution.

MODELS OF INVOLVEMENT

It is necessary to explain the models of involvement to develop a clearer understanding of the mechanisms that serve to map the degree to which service user and carer involvement happens within institutions. The variability of involvement is also reflected in the literature (Mcphail, 2008). Various models are cited (Chambers & Hickey, 2012; Heaslip et al., 2018; Rhodes, 2014; Robinson & Webber, 2013) and focus primarily on the relationships between professionals and service users and carers, explicating the power differential that exists at different levels. It must also be acknowledged that establishing involvement initiatives can be challenging when pursuing the integration of service users and carers into the educational system. The models most commonly use ladders as visual metaphors or continuums. This section will summarise various models used.

Arnstein's (1969) ladder of participation (Figure 1) was the most widely used model that categorises participation from level 1 to level 8. It has three distinct classifications that span from *non-participation* at the bottom, which then moves through to *tokenism* in the middle and *citizen control* at the top. It elucidates the power relations between power holders (government and professionals) and have-nots (service users, carers, marginalised groups, citizens) exercise. The amount of power and autonomy that the have-nots have regarding decision-making is the distinctive feature that differs at each level and is said to increase as you move up the ladder.

FIGURE 1: ARNSTEIN (1969) LADDER OF CITIZEN PARTICIPATION



Looking more closely at the individual rungs, at the base sits *non-participation*, which encompasses two levels. On the bottom rung, level 1 - manipulation and level 2 - therapy. These levels are descriptions of the power remaining with the power holders, and the have - nots are educated and cured. Power is not redistributed, and the relationships developed privileges the power holders and maintain the inequalities in operation.

As you move up the ladder, the second category is *tokenism,* with three levels known as informing, consultation, and placation. Level 3 - informing is an important move toward genuine involvement; however, it is often unidirectional communication where the power holders share information with the have-nots, and there is no scope for feedback. Despite this information being important at this level, it is still very limiting as the have-nots fail to influence decisions made. Level 4 - consultation, as described by Arnstein (1969), is “still a sham since it offers no assurance that citizen concerns and ideas will be taken into account” (p.219). At this level, individuals are encouraged to express their ideas, but there is often no commitment from power holders to take any action as a result. The highest rung of tokenism is level 5-placation. This refers to the have-nots being picked to be part of a board or committee to provide advice. Nevertheless, power-holders make the final decisions on if they will act on the advice given, as there is no requirement for them to do so. Thus far, both non-participation, as well as tokenism, can be harmful, as the have-nots remain subjugated by the power holders. Such involvement perpetuates practices that continue to tyrannise individuals as their voices are further dismissed within systems claiming to empower them. Moving up to the top three rungs of the ladder is *citizen control.* This has partnership at level 6; level 7 is delegation and lastly, at level 8, citizen control. At the level of partnership, an equalisation of power is negotiated. Decisions are jointly made as roles and responsibilities are shared between individuals that have traditionally held the power and the have-nots. Regarding delegation, the have- nots have a majority of the power and thus dominate the decisions made. Finally, in citizen control, the have-nots are repositioned to have ultimate control over policymaking and handling of particular programmes.

Over the years, there have also been adaptations to Arnstein’s ladder model by Wilcox (1994). This five rung ladder has information giving at the bottom - level 1, which then goes all the way to the top, level 5 - supporting the local initiative. Level 2 is consultation, followed by deciding together at level 3, then acting together at level 4. Another five rung ladder that is well accepted within academia and modified from Gross and Miller’s (1995) framework was developed by Tew et al. (2004) (Figure 2). Level 1 is no involvement, level 2 - limited involvement, level 3 is growing involvement, level 4 - collaboration, and level 5 – partnership. Institutions often use this model to rate the progress of their involvement initiatives. The model has been praised because it clearly outlines and qualifies what must occur at each level for institutions to achieve a given level of involvement. The model is based on service users and carers level of activity, payment offered and how the service users and carers are positioned. It also delineates what should be aspired to, which is level 5 partnership. However, empirical studies have identified that this is rarely achieved by institutions. As with Arnstein's model, the have-nots are awarded more power the further you move up the ladder.

FIGURE 2: TEW, GELL AND FOSTER (2004) LADDER OF INVOLVEMENT

LADDER OF INVOLVEMENT

LEVEL 1: ▼
NO INVOLVEMENT

The curriculum is planned, delivered and managed with no consultation or involvement of service users or carers.

LEVEL 2: ▼
LIMITED INVOLVEMENT

Outreach and liaison with local service user and carer groups. Service users / carers invited to 'tell their story' in a designated slot, and/or be consulted ('when invited') in relation to course planning or management, student selection, student assessment or programme evaluation. Payment offered for their time. No opportunity to participate in shaping the course as a whole.

LEVEL 3: ▼
GROWING INVOLVEMENT

Service users / carers contributing regularly to at least two of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. Payment for teaching activities at normal visiting lecturer rates. However, key decisions on matters such as curriculum content, learning outcomes or student selection may be made in forums in which service users / carers are not represented. Some support available to contributors before and after sessions, but no consistent programme of training and supervision offered. No discrimination against service users and carers accessing programmes as students.

LEVEL 4: ▼
COLLABORATION

Service users / carers are involved as full team members in at least three of the following in relation to a course or module: planning, delivery, student selection, assessment, management or evaluation. This is underpinned by a statement of values and aspirations. Payment for teaching activities at normal visiting lecturer rates. Service users / carers contributing to key decisions on matters such as curriculum content, style of delivery, learning outcomes, assessment criteria and methods, student selection and evaluation criteria. Facility for service users / carers who are contributing to the programme to meet up together, and regular provision of training, supervision and support. Positive steps to encourage service users and carers to access programmes as students.

LEVEL 5: ▼
PARTNERSHIP

Service users, carers and teaching staff work together systematically and strategically across all areas – and this is underpinned by an explicit statement of partnership values. All key decisions made jointly. Service users and carers involved in the assessment of practice learning. Infrastructure funded and in place to provide induction, support and training to service users and carers. Service users and carers employed as lecturers on secure contracts, or long term contracts established between programmes and independent service user or carer training groups. Positive steps made to encourage service users and carers to join in as participants in learning sessions even if they are not (yet) in a position to achieve qualifications.

In contrast to the ladder models, another model that is utilised within education is Chamber and Hickey's (2012) continuums. It posits that involvement can be positioned along a continuum. The first is the 'integration continuum' that has systemic user involvement on one end; this represents the involvement of service users and carers on all levels and aspects of the development and delivery of education. On the other end lies 'piecemeal' user involvement. This is defined as limited involvement where service users and carers are often only involved in confined activities such as teaching. The second continuum is the 'engagement continuum'. This spans from 'active' on one end to 'passive' involvement on the polar opposite end. Active engagement is where service users challenge the negative assumptions and take up a more active role. However, passive involvement is where service users are merely used to meet students' training needs. This replicates the power differential that traditionally existed within clinical practice (Livingston & Cooper, 2004).

The models are not without their limitations, which Arnstein herself recognised. The categorisation of the various levels implies that involvement is clear cut and fits into particular steps. However, involvement is full of complexities and is multi-layered, which the models cannot effectively demonstrate (Carpentier, 2016; Robinson & Webber, 2013). The differences in viewpoints within the groups (power holders and have-nots) must also be acknowledged, and assumptions about their needs cannot be implied. Apart from Tew et al.'s (2004) model, it is also difficult to ascertain what activities occur at a given level to place involvement within a particular category, which often causes confusion.

The simplistic nature of the models also fails to recognise the power differentials in operation between the different actors within involvement. It must also be noted that the models focus on outcome and do not consider the importance of the processes that occur during involvement as well as the impact of such processes on stakeholders. Most notably, the models also do not consider the different types of power in operation within involvement and how this impacts stakeholders. For example, with Arnstein's model, citizen control is presented as the optimum level of involvement but this also makes assumptions about power as it is presented as one group gains and the other group loses. However, what is not considered is the fact that this is not always the case and the differing types of power and knowledge in operations in such institutions should be considered and understood. What may also be more fruitful is collaboration between stakeholders that sees a coming together of individuals within involvement where power is shared which may result in more beneficial outcomes.

With an understanding of the historical, social, and political context and knowledge of the various models used to gauge levels of involvement, this chapter will now consider the role of empowerment, as power relations and equity is of importance within involvement.

POWER AND EMPOWERMENT

The term empowerment is frequently used within service provision, education and across various disciplines, including psychology, community development, social work, nursing, politics and many others (Cheryomukhin, 2014). It is commonly a core concept in the development of educational programmes due to Paulo Freire's work in the 1970s that advocated for the emancipation of the oppressed through education. However, despite the proliferation of empowerment in various sectors, what is most troubling is that literature shows that there is inconsistency in how the concept is defined and evaluated (Tew, 2006). Due to the lack of an agreed understanding, it is feared that empowerment has become an empty buzzword that is excessively uttered (Toomey, 2011) and thus requires further scrutiny. As empowerment has been used in grandiose ways to convey ambitions of collaboration and equality, sadly underneath the hyperbole, may exist contradictory agendas. Therefore, when empowerment is expressed in connection with involvement, one should seek to understand if the practices and processes in operation emancipate individuals, with collaborative working that redirects resources to marginalised groups to create social change (Prilleltensky, 2008; Rappaport, 1981).

As a means of conceptualising empowerment, power is a central idea that must also be addressed (Sadan, 2004). Oddly enough, it often does not receive the proper care and attention in the empowerment discourse (Archibald & Wilson, 2011). Power remains an uncomfortable topic to discuss, as many perceive it to be unchangeable and repressive. It is also habitually associated with control, dominance and authority, which can be misused. Weber et al. (1946) defined power as a person's capability to make another do what they want irrespective of their needs and interests. In addition, it highlighted an essential dimension to power, stating that it operates in relationships and does not exist in isolation. It is therefore possible for empowerment to move beyond mere rhetoric when it is a process for change. This was further supported by Page and Czuba (1999) that asserted that empowerment could be a mechanism that challenges presumptions about the way things should be and beliefs about power, achievement, and help. Therefore, if power can change, then empowerment is possible. A second prerequisite for empowerment to be feasible is if power can expand. The statement refers to the concept of power not being zero-sum. Power as a zero-sum is rooted in struggle, dominance and inequality. It is centred on people gaining power at the expense of others, and the have-nots cannot acquire power unless it is given up by the powerful. Subsequently, creating the dynamic - as one person gains, the other loses (Chambers, 2006). However, research on power suggests it can be shared and collaborative (Kreisberg, 1992).

Empowerment theory is an integral concept in community psychology and has been utilised to construct a model of quality involvement (Morrow et al., 2010). Empowerment centres on the control and autonomy that individuals have to do something (Pearsall & Trumble, 2003). Maton (2008) describes it as a "group – based, participatory, developmental process through which marginalised or oppressed individuals and groups attain greater control over their lives and environment, acquire valued resources, basic rights, achieve important life goals and reduced social marginalisation" (p.5). It is a strength-based approach that positions traditionally marginalised groups as individuals with the knowledge, ability and rights to operate autonomously in society realised through the opportunities and resources in their milieu (Moran et al., 2017).

The concept of empowerment is a multi-layered construct applied on a psychological, organisational or community level (Zimmerman, 1995; 2000). On an organisational level, empowerment focuses on the power structure in existence within institutions and seeks to challenge and alter them. Creating new egalitarian structures where there is shared leadership, acquisition of skills and social change. In line with Rappaport and Seidman (2000), a clear delineation has been made between empowering and empowered organisations. Empowering organisations offer individuals the ability to gain control over their lives but may have no impact on policy. On the other hand, empowered organisations impact policy but may not provide opportunities for members to be empowered. Empowerment at a community level fosters opportunity for participation to occur, focusing on collective action that improves community control.

The focus of this study will be Psychological Empowerment (PE), as initially theorised by Zimmerman (1995) (Appendix A), which is the most commonly utilised model when evaluating if initiatives are indeed empowering (Cattaneo & Chapman, 2010). PE refers to the construct at an individual level and encompasses the individual's views about their own capability, efforts to exercise control and their understanding of the socio-political environment (Zimmerman, 2000). Emphasis is not placed on the individual's actions to achieve their goals, as the importance is the individual being involved and seeking to exert control. Empowerment challenges professional expertise in the professional and SU relationship. It focuses on individuals within marginalised groups' strengths as they participate in solution-orientated activities that help resolve important issues through collaboration (Peterson, 2014). Therefore, involvement in the design, implementation and evaluation of services and education from an empowerment stance redefines the professional's role from one that is traditionally seen as an expert position to a collaborator (Rappaport; 1981; Zimmerman; 2000). The professional acquires knowledge of participants by working with them verses taking the role of advocating for them. Berger and Neuhaus (1997) proposed that an individual's sense of powerlessness, alienation, and withdrawal from community living can be minimised by more opportunities for involvement, leading to an improved understanding of the community. Confidence is also fostered as new skills are learnt and an increased sense of control is established.

Zimmerman's (1995) nomological network of PE links individuals and their environment. There are three fundamental assumptions: the first is that PE will be different for different individuals (Zimmerman, 1990). Therefore, there cannot be an expectation that individuals with varying needs will require the same processes and activities to feel empowered. In addition to individual differences, the second refers to contextual differences. As the structures within organisations vary considerably, empowerment will not be the same across all contexts. The third and final assumption places emphasis on time and the dynamic nature of empowerment. This is indicative of empowerment being prone to fluctuation and thus not unchanging. Revealing that individuals can move from positions of feeling empowered to that of feeling disempowered at different time points. Zimmerman (1995) also stated that ubiquitous measures to examine empowerment might be unsuitable due to the personal, contextual and temporal assumptions.

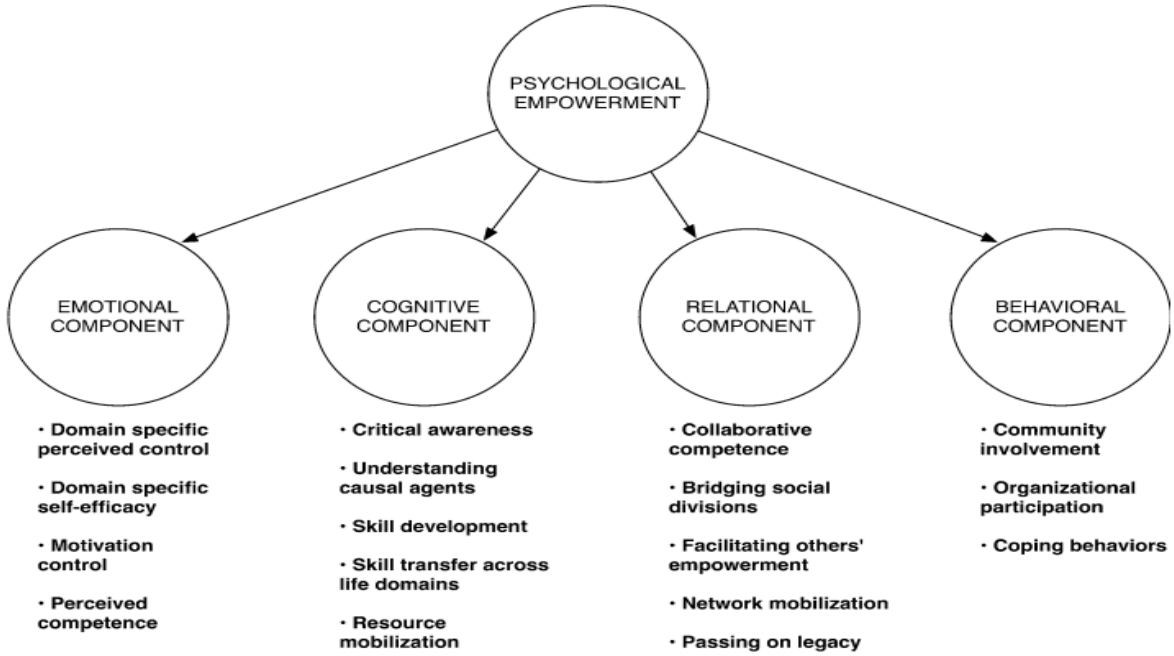
The nomological network presents empowerment as a higher order construct with three interconnected components: intrapersonal, interactional and behavioural. The intrapersonal component is related to people's emotions and encompasses domain-specific perceived control and self-efficacy, motivation control and perceived competence (Peterson et al., 2002). It refers to the individual's perceived capacity to influence socio-political systems. Factors such as lack of social connection, despair, and a feeling of powerlessness may impede intrapersonal empowerment. The cognitive (interactional) dimension that incorporates critical awareness, understanding causal agents, skills development, skills transfer across life domains and remobilisation addresses an individual's awareness of the socio-political environments and the issues in such spaces. Individuals are required to understand the environment and the resources needed and how to obtain and activate the resources to actualise their desired outcomes (McCarthy & Zald, 1978). It is also said to involve individuals developing key skills that enable them to be active in making decisions, solving problems, and leadership, which promotes greater autonomy over lives and encourages action. Lastly, the behavioural dimension encompasses community involvement, organisational participation, and coping behaviours, which indicates the degree to which the individual takes action to influence their environment directly and achieve outcomes through their participation. According to Zimmerman (1995)

> These three components of PE merge to form a picture of a person who believes that he or she has the capability to influence a given context (intrapersonal component) understands how the system works in that context (interactional component), and engages in behaviours to exert control in the context (behavioural component). (p.590).

The interactional component is said to be imperative as it serves to bridge the intrapersonal and behavioural components.

Despite the use of Zimmerman's theory in the literature, Speer and Hughey (1995) critiqued the model by citing that there needs to be a greater relationship between empowerment and the redistribution of power that leads to equality. However, this is often found not to be the case. Various other research also cites that the model fails to reference the relational component of PE as it does at an organisational (Peterson & Zimmerman, 2004) and a community level (Laverack, 2006). Christens (2012) augmented the model to reflect the relational component in PE, as shown in Figure 3. This was based on work by Ginwright (2007); Kunreuther et al. (2009), and Russell et al. (2009). The relational component refers to the collaborative competence, bridging social divisions, facilitating others empowerment, network mobilisation and passing on a legacy. It refers to individual's working as part of a collective and supporting each other to be empowered as they ensure that the work achieved continues.

FIGURE 3: CHRISTENS (2012) MODEL OF PSYCHOLOGICAL EMPOWERMENT



As theorised by Zimmerman (1995) and augmented by Christens (2012), PE will provide the theoretical underpinning for this study. It will be the lens from which the researcher will analyse the data collected from participants.

CHAPTER 2. LITERATURE REVIEW

This section will present the findings from a systematic literature review conducted to evaluate existing peer-reviewed research exploring the experiences of service users and carers involved in health and social care education in higher educational institutions. It is also aiming to reveal the knowledge gap that will then situate this research study. Firstly, the search strategy is outlined, followed by papers that met both the inclusion and exclusion criteria. The quality of each article will then be reported as evaluated using the Critical Appraisal Skills Programme (CASP) tool. The findings will be reviewed and the chapter will end with a justification for this research in light of the results.

LITERATURE REVIEW

Given the growing demand to involve service users and carers in the education of health and social care students (Morgan & Jones, 2009) this literature review has been conducted in an attempt to bring together the current evidence as a means to explore and understand how service users and carers experience their involvement.

The aim of the review is to locate and synthesise studies that focus on service users' and carers' experiences. Papers using qualitative methodology were considered most adequate to address the review question as they would provide rich qualitative experiential knowledge into participants' views, opinions and perceptions. Therefore, papers solely utilising quantitative approaches were not included in this review as such methodology would not allow for the level of examination nor provide an in-depth exploration of participants' perspectives and thus not adequately answer the review question.

Review question: What are the experiences of service users and carers involved in health and social care education in higher educational institutions?

SEARCH STRATEGY

Qualitative approaches were the focus of this search as such methodology privileges individuals' subjective experiences (Greenhalgh & Taylor, 1997) and provide rich and detailed data. Firstly, literature that focused on service user and carer involvement in health and social care education was retrieved on the relevant electronic databases - CINAHL Complete, MEDLINE Complete, PsychARTICLES, PsycINFO, Web of Science and E-Journals. Furthermore, as a follow-up, manual hand searches were carried out in key papers, references and citations (Higgins & Green, 2011). The last search was performed on the 30th of April, 2021.

A closer look at the literature revealed that terminology used to describe service user and carer involvement varied considerably. The review used the terms service user, patient, consumer, user, client, or carer to encapsulate all relevant papers, as shown in (Appendix B). Terms such as public and citizen are not added to the search terms; this is because the review did not intend to capture the general public’s experiences but instead sought to focus and understand the experiences of service users and carers alone.

To locate all relevant studies, all 5 search fields were initially searched using the text field function; however, many were not suitable when retrieved papers were scanned. Therefore, to obtain more relevant papers, the search was modified, and terms 1, 2 & 3 were searched in the title field and term 4 & 5 in the text field (Appendix B).

INCLUSION AND EXCLUSION CRITERIA

All studies were reviewed by reading the title, abstract and full text against the following inclusion and exclusion criteria. Articles that focused on primary research from peer-reviewed journals that reported the experiences of service users and carers involved in the education of graduate and post-graduate students across both health and social care were included in this review.

Considering the exploratory nature of this review question, papers using qualitative or mixed methods were included. However, for this review, only the qualitative responses were considered from the studies that used mixed methods. There were no geographic, age or date restrictions on the search to ensure that the search retrieved all relevant papers.
Research studies were excluded if they did not report on primary research as the review seeks to understand experiences directly from service users and carers or if they were editorials, case studies, commentaries, thesis or dissertations. Studies were also not included if they examined service user and carer involvement in research, services or peer education.

Additionally, studies were excluded if they only employed quantitative methodology and if they were from other academic or clinical environments. An English language limiter was applied across all databases.

REVIEW OF THE LITERATURE

A total of 785 articles were identified using the search strategy (Appendix C). All records were reviewed to ensure the most suitable papers were obtained. A total of 497 duplicates were removed. An additional 205 papers were excluded when reviewing titles and reading through abstracts as the studies were not pertaining to service users' and carers' views. Out of the remaining 83 articles, 63 studies met the exclusion criteria, with the remaining 20 papers meeting the inclusion criteria. A further 4 papers were identified through manual searches of reference lists and from Google Scholar. A total of 24 articles were identified and synthesised in this review following all electronic and manual searches.

METHODOLOGICAL PROFILE

Overview of the studies: All studies were conducted between 2002 and 2020. As outlined in the inclusion criteria, all 24 studies employed a qualitative approach to their research. A range of data collection and qualitative methods were utilised to analyse participants' data. Sample sizes ranged from 4 to 21 service users and carers.

The methods used to collect primary data included individual interviews and focus groups. Individual interviews were the preferred method in a majority of the papers. Interviews were the only data collection method used in 12 studies (Campbell & Wilson, 2017; Cooper & Spencer – Dawe, 2006; Curran et al., 2015; Flood et al., 2018; Happell et al., 2017 Keenan & Hodgson, (2014); McIntosh, 2018; Meehan & Glover, 2007; Rooney et al., 2016; Rooney & Unwin, 2020; Shah et al., 2005; Thomson & Hilton, 2013), which allowed for the comprehensive exploration of participant's thoughts.

Focus groups were implemented by five studies (Dzombic & Urbanc 2008; Lea et al., 2016; McGarry & Thom, 2004; O'Reilly et al., 2012; Rees et al., 2007). Masters et al. (2002) used focus groups in addition to questionnaires. Matka et al. (2010) used surveys and Schon (2016) utilised questionnaires to gather data, thus, yielding both quantitative and qualitative feedback. Three studies used a mixed method design consisting of focused groups, individual interviews and self-complete questionnaires to collect a rich tapestry of information from participants (Anghel & Ramon, 2009; Heaslip et al., 2018; Mckeown et al., 2012; Webber & Robinson, 2012). However, for this review, only the qualitative responses were considered from the questionnaires.

A Participatory Action Research (PAR) approach was utilised in seven articles, where service users and carers were co-researchers (Anghel & Ramon, 2009; Heaslip et al., 2018; Masters et al. (2002); Mckeown et al., 2012; Rooney et al., 2016; Rooney & Unwin, 2020; Webber & Robinson, 2012). Curran et al. (2015) highlighted the specific use of a knowledge café participatory approach to collect data from participants through creative conversations.
To analyse the data, three papers utilised a phenomenological approach (Campbell & Wilson, 2017; McIntosh, 2018; Meehan & Glover, 2007). In 10 of the papers, data was analysed using thematic analysis approach (Anghel & Ramon, 2009; Dzombic & Urbanc, 2008; Heaslip et al., 2018; Lea et al., 2016; Masters et al., 2002; Matka et al., 2010; Mckeown et al., 2012; Rooney et al., 2016; Rooney & Unwin 2020; Webber & Robinson, 2012) and two studies used framework analysis (Happell et al., 2017; Rees et al., 2007). Whilst one study employed a content analysis approach (Schon, 2016) and Cooper and Spencer – Dawe (2006) used a comparative methodology. Finally, grounded theory approach was employed by Flood et al. (2018), Keenan and Hodgson (2014), McGarry and Thom (2004), O'Reilly et al. (2012), Shah et al. (2005), and Thomson and Hilton (2013) to analyse their data.

Despite no location restrictions added to the search, 18 of the studies retrieved were conducted in the UK. (Anghel & Ramon 2009; Cooper & Spencer – Dawe 2006; Curran et al., 2015; Flood et al., 2018; Heaslip et al., 2018; Keenan & Hodgson, 2014; Lea et al., 2016; Masters et al., 2002; Matka et al., 2010; McGarry & Thom, 2004; McIntosh, 2018; Mckeown et al., 2012; Rees et al., 2007; Rooney et al., 2016; Rooney & Unwin., 2020; Shah et al., 2005; Thomson & Hilton, 2013; Webber & Robinson 2012). This may be due to service user and carer involvement in health and social care education being a requirement for institutions in the UK. as prescribed by regulatory bodies. Three studies were in Australia (Happell et al., 2017; Meehan & Glover, 2007; O'Reilly et al., 2012) and one was based in Ireland (Campbell & Wilson, 2017). The study by Dzombic & Urbanc (2008) was conducted in Croatia, and the final study was conducted in Sweden (Schon, 2016).

A NOTE ON TERMINOLOGY

As outlined in the introduction, the complexities around terminology were also evident as there was no consensus on the terms used in the literature to describe participants. A total of 13 papers focused only on service users' experiences. In eight of the studies, participants were called service users (Campbell & Wilson 2017; Cooper & Spencer – Dawe, 2006; Heaslip et al., 2018; Keenan & Hodgson, 2013; Lea et al., 2016; McGarry & Thom, 2004; Rees et al., 2006; Thomson & Hilton, 2012). Happell et al. (2017), and Meehan and Glover (2007) used the term consumer educators, and the label users were employed by Dzombic and Urbanc (2017). Flood et al. (2018) and Shah et al. (2005) referred to them as patients.

Conversely, just under half of the studies examined both service users' and carers' experiences and used terms such as experts by experience (Curran et al., 2015), consultants (Anghel & Ramon, 2009) and Mental health consumer educators (O'Reilly et al., 2012). Masters et al. (2001), Matka et al. (2009), Mckeown et al. (2012), Rooney et al. (2016), Rooney and Unwin (2020), Schon (2016), and Webber and Robinson (2012), referred to participants as service users and carers. Mckeown et al.'s (2011) article discussed the reasons for reporting the views of service users and carers together, citing the themes identified were found to be pertinent across the data gathered by both groups in equal proportions. In the results, both Masters et al. (2001), and Schon (2016) were the only studies that made a distinction between service users' and carers' experiences. In the remaining studies, the responses from both service users and carers were presented together. Consequently, what was not articulated in the findings was an understanding of how their experiences were similar and if they differed. Lastly, the only study that focused solely on carers' experiences was conducted by McIntosh (2018), as their entire sample consisted of only carers.

INVOLVEMENT ACTIVITIES

A total of 11 papers discussed the involvement activities that participants were involved in at the academic institutions. Nevertheless, what was not recorded was the frequency in which participants were involved in such activities. In six of the papers, activities were centred around service users and carers sharing their lived experience in teaching (Dzombic & Urbanc, 2008; Flood et al., 2018; Happell et al., 2017; Meehan & Glover, 2007; O'Reilly et al., 2012; Shah et al., 2005). Keenan and Hodgson (2014), Rees et al. (2007), and Rooney et al. (2016) highlighted participants were involved in teaching as well as assessing students.

Service users and carers were also involved in admission interviews (Heaslip et al., 2018; Matka et al., 2010; Rooney & Unwin, 2020). Anghel and Ramon (2009) described that service users and carers shared their testimonies in lectures; they were also consultants, co-trainers and part of the interview process. Thomson and Hilton's (2013) study reported that service users and carers also interviewed students and, in addition, assessed clinical reasoning skills and facilitated critical group debates. Cooper and Spencer – Dawe's (2006) study described participants being involved in workshops and reviewing case studies. Curriculum development and the evaluation of the programme was reported by Masters et al. (2002). In McIntosh (2018), carers were involved in a range of activities, including student interviews, teaching, module and programme development, and student assessments. In seven of the papers, involvement activities were unspecified (Campbell & Wilson, 2017; Curran et al., 2015; Lea et al., 2016; McGarry & Thom, 2004; Mckeown et al., 2012; Schon, 2016; Webber & Robinson, 2012). As outlined above, there is no mention in the literature of service users and carers being involved in senior management activities.

SYNTHESIS AND QUALITY APPRAISAL

The focus of this review was primarily on studies that sought to understand involvement from service users' and carers' perspectives, illuminating their voices and experiences. Given the nature of the studies in this review, a thematic synthesis framework outlined by Thomas and Harden (2008) was used to synthesize the data whilst staying true to the original data sources, a fundamental aspect of the approach. This was also the methodology chosen due to the quality of the studies found in the search. The approach enabled the researcher to systematically pull out and bring together information from various data sources. The findings were reviewed several times whilst highlighting all the pertinent codes that emerged, these were then grouped together to create themes. Thus, allowing for a nuanced understanding of involvement in health and social care education from service users' and carers' perspectives.

To assess the methodological rigour of the articles included, the Critical Appraisal Skills Programme (CASP, 2018) tool was utilized to systematically assess the validity of the research, the results as well as the value and relevance of the findings. Appendix D features the quality appraisal of the 24 articles in the thematic synthesis. The quality and methodological strength of the papers varied considerably when the researcher considered the studies included against each question on the CASP tool, with several papers lacking adequate detail thus making it difficult to evaluate the trustworthiness of the studies' findings. Despite the variation in methodological quality, all papers were included as they met the research aims and yielded valuable insights into how service users and carers experience their involvement in health and social care education. Appendix E summarises all papers according to methodological strength from strongest to weakest.

All articles clearly provided a statement of the study aims, employed an appropriate methodology, outlined the data collection process and utilized the appropriate research design to answer their research aims. Most of the papers adequately reported the process of recruiting participants (Campbell & Wilson, 2017; Cooper & Spencer – Dawe, 2006; Dzombic & Urbanc, 2008; Flood et al., 2018; Happell et al., 2017; Heaslip et al., 2018 Keenan & Hodgson, 2014; Masters et al., 2002; McGarry & Thom, 2004; McIntosh, 2018; Mckeown et al., 2011; Meehan & Glover, 2007; O'Reilly et al., 2012; Rees et al., 2007; Rooney & Unwin, 2020; Schon (2016); Shah et al., 2005; Thomson & Hilton, 2013; Webber & Robinson, 2012). Various sampling methods such as snowballing technique (Meehan & Glover, 2007) or purposive sampling (McIntosh, 2018; Thomson & Hilton, 2013) were employed and most authors reported that participants were recruited through the educational institution. Flood et al. (2018) cited that their recruitment approach was a limitation of their study.

Methodological shortcomings were evident in some papers. Ethical issues were considered in 18 of the papers with authors stating they obtained ethical approval from the respective institutions ethics committees and informed consent from participants. Just seven of these papers provided wider ethical consideration such as confidentiality and the right to withdrawal (Happell et al., 2017; Lea et al., McGarry & Thom, 2004; 2016; McIntosh, 2018; Rooney & Unwin, 2020; Rooney et al, 2016; Schon, 2016). A total of seven studies reported the role of the researcher within the academic institution and how this may have potentially influence participants' responses (Campbell & Wilson, 2017; Flood et al., 2018; Lea et al., 2016; Masters et al., 2002; McIntosh, 2018; Mckeown et al., 2011; Webber & Robinson, 2012). The study by Flood et al. (2018) acknowledged that the dual role of the researcher as module coordinator may have biased participants' responses. Lea et al. (2016) clearly stated their roles within the training programme but failed to further discuss how this may have impacted participants.

A total of 13 studies provided demographic information about participants. Ethnicity was reported in only five studies (Cooper & Spencer – Dawe, 2006; Flood et al., 2018; Rees et al., 2007; Rooney et al., 2016; Shah et al., 2005) and in these studies, a vast majority of the participants were white. A total of eight out of the 24 studies presented the age range of participants (Campbell & Wilson, 2017; Flood et al., 2018; Matka et al., 2010; Meehan & Glover, 2007; Rees et al., 2007; Schon, 2016; Shah et al., 2005; Thomson & Hilton, 2012) and 11 stated participants' gender. A total of three papers reported employment status (Rees et al. 2007; Schon 2016; Thomson & Hilton, 2012), and the studies by O'Reilly et al. (2012) and Thomson and Hilton (2012) in addition to reporting participants' gender they also reported participants' diagnosis/health condition. The remaining 11 studies failed to explicitly outline any demographic information about their sample. This lack of information makes it challenging for readers to establish if the findings are relevant to their settings.

As outlined above when considering the language used in the studies, 10 studies considered both service users' and carers' experiences. However, all but one of these studies (Mckeown et al. 2011) reported both groups' experiences together thus making it difficult to deduce the commonalities or differences in their experiences. The remaining nine studies failed to discuss this in any detail.

RESULTS OF META SYNTHESIS

When analysing the literature, two distinctive themes were developed. All of the papers highlighted the benefits of participants' experiences, this has been outlined in the first theme *'the positive aspects of involvement'*. Further examination showed that the positive aspects could be further categorised into 2 sub-themes, as outlined in the first sub-theme '*idiosyncratic gains'* there were perceived direct benefits to service users and carers. The second sub-theme '*I am part of the change I want to see*' outlines the impact service users and carers perceived their involvement had on others such as students, staff members, and other service users and carers.

Although there was a consensus in the literature that involvement was a beneficial endeavour, many studies also found that there were challenges faced. This is reflected in theme two 'the barriers to effective involvement'. A total of 19 papers looked at this in detail. The barriers have been categorised in 3 distinctive ways that elucidate the emotional impact, logistical hinderances and lastly where participants think they fit within the institution as outlined in the 3 sub-themes *'the emotional burden of sharing my story', 'circumstances outside of my control' and 'are my lived experiences really valued?'*

The many commonalities and key concepts in the papers will be further discussed below. Appendix F illustrates the prevalence of each theme and sub-themes across the 24 articles reviewed. It is important to note that terms other than service users and carers will be used in this section as a means of aligning with the terms authors have used in their research projects to represent their participants.

1. THEME 1: THE POSITIVE ASPECTS OF INVOLVEMENT

One of the most pertinent themes across all papers were the benefits that service users and carers reportedly gained from their involvement experiences. The benefits discussed were multifaceted in nature and are highlighted in the following sub-themes the *1) 'idiosyncratic gains' and 2) 'I am part of the change I want to see'*

1.1 IDIOSYNCRATIC GAINS

Idiosyncratic gains were outlined in most of the papers, with the findings highlighting that service users and carers experienced several personal benefits from their involvement in health and social care education. These benefits included an improved sense of wellbeing, which encompassed increased confidence, self-worth and self-esteem, as found by Curren et al. (2015), Keenan and Hodgson (2014), Mckeown et al. (2011), and O'Reilly et al. (2012). Heaslip et al. (2018) emphasised that involvement enabled participants to reconnect and regain a sense of who they once were before their illness as outlined in the quote: "for some, it was as if they were reclaiming some lost aspect of themselves that they had before they had become unwell and were unable to formally work, whilst for others it linked to gaining confidence" (p.110). Shah et al. (2005) highlighted that for patients who were not working due to retirement or not being able to as a result of their illnesses, their involvement in health education provided a chance for patients to reengage in meaningful activities. This opportunity gave participants a sense of purpose and boosted their self-worth. Matka et al. (2010) emphasised that in addition to an increased sense of confidence, service users and carers reported that they obtained additional skills through their involvement. The authors stated, “people talked of gaining confidence, a feeling of being heard and valued, of gaining knowledge and insight, or of gaining practical skills” (p. 2148). Findings also illuminated participants appreciated being listened to and respected (Flood et al., 2018). There was also immense value placed on the knowledge participants received about their illness and treatments as found in Keenan and Hodgson (2014). Shah et al.’s (2005) findings went on to link involvement to patients’ belief about themselves and their ability to manage their illnesses. The study reported “as a result of increased confidence and self-esteem, patients were also able to cope better with their illnesses” (p.5).

A total of five papers also documented the sense of empowerment experienced by participants as a benefit of their involvement (Masters et al., 2002; Meehan & Glover, 2007; Rooney & Unwin, 2020; Webber & Robinson, 2012). O’Reilly et al.’s (2012) study reflected on what aspects of involvement left service users and carers with a sense of empowerment as outlined in the following extract: “they all reported feeling empowered in their role of sharing their personal knowledge and experiences of mental illness. It gave them great joy and strength…” (pp. 610- 611). In Meehan and Glover (2007) it was described that participants felt empowered simply because they were asked to be involved and contribute to knowledge. It can be inferred that participants experienced a sense of empowerment due to the shift that moved them from a position of being passive recipients of care to more active and dynamic roles where they were influencing education. Webber and Robinson’s (2012) findings discussed what service users and carers felt was the primary purpose of involvement. Many participants stated that they felt “…its main purpose as being to empower the service users involved and alter the power dynamic between service users and service providers” (p.1262).

Other papers explored the benefits that service users and carers expressed regarding networking with like-minded people such as academic staff and other service users. In five papers the social and supportive nature of the relationships formed were documented (Keenan & Hodgson, 2014; McKeown et al., 2012; Rees et al., 2007; Rooney et al., 2016; Shah et al., 2005) and two papers expressed that connecting with peers enabled a sharing of ideas and a sense of learning from each other as described by Curran et al. (2015). Campbell and Wilson’s (2017) findings also reflected the benefits that came as a result of peer interactions. As outlined in the extract, it was felt that this was due to the shared understanding and mutual appreciation participants fostered, “respect was demonstrated by listening to participants contributions, appreciating alternative viewpoints and valuing the presence of each group member regardless of their level of contribution" (p.8).

Participants also expressed a therapeutic component to sharing their stories as outlined by Keenan and Hodgson (2014), who reported the preventative aspect to involvement. There was a sense that patients felt it was cathartic and, in some cases, even averted the onset of depression as highlighted in this extract:

> Some claim it stopped them wallowing in their own self-pity and could have prevented depression almost using it as a therapeutic activity. Other participants stated that it's easy to become depressed if you think about what you've gone through, but it's good to have people to talk to. (p.260).

Participants in the study also recognised that involvement impacted their relationships with their family and friends, as it was reported that having a space to speak left participants feeling less of a burden to people close to them.

1.2 I AM PART OF THE CHANGE I WANT TO SEE

Moving beyond the personal gains that service users and carers reported, several studies showed a strong sense of advocacy in service users' and carers' experiences. This points to participants' understanding of how service users and carers feel they are continuously marginalised within academia and services. To push against this, service users and carers used their platform in education to challenge general misconceptions held about them (Thomson & Hilton, 2013). McIntosh (2018) found that participants positioned themselves as activists that defended service users' rights as outlined in this quote: "all of the carers spoke of the need to campaign and stand up for the rights of people receiving mental health care" (p.176). Participants also wished to challenge societal attitudes, and through their involvement used their voices to encourage that service users and carers are seen as human beings, thus promoting strengths-based person-centred care and not a disease-focused approach. Closely aligned findings were documented in Anghel and Ramon (2009), Cooper and Spencer – Dawe (2006), Dzombic and Urbanc (2008), Lea et al. (2016), O'Reilly et al. (2012) and Shah et al. (2005). There were 13 studies that also focused on service users and carers using their involvement to tackle the stigma and discrimination that service users all too often experience as a result of their mental and physical health needs. There are wider ramifications to such discrimination. Stigmatisation not only has a bearing on the health and social care provisions that service users and carers receive but it also impacts their social position and their access to opportunities such as jobs, and community resources.

Another central finding across 18 of the papers was participants' desire to use their voice and position within academia to improve students understanding of service users and carers' lived experiences (Lea et al., 2016; Thomson & Hilton, 2013) and their illnesses (Schon, 2016). Keenan and Hodgson's (2014) findings illustrated that service users and carers hoped to demonstrate to students the value and impact of their work. There was also a desire for more prolonged effects as service users and carers perceived that the knowledge shared with students would equally transcend academia and influence their clinical practice: "they believed that through sharing their experiences they could also tell the students what specifically helped them through their difficult times. They hoped that through their involvement that students would help improve the experience of other patients" (p.258). Rooney and Unwin's (2020) study found that participants perceived they were "shaping the next generation of healthcare professionals" (p.7) and thus, improving services for future service users and carers. These findings were also echoed in McGarry and Thom (2004); O'Reilly et al. (2012); Rooney et al. (2016); Webber and Robinson (2012).

It was reported in 14 studies that service users and carers felt they helped students develop integral skills. Anghel and Ramon (2009) stated that through involvement:

> Consultants hoped that the students would retain key messages about the value of 'being human', passionate about the job, empathic, a good listener, open minded, reflective on their role in people's lives, patience, diplomatic and respectful when making decisions as a social worker. (p,194).

Other studies acknowledged that core skills such as inter and intrapersonal skills (Rees et al., 2007); communication and listening skills (Curran et al., 2015) would foster relationships of respect between service users and carers and professionals (Dzombic & Urbanc, 2008) in services and within academia. Ultimately, service users and carers experienced their involvement in education as a place to use their skills and lived experiences to champion social change as they influenced and shaped the students learning (Happell et al., 2017;

Mckeown et al., 2012; Schon, 2016). This perhaps signals how service users and carers position themselves as valuable resources within academia and services. Pushing for service users and carers to no longer be seen as having nothing to contribute and instead, they used their agency, voice, and expertise to drive equality in society for marginalised individuals.

2. THEME 2: BARRIERS TO EFFECTIVE INVOLVEMENT

It should be acknowledged that despite the responses from most papers being very positive, another theme that was generated from 19 studies pertained to the challenges service users and carers faced whilst being involved. This theme encompasses the sub-themes *1) 'the emotional burden of sharing my story', 2) 'circumstances outside of my control' and 3) 'are my lived experiences really valued?'*

2.1 THE EMOTIONAL BURDEN OF SHARING MY STORY

This sub-theme captures the complexities that surround service users and carers being involved in education to shared their lived experiences of services and their illnesses. This at times often leads to a constant repetition of participants distressing experiences. Across five studies it was found that service users and carers expressed that they felt anxious about their involvement in teaching tasks as such tasks were often centred around participants sharing their stories. Flood et al. (2018) reflected on how apprehensive participants felt about their involvement in teaching and the emotional impact of their disclosures. The findings captured how raw and emotive it can be for service users and carers as illustrated in the following quote:

> For many participants involved with the study, the teaching session was a highly emotional experience. The emotions were strongly linked to the participants perceptions of the traumatic nature of their cancer and its associated treatments. These participants were anxious about becoming emotional during the session as they felt that they were in essence 'baring their soul' and 'opening up a box of emotions'. (p.4).

Keenan and Hodgson (2014) also acknowledged the emotional toll service users and carers experience when recounting their stories. This was also supported by Rees et al.'s (2007) study which reported: "…how traumatic it was for mental health service users to repeatedly tell their often-harrowing stories to multiple groups of medical students" (p.381). McIntosh's (2018) study was the only study that investigated the experiences of carers alone and the findings highlighted those carers felt depleted as a result of the continual focus on their lived experiences. This speaks to the complexities around involving service users and carers in academia to just share their stories about their illnesses. It is evident from the literature that this can pose challenges for service users and carers that want to be involved but that are often asked to take up the same role. It can be argued that this also highlights the importance of service users and carers taking up varied roles within academia.

2.2 CIRCUMSTANCES OUTSIDE OF MY CONTROL

In addition to the psychological burden that participants reported in relation to their involvement experiences, there were also other challenges faced as a result of the logistical issues service users and carers encountered whilst being involved. These included issues such as the timing of sessions, lack of adequate notice given to participants (Rooney et al., 2016), and an inability to access the buildings (Dzombic & Urbanc, 2008) which is highlighted in this quote "...participants expressed their dissatisfaction with the fact that the faculty building is inaccessible for people with disability" (p. 384). Thus, showing that despite the fact that service users and carers were being asked to be involved, it was felt the correct provisions were not made by the institution to aid their involvement.

In addition to accessibility issues, challenges were also found directly related to the amount of work service users and carers were asked to participate in on involvement days. Rooney and Unwin (2020) outlined that service users and carers involved in selection days were left feeling fatigued and exhausted due to the volume of work they were required to do. In addition to feeling overworked, consultants in Anghel and Ramon's (2009) study also felt that they were also inadequately prepared for their involvement tasks: "... they criticised the lack of briefing and debriefing, and some reported problems such as perceiving participation as failure... fatigue during involvement, and some difficulties related to access and time allocation" (p.193).

Across four different studies (Cooper & Spencer – Dawe 2006; Masters et al., 2002; Rees et al., 2007), service users and carers also felt that the training offered by the institutions was insufficient and as a result, this impacted their ability to be effectively involved in academia. Dzombic and Urbanc (2008) supported these findings as service users were seeking more support from the institution to successfully carry out their involvement activities. The author stated "the participants stated the need for regular training for their role of lecturers and participants in other forms of teaching in order for the transfer of their experience to students to be more relevant and adequate" (p. 391).

2.3 ARE MY LIVED EXPERIENCES REALLY VALUED?

This sub-theme speaks to how service users and carers experience the tussle between theoretical knowledge and lived experience knowledge. Findings highlighted that service users and carers believed their unique contributions are equally valuable to pedagogical practices (Lea et al., 2016; Masters et al., 2002) as they bring a holistic quality to students' learning (Rooney et al., 2016). However, participants in the studies felt that this was not always reflected within the institution. Service users and carers sought to ensure that students received adequate training that is not just based on theory (Thomson & Hilton, 2013), thus endeavouring to shift what is deemed as critical knowledge in health and social care education.

Cultural issues within academia were also raised. This speaks to the ethos within the organisation, which participants believed served to hinder involvement as service users and carers identified they were not always acknowledged for the value they brought to the institution. This may speak to an environment that privileges theoretical knowledge over that of lived experience knowledge. The findings illuminated service users' and carers' understanding about the value of their lived experiences, which they perceived cannot be replicated or achieved through the sole use of textbooks (McKeown et al., 2012). Lea et al. (2016) highlighted that "service users stressed that professionals should not be over-controlling, and should recognise that they do not know everything" (p. 212). Other studies reflected a call for institutions to place greater value on the 'expert's views' (Dzombic & Urbanc, 2008; Shah et al., 2005), as it is believed this would lead to a better integration within academia (Meehan & Glover, 2007). Campbell and Wilson (2017) suggested that terminology should also be scrutinised as it all too often reflects and preserves the schism between theory and lived experience knowledge. Further exploration of appropriate terminology was reflected in Rees et al.'s (2007) study that stated that service users should be identified as lecturers instead of patients, which helps to acknowledge that service users and carers are valuable members of the staffing team and "carriers of knowledge" Schon (2016). McGarry and Thom (2004) also stated that:

> It was obvious that nurses and doctors did not always have the knowledge they expected them to have...they identified what they saw as a theory–practice gap and felt that they bridged this chasm by being experts in their field. (p.39).

However, as a result of service users and carers not feeling their views and contributions are always acknowledged or valued by academic staff (Meehan & Glover, 2007), they felt that their involvement was tokenistic in nature. This was seen to be perpetuated by the lack of clear expectation for the service users' and carers' role within academia.

These challenges emphasise the negative aspects of involvement that participants perceived and thus must be considered, as they can be deleterious to participants' sense of autonomy and influence. This also highlights the limited roles service users and carers take up, as they feel they are often relegated to activities where they have no real influence to create actual change within the wider system. On one level it raises questions about how institutions understand and use the contributions service users and carers bring to academia. On another level, it is hoped that it will initiate discussions around service users and carers being offered adequate support when they are involved at a level where they are asked to repeatedly share their stories. This review shows the impact of such roles. Thus, highlighting the importance for institutions to make suitable provisions not only before involvement tasks but also during and after tasks. It is hoped this will ensure that service users and carers can access help if they encounter any difficulties that negatively affect their emotional well-being.

Summary: This review aimed to explore current literature that examines the experiences of service users and carers involvement in health and social care education in HEIs. The findings show that service users and carers experienced their involvement as positive, citing many benefits that impacted the students' learning, the broader system, and service users and carers personally. There was also a strong sense of advocacy. Service users and carers believed that through their unique contribution to academia they could use their lived experience-to not only contribute to the knowledge base but they could also challenge social inequalities and champion improvements, in health and social care education as well as service provision. They also hoped their impact on students would be taken into their clinical practice. Despite all of the positives, studies also highlighted several barriers that service users and carers cited as adversely impacting their involvement within academia. The review found that there were emotional costs to participants constant recollection of their distressing health and social care stories. It can be argued that this also serves as a reflection of the types of roles that service users and carers are asked to be involved in within academic institutions. Service users and carers also spoke about the circumstances out of their control such as lack of adequate preparation as well as logistical issues that impeded their involvement. There was also a desire by service users and carers to have their unique contributions and lived experience knowledge appropriately recognised on an equal footing to theoretical knowledge that is often deemed superior within academia.

LIMITATIONS

The purpose of this review was to gain an understanding of the experiences of service users and carers involved in health and social care education within higher educational institutions. By building on the existing knowledge, it has provided further insights into this phenomenon from a service users' and carers' perspective. However, this review is not without limitations.

The first limitation is the fact that it was conducted by one researcher, as a result of time constraints, which raises the potential for bias. Given the nature of the review question and the fact that only qualitative studies were included to gain an in-depth account of service users' and carers' perspectives, what must be noted is that, subjectivity when interpreting the data cannot be circumvented. The principles outlined by Thomas and Harden (2008) were therefore utilised to analyse the data which increases transparency as it enables others to understand the processes undertaken by the researcher.

Another limitation is that due to the variation in terminology used in the literature relating to service user and carer involvement there was a risk of missing pertinent studies. In an attempt to mitigate this and ensure all relevant studies were included to the best of the researcher's knowledge, several databases were searched using a number of different search terms and reference lists were also thoroughly reviewed.

A rigorous search strategy was followed to ensure all relevant papers were included. However, despite no location limiter being placed on the search, studies that were conducted in the UK, Australia and Europe, were the only studies found. The review also only included studies that were published in English; therefore, it is still possible that some papers were missed due to their unavailability in electronic resources and also being in different languages, which limits the scope of our understanding. Additionally, the inclusion of grey literature was not within the remits of this review thus possibly omitting more provocative discussions on the subject matter. What must therefore be acknowledged when considering the findings, is that the literature obtained may not reflect all research in this area and may also be affected by publication bias.

The assessment of methodological rigour as outlined above also unearthed the disparity in the quality of the studies included in this review. However, despite the weaknesses around studies not including enough information around ethical considerations, the process of participant recruitment and sample characteristics as revealed in some of the studies, no study was excluded on this basis. They were thought to provide rich data that contributed to an understanding about how service users and carers experience their involvement within health and social care education in higher educational settings. The themes extricated from the studies helps to build upon the existing understanding of this phenomenon.

RATIONALE FOR CURRENT STUDY

When seeking to understand involvement in health and social care education the focus is often on students' experiences with far fewer studies focusing on service users' views, and even fewer articles exploring carers' perspectives. This review has been able to synthesise existing data that illuminate both service users' and carers' experiences, highlighting the complexities around involvement and the tussle between theoretical and lived experience knowledge. It can be argued that this also reflects the issues around power structures, hierarchies within institutions and a culture that favours theoretical knowledge. This inadvertently undermines other forms of knowledge.

Even though values such as empowerment, respect and equality were cited in the literature as underpinning involvement initiatives in education (Beckett & Maynard 2005), the review findings only briefly touched upon the sense of empowerment in relation to benefits as well as power and inequality. However, what was not explored in great detail was how service users and carers experience power as operating in their involvement, the impact of power relations on the involvement process as well as what aspects of involvement they find empowering as they gain mastery over their lives and affect change.

Given that these are critical concepts in involvement this study aims to complete primary research exploring service users' and carers' experiences in a HEI in the UK. It is hoped that this will stay true to their experiences and enable the hearing of their voices within academia in order to provide an in-depth understanding of involvement from the service users' and carers' perspective. It will seek to get a nuanced understanding as it builds upon the existing body of work by capturing what involvement means to service users and carers, their perceived sense of empowerment and the processes and procedures that perpetuate the power inequalities that subsequently renders them powerless. The study will map the current level of involvement in the HEI, and also through the use of qualitative methods, it will consider three questions:

1. How do service users and carers experience their involvement in health and social care education?
2. How do service users and carers report their own experiences of power and how it operates and impacts on their involvement?
3. What are the recommendations for improving involvement in health and social care education?

Exploring how participants experience their involvement at this HEI will enable comparisons to be made with the review findings. This along with insights into service users' and carers' perspectives about power, empowerment and powerlessness may yield information previously unknown and contribute to the development of involvement strategies and influence policy. It is hoped that this will help move involvement beyond mere rhetoric into the realms of meaningful and empowering involvement that is worthwhile for service users and carers as well as for all other stakeholders. Further exploration within academia is needed to ensure that involvement is an empowering experience and not continued oppressive practices disguised as involvement. Lastly, recommendations provided by service users and carers will outline how participants in this study believe involvement initiatives can be improved. It is hoped this can be used to inform the modification of service user and carer involvement initiatives within academic institutions.

CHAPTER 3. METHOD

CHAPTER OVERVIEW

This chapter serves to orientate the reader, as it provides an outline of the method used to answer the research question. It will begin with a discussion of the philosophical grounding of the study, its ontological and epistemological positioning, which will inform the study design. It will then discuss how recruitment will be carried out, sample size, and research procedure. The data collection method will then be discussed, followed by an examination of ethical considerations and how the findings will be disseminated.

ONTOLOGY AND EPISTEMOLOGY

According to Tashakkori and Teddlie (2003) the research paradigm should be determined by the research questions and not the methodology that the researcher prefers. The section below will outline the ontological and epistemological position of this study.

ONTOLOGY

Ontology is the philosophy of reality; it refers to the study of being (Crotty, 1998) and is linked to beliefs about the nature of reality (Lincoln & Guba, 1985). For the purpose of this research, this section will consider the two main dominant ontological positions, which are positivism and interpretivism. Objectivist or realist ontology beliefs underpin the positivist position. It claims that there is a single objective reality, which exists independent of social actors and can be discovered. It is grounded in the perception that the truth does not change; it can be measured using objective measurements and can also be generalised.

On the opposite end is interpretivism. This position seeks to understand subjective knowledge and claims that there is no single reality as it is constructed in its context. It is underpinned by a relativist ontology, which believes that multiple realities exist and differ from one individual to another (Guba & Lincoln, 1994) as social interactions influence realities. Reality is that which is shaped by the meanings attached to it and thus socially constructed. It cannot exist outside of its meaning, and since it is created by how one sees things, it evolves and changes dependant on experiences. Subjectivity is therefore valued, as reality is socially constructed and not objectively determined (Willis, 2007).

As outlined in chapter 1, this research will focus on service users' and carers' subjective experiences of involvement in health and social care education. Service user and carer involvement lends itself to the relativist ontological position as there are differing interpretations of the phenomenon in question (David & Sutton, 2011), which this study attempts to capture and understand. This is predicated on the idea that there is no one true reality, and instead, there are subjective viewpoints to be understood, drawing from an interpretivist ontology. This is in line with this study as the researcher is seeking to develop an in-depth understanding of involvement from the service users' and carers' perspectives.

EPISTEMOLOGY

Epistemology is the theory of knowledge. It is a philosophical concept that examines the relationship between the researcher and what can be known (Carson et al., 2001; Guba & Lincoln, 1994). Krauss (2005) cited that epistemology is concerned with questions such as what is the relationship between what is known and the person that seeks to know? How do we come to know what we know? Therefore, to identify the appropriate research design for this study, it is crucial to consider the epistemological assumptions that underpin the research and how best to answer the research question.

POSITIVIST

Positivism was coined by Aguste Comte in the 19th Century and has historically dominated psychological research. It seeks objective knowledge and postulated that an objective reality, which is independent of time and context, can be 'revealed' or 'discovered' through the use of the scientific method. Positivists believe in empiricism as a means of determining natural laws through observations of the world. The approach is closely aligned with quantitative methods, and the research aims to make generalisations based on the information gathered. The researcher is also seen to be neutral in the study as a means of limiting researcher bias. Their central role is to acquire knowledge that is pure and representative of the natural world (Blaikie, 2007).

SOCIAL CONSTRUCTIONISM

On the other end of the paradigm continuum, Hammersley (1992) stated that social constructionism takes a relativist stance and is anti-realist. It is believed that no absolute truth exists (Blaikie, 2007); but, instead, knowledge and meaningful reality is socially constructed and derives from the interaction of individuals that is embedded in a context and time

(Crotty, 1998). Within this paradigm, “the knower and the known are inseparable” (Lincoln & Guba, 1985, p.37). Researchers cannot exist as independent observers as their position will impact the phenomenon being studied (Hofer & Pintrich, 1997). The researcher is therefore seen as actively involved and a co-author with participants.

This study is grounded in social constructionist epistemology, as the researcher will seek to understand how participants’ experience this phenomenon and the sense, they make of it (Tuli, 2010). Therefore, the data gathered will yield an understanding of participants’ behaviour, knowledge and perspectives as rooted in their experiences. The researcher is also aware that she is a tool in the analysis and her beliefs, experiences and values also impact all aspects of the study from the method chosen, the questions she seeks to understand, the data collection and how the data was interpreted. She will remain faithful to participants’ experiences by accepting all they bring to the study, with no criticism or judgement on what is shared.

PARTICIPANTS

SAMPLING METHOD

The sampling methods commonly utilised in quantitative research are often deemed inappropriate for qualitative studies. The aim of qualitative research is not for findings to be generalised to the broader population. Instead, the research seeks to gather rich information about the phenomenon in question. Such approaches focus on the opinions and experiences of individuals and are therefore helpful when answering questions such as ‘how?’ and ‘why?’. Whereas with a focus on measurable data, quantitative approaches emphasise testing hypothesis and answering mechanistic ‘what?’ questions (Marshall, 1996).

The study used opportunity sampling (Jupp, 2006) to recruit participants. This sampling technique collected data from participants from the Service Users Reference Group (SURG) affiliated with the School of Health and Social Care at a UK university. All members of the SURG were invited to take part in the study if they wished to. The researcher sought to gain a nuanced insight into participants’ unique perspective as they recounted their involvement journeys, which provided rich data based on their experiences (Mason, 2002). This ensured the collection of appropriate data that met the research aims. In addition to focusing on information-rich cases, it was also important to recruit individuals willing to participate in the research and articulate their experiences (Bernard, 2002).

SURG members are a heterogeneous group, even though the participants recruited for this study were all members of the SURG at the time of the study, the sample consisted of both service users and carers as a means of capturing a multiplicity of views (Kitzinger, 1994). The following inclusion and exclusion criteria are the characteristics individuals had in order to participate in the study:

Inclusion criteria:

1. A service user and/or carer
2. Involved in health and social care education
3. Aged 18 years and above

Exclusion criteria:

1. Service users and carers that are not involved in health and social care education

Service users and carers involved in research have a great deal of knowledge and proficiency that they bring to research (Minogue et al., 2005). The researcher was therefore keen to have service users' and carers' voices represented in the project from its inception. As a result, she worked closely with a service user consultant on this research study. The consultant became involved in the project during the planning phase where the study had a loose outline. Regrettably, due to Covid -19 and time restrictions, a closer working alliance could not be developed.

SAMPLE SIZE

The important consideration of how many participants is sufficient for qualitative research has long been a contentious discussion filled with uncertainty (Morse, 1995; Vasileiou et al., 2018). The sample size of qualitative research tends to be small and dissimilar to quantitative research. According to the literature the researcher will subjectively determine when they have acquired an in-depth understanding of the phenomena investigated (Sandelowski, 1995) when saturation is reached during the analysis phase. The concept of saturation originated in grounded theory but has since become a widely accepted principle used in other qualitative approaches (Saunders et al., 2017). According to Morse (1995) saturation is defined as the point in which no new information emerges from the dataset. Despite being regarded by some as the gold standard in justifying sample size (Guest et al., 2006), inconsistencies still exist when the concept is defined, thus highlighting that it is understood and implemented in different ways.

Braun and Clark (2013) guidelines for thematic analysis sought to classify projects into ‘small’, ‘medium’ or ‘large’. They further outlined the sample sizes range for each category as they suggested 6-10 participants for small projects. The numbers can then range anything up to 400+ participants for a larger project. However, it is ambiguous how the authors obtained these figures (Fugard & Potts, 2015).

In line with Braun and Clarke (2013), this study initially intended to recruit 16 participants - an equal number of service users and carers. However, due to time pressures and the global pandemic, this was not possible. Despite several attempts being made to recruit more SURG members, there was a total of 10 participants interviewed, nine service users, and one carer.

RESEARCH PROCEDURE

Interviews were conducted with ten service users and carers recruited from the SURG, affiliated with the School of Health and Social Care at a UK university. Thematic analysis methodology was utilised to analyse the data.

PARTICIPANT RECRUITMENT

The researcher planned a two-phase recruitment process. In the primary phase, email correspondence was the researcher's initial preferred contact with the SURG to ensure the most expansive reach. This provided the opportunity for all members to receive information about the project and participate if they wished to. The SURG is a group with members who attend SURG meetings held quarterly and there is also an active group of members that engage in involvement activities through email correspondence only. The researcher therefore asked the SURG facilitator to circulate the research project advert (Appendix G) and information sheet (Appendix H) that outlined the study’s aims, why participants were invited to participate in the study, how their data will be used, their rights, and confidentiality and anonymity. Unfortunately, following three rounds of email communications sent out, the researcher only received one expression of interest.

In the second phase of recruitment, the researcher attended SURG meetings held on zoom across two campuses to share the details of the project. The meetings provide a space for members to speak about the work they are involved in and hear about any upcoming activities and projects. She was given time on the agenda where she outlined the research aims, level of commitment required from participants, and how the data gathered will be used and stored. She made herself available to speak with SURG members on the phone or via email if they wished to gain additional information about the study. All SURG members that wished to participate in the study were asked to contact the researcher following her presentations. They were given the time to think about their involvement. The researcher also provided participants the opportunity to provide their email addresses if they preferred for her to make direct contact with them to provide more information and arrange an interview date. All participants recruited in this study were from the SURG meetings.

Following several members expressing an interest in the study, the information sheet and consent form (Appendix I) were emailed out to each participant, with an accompanying email seeking to arrange an interview date. During this phase, some members did not respond to the researcher's email communication. In such instances, a reminder email was sent out a week later, encouraging the participant to get back in touch if they still wished to be involved or required additional information. The SURG facilitator was also asked to send one reminder email to these members. For all members that agreed to be involved in the study, no interviews could be conducted face-to-face due to the pandemic and subsequent lockdown restrictions. Therefore, a total of nine participants requested zoom interviews, and one interview was over the telephone.

DATA COLLECTION

Interviews are a commonly used data collection method in qualitative research (DiCicco-Bloom & Crabtree, 2006) and were the preferred method employed in this study to explore how participants' experience their involvement in health and social care education. In-depth semi-structured interviews were conducted with participants, with each interview lasting approximately 1 hour. All interviews were conducted between July and November 2020. Whilst determining the line of questioning, it was agreed with the service user consultant that the questions would be co-created with a service user group he was facilitating. They were a local group that worked closely with various organisations in order to tackle pertinent issues as they advocated for service users' voices to be at the heart of all processes. Unfortunately, this initial plan could not be carried out as the pandemic hit, and the researcher was unable to meet with the group. This was initially halted with the view to continue with the plans after the pandemic. However, this was not possible due to time constraints. The researcher then formulated the topic guide (Appendix J) after reviewing pertinent literature and discussions with her supervisor and the consultant. The consultant's input was instrumental as he helped to ensure that the questions were clear, met the research aims and the most appropriate terminology was used. Questions were framed broadly and consisted of open-ended questions that enabled participants to share their experiences freely. Prompts such as 'how', 'why' and 'can you tell me more about that?' were used in order to encourage participants to elaborate on their responses and explore unforeseen areas which enabled the researcher to gain further information, or clarification on experiences shared (Adams, 2015). Using the topic guide in a flexible manner (Holloway & Galvin 2017) allowed the interviews to flow naturally and meander around the topic in a coherent order. During interviews, silences also enabled participants to think about the questions, reflect on their answers and ask clarifying questions if required.

The researcher did not underestimate the impact of interviews being conducted over zoom as all activities were online at the time. As a result, zoom fatigue was also being discussed (Lee & Jeong, 2020). The researcher was aware this could have impacted participants and her ability to remain connected and present in interviews. To manage this, the researcher tried to ensure that the participants felt at ease with the interview method, offering them the opportunity to take as many breaks as they required and for the interview to be conducted at a comfortable pace. She also made sure she had enough time between interviews by scheduling one interview per day and only on specific days due to other commitments.

At the start of each interview the study information sheet was reviewed and the aims clearly outlined. Despite participants being asked to email in their consent forms before interviews commenced, the researcher also obtained verbal consent and limitations to confidentiality were explained. Participants were given the opportunity to ask questions at this point and were reminded that interviews could be stopped at any point they wished. Their right to withdraw was clearly outlined. All interviews were audio-recorded and later transcribed (verbatim). Following each interview, all participants were debriefed, and a space was left to discuss any questions participants had or to speak about any distressing material that came up during the interviews. After each interview, the researcher immediately wrote memos to capture her thoughts, feelings, and impressions as they were relevant to the data analysis.

THEMATIC ANALYSIS

Thematic Analysis (TA) is an approach widely used to analyse data; however, data analysis can still often be complex and challenging to manage (Calman et al., 2013). Braun and Clarke's (2006) six-step guideline for examining qualitative data was employed to analyse data from the interviews. The methodology identifies and organises pattern/themes in the data set in a rich and detailed manner (Boyatzis, 1998; Braun & Clarke, 2006). Data analysis is a continuous process and can start when the researcher collects data from participants as she notices any patterns or interesting aspects within the data set. Additionally, writing is also identified as an essential element of the data analysis process and therefore occurred from the very beginning as the researcher noted down coding schemes (Braun & Clarke, 2006). This continued throughout the entire analysis process, as the researcher took an active role in analysing the data. The methodology complements this study's interpretivist ontological position and social constructionist epistemology as it enables the researcher to understand participants' subjective experiences. The data analysis process was inductive as the interpretations and synthesis of the data was grounded in participants' narratives.

To make sense of the rich data gathered, the six steps were used flexibly, and the process was recursive as the researcher moved back and forth. The researcher actively engaged with the data as she reflected on what was of interest, what she brought to the data from her experiences and how the participants' accounts helped her to make sense of the data. This was recorded throughout the entire process. The qualitative data analysis software program NVivo (Appendix K) was used to help manage the data. As outlined by Azeem and Salfi (2012) NVivo enabled the researcher to systematically work and move through the dataset as she coded, synthesised and compared the data. Braun and Clarke's (2006) six- step thematic analysis procedure is detailed below:

Familiarisation: in line with the principles in phase 1, the researcher immersed and familiarised herself with participants interviews. All interviews were audio-recorded and listened to a minimum of twice before the transcription. As this is a vital stage of the process, the researcher used this time to build on her initial thoughts as she noted any critical points of interest from the data. Interviews were then transcribed, which provided the researcher with the opportunity to immerse herself in the data further. The transcriptions were read repeatedly (Bogdan & Biklen, 2007) as initial ideas and meaning of the data were developed upon.

Generating initial codes: During this phase, all the codes of interest were generated and collated. The researcher highlighted relevant words, phrases and sentences in transcripts, which was done systematically. Semantic codes capturing surface meanings of what the participants communicated, and latent codes that captured implicit assumptions and ideas being discussed were highlighted.

Searching for themes: Following the coding process, themes were generated as the researcher pulled together the commonalities and differences across the dataset. They were then organised into broader general themes and more specific sub-themes by bringing codes together to create a more comprehensive picture of participants' experiences. In this initial phase of theme development, the researcher looked for the patterns and shared ideas that cut across data sets. She examined the data on a more general and abstract level as she conceptualised the data. Themes were then generated from clusters of codes that were pulled together.

Reviewing themes: In this phase, themes were labelled and reviewed. As this was an iterative process, it occurred throughout the theme development phase. The most relevant themes with the accompanying extracts that best describe participants' experiences were then used.

Defining and naming themes: Themes were named and refined as the researcher outlined what each theme and sub-theme was about and how best the data will be conveyed to tell the story.

Producing the report: The researcher then brought all aspects of the data analysis process together coherently when writing up her results. She outlined each theme, the sub-themes, and the accompanying extracts as she further elucidated the themes and how they are connected. Through the data synthesis, she endeavoured to provide detailed insights into participants involvement experiences. She then went on to link her findings back to the introduction, showing how the results relate to previous literature and outlined areas of new insights previously unknown in the field.

THE RESEARCHER'S POSITIONALITY

As outlined by Malterud (2001):

> A researcher's background and position will affect what they choose to investigate, the angle of investigation, the methods judged most adequate for this purpose, the findings considered most appropriate, and the framing and communication of conclusions. (p. 483-484).

Einstein (2012) therefore claimed that it is always beneficial for researchers to explore how their positionality impacts the research they are involved in. As outlined by Jacobson and Mustafa (2019), research is impacted by how the researcher understands and sees the society they live in. This is mediated by how the individual is positioned in any given society. This research study is from the viewpoint of a Black African Trainee Clinical Psychologist, born in Nigeria and raised in the UK. She is currently in her final year of a Doctorate programme. Whilst immersing herself in this research that sought to critically understand participants' experiences of involvement and how they understand power to operate through an in-depth enquiry, it was essential she acknowledged her pre-existing beliefs, experiences and personal values (Gavin, 2008). She has experienced discrimination whilst growing up and in her professional life. She also has over 10 years' experience of facilitating service user involvement initiatives, primarily in the context of service development. These experiences have fuelled her passion for advocating for seldomly heard groups in an attempt to break down barriers. Over the years, she has worked collaboratively with service users and other marginalised groups to ensure their voices are respected and accurately represented in all aspects of service development and projects. Taking a position of respect when working with various groups, she strives to challenge acts of discrimination and harm perpetuated.

The researcher was aware of how her pre-existing views on involvement as based on her previous work, academic knowledge, and clinical work over the years impacted the way she approached this research, her contact with participants, and the data analysis. As a means of managing this, throughout the research study, she has constantly critiqued herself. To ensure transparency and trustworthiness, reflexivity was an integral aspect of the research process. Reflexivity is defined as "the process of a continual internal dialogue and critical self-evaluation of researcher's positionality as well as active acknowledgement and explicit recognition that this position may affect the research process and outcome" (Berger, 2015, p.220). To aid reflexivity, throughout the entire process, the researcher systematically attended to and recorded a reflexive diary that documented how her experiences, explicit and implicit assumptions impinged on the research. She also discussed pertinent issues with her supervisors.

ETHICAL CONSIDERATIONS

In adherence to the University of Essex code of practice, ethical approval was obtained from the University's Ethics Committee before the research commenced (Appendix L). In January 2020, an amendment was made and granted to change the study from a longitudinal study to data being collected at one-time point where the focus would be on participants' experiences of involvement. This was a direct result of time constraints which made it difficult to interview participants twice.

A key point for the researcher was that participants felt respected and valued throughout the entire interview process as she ensured that their rights and dignity were upheld from the very inception of this study. This was achieved by participants being placed at the heart of the study, which shaped how questions were written, her email communications with participants and during interviews. Even when writing up the results, the researcher wanted to ensure that the findings were rooted in participants' data.

INFORMED CONSENT

All participants were given a week to deliberate their involvement in the study and were asked to sign and email back their consent form before their interview commenced. At the start of each interview, the information sheet and consent form were reviewed in detail and space was provided so participants could ask any questions to gain further clarity about the information and their rights. Participants were also reminded that signing the consent form permitted for interviews to be audiotaped. They were informed that all recordings were going to be securely stored.

SERVICE USERS' AND CARERS' RIGHTS

The researcher respected participants freedom by informing them of their right to withdraw at any stage during the study without providing a reason. She also shared that it was well within their rights not to answer particular questions if they did not feel able to. The researcher provided her contact details, which could be used by participants if they wished to withdraw their data from the study after their interviews.

CONFIDENTIALITY

To maintain participants anonymity, each participant was allocated a unique number and pseudonym from the point at which they agreed to participate in the research. The researcher was, therefore, the only person aware of the participants' identities. No personal or identifiable information was disclosed throughout the interviewing, transcription, analysis and write up stages. When the data was discussed with her internal thesis supervisors, only pseudonyms were referred to at all times.

Due to the majority of the interviews being conducted over zoom, the audio recordings were saved on a personal laptop and password protected. The Dictaphone used to record the telephone interview was also password protected and securely locked away to ensure the recording was safe. In addition to audio recordings, all transcriptions were anonymised and saved as password-protected documents. The audio recordings and transcriptions will be permanently deleted once the research has been graded.

RISK OF INTRUSION

Due to the nature of this study, the risk of harm was predicted as low as the focal point was to gain an understanding of how participants experienced their involvement. Nevertheless, the researcher pre-empted that there may still be a possibility that some participants' lived experiences of services may equally be linked to their responses about their involvement and shared during interviews. As a means of circumventing participants possibly feeling intruded upon, the researcher clearly communicated the aims of the study throughout the recruitment process. This was reiterated when meeting with participants for their interviews. Participants were also reassured that if things became distressing, their interviews could be stopped at any point in time.

To help further mitigate harm, the questions asked were also directly in line with the research aims, and the prompts utilised to gain clarity and to gather more information were also focused on participants' experiences of involvement. As it was well within participants' rights to share their entire experience with the researcher, these measures were not taken to dismiss participants' lived experiences of services but were put in place to protect participants from any potential harm.

If during interviews participants became distressed, the interviewer had planned to immediately stop the interview and provide some space for the participants to avoid any further hurt being caused. In such instances, the participants would be asked if they were happy for the researcher to inform the SURG coordinator to provide additional support if required. At the end of the interviews, there was also a debriefing, and the researcher answered any questions. The researcher's details were also specified, and participants were informed that they could contact her if they had any further questions. It must be noted that no participants became distressed during any of the interviews. Instead, service users and carers also shared their lived experiences of services which added a richness to participants' stories.

COMPENSATION

At the end of each interview, participants were thanked for their time and offered a £10 gratitude voucher for their involvement. All participants were grateful for the offer; however, it is essential to highlight that not all participants wished to accept the voucher for their time. The participants who accepted the voucher were asked which voucher they preferred; this was then purchased online and sent to them electronically. They were then asked to send in an email confirming that the voucher had been received.

DISSEMINATION

The dissemination strategy involves communicating the research findings on various platforms. Findings will initially be presented in a SURG meeting. It will also be requested for the findings to be posted on the SURG blog. The blog will increase the reach beyond the group, as the findings will be available to students, other organisations, the community and staff members. The researcher will draw on the expertise of members to assist with the dissemination of the research findings. The group as well as the service user consultant will help identify key individuals and organisations the findings should be communicated with. In addition, findings will be presented at the Involvement Matters Conference and the annual staff-student research conference organised by the School of Health and Social Care at the University of Essex.

The researcher will seek to have the findings published in peer-review journals that have a health and social care focus to contribute to the existing body of work in the area by providing service users and carers with a voice. Additionally, the findings will be submitted to conference organisers to be presented orally or as a poster at regional, national and international conferences as well as events held by the Care Quality Commission (CQC), Health & Care Professions Council, Clinical Commissioning Groups (CCG), British Psychological Society (BPS), Essex Partnership University NHS Foundation Trust and other NHS Trusts.

It is intended for the findings to inform involvement initiatives; therefore, the findings will be circulated throughout Health and Social Care and other faculties. The researcher will attend meetings with the staffing team and senior management. This will also be extended to other universities as it is of great importance that the study is shared with other institutions that involve service users and carers in their pedagogical practices and institutions that wish to start incorporating involvement in their programmes.

A crucial aspect of the dissemination strategy is for the findings to inform policy and procedures across the country as it contributes to the body of work on service user and carer involvement. The researcher will endeavour to achieve this by communicating the findings to lead policymakers in the NHS and Department of Health and Social Care so the findings can be shared with clinicians and academic staff across various disciplines.

CHAPTER 4. FINDINGS

CHAPTER OVERVIEW

This chapter will present the findings of this qualitative study. Firstly, the demographics of the participants will be outlined, followed by the length of time participants have been involved in health and social care education and the types of activities they have been involved in. Lastly, the chapter will focus on the themes and sub-themes that emerged from participants' interviews using thematic analysis.

DEMOGRAPHIC PROFILE OF PARTICIPANTS

A total of 10 participants were interviewed in this study. The data was collected between July and November 2020. Participants' demographic information is presented in Table 1, which illustrates personal characteristics such as gender, ethnicity, and, lastly, if they have used or cared for people supported by mental and/or physical health services. To maintain participants' anonymity, they have been given pseudonyms. This is in alphabetical order by when their interviews were conducted. For the same reason, participants' ages were also obtained as well as if they identified as a service user or carer, but this has not been added to Table 1.

STUDY SAMPLE

All but 1 of the participants were service users. There were eight participants that identified as male, and two females. All participants described their ethnicity as White-British. When participants were asked to describe what services, they had used, six participants stated that mental health services had supported them, one reported using physical health services, and the remaining three used or cared for people who had accessed mental and physical health services. Participants ages ranged from 31 to 82. There were three participants aged between 30 to 49, and the remaining seven participants were aged over 50.

TABLE 1: PARTICIPANT DEMOGRAPHICS

Participant Pseudonym	Gender	Ethnicity	Mental and/or physical health services
Andrew	Male	White-British	Physical health services
Barry	Male	White-British	Mental health services
Carl	Male	White-British	Mental health services
Dale	Male	White British	Mental health services
Elaine	Female	White-British	Mental and physical health services
Franky	Male	White-British	Mental health services
Gill	Female	White-British	Mental health services
Harry	Male	White-British	Mental health services
Ian	Male	White-British	Mental and physical health services
Jason	Male	White-British	Mental and physical health services

FIGURE 4: DURATION SERVICE USERS AND CARES HAVE BEEN INVOLVED AT THE UNIVERSITY

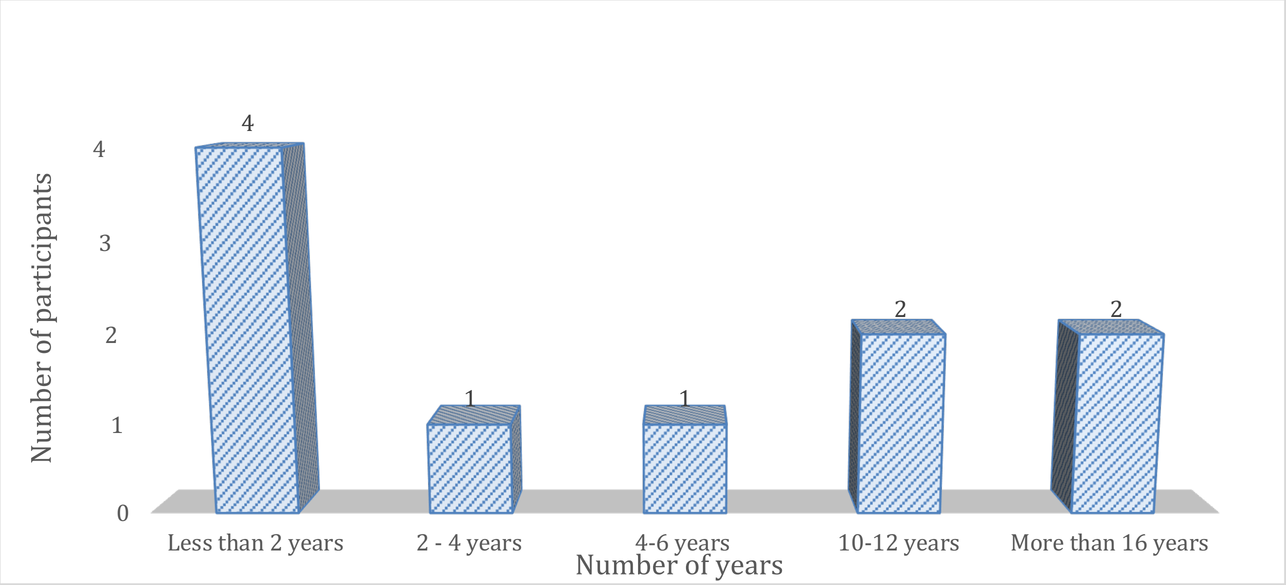


Figure 4 represents the length of time service users and carers have been involved in health and social care education at the university. A total of 4 participants were involved for less than 2 years. An equal proportion had been involved for more than 10 years. The remaining 2 participants reported they had been involved for between 2 and 6 years.

SCOPE OF SERVICE USERS AND CARER INVOLVEMENT

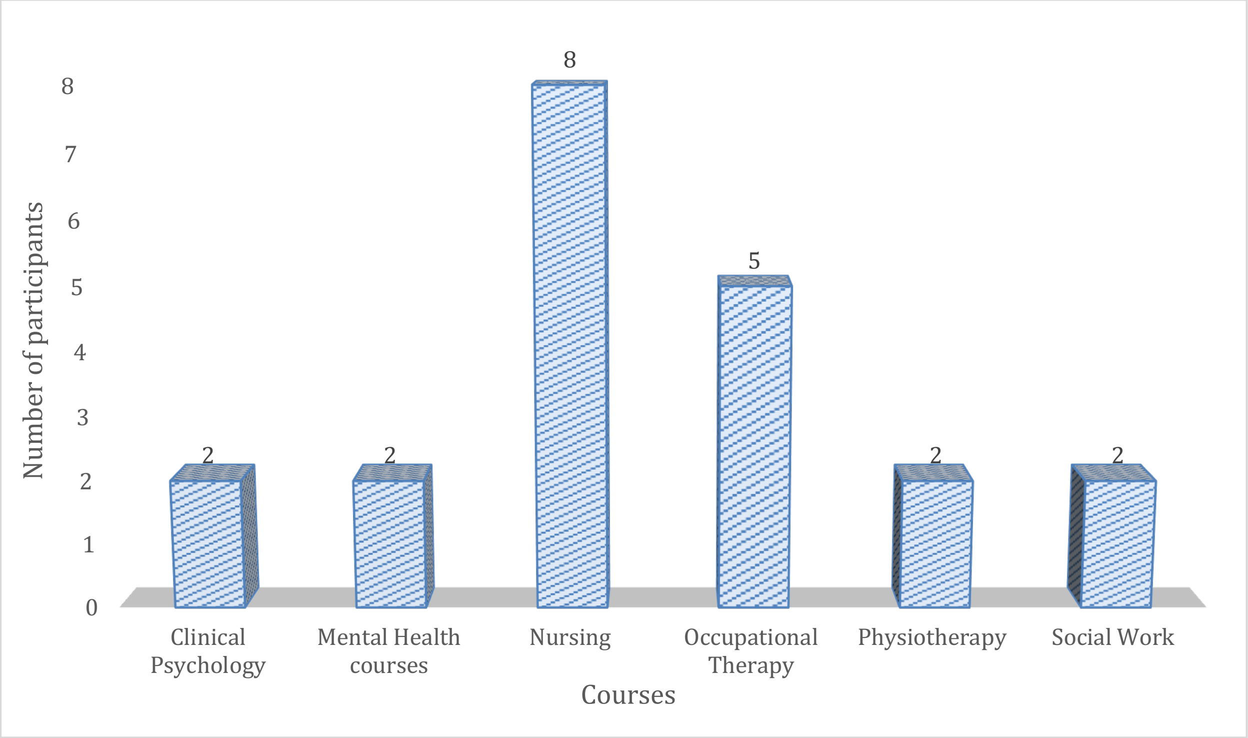
In the interviews, participants were asked to describe the activities they were involved in; this is outlined in Table 2. All the participants attended SURG meetings, 6 participants had been involved in lectures/ oral presentations, and 5 participants had been involved in student interviews. A far lower proportion was involved in role-plays, sitting on disciplinary panels and curriculum development.

The researcher also asked participants to briefly speak about their involvement outside of the university. All participants reported that they had been involved or are currently still involved with other academic institutions (in the UK and abroad), charities, third sector organisations, the government or NHS Trusts. These involvement activities ranged from sharing their lived experiences, interview panels, co-creator of coproduction centre, Governor, change champion, mental health ambassador, mental health worker, and peer reviewer.

TABLE 2: INVOLVEMENT ACTIVITIES

Involvement activities	**No of service users and carers % (n)**
Case study participant	10 (1)
Curriculum development	30 (3)
Creating a digital story	10 (1)
Lectures/oral presentation	60 (6)
Recruitment of SURG members	40 (4)
Roleplays	20 (1)
Scenario writing	10 (1)
Sitting on disciplinary panel	10 (1)
Student assessments	10 (1)
Student interviews	50 (5)
SURG coordinator	10 (1)
SURG meetings	100 (10)

FIGURE 5: COURSES SERVICE USERS AND CARERS REPORTED BEING INVOLVED IN AT THE UNIVERSITY



As outlined in Figure 5 each participant expressed, they were involved in multiple courses across the School of Health and Social Care. The greatest proportion was in Nursing (n=8) and Occupational Therapy (n=5). An equal number (n=2) of service users and carers reported being involved in Clinical Psychology, Mental Health courses, Physiotherapy and Social Work.

RESULTS

ANALYSIS

A thematic analysis using Braun and Clarke's (2006) methodological approach informed the researchers analysis of the data. A total of four themes and 12 subthemes were developed from service users and carers interviews that explored their experiences of being involved in health and social care education. Table 3 outlines the themes and sub-themes and also shows the cross-comparison of participants by themes and sub-themes. The PE framework, as theorised by Zimmerman (1995) and augmented by Christens (2012), were the theoretical lenses used to analyse aspects of the data.

Data synthesis revealed themes had varying numbers on subthemes as participants spoke on both a general and specific level. For example, five subthemes were generated for theme 1 *the involvement journey*. Participants not only spoke on a specific level about the importance of who they are and what they bring to the journey as categorised in the sub-theme 1) *involvement identity.* Their expressions also operated on a general level which has been categorised in sub-theme 2) *ignites passion for involvement* as it broadly pertains to participants' descriptions of their overall journey at the academic institution. Further synthesis revealed that participants also described their experiences in more specific terms, where they provided descriptions of important facets which related to relationships developed, and involvement outcomes which is reflected in the sub-themes 3) *the growth process,* 4) *an acknowledgement of value placed on involvement* and 5) *not alone in all of this.*

When further thinking about power and empowerment, data analysis of participants' narratives revealed the practices and processes in place at the university that impacted their involvement as explicated by most participants. This was categorised in theme two *managing processes of involvement: systemic distortion of equality.* There were only two associated sub-themes constructed when analysing participants' narratives as outlined in 1) *there's still a bit of them and us* and 2) *it all boils down to communication*. Similarly, the same was found for theme three *negotiating practices of involvement: one size does not fit all* and its accompanying sub-themes 1) *just wish people thought about access* and 2) *navigating uncharted terrain.*

The final theme *maintaining processes and practices of involvement: The journey ahead* and associated sub-themes 1) *you cannot achieve intentions without higher investment*, 2) *opening up the boundaries a bit more* and 3) *their voices are equally as important* demonstrated a coming together of all aspects of participants' experiences as they provide resolutions in response to their journey. The above themes and accompanying sub-themes will be further discussed in the sections below.

TABLE 3: CROSS-COMPARISON OF PARTICIPANTS BY THEMES AND SUB-THEMES

Participant name	Andrew	Barry	Carl	Dale	Elaine	Franky	Gill	Harry	Ian	Jason
Theme 1: The involvement journey	*	*	*	*	*	*	*	*	*	*
1.1 Involvement identity	*	*	*	*	*	*	*	*	*	*
1.2 Ignites passion for involvement	*	*	*	*	*	*	*	*	*	*
1.3 The growth process	*	*	*	*	*	*	*	*	*	*
1.4 An acknowledgement of value placed on involvement	*	*		*	*		*	*		*
1.5 Not alone in all of this		*	*	*			*	*	*	
Theme 2: Managing processes of involvement: systemic distortion of equality	*	*	*	*	*	*	*	*	*	*
2.1 There's still a bit of them and us	*		*		*	*		*	*	
2.2 It all boils down to communication		*		*		*	*		*	*
Theme 3: Negotiating practices of involvement: one size does not fit all	*	*	*	*	*	*	*	*	*	*
3.1 Just wish people thought about access	*	*		*		*				*
3.2 Navigating uncharted terrain	*	*	*	*	*	*	*	*	*	*
Theme 4: Maintaining processes and practices of involvement: The journey ahead	*	*	*	*	*	*	*	*	*	*
4.1 You cannot achieve intentions without higher investment	*	*	*	*	*	*	*	*	*	*
4.2 Opening up the boundaries a bit more	*	*			*	*	*	*	*	
4.3 Their voices are equally as important	*	*		*		*		*		*

THEME 1: THE INVOLVEMENT JOURNEY

This theme represents participants' involvement journeys and the sense of power and empowerment that they experienced. It outlines two main aspects narrated by participants as they discussed what they brought to the involvement journeys that enabled them to be part of the process and in return, what they received from embarking on the journey. They also shared its impact on learning as well as their personal evolution, sense of value and connectivity developed through their involvement. The first sub-theme *'Involvement identity'* reflects how participants narrated the power in who they are and their unique contributions to academia. This is a significant analytical consideration because the importance of identity is featured in several participants' narratives.

The second sub-theme '*ignites passion for involvement*' explores the sense of value, autonomy and strength participants described receiving from their overall involvement journey in health and social care education at the university. All participants narrated how overall their involvement was a positive experience. Participants also expanded upon this and discussed the specific aspects of their involvement that endorsed their autonomy, uniqueness and how that contributed to making their involvement a meaningful, empowering and valuable experience. This provided further information on how participants experienced their journey, which is captured in the sub-themes '*the growth process', 'an acknowledgement of value placed on involvement'* and '*not alone in all of this'* which are the three significant facets that played a part in their positive journeys.

1.1 INVOLVEMENT IDENTITY

The first sub-theme explores participants' distinctive involvement identities which emerged in multiple participants' narratives. They reflected on their unique voice, their identities within the institution and also went on to describe the specific perspective this enabled them to bring to their involvement journey. It highlighted the sense of empowerment that participants experienced as it explained the proud nature in which service users and carers spoke about their lived experience identity. As well as expressions of their sense of mastery over what they shared and what this enabled them to contribute to education that academic knowledge fails to bring to the learning space.

The extracts that make up this sub-theme also look at the multiple aspects of participants' identity as they also referenced their professional and academic qualifications they achieved over the years. This revealed the interconnectivity of their identity as a service user or carer, professional or academic, which many participants expressed as being fundamental. Participants passionately shared the distinctiveness of their roles which enabled them to reclaim their influence and control within the academic realm. This illustrates empowerment as service users and carers took up this valuable position, which contrasts traditional misconceptions about individuals' ability to contribute to service development or academia due to their health needs. Participants now use their position to challenge injustices embedded in pedagogical practices.

The first aspect of this role was the ability to share their lived experiences. All participants reflected on their role within the institution and how they were positioned as experts by experience. They shared a sense of pride in who they are as a result of their lived experience journeys, which enabled them to share their experiences of services and their illnesses. Participants also spoke about how their identity added depth to their involvement and provided students with a more rounded education. Their expression of such experiences enabled them to bring textbooks to life, it provided a divergent perspective, and offered a different dimension to academia. There was a strong emphasis on knowledge being power, which then enabled service users and carers to make a unique contribution to academia in a different but equally powerful way to theoretical knowledge.

Participants understood how theoretical knowledge (what they termed textbooks) has traditionally been valued over lived experiences. However, through their involvement, there was a feeling of being able to push back as they sought to challenge the status quo and create a curriculum that also emphasises the lived experience component of teaching. This links to the position that service users have conventionally taken up within institutions from passive recipients of care to them shifting to a position where they are acknowledged and valued. They take up an active and influential role through their interactions with students. Many service users' self-perceptions were that they were more than competent to speak about their experiences of services and their mental or physical health difficulties that other academic staff would not have accomplished. This provides service users and carers with the ability to influence what students learn. Thus, creating a new understanding of what is deemed pedagogically appropriate, highlighting the different constructs needed for teaching to be successful. The extract below by Dale articulated the knowledge that participants hold about the apparent divide between theoretical knowledge and the lived experience knowledge-base. In this extract, he shared his distinctive personal experiences and how they allowed him to share a balanced view about the care he has received.

> *"Although a lot of my, shall we say technical knowledge of different mental health acts is a bit out of date. My current personal situation as I still have mental health problems is useful and it's part of who I am. I am all for a wider learning pattern and not just textbooks…. When being involved, I only did quotes of my own direct experiences but I heard so many of the students were shocked. Don't get me wrong, I also try to be fair. So, I can give an all-round view because I've actually lived through it" – Dale*

Several participants also asserted that they used this position to share their experience and prepare students for professional careers in advocating that recovery is possible, as expressed in Carl's extract. In turn, helping to reduce societal marginalisation that service users and carers face. This was achieved by using their voices, and their presence also served to reinforce this. They used their involvement in teaching to generate curiosity and humanise care as they focused on the idea of hope. This demonstrated that users of services could live a meaningful life rather than having a sole focus on the message of disease and distress. Thus, highlighting the importance of teaching integrating various sources of information into academia to help challenge pre-existing models of what knowledge is and who service users and carers are.

> *"With my own involvement, I just want to keep being involved, keep bringing their textbooks to life, which is something I am able to do which I have heard is inspiring to people…so I'm also getting the message out there that, you*

> *know, people can recover from these experiences so they know it's possible" – Carl*

Participants' stance on teaching students about recovery is in line with policies that encourage the recovery model. Another participant also expressed the privileged position she felt she was in as she shared her recovery journey. She used her story to demonstrate to students that service users are about more than their mental and physical health needs and do get better. She described that her lived experience allowed students to interact with Service users at a different stage of their journey as they are often seen and cared for *"at their lowest points and at their worst" (Gill).*

Just less than half of the participants expressed using their involvement as a tool to show the strength service users have with the view of this impacting the care service users receive in the future. This appears to be multi-layered as it speaks to the service users and carers students will meet in clinical practice and their identity as SURG members and knowledge providers. This shift in service users and carers positioning provokes an alternative discourse that addresses the power inequalities that moves students away from seeing service users and carers as incapable and inferior within academia. Service users and carers hoped this would be transferred to students' clinical practice where they can work collaboratively with service users and carers as they are the experts on their own lives and professionals do not have to exert power over them.

> *"…I can show the fact that people do recover. So, I think, um certainly my experience of working and mental health is that often you see people in crisis phase, um and you see them at their lowest points and at their worst and it is hard to imagine what their life might look like, um five, six years down the line and what they might be capable of. And I think bringing people back into the classroom, that are achieving things and are doing what they want to do despite their mental illness is really important as well" – Gill*

Participants also pointed out that in addition to the recovery model, they felt able to provide a real, unfiltered, raw account of their experiences to aid students' understanding of the individuals they engage with in the clinic. Participants expressed the importance of creating an environment that facilitates substantive discussions where honest conversations can be had about lived experiences. They hoped that this fosters a unique learning relationship where students are encouraged to see lectures as a safe space to take risks, ask any questions and delve deeper into participants' unfeigned experiences in a supportive environment. Participants hoped this would help to achieve greater depth and make teaching far more emotive and experiential for students, and thus encourage a respect for service users' and carers' perspectives. The extract below by Barry highlights the importance of bridging the gap between service users, carers and students to open a line of communication that would provoke and facilitate such conversations that had the potential to break down barriers. Participants wanted the teaching space to be conducive for students to take in information and seek to understand more about service users and carers by being able to "*ask questions that maybe they felt they couldn't ask" (Barry).*

> *"Students have felt able to approach me and ask questions that maybe they felt they couldn't ask. I have been able to just put child abuse in context and demystify some of those and take away some of the anxiety people may have around working with that.... But it's that sense that we are allowed to say what we want to students about what we have experienced without that sort of censorship. We can say it as it is. I think what I try to bring is a realistic balanced view on what those issues bring up for people as they move forward in their lives and about recovery from those issues. The way I work professionally is very much about a recovery model and these kinds of issues are not life sentences" – Barry*

Secondly, there was a consensus amongst participants about the multiple aspects of their identity as they provided accounts of a broader sense of self, which is often not discussed. Participants described bringing more than their lived experiences to their involvement journey at the university. This is of significance to this sub-theme as it shows how multifaceted service users and carers are. Participants asserted that they could draw upon their professional careers, qualifications, and skills acquired in other aspects of their lives, as many participants articulated "*I kind of bring two aspects" (Barry)* to involvement. This shows the importance of not reducing service users and carers to just their lived experiences, which is how they felt they were usually positioned by institutions as if to say that is all that defines them. In sharp contrast, they should be seen for who they are in their entirety.

Furthermore, as an expression of empowerment, participants also regarded themselves as professionals in their own right. The extracts below illustrate how participants could not approach involvement tasks just as service users, but there was strength in their ability to bring their other knowledge to involvement. There was pride in the relationship between their lived experiences, their qualifications and previous careers as this was particularly significant for participants. This speaks to the fluidity of their identity and not the rigid view conventionally taken, as elucidated in the extract below.

> *"I've worked professionally in mental health which means I kind of bring two aspects. One is my personal experience of having mental health difficulties but I also bring my experience of working in mental health as a trainer and a qualified teacher. So, I can sort of teach about what it's like to be on both sides" - Barry*

Nearly all participants articulated how they have several core skills that they bring to pedagogy. They felt empowered as they built up and strengthened their multifaceted identities, impacting how they position themselves within the academic institution. However, as with this study, participants are often asked to participate in tasks that require them to speak about their lived experience, which may be limiting and may not fit how service users and carers see themselves and their contributions. This highlights the importance of institutions expanding how service users and carers are seen within academia, and involvement would benefit from service users and carers being involved in a variation of involvement tasks. The extract below explicates this, as Elaine spoke about her previous nursing career, which meant that "*my experience as a nurse is always there" (Elaine).* This intertwined with her lived experience, which was not seen as something that could be distanced from the other qualifications she had.

> *"I'm interested generally in health and social care anyway as much as anything else. I have a background of having done some nursing too. Well, at*

> *my age, I suppose dare I say, I've met quite a few people in different scenarios and also people with health and social care problems. My experience as a nurse is always there. And also, my own personal general education as well and all the various things that I've done in the past" – Elaine*

For other participants, academic knowledge was also present, as explained in the extract below. For Andrew, he vehemently spoke about the amalgamation of his identities that he characterised by the coming together of his lived experiences and professional and academic qualifications. He expressed that this positioned him as a "*lived experience teacher" (Andrew)*. This extract may also reflect the limitations within the institution as Andrew shows an understanding of how pedagogy at its core is based on lecturers sharing theory. However, dual expertise enables him to teach the curriculum from both standpoints, which is a rare position of influence.

> *"...But I see myself as, I suppose a lived experience teacher because I have got a PhD. I know I've done lots of teaching in the past. You know, so, I'm not just a service user, but I've got that extra sort of bit attached to it... You know, if you can do that, mix that knowledge, skills and the theory with your lived experience, isn't that good. Linking that with lived experience is not a better way, but a different way of doing it. Yeah. And I wouldn't say that any social work lecture that isn't disabled shouldn't be doing the job because they're brilliant. But it gives a different perspective to the students by mixing both so it's halfway between lived experience and academic theory, it's somewhere in between that I think is a good way to do it" – Andrew*

This sub-theme maps how service users and carers position their knowledge as equally crucial to theoretical knowledge, highlighting the value they feel they bring to academia. They express how their unique identity enhances their role and how this leaves them feeling empowered.

1.2 IGNITES PASSION FOR INVOLVEMENT

All participants' narratives referred to their involvement as a positive experience. In describing their involvement journeys, participants used words such as love, impressed and enjoyed to express their passion for their role. For some participants, the positive experience was a feeling that had been maintained over a prolonged time. To further elucidate this point, some participants reflected on their experience that spanned over a decade at the university. A sense of ownership and pride was expressed, as articulated in the extract below by Franky that had been involved at the university for over 10 years. Despite things changing over the years, he still rated his experience highly and stated *"it was brilliant" (Franky).*

> *"It was for when the nurses were in the first year, so like their first-year admission, we used to do interviews with them. So, it was very much like role play, you'd go in there and you'd be the patient and the nurse would sort of triage you and things like that. And it was brilliant. I loved that…When I do my work, I love it so much" – Franky*

For other participants, there was a sense of alignment between what they wanted and what the university could offer, as expressed in Dale's extract. He speaks about an alignment in the way he was treated, which made for a positive and meaningful experience. This highlights the importance of participants' expectations being matched by what the university has to offer.

> *"…it was positive for me for sure… Yes, I think our needs are met and considered as well as the staff and anybody else. I am really happy with it. On a personal level, I have been very impressed with the way I have been treated, which is my preference, and I'm generally very happy with my role" – Dale*

As all participants also experienced being involved with other institutions and organisations, they used such experiences to compare their involvement at the university to their previous involvement. As asserted in the extract below, Barry's experience was worthwhile because of the lengths he perceived the university went to *"meaningfully engage with service users"*, which he found to be *"refreshing" (Barry).* Thus, highlighting that for participants it is not just about being asked to participate, involvement being meaningful makes it a reciprocal experience where all stakeholders can benefit.

> *"I think I've already said it, but my experience of the university as a service user and this isn't just me soft soaping the university, but seriously, I think that it has been extremely positive. The extremes the university goes to meaningfully engage with service users has been very refreshing, and I think it really needs to be acknowledged compared to other places, I think it's a really good model... It's ignited my passion for involvement because it's done well" – Barry*

The data analysis revealed that on a general level, participants perceived their involvement to be a positive experience. Through further exploration, it was possible to get a sense of what aspects of their involvement felt positive and why they perceived that to be the case. This will be further explicated in the sub-themes later discussed.

1.3 THE GROWTH PROCESS

The third sub-theme the growth process discussed in all participants' narrative was the personal transformation they experienced which left them feeling empowered. The extracts encapsulated participants' strong expression about the improvement of their psychological well-being and the positive changes in attitudes and beliefs they held about their ability to be involved. Participants identified their involvement as important in maintaining their mental health, building their confidence, and giving them a sense of purpose and self-worth.

The extract below speaks to how participants asserted that they felt personally empowered within the context of their roles because it helped to maintain their well-being and there were-immediate feelings of gratification. Franky affirmed this view as he expressed that his involvement in teaching activities helped him feel better on days, he found difficult. He stated that *"it's kept me well" (Franky)*. He expressed the emotional response, which is linked not only to the actual involvement task that was completed but to all the other practicalities surrounding it as it gives his day structure when involved. This extract highlights that it goes beyond the involvement task for participants, and the actions around the task are just as crucial in helping their well-being.

> *"Well, it makes me feel good… It keeps me grounded in it. There's such a passion there and it keeps me well. Keeps my mental health well… actually it's helped me sometimes on the most really rubbishy day that I've had, when I've had to get up early and I know that I've got like a presentation, and I've gone and done it and it actually helped me get everything off my chest, even though it's not relevant to what I've done, but to actually then just speak about things. Again, it's put my mind back into perspective. I do feel better" – Franky*

Several participants commented on other transformations experienced through their involvement journeys, as highlighted below in Carl's extract. Carl spoke about a sense of empowerment as he reflected on his life now compared to what he felt able to contribute when he was unwell. This sense of empowerment is linked to a transformation that occurred over many years, he perceived himself as once *"useless"* to feeling more *"useful" (Carl)* when at the university. He pointed out that being involved enabled him to "*feel like I'm contributing" (Carl).* He spoke about how this improved his situation and how before his involvement, his identity centring around his illness was one where he felt unable to be a valued member of society. However, being in an environment where he has been able to speak his truth, gain control and contribute based on his lived experiences that once left him feeling inferior and stuck was now being used to liberate him.

> *"It (being involved) has impacted my life really well. I'm happy to keep going there or you know, attend via laptop… It gives me a sense of well-being. … most of the ideas that come out of SURG meetings are really positive. So even just being there to listen to that kind of thing, I feel like I'm contributing because I was useless for like years really, you couldn't trust me for anything. All my ideas would have fallen flat and I was totally distracted with all this paranoia and things but now I feel quite useful and that's a good feeling to have" – Carl*

In addition to the personal growth, there was also a sense from other participants that their courage and voices were used to effect change and challenge social injustices in other areas of their lives. Instead of taking on the sense of inferiority prescribed by the inequalities experienced due to their mental health needs, the strength developed through their involvement gave them the bravery to push back and use their voice in society when feeling mistreated. This also shows how the benefits of involvement can be far-reaching as participants carry it into various settings. They described having gained greater control in other aspects of their lives using involvement at the university as an anchor. Participants spoke about no longer accepting where they are so often positioned within society and instead resisting oppression as in Gill's case. The extract below speaks to this sense of personal empowerment gained through the courage to find and trust her voice. Her increased self-confidence saw her use her voice within academia and beyond.

> *"I did the event but I didn't really have the belief that I could do it. It's given me a lot of confidence and off the back of that it's kind of made me less prepared to put up with situations in which I might be experiencing some form of discrimination so in my head, I can be like well, the university values my lived experience and thinks that I have enough of a point to say to potentially put me in a classroom of students. If in other areas of my life I'm faced with something where people are like don't say that, don't talk about it you can't do XYZ because of this. It kind of gives me a point to go back to, of well, other people don't believe that. So, why should I follow the person that's telling me that I can't do something?" – Gill*

Dale's extract below demonstrates the sense of achievement almost all participants asserted they received as a result of their involvement. It also illuminates the social divisions experienced as there is often an expectation that service users and carers may be too vulnerable to participate because of their experiences. However, Dale communicated that despite his mental health difficulties, being involved and becoming more confident has left him feeling "*quite proud" (Dale)* and he now trusted in himself to go out and engage in things he once enjoyed doing. This extract also shows that even though participants have judgements about what they feel able to do, their involvement and increased confidence enables them to get back in touch with other aspects of their lives.

> *"I am not the best professional speaker but I'm getting better at it. But it felt quite good as well even though I was really nervous, I have an anxiety disorder but I felt quite proud of myself. I will attempt it again… I think I would still be nervous and not the best but that would improve with time. My confidence sort of builds up slowly. Errrm so it is very good for that. It has given me a purpose – no I wouldn't say a purpose to life because that's a bit strong. I would say it has given me the desire to get back into other things I liked, you know" – Dale*

1.4 AN ACKNOWLEDGEMENT OF VALUE PLACED ON INVOLVEMENT

The importance of remuneration was evident in most participants' narratives as it was viewed as a form of recognition for their involvement and the value the institution places on their contribution. Many agreed as they pointed to the significance of being recognised through financial means. Participants commented on how they perceived payment to be "*an acknowledgement of value" (Barry)* and a way for the university to demonstrate "*that they value what we do" (Elaine).* Both Elaine and Barry also expressed how surprised they were to learn they were going to be paid for their involvement. For Barry, it was also the fact that he was going to be given "*the same as another lecturer" (Barry).*

> *"I do get paid and again, that's not why I do it. But I think that's an acknowledgement of value which is more important in some ways than the monetary value. Again, it's not just, a tokenistic payment. It's a payment on the same scale as other health professionals. It shows value and it's not so much the pound notes… I think that you know, psychologically, I didn't realise what a difference that has made to feeling valued…When I was first asked to lecture, I said yeah, I can do that for you. The university then said we will pay you. I said, oh wow, I wasn't expecting it. And they said oh we are going to pay you the same as another lecturer. And that was just such a surprise" – Barry*

> *"Well it was, to be honest, it was an unexpected extra because when staff said oh you are going to be paid for this, I was just happy to be a volunteer but that was a very nice extra, yes it was. I think it shows that they value what we do" – Elaine*

Gill echoed this sentiment as she acknowledged in her interview that even though she opted not to access the money available from the university, the fact that it was offered in the first place "*shows the level of respect they have for the role" (Gill).* She was able to identify that the money not only represented how the university values participants but it would also enable her to continue to be involved.

> *"Not at the moment, but if I was to go through a period where I was unemployed. I think the fact that they would pay my expenses is helpful. It also kind of shows the level of respect they have for the role as well" – Gill*

Participants like, Dale and Harry described how financial gains also provided a sense of freedom as they get to "*spend it how I like" (Harry)* and the money "*helps when on benefits" (Dale).*

> *"Yes, you get paid for sessions that you take part in which is lovely. Because I always used to be voluntary at one time but people have said to me the money is there so we are willing to pay you for the work you do. So, I accepted but still a lot of stuff that I do, I do not claim for because you know, I just want to help. You know, it's nice to earn money again and spend it how I like" - Harry*
> *"… and obviously the cash, which makes a big difference if you are on benefits. The payments really help" – Dale*

The two previous sub-themes discussed above have focused on the personal aspects of participants involvement journeys, through the understanding of individual outcomes. The next sub-theme will move beyond the individual and focus on the interpersonal aspects of involvement to understand participants' experiences of others and their relationships.

1.5 NOT ALONE IN ALL OF THIS

In addition to idiosyncratic considerations, this sub-theme explores the relational dimension of participants involvement experiences. This places a lens on the relational components of involvement and how powerful participants' experience their connections with their peers and academic staff when working together to achieve a common goal.

Several participants expressed the empowerment gained through the reciprocal relationships developed and the connections made with the staff and other SURG members. It is important to note here that there are different power dynamics at play within the different relationships. However, despite this, the relationships developed appeared to be central to participants' experiences. This sub-theme identifies how participants' expressions of building valuable relationships contributed to a meaningful experience. Participants also identified the quality and importance of these relationships. However, what was not further discussed are the processes involved in developing such relationships.

Regarding the interactions with the staffing team, the complexities of the power operating are often not discussed even though they exist. Traditionally, the power relation is one of the professionals helping an individual in distress. However, participants' narrative described their relationship as one where they were on an equal footing with staff as they used terms such as *'collaborative' (Barry)* and *'equal' (Dale*) to describe the dynamic at play. Participants felt valued, respected, and in response, articulated that they valued staff they worked alongside. They experienced them as allies united to work towards a common interest. Participants credited the staffing team for making it possible for them to do their involvement tasks without hindrances. This level of association appears to be of great value within involvement as there is a sense that it helped to bridge a divide. However, what must also be acknowledged is that when speaking about supportive academic staff, it was clear that this could not be said for participants relationship with the senior management team. They were experienced as a powerful force that had little to no contact with participants. This idea is further discussed in the theme below.

The extracts will explicate the different functions participants perceived staff played that enabled them to feel more integrated into academia as collaborators and less in a tokenistic manner. For example, over half of the participants, like Barry, spoke to the collaborative elements of their involvement. It was also apparent that participants recognised the structures at play within the institution that often marginalises them. These are the same processes that use service users and carers to meet regulatory obligations as this is often the driver to involvement. However, Barry positioned himself as a colleague where he works in partnership with staff. He showed a sense of autonomy over his work and its delivery. There was an awareness of the significance of his contributions and how each person's knowledge complements one another through collective action and mutual support.

> *"I wouldn't be involved unless I thought I was making a difference, is the bottom answer... I am often asked you know Barry we want to do a session on this. Do you think this is appropriate or could you do something on this subject? And then its left to me to start to develop something and we will knock it backwards and forwards. It has been very collaborative and that has been very refreshing as well...Genuinely, I haven't met a professional that I have worked with that I've had a negative experience of"– Barry*

Similarly, to participants like Barry that positioned themselves as colleagues to staff, Dale also spoke about equality. However, his narrative was centred around the way he was treated, and his extract highlighted how some participants perceive equality is established within the academic institution. There was a sense that participants were not equal to academic staff because of their lived experience and the importance of their contributions. Instead, this inferred that empowerment resulted from interactions with others and parity was earned by the way others treated you. This speaks to a possible implicit belief that the power resides with the staff and the students, so, therefore, it can be argued that a sense of equality can only be acquired if the people in power deem it appropriate to treat service users and carers in a manner that reflects this. For Dale, because he was treated with respect, he felt empowered.

> *"It has helped that all the staff and the students I have met are pretty understanding and treat everybody as equal. When I first got involved with*

> *service user involvement in drug and alcohol you would get some real hard times from professionals that didn't want you there. So being so welcome at the university is a big difference than not to be welcomed. It has been empowering, that's a good word for it"– Dale*

Participants also discussed the shift toward a more person-centred approach that maps the meaningful progress and journey that involvement has made over the years. This movement has been driven by service users and carers campaigning for the right for their voices to not only be heard but respected within services and academia, and it elucidated how external pressure impacts internal procedures. This was articulated by the extract below. Harry reflected on his experience over the 10 years he has been involved at the university. He shared that he perceived an unprecedented move and an increased sense of empowerment from a time when service users were not given the space to share their opinions, and academic staff were too often placed in a position of power. To now where he feels "*Service users know in some cases, a lot more than what the academic may" (Harry)*. He was able to provide an example to illustrate where he had experienced his involvement as collaborative. He felt he had just as much influence on the appointment of students onto the course.

> *"Service users were just purely service users. Their views didn't really matter. The academics always thought well I know best. What does he know he is only a service user? Service users know in some cases, a lot more than what the academic may… For example, when we interview students. There's myself and academic staff. Once the student has finished and its off-air, we then go back and discuss it all, we give our views whether it was a weak, average or strong interview. The academic running the interviews then takes it from there to decide whether they are suitable to be accepted in the uni. I'm definitely involved with the decision-making process and its collaborative" – Harry*

Participants also asserted the process needed for the relationship with staff to be supportive. This is not directly related to the sense of sharing knowledge or equity in the relationship. Instead, it speaks to the quality of the interactions as participants expressed an encouraging function to their relationships with staff which enabled them to be far more involved as they gained a realisation of their inner strength and skills. Participants described how staff feedback gave them the vigour to be involved at a level that they once could not imagine. There was a sense that participants found assurance in staff opinion given their knowledge. This may also speak to how service users and carers position staff as supportive, knowledgeable and trustworthy. Through their contact with staff, participants like Gill attributed the unearthing of skills she was unable to recognise in herself, to her relationship with the staff she trusted.

> *"So I think a lot of it is about maybe I had some of the skills, but I wasn't able to recognise that they were there and it was about other people saying to me you know you can do this at a level that is good enough to stand in front of a reasonably large group of students and do it…. I trust their opinion and that's really important because, I think, it wouldn't have meant so much if it had been a group of people, I didn't know so well, saying, we've got this belief in you. So, to hear it from the staff was really important" – Gill*

There was also an agreement amongst participants that their relationship with SURG members was an essential aspect of their involvement. When speaking about the relationship with other SURG members, participants expressed a bonding function to their interactions. They described a sense of social connectedness that helped to foster friendships with individuals that were also working towards a common goal of making social change and progressing the movement to ensure that service users' and carers' voices are firmly embedded within academia. The feeling of connectivity and strength might also be aided by the support and the sense of belonging to a broader group that participants felt when achieving their desired goals. For example, the extract from Carl illustrated the importance of belonging to a community that helped participants feel empowered as they met with like-minded people passionate about creating change within a system. This also speaks to how marginalised groups can come together and challenge the imposition of exclusionary activities within academia and mental health services.

> *"Seeing other people. You know, discussing ideas about how to improve stuff so it seems that there is no hidden agenda in these SURG meetings. Everyone is on a level and everyone wants to help because most people there have had*

> *the first-hand experience of the care they (other service users) are going to receive, you know, especially in that area" – Carl*

Participants referred to the benefits of being part of the collective as it averted the sense of solitude as spoken about in the extract below by Ian. Participants fostered strong friendships, and there was a feeling of closeness with Ian describing "*the sense that I'm not alone in all this (Ian)"*. Connections in the SURG were deemed to foster a sense of togetherness amongst peers, and also offered social support.

> *"... I've met two or three people who no longer on SURG but they are still great friends. I mean, I'm a very isolated person. I think one of the nicest things is the sense that I'm not alone in all of this" – Ian*

THEME 2: MANAGING PROCESSES OF INVOLVEMENT: SYSTEMIC DISTORTION OF EQUALITY

The second theme presents the managing processes of involvement as related to the systemic distortion of equality that many participants discussed in their interviews. It elucidates the role of power, who participants perceived had the power and how it operated in the context of their experiences. With the university being a complex system with structures and processes in place, participants explained the paucity of equity they felt at times when involved in health and social care education.

This was an important consideration in participants narratives as it sought to shed light on where participants perceived they were positioned within the institution, the university culture and the power differentials they faced. It highlights the practises linked to broader institutional structures at play that render service users and carers feeling a sense of powerlessness as it focuses on experiences that participants believed endorsed the gap between academic and lived experience knowledge. In their narratives, they articulated processes in place that were unhelpful and left them feeling like their involvement was tokenistic—for example, having no influence over the decisions made. Participants also expressed their displeasure with hierarchical power relations that disadvantaged them and maintained the inequality within the institution.

It also speaks to participants views of the institution being a space where power inequalities are perpetuated as hierarchical structures create various different forms of control that restrict involvement. In such instances experts other than service users and carers preside over the decision-making processes, even with regards to if service users and carers can or cannot be involved.

The two core areas that emerged will be teased out further in the subthemes *'There's still a bit of them and us'* and *'it all boils down to communication'* which are the distinctive areas in which participants expressed such feelings of inequality, tokenism and powerlessness within academia.

2.1 THERE'S STILL A BIT OF THEM AND US

This sub-theme speaks to the power disparity that operates within the academic institution as manifested in decision-making processes. Participants asserted the unhelpful experiences that left them feeling their voices were not heard and they had no influence. They shared that their responsibility and impact felt limited as the power was held by academic staff in more senior positions. Thus, they perceived that at times their involvement was tokenistic in nature, with no space for inclusion and collaboration. This left them feeling powerless as traditional power relations were enacted in such processes. This does not favour mutual and dialogic relationships that foster partnership but instead risks maintaining conventional hierarchical relations that positions professionals as best placed to make decisions that may silence service users' and carers' views. For Ian, the involvement did not always reflect collaboration or partnership working, as seen in his extract below. Ian is also able to think about this in relation to the incongruence experienced in the importance the institution places on having a strong involvement component to their courses.

> *"I think that the teaching staff know involvement is something they need. Even more senior staff know that to sell their courses, you know, to different professional bodies and to do that successfully in the face of competition from other universities, then they're going to need a good strong SURG element.*

> *But irrespective of erm that, no, I don't think SURG is very much involved in decision making, to be frank. No, I mean, I think we're certainly not as involved as we might be" – Ian*

Such processes in place are seen to perpetuate the power imbalance. Thus, underpinning the idea of power not being with service users and carers despite their importance but instead remaining with the powerholders, which is believed to maintain their dominance. Therefore, on one level, the institution may seek to empower participants, but this is not always experienced in the same way with some service users and carers feeling they have little to no power or influence. It favours the social order that continues to sustain the inequalities at play. It shows that some participants understand their role and where they are positioned in relation to the staffing team. Elaine perceived she did not have much authority over what happened. She expressed that the staffing team that worked directly with the SURG held the power that aligns with the institutional structures. Thus, indicating the possible internalisation of power inequalities played out by participants as they see themselves in a subordinate or supportive role.

> *"No, I don't have the ability to make decisions because I'm not senior enough to do that, I am not a regular member of staff. I just feel that my role at the SURG is to support ...as the university is a big place, I suppose I may just be a clog in the wheel, as it were, and every little bit helps" - Elaine*

As shown in Andrew's extract below, the complexity of the relationship between senior managers and participants was highlighted. It asserted that the power and influence are only in the higher echelon because of the perceived foundational errors within academia's hierarchical structures. This highlights a quagmire, as participants expressed being involved but they did not feel they had the power to influence changes effectively. In addition, this speaks to the levels within academia that participants are asked to be involved in, as there may be a shutting down of involvement opportunities on a senior management level. This emphasises the limited nature of involvement with participants often involved in tasks where they share their lived experiences. This leads to powerholders being seen as continuing to dictate and enforce their agenda without SURG members contributions. Therefore, it can be argued that as a precursor to involvement, there is a requirement for the institution to value service users and carers and have them represented in all aspects of academia.

> *"I don't think we are involved in any decision-making processes at all which is Um, disempowering. If we are, it's very minor if at all. To a certain extent, I think the way that higher education is established, is that there's no decision making at all at the lower levels. There's no decision making by staff that work with the SURG really. Um but really the decision making doesn't really happen until you get to senior management level. Staff that work with us have to refer higher in order to get things done. So, our ability to be involved in the decision-making process is zero…" – Andrew*

Participants also highlighted a lack of collaboration and parity present from the very beginning, which manifested in the language used by the institution to describe participants. This highlights the sense of 'othering' in society that is maintained within the academic institution, rendering participants and their contribution inferior to the academics and their knowledge. The extract below speaks to how service users and carers have historically been positioned in services and how the terminology used by the university is also often problematic as it is believed to perpetuate the power differential between academic staff and service users and carers. This is experienced as fuelling the divide.

> *"The thing is, for a lot of people who use mental and physical health services, you get a lot of that sort of positioning in that life. So when you are actually then doing something out of the goodness of your own heart let's say, even though it's connected it still becomes a bit of a barrier, there's still a bit of 'them and us' sort of thing and that's what you need to just get rid of...., this is Franky of such and such and maybe even give us different titles like sort of user lecturer or something like that. You see what I mean. So that would be better…"– Franky*

Franky then went on to speak about a process where both professionals and service users and carers come together and coproduce material in an equity of knowledge. In his quote below, he articulates how service users and carers only come to be involved after certain decisions have already been agreed by the institution. There appears to be a wish for involvement to occur in a very different way.

> *"Sometimes, they've got the written piece of what they want. So it's just bringing us in and then sort of using the person for a means to an end and actually there shouldn't be that sort of sometimes tokenistic approaches, it should be actually we're getting you in for a purpose… We need proper co-production where you have a blank piece of paper and the professional and the lived experience person works together."– Franky*

The above sub-theme speaks to the lack of power service users and carers feel they have in decision-making processes and where within the institution they perceive the power resides. It highlights exclusionary processes in place, that results in involvement being experienced as tokenistic. Additionally, service users and carers also identified that their voices remain unheard on certain levels within the institution, thus diminishing their influence. The impact of language was also considered as service users and carers experienced certain terminology positioned them not as colleagues to their academic counterparts but instead upheld a challenging dynamic. The sub-theme below will go on to build on service users' and carers' experiences of the power differential.

2.2 IT ALL BOILS DOWN TO COMMUNICATION

There was a clear thread of poor communication that weaved through participants' narratives. It signified an additional barrier that left participants feeling powerless as they believed this also sought to solidify their positioning on the periphery of the institution. This impacted their sense of equality in relation to their academic colleagues. Participants provided examples of inadequate dissemination of information that often hindered their ability to feel connected to the programme and was an inhibiting factor in participants' involvement. This was described as leaving them further ostracised and impacted service users and carers health and well-being. Even in situations where the power of choice should have been with participants, they spoke of the times they were prevented from making the choice about if and how they wished to be involved as contact was not made.

On reflection, this may also indicate how much the institution prioritises having service users and carers involved in their courses if adequate information about opportunities is not readily available or shared with participants. The impact is felt on an individual level but also has wider ramifications for the SURG movement. Therefore, it is difficult for working alliances to be created based on equality and mutual agreement when the flow of information through any median is ruptured.

Several participants highlighted the inadequate contact they had with the university during their involvement, as communication difficulties were occurring on several different levels. The first being between staff and SURG members, and the second were issues between staff members. For most participants, this was a longstanding issue that was also ongoing when the interviews were conducted. This also shows that even though service users are deemed as lived experience lecturers in their title, participants believed they are not firmly embedded within the organisational structure and thus, contact can be severed at any given time. This highlights the precarious nature of the relationship service users and carers have with the academic institution. For example, one participant described how central communication is at the university as he stated that *"I have always been here to get involved but I've not always been communicated with" (Jason).* He used an analogy of a satellite unable to transmit information and how that resulted in SURG feeling stagnant when information failed to flow through. The other drawback was involvement being perceived as championed by certain staff members and not by the organisation. Thus, when passionate staff members left, then there was a breakdown in the movement.

> *"The communication is a big issue at times. It all boils down to communication. Let's face it. It's the cause of most problems… If you haven't got the communication then all the satellites cannot talk to find out who to speak to and the people in the centre saying oh, we could do with this, oh but we can't find anyone to ask. I have always been here to get involved but I've not always been communicated with because a person has left... So, I've had peaks and troughs like that all the time. Going up like that (making gestures with his hands) it's like a staircase. "It's like a yo, yo, but going in an upward curve… oh, of course, it has impacted me. ...It actually also gets us to lose*

> *certain people at times, I've seen that happen because they don't feel their worth..." – Jason*

Participants highlighted the disparity in the university's involvement rhetoric and their actions that left participants feeling confused, uncontained and disposable. It can be argued that this speaks to how participants are positioned by the institution as they work on the organisation's terms. This invalidates their position as equals. Franky also added that the conflicting messages received from the staff were not very helpful for "*people with mental health issues" (Franky)*.

> *"You don't know what you're doing yourself because it's mixed messages, isn't it? So, it's like, well, we want you to be involved with this and then you're not used... you know, they are saying in one breath that they want you and then they are saying in another breath that, we don't. It doesn't bode well especially if you've got people with mental health issues, because that's the last thing we need is inconsistency in the message we get. It's like just clearly tell us what you need" – Franky*

Further to communication setbacks between staff and SURG members, participants also described a sense of poor communication between staff members in relation to the SURG. Even though the university is required to have service users and carers involved in all aspects of education, participants felt staff did not have the capacity in their schedules to see this through. As outlined in Ian's extract about inadequate communication, he perceived was happening within the staffing team. He attributed this breakdown to staff feeling overworked.

> *"I think the only caveat to that is communication amongst the staff is probably at its weakest point and that is probably because they're all overworked. You know that communication at a peer level is one of the first things that starts to drop out when people are under too much pressure. They put their head down and get on with their own bit of it. And I think I have seen it get worse at the university, rather than get better" – Ian*

As outlined above, two aspects of involvement that focused on participants' experiences of feeling like they did not have any influence or power within the system were discussed. In addition, processes within the institution that participants believed failed to acknowledge their positions as educators to the same degree as their academic counterparts also emerged from participants' narratives. The dissemination of information and opportunities, as cited above, further impeded involvement and left participants feeling a sense of powerlessness.

THEME 3: NEGOTIATING PRACTICES OF INVOLVEMENT: ONE SIZE DOES NOT FIT ALL

This theme captures how participants experience the institution's standardised approach to involvement. It highlights how participants are faced with various barriers that impede their ability to freely engage with the university as well as involvement tasks. The sub-theme *'just wish people thought about access'* explores how participants experienced aspects of the university milieu and the disparities in accessibility. It also speaks to the involvement processes that are not effectively negotiated and thus, further intensifies the idea that all service users and carers are at times treated the same. Such important factors feed into the existing dynamics at play and may continue to ostracise participants and hinder effective involvement. The second sub-theme *'Navigating uncharted terrain'* speaks to the university's response to the pandemic and the impact of the uniform processes employed. It voices the importance of individual needs being recognised and negotiated to ensure individual differences are met through involvement.

3.1 JUST WISH PEOPLE THOUGHT ABOUT ACCESS

This sub-theme will look at the physical barriers that disadvantage participants. As expressed in the extracts below, there were issues highlighted in accessing the physical building for SURG meetings and involvement activities. There were also issues raised about accessing materials sent to participants. Structural barriers maintain inequalities and continue to exclude some service users and carers as they are forced to be reliant on staff members to navigate the site and resources. Even when done unconsciously, this maintains the helper – helped relationship when accessing essential resources. Such resources should be available to all and instead this unhelpful dynamic risks further excluding service users and carers. Jason’s extract expressed a dissatisfaction and frustration with practical issues such as parking and the complexity in moving around the campus. Such issues can have a devastating impact on participants ability to be involved and feel like part of the institution. This practicality is essential to involvement and, if addressed, ensures that more collaborative relationships are fostered. Collaboration is not only seen as staff and service users and carers working together in decision making within academia, but it is all-encompassing, and all barriers must be recognised and tackled as their presence continue to disadvantage service users and carers and further marginalise them.

> *“I always overcome the barriers but there are physical barriers. Parking being one of them. You can park under the palladium to get out if you really needed to and knowing the routes around the university. You know, it’s not the greatest map. It’s a maze (laughs). I tell people if you know what points the compass are, where north is, you’re onto a winner. If you don’t know that, well you will be wandering around for a long time” – Jason*

Some participants also articulated the differences and subsequent divisions between members. These splits are sustained by traditional forms of involvement, which privileges some participants whilst others continue to be disadvantaged by how involvement practises are carried out. For example, SURG meetings only being held on campus. This speaks to the idea that involvement within the group does not always feel inclusive for all. It leaves some participants feeling powerless and continues to alienate them as their needs are not met. In the extract by Andrew, he articulated that his involvement is impacted by the university’s inability to make provisions for people with a visual disability. He had been left feeling that his experience was not always positive as there were times, attending physical meetings and accessing materials was challenging. As the environment does not always make involvement possible, this again recreates the power inequalities as participants are in the position of seeking assistance from students, peers or their professional colleagues just to be involved. This encumbers their sense of autonomy and leaves them feeling powerless.

> *"I hate asking people for help. If I need to go to the loo. I hate it if I have to ask somebody to take me there because I'm very independent. So, it's those sorts of things. It's the inability to be able to read the print-based minutes for the meeting and the agenda and stuff like that…I know I've got a talking computer but, because I have to use a speaking computer, I have to wear earphones. Then you miss some of the conversations that's going on so it gets a bit difficult being a blind person. Going back to the idea of print materials, the forms that are provided are generally inaccessible. So yeah, most places don't understand about access for people that are blind and they wouldn't do unless they're told. But, you know, you just have to get around those problems. You know the form for your lived experience and skills is totally inaccessible. I just wish that people thought about access a bit more in terms of materials" – Andrew*

3.2 NAVIGATING UNCHARTED TERRAIN

This sub-theme explores involvement during a global pandemic. As the study was conducted during the Covid-19 pandemic, all participants' narratives referred to the impact of the crisis on their involvement. Even though a global pandemic is not a traditional aspect of involvement, this unforeseen event required the university to quickly rise to the task and renegotiate what involvement would look like going forward. This theme also highlights the differing needs of SURG members. It speaks to the problematic nature of the uniformed approach as it fails to acknowledge and make provisions for individual differences. It exposes that the same processes that may liberate some members and enable them to be involved also serve as barriers that ostracise other group members from accessing opportunities. Such restrictive practices then determine who can be involved and the voices that are heard, perhaps emphasising how the university needs to understand each member's needs and thus provide adequate support to better engage in academia.

It is important to note that interviews were conducted five months post lockdown. At the time of data collection, participants expressed their involvement activities were instantly halted in line with the lockdown restrictions, and for many, involvement at the university had not yet started as reflected in their extracts. SURG meetings were stopped, so members had little to no contact with the university and each other via official means. This highlights that the institution's immediate response to the SURG in light of Covid was to lock it down for several months. In the background, the university quickly transitioned to remote classes being offered to students within days. However, this did not occur with the SURG, which may reflect how much importance the institution placed on lived experience knowledge versus a traditional knowledge base.

All participants reflected on how the sudden lockdown and new restrictions changed involvement as they once knew it. From some participants' accounts, it was clear that the pandemic had been challenging. They expressed apprehension about their ability to engage with involvement tasks online. When the university began to re-engage SURG members in an attempt to restart activities such as teaching and SURG meetings, some participants were not pleased with moving onto zoom. Several participants described it as not an ideal situation, as highlighted in Gill's extract. She expressed not feeling entirely comfortable with the sudden move online so she opted to postpone her teaching session. This may reflect the training needed to support participants that felt less conversant with technological methods and the transition to remote involvement.

> *"Mainly coronavirus, to be honest, um, so they said if I had a way of delivering it online, but I haven't, I haven't got that much experience and I didn't feel that was the best way for me to like launch off into it. The other challenges I think I witnessed, but maybe haven't experienced personally is engagement online and people knowing how to use the technology, which I think the meeting that maybe you and I attended demonstrated that people don't always feel comfortable to be on a video call, even if they have the technology" – Gill*

Although some participants expressed challenges in navigating the subsequent changes, it must also be noted that the move to remote involvement enabled other participants to connect with the institution without having to be dependent on others around them. This allowed them to regain their sense of autonomy and power, as expressed in Andrew's extract below. For Andrew, this endorsed his independence as he already felt marginalised in the group because of his physical impairment.

> *"Covid 19, I hate to say it but is a godsend. Simply because, you know, we can have the meetings by different means actually than going to the university, it's made it much easier. Yeah, I have to find somebody to take me there. I can't get on the train on my own. Yeah, so I have to make sure that one of my adult kids can drive me there or my wife… or I've got to get myself to Southend somehow, which is difficult" - Andrew*

This sub-theme unearthed some participants anxieties about the university's response to the SURG in the context of Covid -19, and for others, how the changes made involvement far more accessible and inclusive. It is also important to note that the longer-term repercussions of the pandemic are still unknown. There is a sense it may result in further cuts which may directly impact the number of resources allocated to involvement. Despite these changes being difficult to manage, it may provide an opportunity for the university to evaluate its practices and ensure individual needs are accommodated more so service users and carers can access meaningful involvement opportunities.

THEME 4: MAINTAINING PROCESSES AND PRACTICES OF INVOLVEMENT: THE JOURNEY AHEAD

This theme looks to the journey ahead and provides clear recommendations as participants narrated what they perceived needed to be done by the university to improve how service users and carers are involved in academia. Participants shared a desire to improve their own experience and there was also a sense of wanting to make it better for new service users and carers. Many of these ideas came from what they observed as not working efficiently during their time in health and social care education.

The first sub-theme that emerged was *'you cannot achieve intentions without higher investment'* which highlights participants' views on the need for additional resources.

The second sub-theme is *'they need to open up their boundaries a bit more.* Participants sought to steer the university in a new direction that encompasses more involvement on multiple levels. The last subtheme *'their voices are equally as important'* reveals the voices that are regularly heard and the ones that go unheard.

4.1 YOU CANNOT ACHIEVE INTENTIONS WITHOUT HIGHER INVESTMENT

Participants raised inadequate resourcing as a major constraining factor. All participants spoke of their awareness of the limitations (on the level of resources) of the system that restricted service users' and carers' ability to be further embedded within the academic institution. It was believed that this affects the influence service users and carers can have individually and collectively. On a local level, it can be argued that this may reflect the limited resources allocated to involvement, however what must also be noted is that this is in the context of funding cuts institutions have experienced over the years. The essence of this sub-theme is captured in the extracts below that speak to participants' frustration about the current state of affairs that appears to be twofold, firstly their perceived lack of financial backing and secondly, staff members not having enough time to invest in involvement.

Regarding financial investments, there was a general sense from participants that involvement was underfunded at the university and across other institutions. Participants expressed how they believed more resources and funding will enable more significant partnership working. They expressed wanting a relationship with the institution that goes beyond just being contacted on an ad hoc basis. Instead, there were calls for an infrastructure to be in place, which means there is enough consistent staff with adequate time to facilitate and drive the movement forward. This also implies that the strength of involvement as presently set up depends on the academic staff member working with SURG. Thus, showing that involvement maybe based on a lifeline structure attached to individual staff members and service users and carers may not be involved because there is equity in knowledge. This structure is risky as the quality of involvement becomes dependent on staff members' passion and will to move the initiative forward, not on adequate structures embedded that stipulate good quality involvement. This is highlighted in the extracts below by Jason and Franky, which speaks to the importance of having a "*point of contact that is funded correctly" (Jason*) and *"they need to put a little bit more of a budget into user involvement"*

(Franky). It is then believed that this will see involvement move beyond one of the many tasks staff members are required to do as part of their role.

> *"...point of contact that is funded correctly, getting enough hours and driving it forward as opposed to always being on people's goodwill. When you have someone joining in and they know the point of contact, it provides a nice rich tapestry. So, if you lose that person or they leave. Then that drops off a cliff and that's down to resources not being managed within the University" – Jason*

> *"I think that It's not directed just at the university, but it's directed at lots of different establishments, well universities especially, they need to put a little bit more of a budget into user involvement" – Franky*

Participants expressed a disparity between how the university communicates the importance of involvement and their accompanying actions. It asserted that the involvement of service users and carers is spoken about as an essential function in student learning; however, in reality, participants believed this did not translate all the time. Participants felt they were not always respected in such a way as involvement appears to be fragmented and dependent on selected academics. Involvement then feels like a tick box exercise where institutions use participants to meet requirements and recruit students, but it is experienced as not based on collaborative partnerships and mutual respect. This mismatch in agenda can further denigrate service users' and carers' positions within academia as this maintains the role of service users and carers being drafted in when needed rather than being a critical and valued knowledge base in academia. This has a damaging impact on involvement, and participants expressed that more is required to ensure that SURG has all the foundation necessities such as efficient staff support to function effectively and be valued within academia, as asserted in Ian's extract below.

> *"Both with the commissioning agencies and with the students themselves saying that service user involvement is highlighted. Well, if they're going to use that to promote the courses and to get the business, they should be making sure that it really happens and I think the speaking has gone beyond the*

> *practice. I think there's really good intentions no question about that. But you can't achieve those intentions without higher investment. Both in the admin staff to support the SURG work and also in the lead roles within the tutor body. The way to show real appreciation and respect for what we're doing is to make sure that staff support is rock solid…Historically, you know, I can see when we've had that in place, things have prospered. Then the personnel changes and we go back to square one. And it's gone like this over the past 10 years at least and it has made me feel a little bit that I've been taken advantage of. My contribution hasn't been valued as well as it might be and it hasn't been respected as well"– Ian*

Participants perceived that involvement was hampered because it is not a formalised operation within the faculty or an initiative that the broader university values; instead, it is down to a handful to do the work required for involvement. Participants showed appreciation and gratitude for the people within the faculty that pushed the initiative forward. However, it was also believed that more resources need to be made available and the responsibility shared to progress the movement. More resources may enable service users and carers to be more involved at various levels, and the institution can also put resources into engaging more diverse voices.

4.2 OPENING UP THE BOUNDARIES A BIT MORE

Another sub-theme that strongly emerged was that many participants stated that they desired to be more involved. Almost all participants unanimously agreed that they would like to do more at the university. Participants appeared to be highly motivated and passionate about being more embedded within the institutional structure and use their voice and expertise to create change. Participants spoke again about the sporadic nature of their involvement that was on the institution's terms. This fails to reflect partnership working where service user and carer involvement is one based on equality or as a consistent feature within academia. Participants were also seeking varied roles within the institution, to ensure they are more firmly rooted in academia, enabling them to have more significant influence, autonomy, and a variation of skills. However, this is not a common experience for participants as the extract below illuminates. In Franky's narrative, he was also able to draw on positive experiences at other institutions where involvement looked very different.

> *"Yeah, I mean, so with the university, not as frequent or as often as I would like to because they do it in the way of, I suppose, as per the course dictates. You know, so it's like they're doing that part of the course now so that then means that you need to have the service users come in and do the bits and then you go off again. It would be nice to be more involved. As I said with the other university I do quite a lot because they sort of have a way of getting you involved in different parts throughout the year. But it will be nice to get involved more at this university" – Franky*

Franky also spoke about what this would look like as he wished to be part of the *"core faculty team" (Franky)*. As outlined in the following extract.

> *"I think that they need to get with it in the sense of, they need to open up their boundaries a bit more. Well, I mean, I'd like to be involved from beginning to end, from admission right way through to graduation. Yeah, so the point is, you know, if you saw me in the admission process. So say I was part of the interview panel, you might see me through your first year, you might see me through your second year at various different points and then at the end of it, it's a sort of farewell. I think that'd be great, you know, when you join the uni, you know, you've got your core faculty team…" – Franky*

Participants expressed having limited access to opportunities as their roles were restricted within the institutional structure. This speaks to the fact that some participants did not experience involvement to be on a partnership level and instead reveals how involvement can be problematic as one party (the university) dictates how the other party (service users and carers) are involved in the educational processes. This dynamic is complex as it maintains the idea that the professional knows best and is not based on a coming together and co-production within the institution as outlined in Harry's quote.

> *"We're going to have a relationship and that doesn't mean the relationship shouldn't be equal. It should be academic staff have a qualification, but my qualification is a lived experience qualification and should be brought on the*

> *same level. So it's taking away the situation of well staff know best, because they are the ones with a qualification. Actually, let's work together" - (Harry)*

Even when participants challenged this, their voices were dismissed, reinforcing this dynamic as outlined in Andrew's comments. This can be experienced as contradictory as they were asked to use their voices to share their expertise, but in the same vein, it appeared to be rejected by the university when it was not within their parameters. Andrew shared when he asked to be more involved in the past; he described it "*fell on deaf ears to a certain extent" (Andrew).*

> *"Yeah, not very frequently (laughs) I do things once or twice a year. Is the maximum. I'd like to do more. I'd like to be involved more and I actually brought that up in the meeting about marking essays but that sort of fell on deaf ears to a certain extent. But I'd like to get involved, you know, I'm not blowing my own trumpet, but I'm good at it. I'm good at teaching. I'd like to do other things, but I'm not asked to do them anymore. I am there for one session and I wish I could be there for 10" - Andrew*

Despite participants being passionate about being involved, there was also a sense of ambiguity in where they positioned themselves within the institution. This lack of clarity on how they see themselves may also be reinforced by the uncertainty surrounding how they are positioned by the university. Are they a key function within the faculty and learning, or are they somewhere on the periphery? This once again, expresses the inequality that exist between them and academic staff. Therefore, it was hard to have collaborative working relationships when their position was unknown as expressed in the extract below. The participant referred to wanting to do more but this was not possible due to him not being a staff member, thus indicating that his position in the institution limited his involvement.

> *"Oh my philosophy of engagement is if I'm asked to do something, I consider that thing in its own right, as it were, I don't have any expectations in particular or I try not to have but I would like to contribute more, but I recognise, you know, I'm not a member of staff, I am. I don't know quite what I am (laughs)" – Ian*

4.3 THEIR VOICES ARE EQUALLY AS IMPORTANT

The idea of sameness and difference was also explored within participants' narratives as the subject of inadequate representation was considered a crucial issue. Participants stated that there was a lack of diverse voices being heard, thus highlighting that there are sections of society still being marginalised even in involvement. It is important to note that service users and carers are not a homogenous group, so it cannot be assumed that their needs and experiences are the same, and thus, the lack of diversity is problematic. This point is illustrated by the extracts below by Barry and Dale as they spoke as white, middle-aged men. They expressed that in their experience the SURG members fail to represent the student body or the community that students will work with once qualified. Participants were urging the institution to engage a more diverse group of people to ensure that more voices are heard and represented in the SURG. They expressed that young people, the LGBT community, individuals with different health issues, different ethnicities and social class were not adequately represented in the group. There was also a sense that students' learning may be limited due to the lack of diverse input.

> *"One area I would like to see different is I think its predominantly mental health. I do see some gaps in other kinds of health issues. I mean, I come from a mental health background and most of the service user meetings are predominantly done with people with mental health problems. So, I think the university, not just the university, but across service user involvement in its entirety needs to diversify around health. It concerns me that there are groups that are not represented. I think really where possible we need to look, further, than mental health... I think to me that's really the next step" – Barry*

> *"...I think what is an issue is if you look at the membership of the SURG. It is very undemographic to the nursing and social care students that they get because you have a higher ethnic minority in the student base and the SURG is full of middle to older age white middle-class people or people who are on benefits. But again, their ethnicity is of course white. We don't have people who actually represent the communities in our areas. If you look at the local area it's a very high ethnic minority community...Also, we've got to be open.*

> *I've never been asked, and it's very weird, about my sexual orientation or gender. Our world has changed so differently that we've got high levels of people who are trans. We've got a lot of LGBT community we've got a great BAME community. So, do you see what I mean, it always seems to be you get the same faces and even though that's great. We need to be proactive and trying to get other people involved too because their voices are equally as important" – Dale*

As some participants also felt marginalised within the group, they drew upon their personal experiences to explicate this point. This speaks to the divide experienced by some in society where particular health needs are seen to be prioritised over others. It is perceived that this has been recreated within the SURG group. There is a sense that once again, disadvantaged groups are left competing for resources, and struggle to be seen amongst others. This can locate the struggle within the group versus looking at the structures in place that maintain the inequalities. It was perceived that the university created a dynamic where some participants experienced that one group was prioritised over the others, as explained in Andrew's extract. He shared his experience of feeling marginalised in the group, "*fighting against it" (Andrew)* and how he was left with the sense of the department not prioritising physical health difficulties as mental health was given more attention.

> *"I think the curriculum is less about physical impairment and more about mental health. I always get the sense that I'm a minority as a physically impaired person you sort of tick off the people in those groups and a majority have mental health issues, and those mental health issues, always seem to take prominence. I am always fighting against it as more needs to be done, well, hang on a minute, people with mental health issues are not the only people here. My voice is also important because I'm the only blind person now" – Andrew*

This sub-theme illustrates that certain disadvantaged groups are still unseen and unheard within involvement. Participants recognised that this issue needed to be addressed by the institution to increase diversity. They expressed a desire for involvement to be a more inclusive space that draws on differing experiences and voices as a means of expanding the involvement landscape. Participants also raised questions about the richness of students learning if they are not given the opportunity to hear a multiplicity of voices. In addition to increasing diversity by involving more SURG members, some participants also highlighted their experiences of marginalisation within the group as there was a sense within the SURG that mental health was prioritised over physical health.

CHAPTER 5. DISCUSSION

CHAPTER OVERVIEW

This final chapter will begin by discussing the key findings in relation to the literature reviewed in chapter 1. It will then outline the study strengths and limitations to better understand and appropriately situate the findings in the context of the study limitations. This study's contribution to the existing knowledge base about service user and carer involvement will then be explored before outlining areas for future research. Lastly, the chapter will then provide the researcher's reflections on her journey.

OVERVIEW OF THE FINDINGS

The aim of this study was to explore how service users and carers experience their involvement in health and social care education at a UK. University. The research questions that were outlined to be explored were:

1. How do service users and carers experience their involvement in health and social care education?
2. How do service users and carers report their own experiences of power and how it operates and impacts on their involvement?
3. What are the recommendations for improving involvement in health and social care education?

Ten service users and carers shared their experiences of being involved in health and social care education. Through the use of a thematic analysis methodology, four main themes emerged from participants' interviews as they shared their experiences of being involved. These themes were the involvement journey, managing processes of involvement: systemic distortion of equality, negotiating practices of involvement: one size does not fit all and maintaining processes and practices of involvement: the journey ahead.

As participants reflected on their involvement experiences over the years, it was evident that many found it an enriching process. Participants also articulated the empowering aspects of their involvement as they spoke about the uniqueness of their lived experience identity and their distinctive contributions to academia. Participants believed that theoretical knowledge lacks this component, and their identity legitimised their positions within the academic sphere. They also reflected on how their lived experience identity intersected with their professional and academic identities.

Participants described that overall, they were happy with the way the university treated them. Many participants spoke about the growth process and how their involvement transformed their self-confidence, improved their mental well-being, and self-belief, which they expressed directly resulted from their involvement. They also shared the importance of the interpersonal connections they developed with academic staff and other SURG members. Participants spoke highly of their interactions with academics and reported that they were instrumental in the belief they developed in themselves and their ability to stay connected with the SURG. Another aspect of the relationships developed pertained to SURG members relationships with each other. They described feeling very connected with like-minded people as they developed close and lasting relationships, and there was a sense of solidarity when working towards a shared goal. When speaking about the value participants felt was placed on their involvement, participants recognised the renumeration they were offered at the university as an acknowledgement of value. They described how satisfied they were to learn they were going to be paid, the importance of it being the same rate as their academic colleagues and the sense of independence this offered them.

A significant aspect of participants narratives looked at the managing processes of involvement in relation to the systemic distortion of equality and the feelings of powerlessness that accompanied this. Participants recounted the processes and procedures at the university that they felt continually maintained power inequalities that excluded them from positions of influence. This focused on the lack of collaborative working that left service users and carers feeling their involvement was tokenistic. In such instances, participants perceived that their contributions to academia were not always valued. There were also concerns expressed about the inadequate levels of communication. This appeared to be multi-layered as participants expressed it being between staff and SURG members and also between staff members, which they identified as disrupting the service user and carer movement.

The data analysis also revealed negotiating practices of involvement as participants spoke about how standardised processes were not always adequate for their involvement as the idea of one size does not fit all was present in participants interviews. Accessibility issues were highlighted and served as barriers.
This encompassed parking issues and difficulties navigating the campus, leaving some participants unable to freely move around. Such difficulties often left participants reliant on others to access basic facilities, which eroded their sense of independence. Participants expressed feeling stifled as adequate provisions were not always made to support their additional needs. Navigating uncharted terrain highlighted the impact of Covid-19, which was evident in participants' narratives. Despite this not being a traditional feature of involvement, it must be recognised that the study was conducted during a global pandemic that impacted everyone's lives. All participants spoke about how the pandemic affected their involvement as it put an immediate halt to all activities. This required participants to adjust to a new way of being involved, which some found unnerving and for others it opened up involvement opportunities in ways that were never before experienced. This improved accessibility and engagement for some participants and thus speaks to the importance of practises at the university being tailored to meet individual needs as a means of opening up involvement.

Lastly, participants shared the maintaining processes and practices of involvement as they considered the journey ahead. This highlighted their vision for the future as they described what they perceived necessary for involvement to be maintained and progress at the university. Several participants believed that far more financial investment was needed to progress the SURG movement. It was believed that this would mitigate staff feeling overworked as many participants experienced staff as juggling SURG and their other jobs due to the pressures placed upon them by the system. Crucially, participants also articulated a lack of representation such as the LGBTQI+ community, diverse social status, ethnicities and individuals with different health issues in the SURG membership. This resulted in some SURG members feeling marginalised, as they struggled to have their voices heard as it was felt that mental health issues were prioritised over physical health issues within this group. Several participants felt the university needs to engage diverse voices that represent the student and clinical population as they are equally valuable in creating change. Finally, all participants shared a strong desire to be more involved.

What follows is a discussion of each theme in relation to the existing literature. This will shed light on areas of synergy as a number of the findings in this study corresponds with previous literature outlined in the introduction. There were also aspects of participants' narratives that provided further insights into participants' experiences. This builds on existing literature and yields findings that represent the complexities surrounding the involvement of service users and carers in health and social care education.

STUDY FINDINGS IN RELATION TO EXISTING LITERATURE

1. THE INVOLVEMENT JOURNEY

Of particular relevance to participants was the recognition of their idiosyncratic experiences brought through not only their lived experience identity but also their professional and academic qualifications. Participants' sense of self often goes undiscussed in the literature. This is an important finding in itself as it highlights their wider sense of self as organised around their lived experiences as well as their professional and academic identities. Participants spoke about their sense of pride in their lived experience identity and the uniqueness in their privileged role, which they believed placed them in a distinctive position in relation to their academic colleagues. As service users and carers are often positioned as objects without selves within academia, the findings point to the interconnected nature of who they are as more than just their lived experiences. This is also echoed by shaping our lives, who reflected on the restrictive nature of focusing on an individuals lived experience identity alone as it fails to pay attention to other equally valuable aspects of the individual. This, may serve to perpetuate the positioning of individuals based just on their lived experience status.

This raises key questions such as are participants being recognised for all they have to contribute to academia, or are they just limited to sharing their lived experiences? Even though this is central to who they are, is the richness of all other aspects going unrecognised? Although these questions cannot be answered in this study as the focus is on service users' and carers' experiences, it may highlight that greater recognition is required for all that service users and carers bring and can contribute to education so that involvement can be respectful, collaborative and all-encompassing rather than reductive. This could possibly help to reposition them within academia so that their involvement is more on a collaborative and partnership level (Tew et al., 2004). What is not being advocated for is merely more involvement, as this does not mean that service users and carers have a more significant influence on decisions made. Participants felt that their distinct contributions resulting from their identities were a driver to create change within academia. This showed service users and carers understanding of structures that have traditionally positioned them as passive actors; they, therefore, used their lived experience knowledge to confront such structures as they sought to reposition themselves. The study findings illuminated that service users and carers saw the sharing of their lived experiences as a means of influencing students and their clinical practice, which is reflective of their perceived ability to influence systems they are in. This aligns with the intrapersonal dimension of Zimmerman's (1995) model.

To help us further explore the importance of identity and the potential dilemma's that arise for service users within involvement, service users' identity and the authority of their voices will be discussed. Participants in this study spoke with pride about their lived experience identity, which may also illuminate participants understanding about how their lived experiences has enabled them to have opportunities within academia and their desire to use this positioning to effect change. However, the literature also shows that there is often a sense that in order for service users' and carers' views and contributions to be taken seriously there is an expectation for them to be eloquent and rational (Rogers & Pilgrim, 1996). This also speaks to a complexity as some service users may feel they need to compromise on how they present as they try not to adhere to the preconceived views held about service users. This was corroborated by Happell et al. (2017) where service users were not perceived as 'typical' service users in relation to more unwell patients that students were likely to encounter in their clinical practice. They were described by students as being high functioning. As outlined by Beresford (2013) involvement elucidates the complexities around service users' identities and knowledge. Hence there appeared to be a desire for participants in this study to be recognised for their lived experience knowledge as well as the other facets of who they are.

Participants also detailed the perceived impact of their specialised contributions which has also been supported in the existing literature. As with these study findings, Twinn (1995) also highlighted that service users pointed out their involvement was vital in bridging the gap between what students are taught by academic staff and their clinical practice in the real world. The literature also asserts the benefits to service user recovery (Lea et al., 2016) as they challenge societal attitudes that stigmatise them due to their health needs (O'Reilly et al., 2012; Zaviršek & Videmšek, 2009). Thus, challenging the unsubstantiated assumptions that individuals with health difficulties are incapable (Lindow, 1991). Despite the benefits and sense of empowerment experienced by service users and carers through their identities, an aspect that should not be ignored was discussed by Repper and Carter (2011). Their study argued that burnout occurs faster for service users and carers that participate based solely on their lived experiences than other staff members. This elucidates the potential adverse impact of service users and carers continuously sharing their stories and signifies the need for adequate support and diversity in their roles within academia as they are able to contribute so much more. However, this is not always the case as they are often asked to take up the same roles within pedagogy.

As outlined above, service users and carers spoke of what they perceived their contribution added to student learning, however, there are dynamics at play between service users and carers and students that must be thought about. This was touched upon in participants' narratives on a level where service users and carers felt they imparted knowledge on to them and created an environment that brought textbooks to life. In contrast, Stickley et al. (2010) found that students reported that the power given to service user assessors was misused. They described that the critical feedback received from assessors were not a true reflection of their work; instead, this was distorted by their assessor's mental health difficulties. The staffing team supported this position, which meant that service users' feedback was overturned and their voices silenced. This can have a damaging effect as it perpetuates the schism that positions service users as incompetent and academic staff and students as the experts. Thus, highlighting the potential problematic nature of the power interactions at play between service users and carers and students if not appropriately monitored. This would also require further research to gain a more nuanced understanding of how service users and carers experience their relationships with students.

This study's findings also exposed the tensions between lived experience knowledge and how participants perceive it is positioned within academic institutions where academic knowledge and evidence-based practice is given more credence. Participants were seeking for their lived experience knowledge to be equally recognised, which would disrupt the hegemony of evidence-based knowledge. This speaks to the tussle within the academic sphere. This also reflects the hierarchy of knowledge where lived experience knowledge is seen by some to be lesser than evidence-based knowledge (Beresford, 2003), with some professionals interrogating the validity and authority of lived experience knowledge (Callaghan & Wistow, 2006). This corroborates the findings of the literature review. Additionally, Meehan and Glover (2007) outlined that in such spaces, theoretical knowledge prevails and continues to dominate what students learn. It is beyond the scope of this research to understand the institutions position on this area in more depth but this debate is one that has been explored in the literature (Davies & Gray, 2017; Glasby & Beresford, 2002; O'Shea et al., 2019; Page & Meerabeau, 2004).

The definition of evidence-based practice was gleaned from evidence-based medicine which is:

> …the conscientious, explicit, judicious use of current best evidence in making decisions about the care of individual patients. The practice of evidence-based medicine means integrating individual clinical expertise with the best available external clinical evidence from systematic research. (Sackett et al., 1996, p. 71)

This is now a key component in undergraduate and postgraduate training programmes (Sackett et al., 1996). However, the responses have been varied with it receiving both support and critique. With some believing it is not a top-down authoritarian approach and others concerned with what evidence is deemed most valuable, as the ‘gold standard’ has traditionally been randomised controlled trials, systematic reviews and meta-analysis. However, this begs the question, is there a place for service users’ knowledge in systems where evidence-based practise is considered most significant. Participants in this study called for their contributions to be acknowledged and valued as they bring what they perceived is lacking in academia. They sought collaboration and equity in knowledge as they recognised that what they bring to the learning space is of equal value which enhances education. In line with this view, Glasby & Beresford’s (2002) paper critically appraised evidence-based practise and highlighted the dilemma that arises when credence is predominantly given to only one form of knowledge, which results in other equally important ways of understanding the world being disregarded. It was not to denigrate ‘gold standard’ forms of knowledge but they questioned who defines what knowledge is. They also stated that there should be space for clinical expertise, tacit knowledge (Collins, 2000) and service users’ and carers’ experiences (Lindow, 1999) in the alternate approach they proposed, termed ‘knowledge-based practice’.

The author is not advocating for one form of knowledge to be prioritised over the next but identifies the importance of opening up the space for dialogue regarding other forms of knowledge that may be able to inform academia and service development as outlined by policies. One wonders if there is space for more balance, verses lived experience knowledge being pitted against evidence-based practice. It may be possible for both to exist and be equally beneficial in their own rights especially when it is predicated on what we seek to know. Acknowledging the value of lived experience knowledge does not mean that other forms of knowledge lose their importance, what is merely being considered is an acknowledgment of the value lived experience knowledge brings to the learning space. As lived experience knowledge can help to create a more comprehensive understanding of what works well in service delivery and within academia (Townsend et al., 2008).

When speaking about their overall involvement journeys, participants described involvement as a positive experience that ignited their passion. This is consistent with the existing literature as studies have found that a large proportion of service users and carers involved in health and social care education express that their involvement was a beneficial experience that they enjoyed (Flood et al., 2018; Humphreys, 2005; McIntosh, 2018, Skilton, 2010). The findings in this study also closely align with the literature review conducted by Repper and Breeze (2007) that found that the responses were overwhelmingly positive when investigating service user and carer involvement in the training and education of health professionals. However, Rhodes (2012) revealed that researchers' positive outcomes might be biased as they start from a position where service user and carer involvement is seen as fundamentally beneficial. Consequently, they are more likely to find involvement as having a positive impact. It has therefore been proposed that a more balanced assessment is required to reveal the true nature of involvement in education.

Service users and carers shared the transformational nature of their involvement as they described learning new skills that they were also able to transfer to other aspects of their lives. They expressed gaining increased self-confidence, improved mental health, belief in their ability to be involved which are also referred to in Zimmerman's (1995) model as intrapersonal and interactional components of empowerment. These benefits enabled service users and carers to gain confidence in their ability to see themselves as agents of change. This is also supported by broader literature in the area that outline several idiosyncratic gains (O' Reilly et al., 2012) such as increased self-esteem (Keenan & Hodgson, 2014; Masters et al., 2002) and involvement providing respected social roles (Hanson & Mitchell, 2001).

However, as outlined in this study's findings, service users and carers were often involved in sharing their lived experiences. Therefore, if involvement was in all aspects of academia, this could also facilitate the development of new skills as service users and carers are then given the opportunity to develop a variation of skills and gain further confidence in their ability to affect real change within the system and in their lives. This describes the interactional component of empowerment as defined by Zimmerman, 1995:

> These skills may be developed in settings where participants have opportunities to become involved in decision making, or inhibited in settings where participation is not an option. It is these skills that help individuals

> become independent, enable them to control events in their lives, and lead them to become their own best advocates. (p. 589)

Service users and carers in this study also expressed a sense of togetherness and solidarity in their involvement which gave them the ability to press forward in their collective agency (Kieffer, 1984). Hyman (2007) conceived the term ‘insurgent’ social capital, which describes the rich social network of unity developed to accomplish societal change. Looking closer at the relationships developed in involvement, existing research revealed that respectable and mutual relationships are required in order for involvement to be meaningful (Hitchen et al., 2011). The relational dimension of Christens (2012) PE model is particularly relevant to this study’s findings. This component defines the sense of empowerment participants developed through their confidence and relationships within a group, which service users and carers also expressed in this study. They shared the collaborative elements of involvement, the importance of the relationships developed with other SURG members and academic staff. This for service users and carers resulted in feelings of mutually fulfilling connectedness and belonging due to their shared beliefs and their work towards a collective vision (McMillan & Chavis, 1986). As stated in the findings, the relationships developed with some academic staff and SURG members was one of care, support, and respect, which participants highlighted was a crucial aspect of their experiences as they gained resources and benefits from their interactions. This highlights the level of empowerment realised through relationships and collective efficacy with others (Jex & Bliese, 1999).

More pointedly and novel to this research was participants’ wish to draw attention to the sense of value they felt as a result of the renumeration they were offered at the institution. This shed light on the importance participants placed on the money being offered, which in part pertains to the direct financial assistance and the independence this afforded some but also in part to the recognition of worth participants perceived institutions placed on their involvement. This for participants bolstered their involvement experience.

Over the years, service user organisations have made explicit the importance of service users and carers being paid for their contributions. However, the Social Care

Institute of Excellence (2004) described that there is no clear guidance on how much individuals should be paid, how they are paid (gift vouchers, cash, payments 'in kind') and what they are paid for (lectures, attending meetings, travel or expenses) which leads to a variation in payments across institutions. However, in April 2021 the National Institute for Health Research (NIHR) published guidance for payments in involvement. It must also be acknowledged that some service users and carers do not wish to receive any financial benefits for their contributions.

Furthermore, the literature shows that financial payment for involvement is often an emotive and complex issue that impacts individuals in very different ways (Townend et al., 2008). As a result, matters pertaining to payment must be handled with care as each service user and carer must be aware of payments and its impact on their personal circumstances. This is in order to ensure the decisions made adequately meets their financial circumstances. (Boaz et al., 2011). What must also be noted is that on the one hand, the funding available to pay participants may restrict the amount and extent to which service users and carers are involved within the academic institution. On the other hand, the level to which participants want to be involved at the university may impact the budget that is needed to bring this to fruition.

Often research studies exploring involvement in education do not discuss renumeration, let alone participants' views on it. This was also found to be the case in Repper and Breeze's, (2007) literature review that explored user and carer involvement in the training and education of health professionals. The review found that only five studies out of the 38 studies included in their review outlined how service users and carers had been renumerated for their involvement. This may speak to the variation of payment methods that makes it challenging to fully understand. However, what this study shows it that despite the processes of payment not being clearly defined, participants experienced the financial reward offered as an acknowledgement of value. Even though not all participants took up the payment. Looking at the involvement journey theme against the dimensions set out in Zimmerman's (1995) model and Christens (2012) augmentation of the model, the findings of this study support all four dimensions of PE. Participants in this study stated their involvement increased their sense of self, and through the sharing of their lived experiences, there was perceived control over what they shared with students. In addition to service users' and carers' identity, the findings also highlighted the transformational nature of involvement that improved their self-confidence, self-efficacy and skills developed. Service users' and carers' identity and transformation of self are essential components of intrapersonal empowerment (Zimmerman, 1995). Service user and carer involvement in health and social care education also demonstrates the behavioural dimension of PE as service users and carers take action to make changes to their environment and challenge the status quo (Christens, 2012).

2. MANAGING PROCESSES OF INVOLVEMENT: SYSTEMIC DISTORTION OF EQUALITY

The theme managing processes of involvement: systemic distortion of equality was striking within participants' narratives. To better understand this, it may be helpful to summarise the shift in service users and carers positioning over the years. Historically, service users and carers have been in positions where they have felt devalued, have little to no say in the services and support they receive (Lea et al., 2016) and have been reliant on professionals that are seen as the experts. However, over the last two decades and through the introduction of policies and legislations that recognise how central service users and carers are in the design, delivery and evaluation of services (Edwards, 2003; Hatton, 2017) a shift has emerged. Given the history, it is of equal importance to consider the power dynamic within the academic institutions before service users and carers can be successfully and meaningfully involved in education (Skilton, 2011).

Many institutions and governing bodies use the term partnership in service user and carer involvement in education (Edwards, 2003; Levin, 2004); however, this is often aspirational (Tew et al., 2004). As academic institutions have also traditionally privileged academic knowledge over lived experiences and re-enact the unhelpful inequalities, placing service users and carers once again in roles where they feel powerless (Hatton, 2017; Lathlean et al., 2006). The literature shows that, in reality, the equal distribution of power in decision-making is hard to attain (Crisp et al., 2006). Russel et al. (2009) claimed that the power of traditional structures outlined above create and maintain social inequalities. It is therefore hoped that such social structures can be challenge in order for service users and carers to have genuine change and be collaboratively engaged in academia. Thus, making the shift from academic staff positioned as experts to service users and carers similarly having the power and influence as they work alongside their academic colleagues as experts in their own right. Service users and carers can then be instrumental in coming up with a solution to issues they face as a community (Zimmerman, 2000) and effect genuine systematic change. However, service users' and carers' experiences in this study indicated that involvement at the institution is not yet on such a level. Participants expressed that their involvement did not always feel collaborative, their communication with staff at times was very poor and they had little to no power in decision-making processes. This is consistent with the interactional component of Zimmerman's (1995) model as participants expressed an understanding of the challenges that contributed to their feelings of powerlessness.

Power operates between all stakeholders to differing degrees. Foucault's (1972) work details how institutions, dominant discourses along with medical structures often hold the power. The emergence of involvement was a means of trying to challenge this. However, in alignment with participants' views, the literature also continues to question how much impact service users and carers possess in decision making processes (Brett et al., 2014; O'Shea et al., 2019). The power that participants refer to in this research is that which exists between service users, carers and academic staff. With service users seeking greater control in their involvement and decision-making processes. This aligns with Humphreys (2005) research findings that suggested that service users often wanted more power when involved in activities at institutions. The 10 service users and carers in this study described their experiences were primarily limited to teaching, student interviews and SURG meetings which was accompanied with a lack of influence in the decision-making processes. This level of involvement left some service users and carers feeling powerless, and as outlined by McEvoy et al. (2008), collaborative decision making is a fundamental aspect needed to advance involvement. Given that service user and carer involvement was established at the university over ten years ago, it raises several questions about how involvement can be progressed. It also hopes that this will provide an opportunity for the university to review its initiative.

The current research interestingly sheds light on where participants believed the power is held within academia. Some believed it remained with academic staff and others perceived that the hierarchical structures at the university meant that the power was located far higher up with the senior management. This suggests participants awareness of a hierarchical structure which they believe continues to place them at the bottom with little to no influence on making real change and having an impact on decision making within the organisation. What may need to be considered is what power is actually held by some of the other bodies as this may not entirely be in line with participants' perceptions and may require further examination.

A study by O'Shea et al. (2019) examined public and patient involvement in healthcare services and the findings mirror participants in this current study's experiences within education. The study found that power inequality was most prominent between service users and professionals but there was also discrepancy in power ownership between staff members dependant on the role they occupied as well as between service users. The research findings highlight the complexity of power that operates within the institution. They stated "what we see is an example of a hierarchy of power in which, predictably, professionals occupy positions at the top and public members at the bottom. However, we suggest this system has complex dimensions" (p.8). This shows that the differing power dynamics at play may possibly mean that different individuals within the academic institutions have differing degrees of power over decisions made. However, without this information this research project is unable to confirm if indeed the staff and the senior management team did in fact hold all of the power within the organisation as described by participants.

There are also other bodies that may need to be considered, an example being that given resources are allocated to the institution to carry out involvement, this may in fact signify that power is also held by structures other than senior managers and staff. However, as outlined in the introduction, when resources come from regulatory bodies, they do not stipulate how the funds should be used. It is also unknown if this is the case with other funding streams. What is beyond the scope of this research, given the focus has been on service users' and carers' perspectives, is a true understanding of the decision-making processes in place at the university. Thus it has not been possible to identify and come to understand the various other power structures at play that mean that staff and senior managers power and influence may in actual fact be curtailed as there are various sources of power operating within organisations.

It is also important to note that a lack of recognition for service users' and carers' contributions may result in them being brought in to fulfil specific aspects of academia as prescribed by the institution's agenda. This calls into question the one-dimensional way service users and carers-are often position by institutions. Hatton (2017) stated that if courses continue to enlist service users and carers to fill particular roles on an ad hoc basis, this may further continue to propagate involvement being tokenistic as the disparities remain. For involvement to be meaningful and anti-oppressive (Wilson & Beresford, 2000), as is often claimed, it is hoped that the institution would pay attention to these features of involvement with more done to address the infrastructures that perpetuate power inequalities that disadvantage service users and carers and maintains tokenism. The literature shows that institutions enlisting service users and carers to tick boxes that help meet their professional obligations on levels they feel most comfortable with, fail to take into account the true value and the needs of service users and carers they work with (Beresford & Boxall, 2013).

Along with processes that render service users and carers feeling powerless and like they are positioned on the periphery, participants in this study raised concerns about communication difficulties. Participants expressed that their communication with staff at times was very poor and this impacted their ability to engage with the SURG. This also reflects that even though service users are deemed as lived experience lecturers, they may not be firmly embedded within the organisational structure and thus, contact can be severed at any given time. This highlights the precarious nature of the relationship service users and carers have with the academic institution, which has the ability to perpetuate the power inequalities. This is also supported by the literature which highlights the difficulties experienced with the communication of information and opportunities which also hindered service users and carers involvement (Chamber & Hickey, 2012). This further preserves a gulf between service users and carers and their academic colleagues.

The findings show the importance of power inequalities being acknowledged as it is hoped that they will constantly be challenged when traditional hierarchical structures and processes that privilege some (whether that be staff that are often position as the helpers) and obstruct others (service users not feeling prioritised) are maintained. Such inequalities operating between and within groups of different stakeholders creates a ‘them and us’ divide. This then preserves the status quo and fails to promote genuine change where marginalised groups can use their voices to take social action and affect change (Christens, 2012) through the collective effort in providing and getting social support to achieve a goal. This has the potential to lead to involvement that is not predicated on partnership and collaboration, despite there being a drive towards true partnership between all stakeholders (McAndrew & Samociuk, 2003).

3. NEGOTIATING PRACTICES OF INVOLVEMENT: ONE SIZE DOES NOT FIT ALL

Whilst participants spoke about the involvement practices at the university, there was a strong sense that one size does not fit all. Participants reflected on how certain practices served as barriers to involvement and at the same time the identical practices were welcomed by others. This reflects the importance for institutions to ensure that participants’ individual needs are understood so adequate adjustments can be arranged. Participants in this study particularly raised concerns about accessibility issues, this was in reference not only to the building and campus but also accessing involvement material which made it more challenging for them to be involved in the capacity they wish to be. This aligns with various studies that have suggested that issues such as getting to and from sites (Stevens & Tanner, 2006) and difficulties moving around buildings (Branfield, 2009) that are not accessible to people with impairments or disabilities (Dzombic & Urbanc, 2008) impeded involvement. The literature also highlights service users and carers difficulties accessing involvement materials (Allain et al., 2006) and the use of jargon within institutions (Chamber & Hickey, 2012), which also hindered involvement. These barriers result in service users and carers becoming reliant on others to navigate the building, access materials as well as involvement activities, which has a detrimental effect on participants sense of autonomy.

Despite there being no previous literature exploring involvement in times of crisis, it can be seen in this study that some participants found the change amid such global chaos challenging to navigate on several levels, and others found that it opened up involvement opportunities. It is hoped that this study has begun to help us understand the importance of institutions making involvement activities more accessible to all. It has highlighted how traditional forms of involvement such as coming to the campus can be liberating for some and equally excludes others. It speaks to the damaging effects when individuality is not acknowledged as institutions press forward with their involvement agenda (Gallagher et al., 2012) using the 'one size fits all model'. This may lead to involvement being experienced as being on the organisation's terms and not adapting to meet individual's needs. This may also result in voices further marginalised because of the standard processes that serve as barriers. The findings also showed the institution's response to the global crisis which saw the university speedily reinstate online teaching and involvement was halted. This may be indicative of the universities teaching priorities and the inequality between theoretical and lived experience knowledge. However, such a claim could in itself be inaccurate as this study did not interview university staff as a means to understand their response to the pandemic.

4. MAINTAINING PROCESSES AND PRACTICES OF INVOLVEMENT: THE JOURNEY AHEAD

The recommendations for future involvement were the fourth significant findings. Participants explicitly described the actions required to effect change and progress the movement, which is representative of the behavioural component of PE Zimmerman (1995). Despite all participants being incredibly passionate about their involvement and contribution to academia, this theme discusses the critical areas that participants perceived needed improvement. Participants sought a cultural shift where service user and carer involvement would receive far more recognition and respect within academia. For some, this was moving from tokenism to collaboration and for others, there was a desire to have far more voices represented within involvement, so the disenfranchised are no longer marginalised within academia. Lastly, it was observed that all participants expressed a wish to be far more involved and integrated into the faculty than they currently were.

Service users and carers, in this study, believed there was a need for increased investment in involvement and highlighted how they perceived the movement had been hindered as a result of inadequate resources -time and finances (Mckeown, 2012). This is a bone of contention commonly discussed in the literature (Beresford, 2019; Gutteridge & Dobbins, 2010; Robinson & Webber, 2013; Stickley et al., 2009). Although-involvement is an increasingly central part of education as stipulated by government policies and course regulatory bodies, research has shown that fewer resources are available to support involvement initiatives (Beresford, 2019), as there are continued cuts to funding and resources. It must also be noted that the lobbying that advocated for service users' and carers' voices to be heard over the years never intended for it to be done under the guise of liberation whilst upholding traditional practices. This in no way challenges the inequalities or effects any real change. In line with Morgan and Jones's (2009) findings, it is thought that greater clarity on the impact of involvement within institutions is required. As it is believed that involvement that is not backed by adequate resources runs the risk of being merely grandiloquent as service users and carers continue to have subordinate roles in institutions.

Additionally, the full impact of Covid -19 is presently unknown, and it may further hinder finances and the allocation of resources within academia. The dilemma arises if institutions need to make decisions between theoretical knowledge and lived experience knowledge, as the structures in place that privilege theoretical knowledge may prevail and lead to further cuts to service user and carer involvement. As this is unknown and may not be known for months to come, further research will be required to understand how involvement is impacted.

A lack of adequate representation has plagued involvement for many years (Campbell, 1997; Forrest et al., 2000; Masters et al., 2002), and the issues were broached in several ways in this study. Firstly, it was found that participants felt there was a greater priority given to mental health over physical health issues within the SURG. This resulted in service users and carers with physical health needs feeling as though they needed to fight to be heard within the group, which does not foster collaboration but creates competition. These findings were echoed in Repper and Breeze's (2007) review, which found that in the 38 articles that met the inclusion criteria, all studies focused on mental health service and failed to represent other health issues.

Secondly, some service users felt that marginalised groups were not adequately involved at the university. Beresford (2013), in his beyond the usual suspects report, addressed the lack of representation in involvement and how such initiatives fail to hear the voices, views and opinions of service users from marginalised groups that in society are subjected to poor treatment and inequalities. The report posited, in addition to retaining and harnessing the expertise of service users and carers that are commonly heard from known as the ‘usual suspects’, there is also a need to build trusting relationships with marginalised groups as a means of hearing and understanding their experiences. This will ensure that involvement becomes far more diverse concerning age, gender, ethnicity, sexuality, beliefs and disability (William, 1989). Institutions may also need to not only examine groups with single axis disadvantages but they will also benefit from engaging groups that experience multiple disadvantages.

Lastly, participants expressed a wish to be more involved and further integrated at the university. It is interesting to note that the findings in this study highlight the variability in the involvement tasks and the ad hoc nature in which service users and carers are involved in health and social care education which aligns with Happell et al. (2015), Mc Cann et al. (2009), and Minogue et al.’s (2009) findings. In this study, most participants reported being involved in the quarterly SURG meetings and sharing their personal experiences in lectures or teaching, which appears somewhat limited in what SU can contribute. However, outside of that, there was no mention of service users and carers partaking in senior management strategic level tasks. Even though it is now mandated that service users and carers are involved in all aspects of the educational process, including on a senior management level as proposed by the Social Care Institute for Excellence (2004). Wilson and Beresford (2000) stated that academia should not limit service users and carers to only participating in aspects of the curriculum they are seen to be an authority in because of their lived experiences. There should be a drive for them to become involved on a strategic management level from an early stage (McPhail, 2008) so service users and carers are represented within decision-making processes. However, the literature shows this is yet to be the case at some institutions (Hatton, 2014) as service users and carers are most often involved in teaching.

For a shift to occur, Townend et al. (2008) expressed the importance of training, which participants did not speak about in this study. Training may enable service users and carers to acquire the skills to be involved in various stages and on different levels of academia (Beresford & Boxall, 2013; Gallagher et al., 2012). This would see service users and carers becoming familiar with institutional processes and procedures (Branfield, 2009; Rhodes & Nyawata, 2011). Involvement in areas where service users and carers have not had adequate training may be experienced as tokenistic and, equally, render them powerless. Due to the range of skills and life experiences service users and carers bring to education, training will need to be targeted to meet individual needs. Campbell and Lindow (1997) found it was unfeasible to involve service users and carers in all aspects of their study due to the differing levels of expertise within the group. Therefore, to ensure that all service users and carers have the appropriate knowledge, institutions may benefit from strategically incorporating training into their offerings to service users and carers. This may then enable involvement to move beyond teaching, student interviews, and attending SURG meetings to far wider-reaching activities within the department, which may be all-encompassing and less tokenistic if done suitably (Forrest et al., 2000; Happell et al., 2015; Simons et al., 2007). This may also result in more consistent and embedded involvement. This elucidates the importance of training as a fundamental element that will progress the movement as it will enable the above to be achieved and for involvement to be meaningful and beneficial. However, what support and training looks like may differ across universities and must reflect all stakeholders' needs.

STUDY LIMITATIONS

In acknowledging the study's findings, it is essential to note that the study is not without methodological issues that must be considered when interpreting the results. The findings are locality-specific and only represent the 10 participants' viewpoints on their involvement at one UK HEI. Even though participants had years of experience across various organisations and institutions, this study aimed to better understand participants' involvement within an educational context. As the study was conducted in a single UK university, transferability of the study findings to international contexts may not be possible as various factors in operation within this institution may not be replicated elsewhere.

Small sample size is a feature of qualitative methodologies. A thematic analysis was the qualitative approach employed as it best answered the research questions. This was advantageous as it enabled a rich and in-depth examination of participants' experiences (Braun & Clarke, 2006). However, as a qualitative exploratory study, it is not intended to be generalisable (O'Reilly et al., 2012) and, therefore, it is recognised that the themes that emerged in the findings cannot be used to draw inferences about other services users and carers involved in education. Furthermore, the results are biased due to the opportunity sampling method that was used to recruit participants. It cannot be said that the participants are representative of the wider SURG but probing questions enabled a more comprehensive inquiry into participants' experiences. These participants' perspectives represent only a subsection of the SURG members involved at the university. Despite the research opportunity being sent to the entire network of SURG members, the researcher was only able to recruit via SURG meetings held quarterly at the university. Consequently, these findings are limited to participants who have contact with the university and other service users and carers at the quarterly meetings. What was not captured were the experiences of service users and carers that do not attend meetings but choose to engage with the university only through specific activities emailed out to them. How such members experience involvement is unknown, and their sense of power, empowerment, powerlessness and the recommendations proposed may differ significantly.

It must also be noted that all participants were White British, and a vast majority were male aged between 50 and 82 years old. As outlined by Henrich et al. (2010) "Western, Educated, Industrialized, Rich and Democratic" (WEIRD) societies is the sample often used within empirical research that perpetuates the idea that this is the only viewpoint of significance. Such societies are not representative of all populations. Other groups that are also marginalised in mainstream services due to various protected characteristics are similarly underrepresented in service user and carer involvement (Carr, 2004). Therefore, to advance the knowledge, further research that incorporates non-western viewpoints and the voices of other disenfranchised groups is required.

Looking more specifically at ethnic minorities and the literature that shows an over-representation of certain ethnic groups in specific mental health services (Berzins et al., 2018), it seems problematic that such voices are underrepresented in involvement. In addition to ethnic minorities' voices not being represented in these findings, there is also an underrepresentation of females, young people, physical health needs and carers. The researcher also made several attempts to engage younger members of the SURG and more carers. However, this did not prove successful when information about the project was sent out to all members as participants did not respond. It raises questions such as how can disenfranchised groups be more involved? If they are not represented through involvement initiatives and the literature, how can we ensure that students have a comprehensive understanding of specific issues related to particular groups before they embark on their clinical work? Do such cohorts feel a sense of empowerment, or is that not their experience at all? This study has not addressed these questions and, due to time constraints, also failed to capture a diverse range of voices in addition to the valuable voices heard. This highlights there may be institutional and structural forces in operation that are barriers to involvement, and therefore, involvement itself is not equitable as there are groups of people left out. This in no way seeks to disregard the important voices represented in this study, but it highlights the voices omitted from conversations which institutions and researchers should work to address.

It must also be acknowledged that it was initially anticipated that there would be a minimum of 16 interviews conducted, to represent equal numbers of service users and carers so that similarities and differences in their experiences could be explored. A factor that hindered recruitment was the pandemic, as it impacted service users and carers participating in a study amid a global crisis that had people worried for themselves and others. This resulted in only one interview with a carer which further restricts the transferability of this study. The carers view in this study was not divergent from the service users' and carers' views; however, data from an individual case was not enough to look at the similarities and differences between both service users and carers. It was also initially arranged for the researcher to attend SURG meetings in-person to connect with SURG members and share information about the research project. At the time recruitment began, the SURG meetings had just moved online due to the national lockdown. This then resulted in a reduced number of SURG members attending meetings due to several different reasons that the researcher could not explore thoroughly.

As initially intended, participants were offered a range of interview options (face to face, telephone or internet-based communication methods) to make the research opportunity accessible to all, increase recruitment and address the barriers to partaking in research studies. Face-to-face interviews for many years have been the dominant approach used as it is deemed to enhance the development of rapport in qualitative interviewing (Gillham, 2005; McCoyd & Kerson, 2006) as visual cues convey greater meaning. Some participants requested face-to-face interviews, which was not possible due to Covid - 19 and time restrictions. These interviews were forfeited as all interviews had to be conducted either over zoom or the telephone. There has been an increasing use of internet-based communication methods to broaden data collection strategies in more recent years. Kings and Horrocks (2010) stated that such methods should be used with caution as technical issues that interfere with video and sound quality can be experienced. In this study, nine interviews were conducted via zoom, and the remaining interview was over the phone, as requested by the participant. Technical glitches occurred in two of the zoom interviews, which the researcher managed by asking the participants to repeat their responses. This did not appear to be too onerous for participants as there was a shared sense that everyone was trying to adjust to life over zoom in response to the pandemic. However, the researcher provided options of rescheduling interviews or moving to the telephone if required; both participants were happy to continue with their interviews.

As this research on empowerment centres on service users and carers perceived sense of control, it fails to capture if service users and carers, in reality, have the power or authority to make decisions within the academic institution. As this study does not focus on the perspectives of other stakeholders such as the senior management team, SURG facilitators, faculty staff and strategic leaders within the institutions, it is therefore impossible to determine this fact. However, this can be an area of further research that explores power distribution, collaboration and partnership within academia.

STRENGTHS OF STUDY

Despite the study being conducted during a global pandemic and the methodological limitations, it is still believed that the findings make a significant contribution, as it sought to gain a more nuanced understanding of service users' and carers' experiences in health and social care education. More specifically, the processes and practices within the HEI that leave service users and carers feeling empowered or powerless. Additionally, it elucidated gaps within involvement, and recommendations are offered to progress such initiatives. This study aims to stimulate further dialogue and debate about the notion of involvement in itself as empowering. It scrutinises the lack of focus on how power operates within HEI that uphold inequalities and the cultures that promote hegemonic agendas under the guise of empowerment, involvement and liberation. The mere involvement of service users and carers in academia can itself obscure the power inequalities. This is not to say that this is present in all institutions to the same degree, but the dialogue about such essential issues can improve practices or foster continual good practice. Involvement requires constant attention to ensure it is beneficial and meaningful to all stakeholders.

Power operates on each level and in all aspects of pedagogy. However, the impact of this is rarely dissected and understood from the service users' and carers' perspectives. This study has initiated the conversation about structures that perpetuate the power divide that result in tokenism, which should by no means be the intended outcome of service user and carer involvement in academia. In addition, this study adds to the scarcity of research that looks at empowerment and powerlessness within involvement in health and social care education. The findings will help to facilitate such conversations and more importantly challenge the power structures and procedures in place that seek to empower but inadvertently disempower service users and carers.

The study has engaged with individuals marginalised because of their physical and mental health needs. It is of great importance that marginalised groups are given the space so that their voices can continue to be heard and represented in the literature. A vast majority of the literature seeks to understand involvement from students' and staff members' perspectives rather than from service users and carers themselves.

Hearing directly from service users and carers can improve involvement from its inception and challenge the structures that on the surface seek to engage with them but further marginalise them within complex and dynamic institutions. Understanding such complexities will help move involvement into realms of collaboration and partnership where service users and carers can effect real change in all aspects of academia as outlined by Tew et al. (2004), helping to change the landscape of service user and carer involvement in HEIs thus creating a safe space.

The researcher worked closely with a service user consultant to think together about the questions used in this study. This was an essential aspect of the study; however, it did not go far enough to work collaboratively with the consultant from the inception of the research due to time constraints. Also, carers views were not present at this point. This can be expanded upon in future research.

FURTHER RESEARCH

Empirical evidence exploring involvement in health and social care education from the service users' perspective is somewhat limited, with far less research that focuses solely on carers' experiences. Unfortunately, in this study, it was not possible to make the carers' views explicit in order to maintain anonymity. As with the findings from the literature review in chapter one, studies often conceptualise service users and carers as homogeneous without clear distinctions between the two groups, which is a concern that would need to be further examined (Manthorpe, 2000). This failing means that carers' voices, even though they may be similar in some instances to SU, are not adequately represented in the literature. As with SU, carers are not a homogenous group, and assumptions cannot be made about their experiences of power, sense of empowerment, powerlessness and the impact of their involvement as educators. Therefore, to better understand their needs, research looking specifically at carers' experiences within academia is recommended. Thus, creating a more robust evidence-based approach to carer involvement (Robinson & Webber, 2012).

As a means of fully honouring service users' and carers' voices, a study can be conducted that delves deeper into their experiences using reflexive and participatory methods (Alvesson & Sköldberg, 2017; Reason & Bradbury, 2000). Participatory Action Research (PAR) methodology promotes empowering processes (Chesler, 199) and tackles power inequalities in research. Despite its best intentions, PAR must be conducted with care as Christens and Speer (2006) pointed out their concern that participatory methods advocate use terms such as empowerment. However, at times there is little to no evidence to support this in their work. It would be important that if such research is conducted, outcomes are effectively monitored to establish if it is indeed empowering for all stakeholders involved.

Another potential avenue for future research is using a longitudinal approach that is often recommended with involvement in HEI to measure the impact on students' post-qualification. However, as it is also unknown what service users' and carers' experiences are over time, it may be beneficial for a longitudinal controlled study to be conducted that evaluates the longer-term impact of involvement (Robinson, 2012). This would help evidence the success of involvement practices in HEI and if this is sustained over time. As with this study, participants have been involved with various institutions and organisations in different capacities over many years. Thus, a longitudinal study would further examine the factors at play that further impact service user and carer involvement over a prolonged period.

CLINICAL IMPLICATIONS

The involvement of service users and carers in academia is a challenging process that requires vigilance to ensure its success. It is complex, and despite empowerment being often uttered, power issues are difficult to think about and are often omitted from involvement conversations and practices. However, it is vital that it is brought to the fore and grappled with as it is constantly in operation and must be challenged for involvement to be genuinely meaningful. The findings suggested in this research are not proposed as an exhaustive or conclusive discussion, it is being proposed as aspects of involvement that can be taken into consideration within the educational milieu. It is also important to note that given the exploratory nature of this study, the following recommendations are tentative.

Overall, this study elucidates aspects of involvement that service users and carers experienced as empowering and some of the antiquated and outdated structural inequalities and physical barriers that perpetuate powerlessness within academia. Recommendations for progressing the involvement movement were also described by participants. It is hoped that the findings of this study can be used to inform involvement initiatives in education across various disciplines, practices within institutions, and policy. It is not intended for these findings to perpetuate tokenism; instead, it continues to advocate for collaborative involvement where institutions work to understand the individual needs of service users and carers to create initiatives that are accessible and worthwhile for all.

The findings contribute to the debate of empowerment within service user and carer involvement and seeks to encourage institutions to scrutinise their involvement initiatives and acknowledge and seek to change practices that maintain power inequalities that further disadvantage service users and carers. Even though the study's findings do not give us an entire picture, it does contribute knowledge to the debate and existing literature. It highlights critical aspects of involvement that service users and carers experience as empowering, which is in line with the PE model theorised by Zimmerman (1995) and augmented by Christens (2012). It is therefore hoped that these aspects can be shared as best practice with other institutions. It also highlights gaps and aspects of involvement that may need to be thought about at this university and beyond. This knowledge can inform procedures and guidelines that institutions create. Co-creating this with service users and carers will ensure that all stakeholders' voices are firmly embedded (Repper & Breeze, 2007).

Thinking more specifically at the direct implications for service users and carers, these findings can be utilised to explore what they wish to get out of their involvement and inadequate practices can be challenged when their involvement is being experienced as tokenistic. Through the use of the present findings, models and theories outlined in chapter 1, service users and carers can use such additional information to examine the current status of their involvement and where they aspire to be. The accompanying actions required to achieve desired outcomes can then be developed as a roadmap with other stakeholders and regularly evaluated to hold institutions accountable and ensure that initiatives meet all individuals' needs. This study can contribute to the development and implementation of accountability mechanisms within HEI that can detect issues and barriers to involvement, highlighting ways to deal with such issues promptly. Systems that track the outcomes and experiences of all stakeholders should also be a standard component of involvement (Repper & Breeze, 2007).

What must also be noted are the valuable recommendations suggested by participants that can be considered when seeking to improve processes and ensure involvement is inclusive and beneficial to all stakeholders. In addition to service users and carers seeking their expertise to be utilised more at the institution, as they believed they contributed a wide range of skills and knowledge to academia, there was also recognition that more diversity in the voices heard was required. Therefore, what may be required by the institution is active engagement strategies to connect with the community, other service users and carers organisations and joint working across institutions to allow for a broader range of voices to be understood and involved.

The study also suggests areas of contention that need to be addressed within HEIs. As the challenges are context dependant and differ from one individual to the next, structures that effectively support involvement initiatives can be co-created. Institutions may therefore benefit from conducting a needs assessment followed by strategic action plans with service users and carers that guide their initiatives. These study findings can also inform such practices as at present regulatory bodies such as the HCPC merely stipulate institutions must evidence service user and carer involvement in their courses without guiding how this should be done. This lack of advice has led to sporadic involvement of varying quality across institutions. This study is not advocating for rigid guidelines, as there is an understanding that empowering and meaningful involvement will be locality specific. However, it seeks progressive change where institutions are held accountable in policies for their quality of involvement. This will require far more work on a policy level to ensure that involvement promotes social inclusion and change (Hatton, 2012).

When thinking about the implications for clinical psychology training programmes, programmes may benefit from creating opportunities for service users and carers to be firmly embedded within all aspects of clinical training to address the ‘them us divide’ that was described by participants. It is hoped that this will place service users and carers in varied positions where they feel they influence decisions made and have continued valued input on the courses. What this looks like on each course can be collaboratively created. It is also imperative that honest discussions concerning the issues around power differentials, empowerment and powerlessness are constantly addressed. In addition, service users' and carers' experiences within the academic institution and their individual need should also be part of continued conversations, as it is evident that an individualist and tailored approach is going to be required. This will enable courses to recognise the progress that has been made, along with the changes that need to be made.

Within the climate of evidence-based practice being a core component in Higher Education as well as the findings highlighting the continuous tussle between lived experience knowledge and evidence-based knowledge, clinical programmes may benefit from developing ways of evaluating involvement as well as its impact. This may help to continue to investigate the importance and value that lived experience knowledge also brings to academia.

There may also be scope within the staffing teams remits to make adjustments that take into consideration the findings of this study as they seek to support service users and carers involved. It is hoped that the barriers outlined in these findings can be addressed whether it's maintaining open dialog to manage the ruptures in communication, the way in which service users and carers are asked to be involved in clinical training and what involvement looks like instead of involvement initiatives perpetuating the power inequalities. What is unknown is if staff equally feel they are restricted in how they involve service users and carers in their programmes or if they are given the freedom to incorporate involvement into their courses as they wish. These questions are beyond the scope of this research and will require further examination as information from all stakeholders will be required to progress involvement initiatives in training programmes.

PERSONAL REFLECTIONS

Embarking on this research journey has been challenging, but I have equally learned a tremendous amount from conducting this research as SU involvement has been close to my heart for many years. To provide some context, before getting on to clinical training, I worked as a service user involvement lead that worked alongside young people to co-produce a health and wellbeing hub. In this role, I was faced with the complexities of involvement and the difficulties in negotiating competing agendas. In addition, the influence of power inequalities often seeped into and was replicated within the project, which at times threatened the ethos of young people being placed at the heart of the project as collaborators. Through my work, I have developed a strong affiliation with co-production as a critical principle that connects to my values of respecting people's voices, honouring their contributions and learning from their experiences.

When I started clinical training, I chose to immerse myself in this research area to honour participants' experiences and use it to contribute to the knowledge base. However, I was a little apprehensive and thought long and hard about the appropriateness of engaging in this research. I was mindful that I did not want my previous involvement work and, on a more personal level, my experiences of power and marginalisation as a Black African female to taint this project and skew the findings in any one way. I was clear I did not want to stray away from participants' voices, which for me goes against my entire ethos. When I decided to go ahead with the study, I engaged in conversations about my apprehensions to gain some clarity on how to move forward. Also, during interviews, I monitored my responses to participants' experiences to stay closely aligned to what they shared, as I did not want to drive the interviews in any one direction. I was keen to ensure I accurately conveyed participants' experiences as it was vital for me to do justice to their stories. Initially, I found this challenging, but as interviews progressed and through my reflexive diary and talking through any concerns with my supervisors, this became easier to manage during interviews and when synthesising the data and writing.

Prior to conducting my interviews, I was conscious of how the different facets of my identity as a researcher and doctoral student may impact this research as I would occupy different positions in participants' minds. I had initially considered my position as a student and wondered if this aspect of my role may result in participants focusing on their lived experiences of services versus their involvement experience as this is the role they often occupy in the institution when meeting students. This worked out really well in the interviews as I was keen to hear everything participants wanted to share with me and provided the space for this to happen. I found that their lived experiences aided my understanding of their involvement, and as participants stated, their identities and experiences are intertwined and added a richness to the study.

Nevertheless, what I did not consider from the outset was the additional layer of being an employee of the local NHS Trust. I never envisaged; this would impact my research. For many participants, they had received care from the very same Trust, and this had not always been a pleasant experience. This also in some peoples' minds, may have placed me in a position of power and made me the face of the Trust. I quickly found that my dual role as a doctorate student at the university whilst also being employed by the Trust put me in a precarious position. From one experience, a SU had contacted me early on to express an interest in participating in the study. When my affiliation with the Trust became apparent, she was reluctant to participate in the interview as I was seen as part of the institution that had perpetuated harm she experienced. To navigate this, I had to situate myself and the research so that the participant was clear that the research was not with the Trust, but I was still a doctorate student, and my research was a fulfilment of my doctorate. Despite this being resolved during a pre-interview discussion, unfortunately, I could not conduct this interview due to other constraints. This is a clear illustration of how power affected my recruitment. I am also left wondering how this played out with other participants. It was not explicitly discussed, even though a space was allocated before and after interviews to discuss any pertinent issues.

I found myself being very conscious of occupying a position of power within my interviews which in my mind was also linked to my role as a Trainee Clinical Psychologist. I was watchful that my interviews did not feel like therapy sessions which may have impacted what participants shared. I found myself working hard to take up the position as a researcher as I sought to gain a nuanced understanding of the perspectives shared. As I engaged with my research, I realised how privileged I was to hear my participants' stories. I was mindful that there was a lot to contend with during this study, as the impact of the pandemic was devastating and anxiety-provoking, which could have thrown this project entirely off course; I was therefore honoured participants were willing to share their stories with me and greatly respected the service user consultant that worked with me to make this project happen. Participants conveyed a deep passion for creating change within academia despite all of the pain and struggles some had experienced by not receiving adequate care when they required it. I was struck by the multitude of feelings the interviews left me with following participants open and sincere accounts of their experiences. I was equally struck by the lack of representation in my sample, as despite my efforts I too had failed to capture voices seldomly represented in the literature.

CONCLUSION

This study gained insights into how service users and carers experience involvement in health and social care education. It elucidated their experience of power and how they perceived it operates within academia. Lastly, the way in which participants felt involvement initiatives could be progressed were also explained. The data obtained through semi-structured interviews were analysed using thematic analysis and revealed 4 themes: The involvement journey, managing processes of involvement: systemic distortion of equality, negotiating practices of involvement: one size does not fit all and maintaining processes and practices of involvement: the journey ahead.

Service users and carers expressed that their involvement experience was positive. They were passionate about their involvement and spoke highly about the meaningful contributions they made to future health care professionals. Service users and carers also expressed how they felt a sense of empowerment through their lived experiences and professional and educational identities. In addition, they reported outcomes such as an increased sense of confidence and self-efficacy and placed significance on the relationships they developed that enabled their fight for social justice. Participants also spoke about the sense of value they felt through the renumeration they received from the institution. It is hoped that such experiences can be shared and help guide the formation of involvement initiatives within academia that observe fairer and supportive institutional arrangements.

On the contrary, service users and carers also shared the processes they experienced at the university that left them feeling powerless. As educational institutions are hierarchical environments, involvement cannot be devoid of power relations. Ignoring such entrenched structures reinforce power inequities, especially in instances where service users and carers feel they have little to no influence or autonomy to create change. There was a sense that people in positions of power did not wish to have service users and carers involved in decision-making as participants cited a lack of influence in such processes. In addition, service users and carers expressed that poor communication experienced also hindered the flow of important information and impeded their involvement. Participants also highlighted the physical barriers faced in accessing and navigating the building and resources. Conducted during a global health crisis, the impact of Covid-19 was present in all service users' and carers' narratives. Service users and carers responses emphasised the challenges some faced in adjusting to remote involvement, but the findings also revealed that the move online served to open up involvement for some service users and carers to maintain their independence whilst engaging with the university. As shown in this study, there is also a sense that the 'one size fits all' approach at times adopted by HEIs left certain service users and carers further marginalised as it made some involvement activities inaccessible. When such practices are continually embraced, valuable perspectives are left out of the conversation. For the participants in this study, these factors rendered them powerless as they felt they remained on the periphery of the institution and this hindered them from taking up a collaborative role with their academic colleagues.

Service users and carers were explicit about their recommendations for future involvement. They felt there was a need for increased investment and resources to ensure involvement is adequately resourced. Additionally, all service users and carers also cited that they wanted to be far more involved at the university, less on an ad hoc basis where they fulfil prescribed roles, but more collaborative involvement in all aspects of academia. Service users and carers representation on all levels will ensure that their experiences are used to shape processes throughout pedagogical practices. A commitment to such a pledge will require a culture change so that service users and carers are not seen as superfluous to academia but lived experience becomes a solid knowledge base within pedagogy. The findings also highlighted that service users and carers felt it essential that more diverse voices are involved in education. Students can then have an understanding of the issues prevalent within specific communities. Institutions may benefit from examining the barriers that hinder certain groups from engaging as involvement can then be more inclusive.

This study highlights that the discussion about involvement cannot be parochial as it is a complex process that requires acknowledging power inequalities that traditionally exist within services and academia. There is a pressing moral imperative to move involvement from rhetoric toward co-production and partnership working where all key stakeholders are valued as essential and equal contributors to knowledge. It must be a collective effort, and ancillary work will be required to ensure that traditional processes that uphold problematic ideologies are challenged and eradicated. This will endeavour to abolish the elitist claims to knowledge and instead negotiate and create constructive alliances. Abolition may seem a little grandiose and unattainable at present, but knowledge of such privileging can be challenged, and actions taken to address them. Additionally, this desire for a cultural change cannot be located within pockets of academic staff. Instead, it must be reflected in all aspects of educational processes so that the hegemonic normative structures can be contested and involvement firmly embedded in all aspects of pedagogical practices. This will avoid inconsistent involvement that runs the risk of being tokenism, consultation or manipulation.

This study has highlighted that there are aspects of involvement that are being experienced as beneficial and empowering. However, this study also reinforces the need for involvement within academia to have processes and procedures that have evaluative and accountability mechanisms built in as a critical aspect of initiatives. This will enable good practice to continue to be replicated and contradicting processes to be tackled. Service users and carers will also have the ability to share their experience and hold the powerholders to account. Thus, creating new standards of involvement based on more equal distribution of power.

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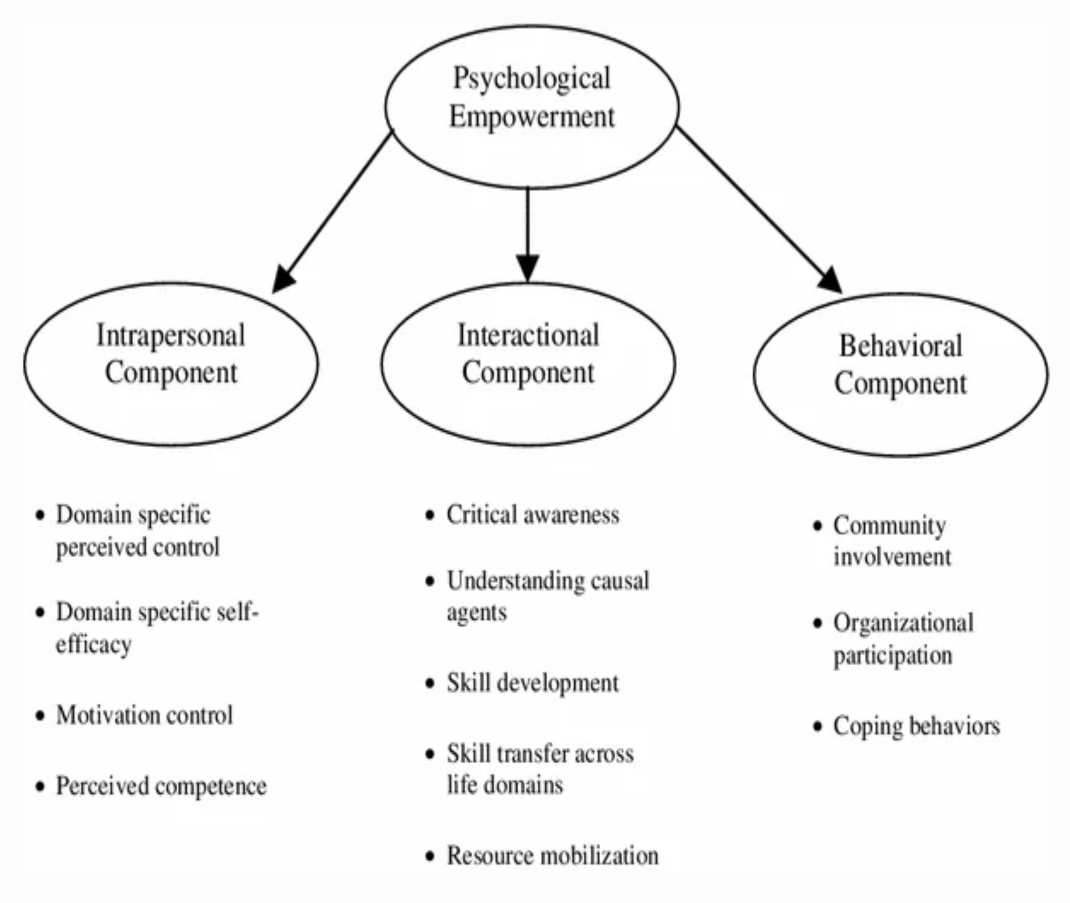
APPENDICES

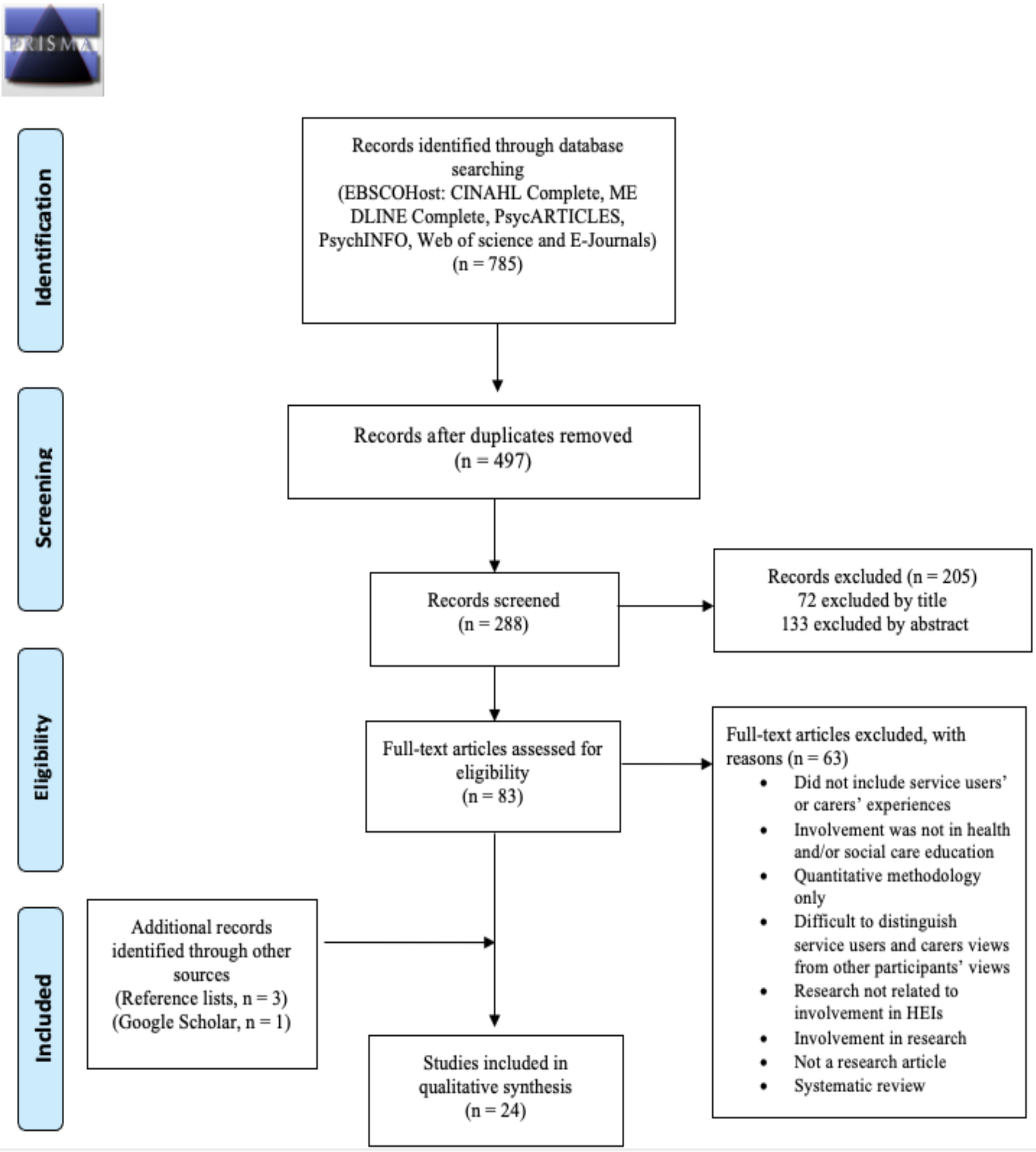
APPENDIX A: ZIMMERMAN (1995) NOMOLOGICAL MODEL OF PSYCHOLOGICAL EMPOWERMENT



APPENDIX B: LITERATURE REVIEW SEARCH STRATEGY

1	service user* OR patient* OR consumer* OR client* user* OR carer* OR family*	Title field
2	involve* OR engage* OR participat* OR inclusion OR collaboration* OR partnership*	Title field
3	educa* OR train* OR curriculum* OR teach* OR learn* OR course* OR module* OR consult* OR user led OR co-produc*	Title field
4	nurse* OR social work* OR health OR health and social care OR higher education OR physiotherapy OR psychology OR mental health OR medicine* OR physical health	Text field
5	qualitative OR focus group* OR qualitative study* OR qualitative research OR questionnaire* OR survey* OR interview* OR focus group	Text field
6	1 AND 2 AND 3 AND 4 AND 5	

APPENDIX C: PRISMA DIAGRAM



APPENDIX D: QUALITY APPRAISAL OF ARTICLES INCLUDED IN THE THEMATIC SYNTHESIS (CASP, 2018)

				Quality	Appraisal	Criteria				
Article	Was there a clear statement of the aims of the research	Is a qualitative methodology appropriate?	Was the research design appropriate to address the aims of the research	Was the recruitment strategy appropriate to the aim of the research?	Was the data collected in a way that addressed the research issue?	Has the relationship between researcher and participants been adequately considered?	Have ethical issues been taken into consideration?	Was the data analysis sufficiently rigorous?	Is there a clear statement of findings?	How valuable is the research?
Anghel and Ramon (2009)	✓	✓	✓	✗	✓	✗	Can't tell	✗	✓	✓
Campbell and Wilson (2017)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Cooper and Spencer – Dawe (2006)	✓	✓	✓	✓	✓	✗	Can't tell	✓	✓	✓
Curran et al. (2015)	✓	✓	✓	Can't tell	✓	✗	Can't tell	✗	✓	✓
Dzombic and Urbanc (2008)	✓	✓	✓	✓	✓	✗	✗	✓	✓	✓
Flood et al. (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Happell et al. (2017)	✓	✓	✓	✓	✓	✗	✓	Can't tell	✓	✓
Heaslip et al. (2018)	✓	✓	✓	✓	✓	Can't tell	✓	✓	✓	✓

Keenan and Hodgson (2013)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Lea et al. (2016)	✓	✓	✓	✗	✓	✓	✓	can't tell	✓	✓
Masters et al. (2002)	✓	✓	✓	✓	✓	✓	Can't tell	✗	✓	✓
Matka et al. (2010)	✓	✓	✓	✗	✓	Can't tell	✓	Can't tell	✓	✓
McGarry and Thom (2004)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
McIntosh (2018)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Mckeown et al. (2011)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Meehan and Glover (2007)	✓	✓	✓	✓	✓	✗	Can't tell	✗	✓	✓
O’Reilly et al. (2012)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Rees et al. (2007)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Rooney and Unwin (2020)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Rooney et al. (2016)	✓	✓	✓	Can't tell	✓	✗	✓	✓	✓	✓
Schon (2016)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Shah et al. (2005)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Thomson and Hilton (2012)	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓

Webber and Robinson (2012)	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓

APPENDIX E: SUMMARY OF LITERATURE REVIEW PAPERS

Author and date	Country	Sample size and characteristics	Study aims	Study design and data collection	Data Analysis	Findings
McIntosh (2018)	UK.	* Carers = 5 * Females = 5	An evaluation of family carers' perception of their contribution to the learning, teaching and assessment of student nurses on the Mental Health Nursing programme.	Semi-structured interviews	Interpretive phenomenological analysis	The findings provide insights into why carers become involved in the education of nurses as the common goal was to make a difference. Findings also highlight the impact they believe it has on themselves and students as well as the meaning they made of the feedback they receive.
Webber and Robinson (2012)	UK.	* Service users and carers = 4	To explore the level and nature of involvement and the extent to which service users and carers feel it is meaningful for themselves and social work students in post - qualifying education.	Semi-structured interviews, focus group & self-complete questionnaire. Participation Action Research (PAR)	Thematic analysis	A majority of the participants supported involvement in advanced post qualification education and the findings highlight participants' perspectives on what constitutes meaningful involvement in education. The Four models of involvement that were also identified were consultation, partnership, political and user control.
Mckeown et al. (2011)	UK.	* Service users and carers = 21	The study focused on developing service user and carer involvement in a university setting and aimed to explore participants' motivation to be involved.	Data collected from meeting notes, actions and observations, reflective diaries, formal reports, talk between participants, recorded interviews and focus groups. Participation Action Research (PAR)	Thematic content analysis	The findings outline the way in which service users and carers obtain a sense of value from their involvement. It developed an understanding of the relationship between involvement and reward. It also highlighted the tensions between aspirations of best practice and the actual complexity of service user and carers positions regarding sense of value.
Campbell and Wilson (2017)	Ireland	* Service users = 5 * Females = 3, Males = 2 * Age range = 34 to 67	To explore mental health service users' experiences of involvement in a clinical psychology course.	Semi- structured interviews	Interpretive phenomenological analysis	The findings highlight service users' experiences on the personal, the professional and group level. They also outline the personal and political change for participants and challenge the notion that involving service users alone is conducive to positive outcomes.

Happell et al. (2017)	Australia	* Consumer educators =12	To enhance understanding of the role consumers can play within mental health nursing education.	Semi- structured interviews	Framework analysis	The findings reflect the importance of service user involvement in education as a means of demonstrating recovery first hand by those that have undertaken the recovery journey. With the concept of recovery emerging as a clear alternative to the medical model.
O'Reilly et al. (2012)	Australia	* Mental health consumer educators with a diagnosis of psychotic disorders = 10 * Mental health consumer educators with depression and caring for individuals with schizophrenia = 2 * Females = 6, Males = 6	To explore the self-reported effect of consumer and caregiver-led education for pharmacy students and to explore the goals, challenges and benefits of mental health consumer educators providing education to health professional students.	Focus groups	Grounded theory	The findings highlight that the primary reason service users and carers became involved in education was to increase awareness and reduce the stigma associated to mental health issues. The three major themes identified were raising awareness about mental health, impact on professional practice and impact on mental health consumers.
Rees et al. (2007)	UK.	* Service users = 19 * Female = 12, Male =7 * Age range = 44-68 * White = 19 * Socio - economic status: * High managerial= 2 * Lower managerial = 10 * Intermediate = 4 * Small employers/account workers = 1 * Missing data = 2	To explore the views and experiences of participants regarding service user involvement in medical education.	Focus groups	Framework analysis	The results reveal there was no clear consensus regarding the terminology used when describing service users. It also highlighted the benefits and concerns about involvement as well as the need for service users to be involved in all aspects of education from the start of students' education. However it was recognised that this must be done in a gradual and sensitive manner.
Schon (2016)	Sweden	* Service users = 21 * Female = 15, Male = 6 * Carers = 4 * Female = 4 * Service users and carers = 8 * Female = 8 * Age range = 21-64 * Employment status: * In open labour market = 19 * Disability allowance = 10	To explore the reasons service users and carers became involved in social work education and the way they define their potential contributions.	Questionnaires	Content analysis	The findings illustrate that participants' reasons for joining the user panel was to contribute to the knowledge base (illness, patient and recovery knowledge) and reduce stigma (societal attitudes, social improvement and personal growth).

		* Runs day care centre = 4				
Flood et al. (2018)	UK.	* Patients = 7 * Female = 5, Male = 2 * Age range = 42 - 70 * Caucasian and resided in Northern Ireland = 7	To explore service user perspectives on relaying their personal experience of the cancer treatment pathway to students in an undergraduate Radiotherapy and Oncology programme.	Semi- structured interviews	Grounded theory	The findings demonstrate that the primary motivation for participants to be involved was the desire to have the patients' story included and their voices heard. They also wished to influence the future behaviour of student health care professionals.
Shah et al. (2005)	UK.	* Patients =14 * Female = 5, *Male = 9 * Age range = 40 - 80 (Mean = 61.9) * White Caucasian = 14	To explore patients' experience of teaching undergraduate pharmacy students, their perception of their role and to discover what patients themselves have personally gained from this experience.	Semi- structured interviews	Grounded theory	The findings illustrate that all participants felt positive about their involvement in education. They saw their involvement as a way of investing in the future by sharing their expert view on their illness and their journey.
McGarry and Thom (2004)	UK.	* Service users = 5	To explore service users' experiences of involvement in nurse education, to identify key issues of concern and to help shape the development of user and carer involvement.	Focus groups	Grounded theory	The findings illustrate that all participants expressed that involvement in nurse education was valuable and provided students insights into participants' experiences of illness and care. The participants also sought to share the importance of improving care provision by understanding the more personal elements of care.
Lea et al. (2016)	UK.	* Service users =8 * Female = 4, Male = 4	To examine the impact of service user involvement in mental health training.	Focus groups	Thematic analysis	Participants wanted to influence future professionals and involvement was seen as a way to do this. They also wished to challenge the them and us thinking as service users highlighted equality with mental health professionals was an important outcome of their involvement in teaching.
Thomson and Hilton (2012)	UK.	* Service users = 7 * Female = 5, Male = 2 * Carer =1 * Female = 1 * Age range = 50 - 90 * Employment status: * Finance consultant = 1 * Night security = 1 * Business owner = 1	To explore service users' perspective of their involvement in a physiotherapy educational programme.	Semi-structured interviews	Grounded theory	The findings illustrate that all participants wished to foster a sense of partnership and communicate what it was like on the other side. Their motivation for being involved were to challenge the students' assumptions regarding disability, to give something back for their healthcare and to communicate their dissatisfaction with present healthcare provisions.

		* Formally employed = 5 * Health issues: * COPD = 2 * Double amputee = 1 * Tetraplegic = 1 * Arthritis = 1 * Back problems = 2 * Carer for husband with dementia = 1				
Keenan and Hodgson (2013)	UK.	* Service users = 5	To explore the motivations and experiences of service users involved in radiotherapy and oncology education.	Unstructured interviews	Grounded theory	The findings show that participants expressed that being involved gave them a sense of wellbeing and purpose. They also wanted to promote awareness by sharing their experiences of cancer and improve patient care.
Rooney and Unwin (2020)	UK.	* Service users and carers = 10	To evaluate service users' and carers' experiences of being involved in the selection of students across health and social care disciplines.	Semi-structured interviews. Participation Action Research (PAR)	Thematic analysis	Participants believed that their inclusion in selection day processes was valuable. They believed they provided a focus for potential students from individuals that are in receipt of healthcare services. They expressed the benefits as well as challenges faced and expressed areas of improvement.
Heaslip et al. (2018)	UK.	* Service users = 9	To evaluate the inclusion of service users in value-based recruitment processes within an adult nursing programme.	Interviews, questionnaires & focus group. Participatory mixed methods	Thematic analysis	The findings highlight that involving service users in value-based recruitment of student healthcare professionals has benefits to service users and students as it provided an added dimension to the recruitment process.
Rooney et al. (2016)	UK.	* Service users and carers = 15 * White British = 14 * BME group member = 1	To explore service users' and carers' motivations for involvement.	Semi-structured interviews. Participation Action Research (PAR)	Thematic analysis	The finding shows that service users and carers perceived their involvement brought benefits to academic staff, students, the university as well as the wider community. Participants reported personal benefits such as a sense of achievement, enjoyment and access to training. They also reported the barriers to involvement which prevented greater participation.
Masters et al. (2002)	UK.	* Users = 3 * Carers = 2	To explore the origins, progress, aims and level of resources in the involvement initiative.	Focus group and questionnaires. Participation Action Research (PAR)	Thematic analysis	Participants raised issues of representation and expertise in involvement. They also highlighted the importance of the process of involvement. Challenges to developing meaningful involvement was also identified.

Cooper and Spencer – Dawe (2006)	UK.	* Service users =14 * Female = 6, Male = 8 * White = 13 *Other ethnicity = 1	To investigate the involvement of service users in the delivery of interprofessional education for undergraduate students.	Interviews	Constant comparative method	Findings showed that service users can make an important contribution by breaking down communication barriers and preparing students for the practitioner-service user relationship.
Curran et al. (2015)	UK.	* Experts by experience - Service users and carers = 14	To explore participants shared experiences of what it means to be an expert by experience and the extent to which the role can be understood in terms of leadership.	Interviews	Knowledge café	The findings show how involvement as a service user emerged out of a personal drive to challenge and change appalling exercises in health and social care services. The findings show how experts by experience provided mutual support in situations of crisis and generated knowledge together. The study also illustrates the concept of leadership.
Matka et al. (2010)	UK.	* Service users = 15 * Carers =6 * Age range 17-76, (Mean = 54)	To explore the experiences and expectations of service users involved in interview panels at a university with the aim of highlighting underlying rationales and informing future practice.	Surveys	Thematic analysis	Findings highlight the importance of involvement with value based and outcome-based rationales put forward for the involvement of service users and carers in educations. All service users and carers agreed that it was important to be involved in interviewing applicants as they provided unique insights for a plurality of views.
Anghel and Ramon (2009)	UK.	* Service user and carer consultants =15	To explore the positives and negatives associated with acting as educators; their needs and expectations, the meaning of involvement and their strategies of dealing with difficult emotions generated.	Questionnaires and interviews. Participatory mixed methods	Thematic analysis	The findings highlight the value of service user and carer involvement in social work. There was a desire for the steps needed for a cultural change for such involvement to become more comprehensive and embedded in the degree.
Meehan and Glover (2007).	Australia	* Service user consumer educators =11 * Male = 11 *Age range = 28-54	To explore the meaning that former consumers involved in the education and training of mental health staff attributed to their role.	Interviews	Phenomenological analysis	The findings highlight the need for an ongoing critical review of the way in which consumer educators are engaged in the education and training of mental health professionals. Findings also show that consumer educators also identified that sharing their stories left them feeling vulnerable and exposed.
Dzombic and Urbanc (2008)	Croatia	* Users = 4	To explore the experiences of social service users with disability in the teaching process, as well as their views on the processes of educating social workers and the possibilities of enhancing the quality of their education.	Focus group	Thematic analysis	The findings illustrate that participants characterised their participation in education as collaborative. They highlighted the complexities of the collaborations and also expressed their dissatisfaction with accessibility issues at the university.

APPENDIX F: PREVALENCE OF EACH THEME AND SUB-THEMES ACROSS THE ARTICLES

	Themes						
Articles	The positive aspects of involvement	Idiosyncratic gains.	I am part of the change I want to see.	Barriers to effective involvement.	The emotional burden of sharing my story.	Circumstances outside of my control.	Are my lived experiences really valued?
Anghel and Ramon (2009)	*	*	*	*		*	
Campbell and Wilson (2017)	*	*	*	*			*
Cooper and Spencer – Dawe (2006)	*	*	*	*		*	
Curran et al. (2015)	*	*	*	*			*
Dzombic and Urbanc (2008)	*	*	*	*		*	*
Flood et al. (2018)	*	*	*	*	*	*	
Happell et al. (2017)	*		*	*			*
Heaslip et al. (2018)	*	*	*	*	*		*
Keenan and Hodgson (2014)	*	*	*				
Lea et al. (2016)	*	*	*	*			*
Masters et al. (2002)	*	*	*				
Matka et al. (2010)	*	*	*				
McGarry and Thom (2004)	*	*	*	*		*	*
McIntosh (2018)	*		*	*	*		
Mckeown et al. (2011)	*	*	*	*		*	*

Meehan and Glover (2007)	*	*	*	*	*	*	*
O’Reilly et al. (2012)	*	*	*				
Rees et al. (2007)	*	*	*	*	*	*	*
Rooney et al. (2016)	*	*	*	*		*	
Rooney and Unwin (2020)	*	*	*	*		*	*
Schon (2016)	*	*	*	*			*
Shah et al. (2005)	*	*	*				
Thomson and Hilton (2013)	*		*	*			*
Webber and Robinson (2012)	*	*	*	*		*	*

APPENDIX G: ADVERTISEMENT EMAIL

University of Essex

Version 3 – May 2020: A Qualitative Exploration of The Experiences of Service Users and Carers Involved in Health and Social Care Education

Service Users and Carers Involved in Health and Social Care Education Needed for Research Study

Tell us about your experience

This research study is part of a professional doctorate and is seeking to interview service users and carers about their experience of being involved in Health and Social Care Education.

Your participation will involve a one-hour interview. The interview can either take place on the telephone or via video call.

Who can participate?

- Adults aged 18 years and above
- Service users that are currently using or have used physical and/or mental health services
- Carer for an individual with physical and/or mental health needs
- Involved in Health and Social Care Education.

Participants will receive £10 gratuity voucher for their time.

If you are interested in participating in the research, or you would like any additional information, please contact the researcher

Name: Maria Shittu

Email address: maria.shittu@essex.ac.uk

APPENDIX H: PARTICIPANT INFORMATION SHEET

University of Essex

PARTICIPANT INFORMATION SHEET

Before you decide whether to take part it is important you understand why the research is being conducted and what it will involve. Please take some time to read the information below carefully. The researcher can be contacted if you would like any additional information. Take some time to decide whether or not you wish to take part.

1. Project title:

A Qualitative Exploration of The Experiences of Service Users and Carers Involved in Health and Social Care Education

2 Researchers details

This study will be conducted by Maria Shittu, a Trainee Clinical Psychologist currently studying a Doctorate in Clinical Psychology at the University of Essex. Email: Maria.Shittu@essex.ac.uk.

3. What is the study about?

The purpose of this study is to gain a more nuanced understanding of how service users and carers experience their involvement in health and social care education.

4. Why have I been invited?

You have been invited to participate in this study because you are a service user and/or carer.

5. What will the study ask you to do?

If you agree to take part in this study, the researcher will conduct an interview with you. The interview will include questions about your involvement in education, your expectations, hopes as well as concerns.

The interview will take approximately 1 hour to complete. With your permission, the researcher would like to audio-record the interviews. Recordings will be securely kept in a lockable cabinet. Audio recordings will solely be used for research purposes and will be destroyed on completion of the study.

6. Do I have to take part?

Participation in this study is entirely voluntary. If you do decide to take part, you will be given this information sheet to keep and will be asked to sign a consent form. You are still free to withdraw at any time during the process of the study.

7. Participant’s rights

- You have the right to withdraw from the study at any time without having to justify your decision. If you decide to withdraw from the study you can tell the researcher whether you are happy for the study to use the information obtained up until the point of withdrawal. If you are not, any information that you have given will be destroyed and the researcher will not contact you again.

- You have the right to refuse to answer or respond to any question that is asked of you.
- You have the right to have your questions about the procedures answered. If you have any questions as a result of reading this information sheet, you should ask the researcher before the study begins.

8. Confidentiality and anonymity

All the information, which is collected during the research, will be kept strictly confidential. The only limits to this confidentiality would be if you were to tell the researcher something that suggested that there would be a reason for the researcher to be worried about harm to yourself, or to someone else. In these circumstances, it would be important for the researcher to share this information appropriately. Please note that this is likely to be a very rare occurrence.

Your data will be anonymised. The researcher will allocate you a number and from that time, there will be no record that links the data collected from you with any personal data from which you could be identified (e.g., your name, address, email, etc.).

9. Benefits and risks

There are no known risks for you in this study. People often find participating in interviews and talking about their experiences enjoyable and worthwhile.

10. Compensation

You will receive a £10 gratitude voucher for each interview in return for your participation.

11. Results of the study

This study will be written up as a thesis for a Doctorate in Clinical Psychology for the University of Essex. Upon completion, the thesis will be placed in the Albert Sloman Library. A summary of the research findings will be made available to the participants if they wish to receive the findings.

12. If there is a problem

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal investigator of the project, Maria Shittu, using the contact details below. If you are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact Maria Shittu's supervisor, Ewen Speed (esspeed@essex.ac.uk). If you are still not satisfied, please contact the University's Research Governance and Planning Manager, Sarah Manning-Press (e-mail sarahm@essex.ac.uk). Please include the ERAMS reference, which can be found at the foot of this page.

13. What is the legal basis for using the data and who is the Data Controller?

The legal basis of processing your data is informed consent. The University of Essex is the Data Controller and the named officer is Sara Stock, University Information Assurance Manager (dpo@essex.ac.uk).

14. For further information

This research has been reviewed and approved by the University of Essex Ethics Committee. Please feel free to ask any questions you have now. Alternatively, if you have questions later, you may contact Maria Shittu (maria.shittu@essex.ac.uk). You can also contact Maria Shittu's supervisor Ewen Speed (esspeed@essex.ac.uk).

APPENDIX I: CONSENT FORM

University of Essex

Participant Identification Number for this study:

Title of Project: *A Qualitative Exploration of The Experiences of Service Users and Carers Involved in Health and Social Care Education*

Name of Researcher: Maria Shittu

Please tick

1. I confirm that I have read the information sheet dated 25.05.2020, versio ☐ for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2. I understand that my participation is voluntary and that I am free to withd ☐ at any time without giving any reason, without my legal rights being affe

3. I understand that all information about me will be treated in strict confide ☐ and
that I will not be named in any written work arising from this study.

4. I consent to my interview being recorded as part of the above study. ☐

5. I agree to take part in the above study. ☐

Name of participant	Date	Signature
Name of person taking consent	Date	Signature

APPENDIX J: TOPIC GUIDE

Interview Topic Guide

A Qualitative Exploration of The Experiences of Service Users and Carers Involved in Health and Social Care Education

Time of interview:
Date:
Venue:
Interviewer:
Interviewee code:

Introduction

Hello, my name is Maria Shittu. I am a Trainee Clinical Psychologist seeking to understand how service users and carers experience their involvement in Health and Social Care education.

Information sheet and confidentiality discussed

Before we get started today, I would like to tell you a little more about this study and how the information I obtain will be used.

[Go through information sheet with participant and explain confidentiality statement.]

I would also like to reiterate that our conversation is confidential. All the information, which is collected during the research, will be kept strictly confidential. The only limits to this confidentiality would be if you were to tell me something that suggested that there would be a reason for me to be worried about harm to yourself, or to someone else. In these circumstances it would be important for me to share this information appropriately. Please note that this is likely to be a very rare occurrence.

I will be recording our interview today for data-collection purposes. All the data collected will be securely stored. There will be no way of identifying who you are as your data will be anonymized. I will allocate you a number and from that time, there will be no record that links the data collected from you with any personal data from which you could be identified (e.g., your name, address, email, etc.).

Do you have any questions?

Please take as long as you need to read through the information sheet and consent form. If you are satisfied with it and you are still willing to take part, I would like you to sign the consent form.

__Introduction to interview__

This study is interested in finding out more about your involvement journey

Indicative Interview Schedule*

Section A

1) Demographic information (age, gender, ethnicity, have you used or cared for someone that has used mental and/or physical health services?)

2) Can you please tell me how long you have been in this role?

3) Can you tell me how you became involved in this role?

4) Can you tell me more about why you got involved?

5) Please describe the scope of your involvement, for example, the activities you do? What subjects do you teach? How frequently are you involved?

6) Were there any specific outcomes/ goals you wanted to achieve?

Section B

7) How would you describe your experience of being involved in Health and Social Care education?

8) What do you think you bring to the role?

9) Can you describe how you feel you have made a difference to students, the university professionals and the curriculum?

10) How has being involved impacted your life?

11) Can you please describe the benefits of your involvement? What are you gaining from it? Have your desired goals been achieved?

12) Can you describe the main challenges you have experienced in this role?

13) How prepared do you feel to participate in different tasks?

14) Has the academic institution provided the support and skills needed for the role?

15) Can you please describe if you feel you are involved in decision-making processes? For example, is it a collaborative process? If so, how?

16) Do you feel able to challenge ideas brought to you by professionals? If not, why?

17) Are there helpful and unhelpful things that the academic institution does to aid your involvement?

18) Is there anything that can be done to improve this role?

19) In the future, what level of involvement in education would you like to see?

20) Is there anything else you would like to add to fully capture your experience of involvement?

The researcher will utilize prompts, probes and will ask participants to provide examples to obtain further detail and clarification.

De-brief

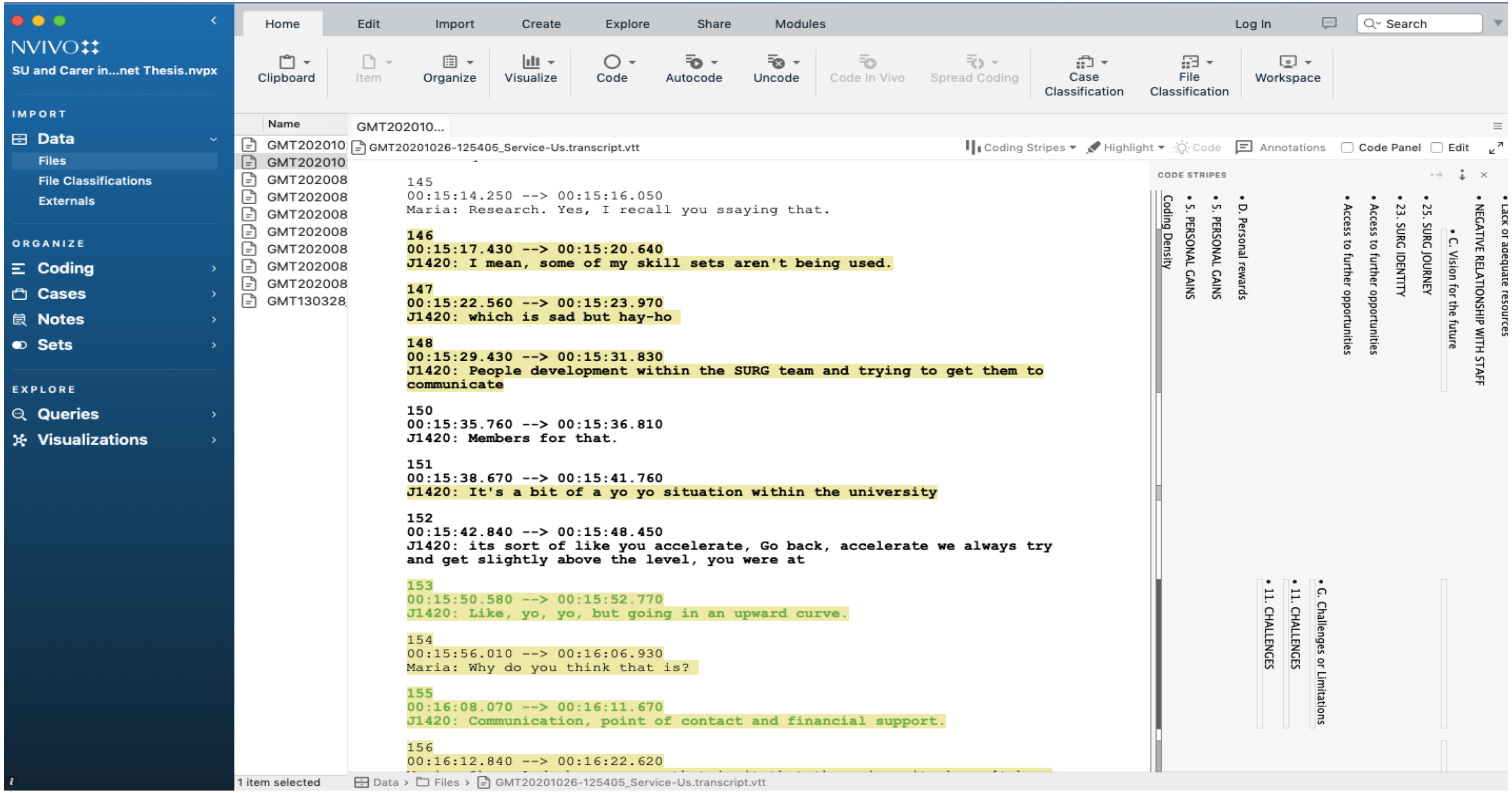
Thank you very much for participating in this study. I appreciate your time and the information you have shared with me about your experience. If anything, we have discussed has upset you in anyway, please do let me know. If you would like to find out the results of this study, I am more than happy to share a summary of the findings with you upon completion.

Do you have any final questions before we finish today?

Please do not hesitate to contact me if you have any further questions about this study.

My observations/comments:

APPENDIX K: NVIVO



```
145
00:15:14.250 --> 00:15:16.050
Maria: Research. Yes, I recall you ssaying that.

146
00:15:17.430 --> 00:15:20.640
J1420: I mean, some of my skill sets aren't being used.

147
00:15:22.560 --> 00:15:23.970
J1420: which is sad but hay-ho

148
00:15:29.430 --> 00:15:31.830
J1420: People development within the SURG team and trying to get them to
communicate

150
00:15:35.760 --> 00:15:36.810
J1420: Members for that.

151
00:15:38.670 --> 00:15:41.760
J1420: It's a bit of a yo yo situation within the university

152
00:15:42.840 --> 00:15:48.450
J1420: its sort of like you accelerate, Go back, accelerate we always try
and get slightly above the level, you were at

153
00:15:50.580 --> 00:15:52.770
J1420: Like, yo, yo, but going in an upward curve.

154
00:15:56.010 --> 00:16:06.930
Maria: Why do you think that is?

155
00:16:08.070 --> 00:16:11.670
J1420: Communication, point of contact and financial support.

156
00:16:12.840 --> 00:16:22.620
```

APPENDIX L: ETHICAL APPROVAL LETTER

University of Essex

28/01/2020

Miss Maria Shittu

Health and Social Care

University of Essex

Dear Maria,

Ethics Committee Decision

I am writing to advise you that your research proposal entitled "How do service users and carers experience their involvement in Health and Social Care education and how does their experience change over time? " has been reviewed by the Science and Health Ethics Sub Committee.

The Committee is content to give a favourable ethical opinion of the research. I am pleased, therefore, to tell you that your application has been granted ethical approval by the Committee.

Please do not hesitate to contact me if you require any further information or have any queries.

Yours sincerely,

Gill Green

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

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