

**SERVICE USER INVOLVEMENT IN THE BRITISH RED
CROSS: EXPERIENCE AND FACTORS AFFECTING
WILLINGNESS TO PARTICIPATE**

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ABSTRACT

There has been an increase in momentum around service user involvement in service evaluation, planning and delivery since the 1980's. This change resulted from both the shift to market-led approaches to service provision, and the rise of influential service user and carer movements. Service user involvement is now a necessity for services in Health and Social Care; however, the coordination of these activities is complex and studies continue to reveal tokenistic practices. Large organisations, especially those with diverse service user populations, have an even greater challenge. Since the introduction of Any Qualified Provider, charitable organisations are now able to bid for statutory services. The British Red Cross has service user involvement at the heart of its corporate strategy, and has already won several statutory contracts.

Nine individuals who had both used British Red Cross services and subsequently been involved in service user involvement initiatives took part in semi-structured interviews. The interview questioned them on their experiences and motivations for becoming involved. Each interview was transcribed and thematic analysis conducted on the data. Four themes were identified across the data, each indicating important areas in the process of service user involvement; 'motivations when starting out', "I committed myself to them", 'barriers and challenges' and 'room for improvement.' Service user involvement was revealed to be patchy within the British Red Cross and participants indicated both a lack of clarity over their role, and lack of follow up after involvement. Despite this, participants described their experiences favorably and all expressed a desire to continue their involvement with the organisation. Key factors influencing participants decision to become involved initially differed from those that impacted on their on going involvement. Experiences key to the continued involvement of the participants were the social aspect of involvement, skills development, and feeling valued by the organisation. This study again highlighted the complexities of service user involvement within large diverse organisations. Implications of the findings for both the British Red Cross and similar organisations are considered.

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1. INTRODUCTION

This research set out to uncover service user's perspectives on service user involvement initiatives in the British Red Cross (BRC). This chapter provides a contextual overview for the study; firstly providing an outline of service user involvement theory, legislation, identified barriers and facilitators, and power and discourse considerations. An overview on the voluntary sector, BRC services and its position on involving service users is then offered.

Subsequently personal motivations of the researcher are put forwards, with rationale for the study and it's relevance to Clinical Psychology. The chapter concludes with research objectives and questions.

1.1 Literature Review

A literature search of PsychINFO, PsychARTICLES and Scopus was performed using a number of search terms depicting 'service user involvement', combined with a range terms including 'willingness', 'feedback' and 'motivation' (appendix A). All searches limited the search years to publications between 1980 and 2016. A snowballing effect from relevant articles was utilised, identifying appropriate literature on their reference lists. Health Expectations, an international journal of public participation, along with Google Scholar and grey literature were also examined for relevant documents.

The researcher prioritised qualitative studies and those focussed on perspective and opinion. Very few articles focussed on the experience of service users who had given feedback on services through focus groups, sitting on boards or volunteering. Many articles had little or no relevance to the type of service user involvement this study focused on; for example, many were related to service user's involvement in their own care such as collaborative decision-making and choice of service. This highlights both the diversity of what is classed as 'service user involvement' and the absence of a single collective definition.

The researcher discovered that the literature on SUI was predominantly carried out within disciplines such as social work and nursing. In addition, focus tended to be on initiatives that took place in the mental health domain or ‘unheard service user populations’, e.g. individuals with learning disabilities. It is likely that these populations were more prevalent due to powerful social movements lobbying for their rights, and advances necessitating the involvement of SU’s since the 1990’s in both health and social care policy. In addition, organisations may identify the involvement of these individuals as being more problematic or complex, for example, due to concerns about impaired cognitive functioning, poor verbal ability and questions about their level of insight (Beresford, 2002; Rose, 2003; Solbjor, Rise, Westerlund, Steinsbekk, 2013). Therefore, the voices in the literature were concentrated around several dominant groups, at the expense of other groups; the likely reasons for this are hypothesised further into the report.

1.2 Service User Involvement

1.2.1 Definitions

Many terms have been used to describe ‘service users’ and the description of a service user varies with time and across contexts. For the purpose of this study, the term ‘service user’ has been used to describe an individual who accesses, has accessed or is eligible to access public, charitable or private services. Whilst many individuals continue to use the term ‘service user’, others feel that it is dated, conjuring the image of a dependent, homogenous group. The researcher acknowledged that the term is reductive and fails to portray the complexity of the experiences individuals face. For the purpose of this report, the terms ‘service user’ and ‘service user involvement’ were used because they hold widespread meaning and are commonly utilised in the literature, but their use is tentative. ‘Service user involvement’ and ‘service user participation’ were used interchangeably throughout this document.

SUI refers to the process of involving service users in a range of activities

focussed on feeding in their knowledge and experience to impose change. The concept of SUI is broad and is referred to in many different arenas; policy and strategy, service development, planning, delivery and evaluation, in the education, training and recruitment of professionals and at all stages in the conduct of research (Millar, Chambers, & Giles, 2015).

Over the years, as SUI has evolved, so too has the way it is defined. Millar, Chambers, & Giles (2015) found that many definitions of SUI were narrow and failed to capture the breadth of SUI activity. After a concept analysis of SUI articles and research in mental health care between 1970 and 2010, they discovered that the concept required further defining. They proposed the following comprehensive definition for SUI in mental health care, which could be applied to SUI in any organisation:

‘An active partnership between service users and (mental health) professionals in decision making regarding the planning, implementation and evaluation of (mental health) policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level.’ (p. 8)

1.2.2 Legislation and Guidance

In the UK, health and social care policy aimed at seeking out the SU voice dates back over three decades. In the early 1990’s the public were put into the role of consumers of the NHS, as highlighted in policies such as ‘The Patient’s Charter’ (DoH, 1991) and ‘Local Voices’ (DoH, 1992). When Labour came into government in 1997 they set about creating more personalised and responsive health and social care systems, the focus shifting from supply to demand. The white paper ‘The New NHS: Modern, dependable’ (DoH, 1997) identified that the expectations of the public should be utilised in shaping the services to better meet the needs of those who used them. They aimed to re-establish public confidence in the NHS by emphasising a public service that was ‘accountable to patients, open to the public and shaped by their views.’ The focus was now not

only on the clinical result of patients, but also the quality of their experience.

In order to meet these targets new National Service Frameworks (NSF's) were set up to aid consistent access and quality of care across the country, plus the National Institute for Clinical Excellence (NICE) began drawing up guidelines for clinical effectiveness and cost-effectiveness across the NHS. The National Service Framework for Mental Health (DoH, 1999a) set out a 10 year agenda to improve mental healthcare in England, central to this was the opinion that service users could help services in being more responsive to the population they serve by providing feedback, thus improving quality of care.

This focus was mirrored in Social Services; 'Modernising Social Services' (DoH, 1998) which set out to tackle low public confidence in Social Services that had arisen from publicised problems and failings. Most significantly, there was a move towards user-centred services more tailored to individual needs and the introduction of a nationwide annual satisfaction survey. As in the NHS, performance targets were set and monitored. For the first time the opinions of patients, carers and service users were to be put at the heart of social services and the NHS.

At roughly the same time, the introduction of a new annual national survey of patient and user experience was a further step towards widespread service user consultation; providing feedback on services offered. If services consistently failed to deliver patient satisfaction, this could trigger the involvement of the Commission for Health Improvement. The NHS Performance Assessment Framework (DoH, 1999b) informed organisations of the criteria against which their performance would be assessed and set out to identify underperforming services. Patient or carer experience was identified as one of the six key areas of assessment.

The 2001 Social Care Act (DoH, 2001) made it a requirement for all NHS services to ensure that treatment decisions, service planning and evaluation involved the active participation of service users. This focus on SUI has not

dropped off the agenda and if anything has become more central to policy in health and social care. In 2009 the Local Government and Public Involvement in Health Act (DoH, 2007) began imposing a duty on public bodies to involve service users, including those from under-represented groups. Local Involvement Networks were created in order to ensure that services were responsive to the needs of the local population (DoH, 2006). One of the key values of 'Equity and Excellence: Liberating the NHS' (DoH, 2010) was putting patients and the public first, using a tagline "nothing about me without me", a slight variation of the slogan of the predating service user movements.

The NHS Performance Framework (DoH, 2012) continues to value 'user experience' as a central domain of assessment. It utilises the National Patient Survey to gather information on patient satisfaction annually, taking into account relationships to staff and information on choice. The Care Quality Commission (CQC) now has a vital role in assuring that essential quality and safety levels are met by all health and social care. The Care Quality Commission distributes user surveys to collect feedback. These questionnaires, however, could be viewed as a crude standardised measure of satisfaction that has the potential to constrain comments to set parameters.

In 2006 the National Institute for Health Research (NIHR) was established under the 2005 Government strategy for health research 'Best Research for Best Health'. Its aim was to improve the health of the nation through research. From the outset it announced its commitment to putting patients at the centre of all stages of the research process in NHS related research activity. It established INVOLVE to promote the public's involvement in research, defining public involvement as research 'with' or 'by' the public, rather than 'to' or 'for' the public.

The NHS Reforms of 2010 (DoH, 2010) and the introduction of Any Qualified Provider meant that more statutory NHS services were to be contracted out to the private and voluntary sectors. At this time Clinical Commissioning Groups (CCGs) were being established and made legally responsible for ensuring that

SUI was taking place within these services. Therefore, whilst charitable organisations are independently governed and do not follow the above legislation, they are subject to the same guidelines when delivering statutory services.

The Charity Commission is the independent regulator for third sector organisations and ensures that organisations comply with charity law and legislation, for example, the Charities Act (2011). In the last decade, the Charity Commission has collaborated with key voluntary sector bodies to develop the Good Governance Code (NHEG, 2005, 2010); guidelines for best practice and principles for charitable organisations. One of the six principles of the Code is being 'open and accountable', which includes "listening and responding to the views of supporters, funders, beneficiaries, service users and others with an interest in the organisation's work" (NHEG, 2010, p. 11). Evidently the voluntary sector values the voice of all of its stakeholders and being responsive to their needs, including services users. The third sector also monitors statutory sector legislation and is increasingly influenced by CQC and the NHS and Social Care authorities.

Ultimately the UK government tends to respond to 'hot topics', when the initial policies on SUI were introduced there was a building pressure from SU groups to bring their lived experiences into the clinical and research sphere.

1.2.3 Social Movements in the UK

Since the 1940's the campaigning of social movements has transformed Britain's political and cultural landscape. These movements have risen from a collective dissatisfaction with experiences of oppression, inequality, or a response to unmet economic, political or social demands. They frequently emerge from groups of individuals who lack access to institutionalised means of power. Social movements are dynamic and contextual, thus may grow or shrink in relation to changes in society. Issues that have built significant momentum are worker's rights and women's rights. A movement may cease to exist as a result of either internal pressures such as conflict or divergent aims between

activist members, external pressures such as harassment or harming of members by those outside of the movement. In addition, if the cause central to the movement is addressed sufficiently the movement is likely to discontinue. Movements are created by their members and must have enough resources and membership in order to develop initially and continue to exist. It is important to recognise that not all situations of injustice are able to initiate social movements and thus many marginalised individuals never get their opportunity to be heard. The voices we hear in the literature, and in practice, are those belonging to larger and more powerful social groups, e.g. within the gay rights movement Stonewall has created a strong narrative around fighting for equality for individuals within the LGBTQ community.

1.2.4 The Rise of Service User Involvement

There has been an increase in momentum around SUI in service evaluation, planning and delivery since the 1980's. Beresford (2002) identified two main factors responsible; firstly, the New Right focus on market-led approaches to service provision whilst devaluing public provision. Second, the development of influential lobbying service user and carer movements, such as mental health service users and individuals with learning disabilities, who campaigned for change. The service user movement's slogan "nothing about us, without us" stresses the importance the movement places on the involvement of service users at every level of organisational decision-making processes (Browne, Lakeman, O'Brien & Chan, 2015). The slogan also gives us insight into the experiences and beliefs of the individuals within that movement, for example, feeling powerless and unheard in their interactions with professionals.

Ultimately the concept of SUI would not have come about without the efforts of the mental health service user movement and disability rights movement advocating for change. The organised mental health service user or survivor movement we know today began with the Mental Patients Union (Crossley, 1999). The general consensus from within the union was that the Medical Model of mental illness, and the associated methods of medicating and incarcerating, were all part of a system of social control, thus they rejected the

services and treatment provided. Experiences in the mental health system had left individuals feeling excluded from much of society and discriminated against, in much the same way as members of the feminist and LGBT movements. The movement was irrefutably political; aimed at fighting the reductionist mental health system. Over the following years numerous groups formed with varying approaches to the problem of the mental health system, including Protection of the Rights of Mental Patients in Therapy, Mad Pride and Survivors Speak Out. Between 1985 and 2005 the number of active service user groups increased significantly from approximately a dozen to over 500 (Coppock & Dunn, 2010).

Market led approaches, as identified by Beresford (2002), brought the ideas of capitalism to the health and social care system. This changing political emphasis on individual rights and choice served to fuel service user movements and open new doors. Whilst not indicative of system wide governance, the collective effect of individual choice can indicate the public's preferences. Whilst in essence these ideals should serve only to benefit society, it could be suggested that the consumer model gives only the illusion of choice. Ultimately decisions on which services are to be offered and what is to be researched are made by the powerful few, for example, commissioners in NHS trusts or councils. The 'choice' discourse ultimately benefits the government as it conveys a sense of control to individuals using services, however, even when the ideological partnership model operates within services individuals involved will merely have control over the small system within which they operate. This sense of control, however small, serves to distract individuals from the wider issues, such as widespread discrimination and abuse. This approach is in contrast to the social action model of involvement in which individuals come together to resist and utilise collective power.

From within the healthcare system, increased involvement of service users was also advocated by two prominent psychiatrists (Bracken & Thomas, 2001) who believed that SUI may contribute to improving relationships with the 'anti-psychiatry' movement of the time. This was a step forwards for mental health,

and launched a new agenda for psychiatry.

1.2.5 Approaches to Service User Involvement

The idea of SUI was not a new one at the time of governmental policy development, but it did push the concept further into the limelight. Arnstein's 'Ladder of Citizen Participation' (Arnstein, 1969; Figure 1) offered an early typology which aimed to draw attention to the differing degrees of participation or involvement, which tended to fall under the same umbrella term. The 'ladder' outlined eight differing levels of participation, with each level corresponding to a different degree of influence over the plan or programme in question. The model highlighted the inadequacies of participation at the bottom end of the ladder, where individuals could be manipulated, pacified and were ultimately powerless. The model shaped thinking, with later 'ladders' of participation being developed Wilcox (1994) and Burns (1994).

Arnstein's model was utilised frequently over the years and relatively uncritically. Tritter and McCallum (2006) questioned the idea that the sole aim of SUI should be empowerment, instead believing that "such an approach limits the potential for sharing experience, knowledge and the harnessing of multiple perspectives inherent in successful user involvement" (p. 166). They believed that given the agency, service users have the ability to shape their own methods of involvement, leading to more effective approaches. Despite this critique, studies have continued to indicate that those individuals involved in SUI initiatives continue to identify their capacity for power and control as central to their experience.

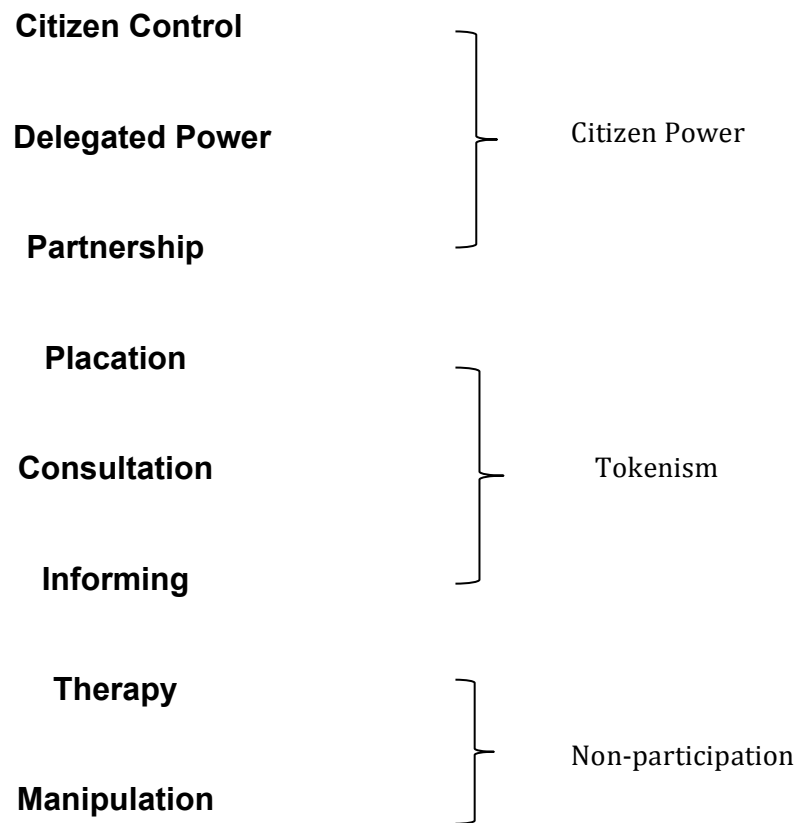


Figure 1. 'Ladder of Citizen Participation' (Arnstein, 1969)

More simplistically, Beresford (2002) splits SUI into two types; consumerist and democratic. The consumerist approach involves gaining feedback on the product or service in order to make improvements to efficiency, economy and effectiveness; utilising activities such as consultation and feedback forms. This approach '*has largely been focused on the planning and management of policy and provision*' (Beresford, 2002; p97). The democratic approach has grown from the collective action of service user movements (Campbell, 1996); emphasising self-advocacy, inclusion and autonomy. This approach aims to provide service users with more say in services or institutions that impact on them, offering them more control over their own society and lives of those within this society. The democratic approach is unequivocally political. Whilst both approaches aim to bring about change, there are vital differences in

terms of power and control. The consumerist approach seeks external input and feedback, then those in power, for example policy makers, decide if and how to use it; there is no impact on the redistribution of power. On the other hand, the democratic approach hopes to put some capacity for control in the hands of the service user and provide 'user led' services; this is a more liberatory approach.

Fraser (2005) describes three components that must be met in order to achieve true participatory parity and ultimately social justice: recognition, redistribution and representation. Recognition and redistribution require the removing of social status inequalities and resource inequalities that stand in the way of equality. Representation refers to having political guidelines that allow the parity of participation, i.e. having a voice. The reality is that equality rarely exists in practice. As suggested by Hickey and Kipping (1998), a continuum of SUI exists; stretching from the consumerist (e.g. Bhui, Aubin & Strathdee, 1998) to the more progressive democratic approaches (e.g. Barnes & Shardlow, 1997) at the top of the hierarchy.

Perry et al (2013) found that a lot of SU consultation is happening as a result of policy initiatives to conduct SUI, however, there is relatively little joint decision making or leadership. Whilst the government and organisations portray SUI as a mechanism of social justice, the service-user movement continues to be dissatisfied with approaches that in no way address the inherent power imbalances. It is possible that this is because in many organisations meaningful involvement is not happening (Bennetts, Cross & Bloomer, 2011; Rosenberg & Rosen, 2012), and 'tokenistic' (Arnstein, 1969) consumerist approaches are still commonly used in the form of placation and consultation.

1.2.5.1 Participatory and Action Research

'Participatory research and action research are two of the most important methodological approaches to involving the public in health research' (Boote, Wong & Booth, 2015). They are both examples of progressive democratic approaches. Participatory research is the process of producing new context bound knowledge through working collaboratively with the affected population,

with the aim to educate or effect social change. Action research is a reflective process between the researcher and population in which the population collects and analyses data with the sole purpose of determining what action is to follow. In both of these approaches the populations that are affected play a leading role in the research process and the interaction between the population and researchers benefits the research.

Participatory action research sets out to improve health and reduce health inequalities by working in partnership with communities, who then take action to improve their own health and the health of those around them. It again utilises reflective enquiry, and increased knowledge can improve the practices of the population and the situations in which they find themselves (Baum, MacDougall & Smith, 2006). Participatory action research ensures that power is deliberately shared between the researcher and the population; in this way they become partners and the participants become active researchers. This approach has been seen as a method of overcoming professional dominance, improving strategies, and committing to democratic principles. Participatory Action Research can be linked to Foucault's theory of power resulting from the interactions between people and the exertion of different forms of knowledge. Thus by becoming active in research agendas and increasing knowledge through reflection they are becoming more powerful agents. This approach is that which the BRC wishes to move towards.

Burns (2007) commented that there is a danger in action research for the facilitator's opinion or reflections to be given authority due to their positional power. He highlighted that the facilitator's perspective is only one perspective of the different stakeholders who uphold differing positions, and should be seen as such. He discovered that, at its best, collaborative working with individuals of differing opinions could lead to deep collective understanding of a topic. This is most likely to happen if a facilitator holds their worldview lightly. On the other hand, if a facilitator comes into this relationship with an opinion that they then try to impose on others, the interactions can be wholly unsuccessful. There is danger of not co-producing and distinguishing participative action research from

action research grounded in 'professional' expertise. In addition, he found the success of projects was dependent on enthusiastic staff taking their insights into a work setting and opening up further discussions. These facilitators and barriers are relevant to other areas of SUI.

1.2.6 Identified Benefits

Since the rise of SUI policy and practice in the 1990's, articles have been published describing the benefits of its use in collaborative practice, research and service development across the health and social care sectors. In an analysis of SUI articles between 1970 and 2010, Millar, Chambers, & Giles (2015) collated the benefits of SUI at an individual, service and societal level; a number of these are displayed in Table 1. Whilst this is an impressive and promising list, each study did not reveal the same result and it is unclear which of these results were reported professionals or service users.

Services and research can benefit from using knowledge rooted in experience; this is the epistemological argument (Boote, Baird & Beecroft, 2010). Ultimately by being closer to the SU experience, it is assumed that SU's and carers can provide more accurate insights than their professional counterparts. Their unique experiences can be shared with the teams and services that they interact with. By introducing understanding of an individual's position based on social perspectives and context, it allows professionals to gain a greater understanding of the impact of these factors on physical and mental health, thus challenging the traditional biomedical model of healthcare (Munro, Killoran Ross & Reid, 2006). This encourages services to move away from a 'one size fits all' approach to service provision, towards more collaborative decision making processes. In addition, involving service users can stimulate staff interest in user views and diverse experiences, thus potentially increasing their ability to empathise with service users. Staff have found this process rewarding (Crawford et al., 2002), and in turn, service users are likely to feel more understood and appreciated as individuals.

Table 1. Individual, service and societal level benefits of SUI (Millar, Chambers, & Giles, 2015)

Individual Level	Service Level	Societal Level
Increased autonomy	Evidence based decision	Reduced stigma
Increased confidence	making	Greater social inclusion
Personal development	Patient satisfaction	Provision of improved
Positive experience of	Services more tailored to	mental health services
care	individual needs	Reduced burden of
Positive view of staff	Improved quality of	mental health difficulties
Decreased feeling of	services	Increased understanding
powerlessness and	Meeting policy goals	of mental health
dependency	Improved communication	difficulties
Social inclusion	between staff and service	
Improved morale and	users	
self-esteem	Raised awareness of	
Knowledge	service user perspectives	
Empowerment	Increased job satisfaction	
	Reduced complaints	
	Improved adherence to	
	treatment and care plans	
	Changed attitudes of	
	mental health	
	professionals	

Again on an individual level, the process of working collaboratively with staff, and feeling that they have more control over their own care has been found to be empowering for many service users (Harrison & Mort, 1998). It can be satisfying for those involved to know that their input can be of benefit to not only themselves, but also hundreds or thousands of other service users in the community. This participation in and influence over the care they receive has been shown to have mental health-promoting benefits (Health Education Board for Scotland, 2000); for example, improved self-esteem, and increased

confidence (Crawford et al., 2002; Tierney et al., 2014).

The Sainsbury Centre for Mental Health (2010) suggested that now SUI is prioritised, service providers are becoming more accountable to the public and responsive to their needs. This naturally moves in to a more demand led structure. Through engagement with service users, services will have more information on which to make strategic decisions on services and reduce resource wastage, thus helping to stretch limited resources further. This is more of a consequentialist view of SUI (Boote, Baird & Beecroft, 2010) emphasising the ultimate goal of improved cost effectiveness, quality, relevance and efficiency of services being offered.

Following a review of SUI literature in primary healthcare Tierney et al. (2014) reported *“the most consistent claim made was that service users offered a unique and practical expertise that added credibility to the work with positive impacts on service delivery of research. Many authors reported that SUI added real-world connection to their research, and changed the mindsets of researchers”* (p. 10). In another literature review on the effects of SUI, Crawford et al. (2002) reported that service user’s have been found to suggest changes that make existing services more accessible (e.g. simplifying appointment procedures, extending opening times, improving transport), lead to the setting up of new services (e.g. advocacy, employment support, crisis services) and some services were even kept open as a result of feedback.

There is also a moral argument when it comes to SUI; ultimately the public have a right to be involved when outcomes may impact on the services they can receive, or their health status (Boote, Baird & Beecroft, 2010). We could argue that the changes to how services are evaluated came too late and acknowledge many years of lost opportunities.

1.2.7 Challenges

Professionals and service users alike have identified challenges and barriers to the successful employment of SUI initiatives (Barnes, 2007; Gordon, 2005). Barnes (2008) has even suggested that the potential dangers of utilising SUI in formal governance outweigh the possible gains. Millar, Chambers, & Giles (2015) identified that despite SUI being advertised as something that decreases inequalities between SU's and professionals, inequality is not addressed and therefore often remains, thus reinforcing feelings of powerlessness, injustice and lack of respect (McDaid, 2009). Radermacher, Sonn, Keys, and Duckett (2010) provide a critical stance on SUI, commenting on the perceived powerlessness of people with disabilities when placed within the structure and culture of large organisations. If individuals feel powerless, SUI becomes a more symbolic or tokenistic activity (Beresford, 2005).

Wright (2015) discovered that even in organisations where service users must make up the majority of the board for state healthcare services, they often lack authority and non service user board members dominated the decision making process. Board members without professional training viewed themselves as less competent than more highly trained counterparts and thought that their opinion would not be valued enough to impact on decision making, thus allowing the more dominant participants to take control (e.g. Partridge & White, 1972). If this is the case, service users who have constructive criticisms to offer are unlikely to feel confident enough to share them; this creates a feedback bias. Coming from a lower socio-economic status can have a further silencing effect. Thus simply being present at service planning and evaluation was not enough to have influence over the decision making process and the voice of service users was often lost (Sabin, O'Brien & Daniels, 2001). Similarly, Horrocks, Lyons & Hopley (2010) found that SU's presence in board partnership meetings was largely symbolic.

Wright (2015) also learned that the majority of service user board members were not demographically typical of the population they set out to represent, for

example, the majority were middle-class and had business or management experience. The representativeness of service users is a concern that comes up frequently in the literature (e.g. Omeni et al., 2014). There have even been suggestions that those coordinating SUI initiatives are selecting service users with views that are in line with the model already being used within a service, and thus fit into the organisational structures (Bramwell & Williams, 1993). This offers a biased view. Participants in Lewis' (2014) study grew silent when deliberations revealed consensus amongst other staff and participants present at meetings, hence motions were 'passed' that people were not happy with. This tended to lead to frustration and guilt. Instances like this give the impression of democracy as those affected were given the opportunity to influence outcomes (Young, 2000), without truly being democratic.

Consequently *'not only do some voices need to be brought in, some voices need to be muted'* (Dovi, 2009). Munro, Killoran Ross & Reid (2006) found that stigma and discrimination of certain groups means that individuals may be more reluctant to even come forwards for SUI initiatives and consequently those involved are predominantly white, middle class and educated; thus risking the reinforcing of existing localised and national inequalities. Consequently recruitment requires careful planning to counteract this uneven weighting, making it a challenging and time consuming process.

Tensions exist between meaningful involvement and balancing competing agendas; this can be both confusing and stressful for staff members coordinating SUI. Within many organisations the views of service users are just one of many factors influencing change; in many cases commissioners or trustees retain the final authority and decide how much weight is attached to the views of service users. When these authorities prioritise SUI, the issue remains that staff lack resources to fulfil the SUI initiatives (Crook, Tomlins, Bancroft & Ogi, 2015) or fully support those who become involved. Thus, it is hardly surprising that literature reviews in the field reveal that professionals are often not involving SU's in any meaningful way (Gibson, Britten & Lynch, 2012). Others are more sceptical about the voice of service users, believing that their

involvement is not intended to devolve power. Instead it can serve to protect professional power (Barnes, 2000), and legitimise decisions that have already been made by management (Shaw, 2001; Crawford et al., 2002; White, 2003). Simply utilising the terms 'collaboration' and 'partnership working' can help to conceal some of these difficulties. Some SUI participants have highlighted that the 'right type' of service user representatives are often utilised to support or advertise particular agendas (Patterson et al., 2014). When service users are invited to participate but never do the inviting themselves, partnership working is not operating. Involvement can thus leave service users frustrated that their feedback or input did not have the expected impact (Carrick, Mitchell & Lloyd, 2001).

Engaging service users effectively and consistently is time consuming and requires adequate personal and practical support (Solomon & Draine, 1996). Hossack & Wall (2005) explained that it is important that service users receive training and supervision in a similar way to qualified professionals. This training and supervision takes staff away from their regular tasks, therefore, a pursuit that is intended to provide additional resources can actually use more than it produces. Understandably this can impact on the enthusiasm of staff to allocate their time to get involved and persist with engagement activities. In services where resources are already scarce and staff members are overloaded, it is hardly surprising that SUI isn't being addressed consistently or regularly. The least time consuming approaches to SUI, and most frequently used, are satisfaction surveys or brief consultations like focus groups; but these involve little genuine partnership or collaboration.

Dissatisfaction with the process of SUI has been reported by service users, who describe difficult relationships with staff (Crawford et al., 2002). Discrepancies between the views of service users and professionals have been widely acknowledged (e.g. Campbell, 2001; Coulter, Peto & Doll, 1994) and the introduction of patient choice has highlighted the potential for service user authority to conflict with professional authority (Rhodes & Nocon, 1998). Service users and professionals have different objectives, beliefs and priorities; for

example, service users rate quality of life as a more important objective than professionals (Thornicroft & Tanella, 2005) and many service users believe in the social model of disability (Morris, 1996). Operational or professional agendas often drive interactions and decisions (Tierney et al, 2014). The continued dominance of the medical model in some organisations perpetuates positivist approaches to evaluation and development, thus closes down opportunities for hearing the voice of service users. Several literature reviews found no evidence that professionals in charge of coordinating SUI believed it to be a worthwhile or valuable way of working (Tierney et al, 2014). Hossack and Wall (2005) stated that some professionals simply do not seem to appreciate the contribution SU's could provide.

When little training and education are provided to staff on the potential benefits of SUI, its importance within organisations can be lost (Tyler, 2006). Unfortunately even when organisations seemingly endorse SUI and acknowledge the unique contribution made by individuals who have used services, there remains resistance to the non-professional view. Middleton, Stanton & Renouf (2004) used the terms 'service red' and 'service green' to represent service readiness for change; this takes into account several organisational aspects that impact on the work of SU consultants. Stigma, service culture and resistance to change were all areas identified as key barriers to effective SUI, thus should be addressed by organisations wanting to approach change.

Studies have highlighted fear within organisations that too much user involvement would lead to unrealistic expectations (Hirschman, 1970), requests for expensive medical care or care that is inappropriate. In order for SUI to be effective, organisations need to be responsive to the feedback they receive from SU's. This becomes more challenging in the current age of austerity where the resources necessary to implement suggested ideas are not available. When changes do not happen, SU's can feel like they are being ignored. Thus it is important that services are clear about the resources available and limitations to changes that can be made.

Ultimately, in some cases the perspective of the professionals has been that SUI complicates and slows down decision-making progress (Todd et al., 2000). McGowan (2010) challenged the idea that services should involve SU's whenever they can. Whilst he acknowledged that SU's do have valid feedback to give on certain aspects of services, and the contributions of staff alone can be limited, he accepted that there are times in which it can be difficult to see the benefit of SUI. Utilising the analogy put forward by Matt Muijen "If you want to know about a restaurant you should ask the diners," McGowan (2010) retorts "we all know what we like to eat, but this doesn't mean we have any idea how to run a restaurant." He observed in practice that some contributions are misinformed and driven by personal agendas; this ultimately does not benefit the rest of the community individuals serve to represent. Unfortunately, for staff it can feel very difficult or even inconceivable to challenge the contribution of SU's and carers in the room, thus they do not, simply ignoring contributions they regard as inappropriate. McGowan makes a hugely valid point that if staff and SU's cannot engage in transparent conversations, the usefulness of SUI is lost. The idea of suggesting that SU's require training to understand the business or meet certain requirements in order to participate questions the value of experience alone. He concludes that open debates are the primary way forwards for SUI.

Kitcher (2003) also believed in the transparent bidirectional flow of information between the professionals and SU's; with SU's teaching professionals on personal meanings, social values and political implications of their knowledge and professionals teaching SU's about the knowledge base in that particular area e.g. conflicts and successes in research, therapy or competing agendas. He called this an 'enlightened democracy' as all individuals involved contribute in an informed way and aid professionals in balancing competing interests, plus learning from each other. When SU participants are aware of the conflicting agendas it is less likely that the mentioned challenges will occur e.g. asking for services that are impractical. This is a long-term goal and takes a lot of investment, in addition the problem of representativeness remains.

As identified within this report, successful social movements emerge from a collective desire for advocacy and change. In many cases, the experiences of injustice link to a core aspect of their identity, for example, being women. These are important considerations when establishing SUI activities within organisations because the individuals approached to participate are unlikely to have the same passion and drive as any activists who voluntarily join or develop groups. As a result, the impact of such approaches to SUI is likely to be restricted, especially when the topic of discussion is not something participants have identified as an issue.

1.2.8 Power and Discourses in SUI

Key factors in the difficulty experienced by those coordinating and participating in SUI initiatives are the power and discourses surrounding it. Whilst there are some strong advocates for SUI, a lot of resistance remains amongst professionals. These considerations, in addition to those already identified, may go some way towards understanding the discrepancies between governmental policy and SUI in practice.

Moving away from the traditional roles of staff and service user can be destabilising for everyone concerned. Positioning theory (Harre, 1999) considers the narratives people use to position themselves and others; particularly the rights and duties of individuals. Considering positioning theory in relation to the staff and service user relationships can be extremely helpful. Staff are likely to position themselves in certain ways, e.g. as a professional with specialist knowledge, the introduction of SUI could be seen as calling this position into question and devaluing it. This can leave staff feeling threatened and thus they may try to further assert their power and position. By utilising technical language they are able to position others in a less powerful position and exclude them from certain conversations.

In much the same way, SU's often experience discursive regulation when brought into a pre-established professional domain that does not sufficiently adapt to their presence. This has exclusionary implications and advantages for

the dominant groups (Barnes, 2002; Young, 2000). As revealed in previous studies (e.g. Wright, 2015), individuals with a professional background will feel more able to attend and contribute, whilst those without will be left feeling silenced (Lewis, 2014). Utilising the pre-existing processes is therefore unlikely to change outcomes (Young, 2000). Quantifiable data is prioritised, and consequently specific knowledge, experience and emotions of service users can be easily discounted (Carr, 2007). Thus simply involving SU's in managerial practice that is already happening has been deemed inadequate by many (e.g. Carr, 2004; Lewis, 2005) because it fails to engage with these inequities. Activists within the service user movement value the open expression of emotion connected with their identity as a service user, a position that is at odds to a management approach (Carr, 2007).

Ultimately organisations find themselves in a difficult position; providing further training and information to SU's could indicate that organisations do not value their experience alone, whilst withholding information can be seen as a way of denying equal status (Lazar, 2005). As indicated in a study by Lewis (2014) SU's viewed training on organisational working as valuable (Lewis, 2014), whilst others rejected this idea, believing that political inclusion requires openness to differing communication styles (Young, 2000).

Beresford (2005) commented that research initiated and controlled by SU's has also been seen as contentious because it privileges only one perspective and moves away from the traditionally valued approach of 'neutrality', 'objectivity' and 'distance.' Ultimately this type of research is seen less credibly and receives minimal research funding, meaning SU researchers find it difficult to gain support (Beresford, 2005). There appears to be reservations about SU research, and it has not developed the same credibility and legitimacy as traditional research approaches. SU's are viewed as 'close to the problem' thus claim that they are not neutral or objective, and therefore a less reliable knowledge source. These attitudes can be applied to all forms of SUI, and consequently individuals involved in SUI are likely to be further invalidated.

Foucault saw power as a source of social discipline and conformity. Rather than the physical forms of control, attention shifted to administrative systems and social services, for example, the introduction of psychiatric hospitals. He became fascinated by the way power surpasses politics and drew attention to how society has been socialised into norms of behavior and deviance (Foucault, 1991) to such an extent that we self-police without coercion. Thus the government is able to control but from a distance, whilst individuals feel that they are in control and have independence. As the SU movement arose from resistance to the abuse suffered at the hands of the medical model and the psychiatric system, SUI could be seen as a way of being more responsive to the requests of the service user movement. It could also be viewed as a further form of social control. For example, a governmental policy to involve SU's in initiatives could be seen as one way of stopping individuals who have been helped by services from becoming unwell again by involving them in work. This keeps them in the system and is a way of both monitoring and controlling. It also fits in with the governmental objective of getting people back to work, even if voluntary, to feed back in to the economy.

Whilst Szmukler (2009) concluded that more progress has been made in SUI in mental health than any other area of healthcare, the voices we hear both in the literature and in practice are limited, and the vast range of SU experiences are not heard. As previously mentioned, those most commonly heard represent a smaller subset of the community or interest group and are prevalent in the service user movement, e.g. Rufus May and the Hearing Voices Network. When a few large well-established SU groups are strongly publicised, there is the risk that society believes SU's to be a homogenous group and alternative experiences become lost, thus perpetuating inequality and disadvantage. The individuals accessed by services are assumed to represent that population, but this is rarely the case.

1.2.9 Where Now for Service User Involvement?

Social Care Institute for Excellence (SCIE) led research revealed that “there is very little monitoring or evaluation of the difference service user participation is

making” (SCIE, 2004). Others have also found that few studies have empirically tested the positive impact of SUI (Simpson & House, 2002; Campbell, 2005) and evidence of change resulting from SUI is scarce (Crawford et al., 2002; Campbell (2001). There is a lack of knowledge about what constitutes successful SUI (Munro, Killoran Ross & Reid, 2006) and little thorough evaluation of SUI initiatives. With limited time and resources in many services currently, guidelines on the process of engagement would be invaluable to staff; this should include how to recruit, training and support needed, and how to balance the opinions and input of service users, staff teams and commissioners.

There is no doubting that service users have unique perspectives and knowledge arising from their direct experience of a particular situation or service use (Hossack & Wall, 2005). This needs to be used to complement professional knowledge and expertise, not compete with it. Judd (1997) stated that tackling the mismatch between attitudes of professionals and service users on the approach to care is central to SUI. Methods of engagement should be agreed and planned alongside service user representatives. Given the barriers identified, those staff passionate about SUI need to think and act innovatively to get others on board (Munro, Killoran Ross & Reid, 2006) and move forwards to a more strategic plan.

Keeping service users engaged with SUI activities should also be high on the agenda. It has been reported that service users often do not see changes in services or receive constructive feedback on their involvement (Tyler, 2006). If changes are made and not fed back, it is unclear to service users whether anything has changed at all (e.g. Stringer et al., 2008). Providing feedback to service users is an important way of providing them with evidence that the time they spend and information they provide is being acknowledged and put into action. Without this, motivation in taking any further part in future participation ‘opportunities’ declines (Tyler, 2006). Repeated disappointments with involvement among specific communities can uncover feelings of disillusionment with the process, which Beresford (2002) named ‘consultation

fatigue'. This ultimately leads to resistance to partnership and collaborations with services or service personnel (e.g. Johnson, 2006).

Whilst time has been spent reporting barriers to effective involvement, biases, and models of involvement, this is often from the perspective of professionals in the field. The voices of service users involved in these activities are far more scarce (Tierney et al., 2002) and relatively unarticulated in the literature. Given the key roles that service users are expected to play in improving the quality and efficiency of organisations, it is essential that we listen to their views on the strengths and weaknesses of SUI as it operates currently and what can be done to improve the process.

1.3 The Voluntary Sector

The voluntary sector or third sector consists of a diverse range of non-profit groups, societies and organisations that exist to enrich communities; for example, charities, community organisations, trade unions and faith groups. Historically charitable organisations in the United Kingdom have filled the gaps of statutory services or complimented services already running. In the 2012/2013 financial year an estimated 160,045 voluntary organisations existed in the UK undertaking a diverse range of services and activities (NCVO, 2015a). The National Council for Voluntary Organisations (NCVO) estimate that the voluntary sector's gross value added (GVA) is £12.1 billion, equivalent to almost 0.7% of the entire GVA of the UK (NVCO, 2015b). This value is based only on the value of paid work within the charitable sector, with volunteer output in the UK estimated at £23.9billion (ONS, 2013). Bubb (2011) defined the UK's charity sector an 'untapped resource waiting to be used'. The BRC is one of the largest of these charities by spending; in 2013/14 it saw an income of £228.4m and spending of £231.7m (NVCO, 2015a).

Many voluntary sector organisations are service user led and set up by the people, for the people. Thus the ways that service users engage with the staff of these organisations appears to differ from that of statutory services; for

example, there are differing perceptions of the status and power of the staff involved. In addition, the development of an organisation or group is often the result of disappointment with mainstream services or the belief that the available services do not appropriately cater for their needs. There is an element of choice when engaging with voluntary service that those utilising public sector services will not experience. In addition, individuals receiving support have no prior expectations of the services they should receive. By publicising the policies and guidelines of statutory services, the UK public have expectations of what they should be receiving from public providers. Charities appear to bypass these expectations even when delivering statutory services.

The existence of voluntary organisations can provide the government and statutory services with essential information on what is missing from state provision or which statutory services are failing to meet the needs of the population. These organisations often find innovative ways to give voice to and make a difference in a specific subset of the community, examples include:

- Mumsnet is an online network set up by parents to share information and advice. The organisation is also politically active and launch frequent campaigns, for example, group members wrote to local MP's and NHS Trusts complaining about sale representatives on maternity wards, which resulted in several Trusts revising or cancelling these contracts.
- Gendered Intelligence was set up to increase understanding about gender diversity and supports the trans community, especially individuals aged 8-25. They deliver trans youth programmes, support for parents and carers, professional development and trans awareness training for all sectors and educational workshops for schools, colleges, universities and other educational settings.

There are many different motivations for groups evolving. As described, voluntary organisations can result from collective action or advocacy, aim to empower and often represent communities who might not otherwise be heard. They are often closely linked to social movements or created to respond to

particular outcry, e.g. the Stephen Lawrence killing. Thus voluntary organisation's independence has been referred to as vital in keeping the confidence of their service users (NVCO, 2015c). As SU groups have called for a shift away from medicalised provision towards social and community approaches, and statutory services have yet to embrace alternative approaches, charitable organisations are continuously being set up to counter these inadequacies. In addition to providing both statutory and non-statutory services, if supported "voluntary organisations can shape and deliver a new generation of user-led, co-produced public services" (NVCO, 2015d).

1.3.1 The British Red Cross

The Red Cross and Red Crescent Movement were established as relief organisations to provide support for those caught up in conflict (Dunant, 1986). Seven Fundamental Principles underpin the International Red Cross and Red Crescent Movement and are adhered to by all staff and volunteers; these are Humanity, Impartiality, Neutrality, Independence, Voluntary Service, Unity and Universality. The BRC provides support for individuals and communities who experience conflicts, natural disasters or individual emergencies. As such, they assist individuals all over the world in preparing for, dealing with and recovering from crises. Short-term crisis support can aid recovery and avoid the development of long-term ill health, harm or exploitation.

The BRC offers a myriad of services to a diverse service user population. Their services come under several broad categories including: Humanitarian Action, Health and Social Care, International Family Tracing and Refugee Support. The organisation depends heavily on a network of volunteers who help to run the services provided, plus monetary contributions from members of the public and organisations.

Within the BRC a single psychosocial framework is utilised across all BRC services and departments; meaning that services provide psychosocial support, as well as meeting the practical and physical needs of those people affected by an emergency. *"Research suggests that psychosocial support is key in*

providing effective help to those in crisis. As well as helping people to cope, psychosocial support can reduce anxiety and pain, increase wound healing and promote overall recovery” (Davidson, 2009). The framework acknowledges the multidimensional psychosocial needs of individuals and communities and emphasises the need to tailor responses to the individual or community. Involving service users in planning, implementation and evaluation should be central in this process.

1.3.2 Service User Involvement in the British Red Cross

Every four years the BRC has a strategic review. The last, covering 2010-2015, focused on the wellbeing of communities and saving lives, advocating for changes that improve the lives of vulnerable people (BRC, 2009). Within the strategy there was an emphasis on the valuable work volunteers do and there was a re-focus on putting the needs of those most vulnerable to crisis at the centre of their work. ‘Refusing to Ignore People in Crisis’ (BRC, 2014), their corporate strategy for 2015-2019, had further ambitions to place people in crisis at the heart of their services. Two key statements from this strategy are; *“By the end of 2019, we will have put people in crisis at the heart of our work by listening, understanding and responding to their needs. All of our services will be designed around them”* and *“In order to ensure that service user involvement becomes part of our day to day work and not an ‘add on’ the value and uses of service user involvement will need to be shared and communicated across the organisation”*.

In addition to the guidance set out in ‘Saving Lives, Changing Lives’, the BRC has already won several statutory contracts in which SUI is a compulsory element of commissioning requirements. As a result, there are already pockets of SUI activity across the different services of the BRC and its wide geographical area. This is set to increase significantly with the changing trajectory of the most recent strategy ‘Refusing to Ignore People in Crisis’. Focus groups and volunteering appear to be the primary method of service user engagement in the BRC. An in-house training is provided on how to conduct focus groups to maximise feedback from service users. Within volunteering,

councils have been established in order to enhance engagement and consultation with the organisation's volunteer base and provide a contribution to Board policy. Waikayi, Fearon, Morris and McLaughlin (2012) conducted interviews with volunteers at BRC shops across the UK; they discovered that volunteer retention is attributed to proactive, friendly and positive management style. Benefits of volunteering included social interaction, acquisition of training and skills, plus self-satisfaction from helping others, being part of the BRC and knowing they are doing something valuable for the local community.

The Research, Evaluation and Impact Department at BRC confirmed that no service-wide research has been conducted on the experience of individuals involved in SUI in the Red Cross. It is unclear whether smaller service specific studies have taken place that this department was unaware of, however, departments contacted during the course of the study were not aware of any. Below is a summary of several SU related activities that have already taken place in BRC in recent years.

The 'Five Minutes of Your Time' project trialled a new way of collecting service user feedback, but unfortunately yielded minimal data collection. The coordinating staff utilised this opportunity to uncover challenges in feedback collection; discovering that the most significant barrier to feedback was staff and volunteers not 'buying-in' to the project for reasons such as capacity or lack of understanding of the value of service user feedback. These discoveries mirror the outcomes of previous literature identifying the common barriers to effective SUI in the public sector. Professionals are likely to assist in services user involvement if it is a policy imperative, but often aren't educated in or fully appreciate SUI as a worthwhile or valuable way of working (Tierney et al, 2014). Lack of resources again tends to impact on the enthusiasm of staff to get involved with engagement activities.

Learning from service user engagement activities was the theme of the 2015 organisational learning publication, an internal peer review journal (BRC, 2015). The journal highlighted various ways in which service users were being

engaged in providing feedback within the organisation. One study summarised key findings from service user feedback on changes to be made to Refugee Support and International Family Tracing services. Staff found that no service users were aware of how the service was run other than the direct support they received, for example, support via drop-in. They were therefore unable to comment in any meaningful way on the proposed topic of discussion. Language was also a concern for many; highlighting the need for more translated documents or interpreters at future SUI events.

SUI activities within the organisation have yielded mixed learning points (BRC, 2015). Many staff discovered that engagement offered them the opportunity to learn more about the wants and needs of the people they were working with. They realised that it takes encouragement for individuals to attend events and even if you facilitate their attendance, individuals may still drop out. Staff also found it difficult striking a balance between individuals who came along to events and said nothing and those who dominated the conversation. Another finding was that BRC service users are often very grateful for any support they receive, thus staff struggled to collect data on what services could improve or do differently.

The BRC have been utilising systemic action research for over a decade and this is set to increase. Burns (2007) documented one such project between SOLAR and BRC staff, and volunteers, focussed on helping the organisation to identify areas of vulnerability to service use. He discovered that although volunteers were extensively consulted initially, knew of the project and were invited to events, they attended less overall when compared to staff. SUI within the organisation was revealed as a challenge, with some taking place but this being limited. Burns hoped that the trend would continue and become more established within the organisation going forwards.

1.4 Rationale for the Study

Third-sector organisations have the opportunity to play a greater role in delivering health and social care and this trend is set to continue. Many voluntary sector organisations already have a financial relationship with the government, with a third of voluntary sector funding coming from contracts and grants from statutory sources; this amounts to £13.3 billion (NVCO, 2015e). In the past decade, this has increased significantly and much funding now comes from payment for the delivery of public services like housing, health and social care. This suggests that the voluntary sector has become a more important economic contributor and a real player in the provision of public services.

While the economy has been slowly growing for the past few years, the voluntary sector is yet to feel any positive impact in terms of its income and continues to face a challenging financial environment. Austerity and cuts in government spending have meant that less money is being spent on services, however, the voluntary sector still only receives a small proportion of the funding and contracts available. Whilst the government spends £182.3bn on purchasing goods and services, and £56.3bn on grants and subsidies, the voluntary sector receives only 6% and 4% of this money respectively (NVCO, 2015c). This shows that there is funding to be claimed if the voluntary sector can compete to the same level as public or private organisations when tendering for public sector contracts, for example, in health and social care. CCG's, who now decide who takes on statutory services, require SUI to take place in all services. Although national legislation like the Health and Social Care Act (DoH, 2001; DoH, 2012) does not currently have jurisdiction over organisations like the BRC, they must move with the times and develop a successful SUI strategy in order to win these contracts.

The previous sections have discussed at length the challenges for SUI within all organisations, it is clear that an improved strategy needs to be identified. Disorganised or tokenistic approaches may lead to further discrimination, thus participants are likely to withdraw from initiatives. Without their vital input time and

resources can be wasted, leading to increased likelihood of losing contracts and funding further down the line. SUI in organisations with diverse populations like the BRC have an even greater challenge in coordinating SUI, for example, recruiting a 'representative' service user group. To date, research on SUI in large third sector organisations has been limited and the researcher was unable to identify research of this kind completed in the BRC.

It is clear that the success of previous social movements has encouraged further social action to take place, with individuals learning that collective action can lead to increased power and change. This is especially true for the service user movement. Despite their successes, however, throughout history social movements have faced conflict within and between groups and organisations about strategies for change and debates over exactly who comprises the constituency that these movements represent. For example, many LGBTQ organisations operating from different contexts have evolved from the gay rights movement; over time organisations have evolved and splintered. This indicates just how challenging it is to work in partnership. The health and social care systems and large organisation like the BRC contain many different SU groups, each comprised of individuals with diverse and potentially conflicting experiences, perspectives and ideas for change. The vast number of active groups set up illustrates this. Large diverse groups are significantly more challenging to consult as energy and focus are dispersed. This creates complexities in who to approach to obtain the voice of the service user or carer and how to take action. Consequently, the marshalling of SUI has been simpler with single issues. The Hearing Voices Network is an example of a successful single-issue activist group with a core identity and clarity in what they are campaigning for. Those with large diverse populations need even more support to discover effective strategies.

In addition, the BRC is a good example of a large organisation that has identified the need to meaningfully engage service users in the delivery, planning and evaluation of the services they provide. Placing service users at the center of their work has been explicitly on the agenda since 2010. This

study should go some way in discovering how they are doing on this so far and how far they have yet to go.

1.4.1 Personal Motivations of the Researcher

The researcher's interest in SUI developed as a result of both personal and professional experiences. Personally she knew individuals who had used statutory mental health services and the services of charitable organisations and over time taken opportunities to discuss these experiences with them. What struck her about their accounts was that individuals had such varied experiences of perceivably similar services. One pervasive element arose in the majority of accounts; individuals had felt that they were not 'in charge' or consulted on what they wanted. In essence, they had not gained a sense of ownership over their care.

The researcher's decision to pursue this subject matter was further influenced by her drive towards incorporating the service user voice into all services and resulted from previous professional experiences. The researcher was very active in SUI activities in several previous roles and looked back at one such service, which utilised a partnership approach to service development, as a standard against which she assessed the approach of other services. As the researcher progressed through training, she began to recognise that SUI was very rarely in the forefront of services' minds and at times appeared to be omitted completely. She had also been present at service user group meetings in which participants had vocalised their frustration with services that were not 'listening' to them; these individuals became disillusioned with the process of SUI and disengaged. Consequently, the researcher embarked on this project from a position of greatly valuing SUI and feeling frustrated that this valuable resource was often utilised ineffectively.

1.4.2 Relevance to Clinical Psychology

A number of reasons justify the relevance of this study to clinical Psychology. Firstly, the current financial climate in the health and social care sectors requires services to adapt and become more efficient in order to assist budget savings. One way of doing this is to prioritise short-term services, both preventative and crisis interventions, over longer-term continued support. Cumbria Partnership NHS Foundation Trust's Short Term Intervention Service is an example of a service already offering short-term crisis support. As the BRC provides short-term crisis support, this research will not only provide an insight into how they could tackle the challenge of SUI as an organisation, but also how best to engage individuals in SUI as more services move towards short-term input. The current literature on SUI is predominantly conducted within organisations offering longer-term support where relationships can develop between staff and service users, e.g. mental health services.

Psychology plays active part in bringing the voice of the service user into the fields of physical and mental health, for example, within a multidisciplinary team or supporting the survivor movement. The British Psychological Society's Code of Ethics and Conduct (BPS, 2009) states that Psychologists should "*Respect the knowledge, insight, experience and expertise of clients, relevant third parties, and members of the general public.*" (p.12) Thus highlighting that we should be attending to the experiences of service users and making SUI our business. Ultimately, the policy directives on SUI are clear, and service user input into organisations is set to continue.

The diversity of the client group of the BRC emulates that of an NHS Trust, thus difficulties identified should be relevant and applicable to the NHS. If we can develop an understanding of the experience of individuals currently involved in SUI initiatives in the BRC, this may go some way towards explaining the current resistance and barriers to effective involvement and move towards more systematic and meaningful methods. Any addition to the knowledge base, especially prioritising the experiences of the service users themselves, is

relevant and applicable to involving service users in the public or private sector.

1.5 Research Questions

Concluding from the above literature, and drawing on their professional experiences, the researcher identified the research problem as: Organisations' difficulty in developing meaningful SUI strategies, especially those with diverse populations, e.g. the BRC. This research aimed to go some way in understanding how organisations can better approach service user involvement by answering the following questions:

- What are participant's experiences of their involvement in British Red Cross service user involvement initiatives?
- What factors influence their participation and continued participation?

This research set out to evaluate service user satisfaction in BRC initiatives, but also provide feedback to the BRC on the strength of their partnership working. If there were reasons why partnership working was not visible or effective, these were to be outlined.

2. METHOD

This chapter describes the methodology used to approach the research questions outlined in chapter 1 of this report. First explaining the researchers epistemological stance, choice of approach to data collection and analysis, and reflexivity. The design and procedure of the study is outlined, identifying key ethical considerations and concluding with an overview of the analytic process.

2.1 Epistemology

'Epistemology is a branch of philosophy concerned with the theory of knowledge' (Willig, 2012; p.4). In order to conduct research, it is important to adopt an epistemological position. Willig (2012) identified three main epistemological frameworks for qualitative research: realism, phenomenology and social constructionism. Realism assumes a direct relationship between reality and what is observed, thus a researcher believes that they are able to uncover this reality through research. Social constructionism acknowledges multiple realities, which are mediated by history, culture and language. Critical realism is positioned between these two standpoints (Harper, 2012); thus data can inform us about reality, but does not directly represent reality.

This study was approached from a critical realist perspective, due to its suitability to the research questions and fit with the beliefs of the researcher. The researcher acknowledges that there is a 'reality' to the experiences of the participants, but this is not an objective reality. The researcher recognises the possibility of alternative accounts and acknowledges their own influence on the data collection and analysis processes. Thus reflexivity is an essential part of this approach, considering how the social, historical and political context of the researcher and participants shapes their unique experiences. The content of the interview accounts were explored and required further interpretation using outside evidence, knowledge or theories (Willig, 2012).

2.2 Data Collection and Analysis

2.2.1 Qualitative Approach

‘There should be no more need to justify the use of qualitative methods than there is to justify quantitative methods’

(Willig & Stanton-Rogers, 2008)

This study took a qualitative approach to data collection and analysis due to the exploratory nature of the research questions posed. Barker, Pistrang and Elliot (2002) recommend a qualitative approach to exploratory research aimed at understanding experiences and processes, both key aspects of this research. Whilst a quantitative approach may have created a more generalisable data set, it would have limited exploration to several chosen variables, based on theoretical justifications (Yardley, 2000). As the literature search revealed limited first-hand knowledge on the experiences of individuals participating in SUI initiatives, the researcher felt it unwise to limit the variables. Hence a small-scale qualitative approach seemed the best fit to openly explore individual experiences and motivations, plus allowed the opportunity to expand on areas of discussion. Equally, smaller participant numbers allowed for the consideration of the context of the participants involved.

The quality of the research will be assessed using Yardley’s (2008) criteria.

2.2.2 Semi-Structured Interview

Two approaches to data collection were considered for this study; focus groups and individual interviews. Whilst focus groups can stimulate varied discussions, participants are more likely to divert from the topic of investigation during group discussions and some individuals may not feel confident or comfortable enough to contribute (Braun & Clarke, 2013). This means that individual voices can be lost. It is important that each participant has the opportunity for his or her perspectives to be explored and included equally, hence the researcher chose to utilise individual interviews. In addition, as participants were spread across vast geographical areas, the practicalities of arranging focus groups would have

been complex and costly.

Interviews have been deemed 'ideally suited' to experience-type research questions (Braun & Clarke, 2013). A semi-structured interview style allows the participant to raise unanticipated topics, thus allowing the discussion of novel data. In addition, the researcher was able to ask follow up questions and clarify anything that was unclear. Wilkinson, Joffe and Yardley (2004) proposed that semi-structured interviews should contain 5-7 prompt topics; providing a loose structure and ensuring that each participant covers the same central areas of discussion. The seven prompts used in the current study were:

- How the participant became involved in SUI.
- Reasons for becoming involved.
- What they did (the process of SUI).
- How they experienced it.
- Positive and negative aspects of their involvement.
- Observed changes made following feedback.
- Whether the participant would continue to take part in SUI.

2.2.3 Thematic Analysis

Thematic analysis (Braun & Clarke, 2006) was used for data analysis due to its epistemological flexibility; it can be applied across a range of theoretical and epistemological standpoints and is well suited to a critical realist approach.

Thematic analysis allows the 'gleaning of knowledge of the meaning made of the phenomenon under study by the groups studied and provides the necessary groundwork for establishing valid models of human thinking, feeling and behaviour' (Joffe, 2011). This study aimed to better understand the meaning made of SUI activities by participants in these activities and do so in a 'bottom-up' way. The resulting themes highlighting the most salient features of the data set and considered individual contexts to aid understanding. In addition, thematic analysis provides an accessible account for a wide population; given the diversity of the participants and BRC staff, this is beneficial to the present study.

Interpretative Phenomenological Analysis (IPA; Smith, 1996) was also considered as an approach to data analysis. This approach would have provided a deeper exploration of how the participants made sense of the phenomena of SUI. Thematic analysis was found to be more appropriate as it allowed for a broader exploration of participant's experiences of SUI, and factors affecting willingness to participate. In addition, participants in research utilising an IPA approach are recruited to represent a homogenous sample; in this study the researcher intentionally kept the inclusion criteria broad in an attempt to discover similarities between accounts given by diverse individuals. Even if this had not been the case, homogeneity could not have been guaranteed because the recruitment process approved by the BRC meant that the researcher handed over control of recruiting appropriate participants to BRC staff.

Attride-Stirling (2001) believed that qualitative psychologists need to be clear about what they are doing and why and include 'how' they conducted their analysis in their reports. Braun and Clarke's (2006) thematic analysis guidelines provide a more systematic approach to qualitative data analysis; meaning that the study is more replicable. Before data collection, as instructed by Braun and Clarke (2006), the following elements were considered:

What counts as a theme?	This question was considered prior to analysis, and as suggested by Braun and Clarke (2006), a quantifiable measure was not chosen. Instead at data emersion stage, the idea of themes was approached flexibly. The researcher particularly paid attention to the frequency with which an idea arose within accounts, across accounts, and utilised professional judgement to identify key ideas within the transcripts to ensure that these were represented within the final themes.
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What is the epistemology of the study?	As identified previously, this research takes a critical realist standpoint.
Inductive or deductive approach?	This study took a predominantly inductive approach, identifying patterns based on the content of the transcripts. This is not a passive process where themes ‘emerge’, thus can never be entirely objective. The researcher acknowledged their theoretical ideas about what the study may reveal, and entered the study with the knowledge of previous studies to avoid replication (Joffe, 2011). Pre-data collection and pre-analysis ideas and attitudes on the subject matter were made by the researcher, and referred to throughout the process. In addition, a reflective diary was kept; this facilitated the awareness of potential biases and kept the researcher open-minded to new ideas and attitudes.
Semantic or latent themes?	This study was predominately approached from a semantic level; going beyond description of the theme to interpretation. The significance of the patterns found and their meanings were hypothesised, and some deeper ideas and assumptions considered, for example, contextual assumptions.

2.3 Reflexivity

Willig (2013) explains that ‘*the researcher influences and shapes the research process, both as a person (personal reflexivity) and as a theorist/thinker (epistemological reflexivity)*’ (p. 25). Reflexivity refers to the process of remaining aware of the way in which the researcher’s context may influence and shape the process and outcomes of a study. In essence, being aware that the researcher and participants co-construct the research findings. Reflexivity is

an essential part of the qualitative research process (Elliott, Fischer & Rennie, 1999; Braun & Clarke, 2013).

The following positions were upheld by the researcher:

- White British female.
- Aged in her thirties.
- Brought up in a middle class family.
- Trainee Clinical Psychologist at University of East London; a course paying close attention to social constructionist teachings that emphasise context.
- Politically positioned to the left.
- Limited personal experience of using the services of 3rd sector or charitable organisations.
- Work and placement experiences of well planned and executed SUI initiatives.

Being explicit about these positions should assist the reader in situating the researcher in relation the participants and research methodology. All of the abovementioned positions are likely to have impacted on each stage of the research process; for example, the decision to pursue the subject matter was influenced by the researchers drive towards the service user voice being heard and linked to previous experience. She also developed frustration that this valuable resource continued to be minimally included or omitted entirely from services.

At interview stage the researcher considered how the aforementioned positions may have influenced what participants felt comfortable disclosing; coming from 'insider' or 'outsider' position (Le Gallais, 2008). The researcher held many insider and outsider positions throughout the process of interviewing; all of which are likely to have impacted on participant's ability to disclose certain information. For example, as a British female the interviewer held an insider position with other British females and an outsider position with African males. Equally, participants from Refugee Services could have questioned the ability of

a British national to understand the arduous asylum system and why these individuals so strongly valued supporting others going through that process.

In order to remain reflexive, the researcher noted down her beliefs and perceptions before designing and planning the research and continued to refer back to these notes regularly. Furthermore, a reflective diary was kept (excerpt can be found in (appendix K) and she met with fellow researchers to discuss beliefs and assumptions throughout the process.

2.4 Participants

Despite aiming for twelve participants, as this is proposed as a number sufficient for data saturation (Guest, Bunce & Johnson, 2006), nine interviews were conducted and included in the final analysis. This study used purposive sampling (Barker, Pistrang & Elliott, 2002); participants were selected systematically according to the below inclusion criteria. All participants were recruited from current Service User initiatives operating in two BRC services; Refugee Support and Health and Social Care. The sample aimed to span as wide a range of SUI experiences as possible.

2.4.1 Inclusion Criteria

- Participants must have both used a BRC service and subsequently been involved in SUI activity; this ensured that individuals had personal experience to draw on. Examples of SUI activity taking place at BRC were; focus groups, research, volunteering and consultation.
- BRC service leads deemed each participant suitable to be approached about the study, based on assessment of psychological and physical wellbeing.
- Individuals involved in SUI at BRC services anywhere in the UK. Those outside of the UK were excluded due to financial resources.
- English speaking to a level that did not require an interpreter. It is likely that certain terms cannot be directly translated, thus the use of an interpreter may have impacted on the participant's understanding of the

purpose of the interview or specific interview questions. Financial resources would not cover use of interpreters.

The above inclusion criteria were generated alongside the researcher's field supervisor, who has knowledge and experience in broad research from an academic and clinical background. The researcher's field supervisor is also Head of Psychosocial at the BRC and as such has direct knowledge of the organisational structures and practices.

2.4.2 Recruitment

Due to the variety of distressing life events that lead to participants accessing BRC services, it was agreed that staff would contact potential participants in the first instance. The researcher believed that staff members were in a better position to make a judgement about whether individuals could take part and ensure that they were not being coerced into participating. This initial conversation between staff and service users introduced the study and requested permission to pass on contact details to the researcher. Although ethically driven, this process required significant time commitment from BRC staff. As staff had limited time and resources, recruitment understandably became more difficult.

The researcher was initially put in contact with four members of BRC staff by their field supervisor; each staff member was identified as working in an area in which service-user involvement had taken place. Via a snowballing effect, over thirty members of BRC staff were identified and contacted by telephone or email. Staff members were located in various geographical areas in the UK and predominantly worked within Refugee Support and Health and Social Care services. Six of these staff members were able to provide the names and contact details of potential participants, nine of whom were interviewed.

2.5 Procedure

2.5.1 Pre-Interview

As previously mentioned, the researcher made contact with over thirty members of BRC staff over the course of the recruitment process. This communication required a substantial investment of time from the researcher. A large number of these staff members were unable to help with recruitment due to heavy workloads, working in inappropriate services (e.g. long term support) or no longer working in the role of coordinating SUI. Other staff did not respond to the researchers attempts at contact. Over a nine-month recruitment period the researcher was provided with the names of nineteen potential participants, of whom nine took part in the final research.

As the researcher had not had any contact with potential participants prior to research recruitment, they contacted all participants by telephone in order to begin building rapport. During these initial conversations, the researcher requested permission to send out information on the research study (Appendices 1 & 2) in the post or by email. The researcher gave each individual enough time to receive and review the information and then telephoned them to discuss their interest in taking part in the study. During this conversation the researcher again summarised what participation would involve and gave each individual the opportunity to voice concerns and ask questions. Any participants who declined the invitation to take part were thanked for their time and not contacted again. For each individual interested in taking part, an interview was arranged at a convenient date and time, with an option of conducting the interview at their home or local BRC office.

2.5.2 Pilot

The interview schedule was not piloted due to insufficient potential participants; however, it was taken to a service user group to review the vocabulary and content of the proposed questions. As a result of this meeting, several changes were made to the schedule; for example, a brief description of SUI was inserted before questioning began, adding prompts to several questions to make sure it

was clear to participants what was being asked. Several 'test run' interviews were completed with colleagues to ensure effective and thorough data collection.

2.5.3 Interview

At interview, each participant was asked to re-read the Participant Information Sheet (appendix B), and encouraged to ask any questions before signing the Participant Consent Form (appendix C). A semi-structured interview was then conducted lasting approximately 60 minutes. The interviews were approached in a conversational style, with each interview loosely following the interview schedule and debrief (appendix D). Prompts and follow-up questions were utilised, for example "can you tell me a little bit more about that?" or "can you give me an example?" All interviews were recorded using a Dictaphone.

Once the interview was complete each participant was given a participant information sheet and support form (appendices B and E) to retain for their records.

It is important to note that power imbalances are inherent in the relationships between researchers and participants. The researcher utilised skills of empathy, reciprocity and unconditional positive regard in an attempt to minimise this imbalance. As a Trainee Psychologist, the researcher was in an advantageous position; over course of clinical training the development of the above skills are fostered, skills vital to the building and maintaining of rapport with participants (Coyle & Wright, 1996).

2.5.4 Post-Interview

Following each interview, the audio recording was uploaded on to a computer, together with a scanned copy of the Participant Consent Form; both were saved onto an encrypted memory stick and deleted from the computer. To allow a space to reflect on the interview process, following each interview the researcher noted thoughts and ideas in a reflective diary. Fossey et al. (2002) identified this as good practice.

2.5.5 Service User Consultation

It was not possible to consult with BRC service users prior to identifying a focus for the research study due to issues of confidentiality and access. Instead, the researcher attended a service user group to consult its members about the research; gaining feedback on what would be useful and relevant topics in the field of SUI. It was at this point that several group members voiced their frustration with their involvement in SUI initiatives in the UK public sector and charitable organisations. As the researcher had heard similar concerns before, this topic seemed pervasive across several contexts and thus a valuable topic to pursue to thesis.

Another service user group was consulted by the researcher at the pilot stage of research development, asking individuals for feedback to ensure that the interview schedule was clear and utilised appropriate vocabulary. These individuals suggested several changes, which were subsequently made to the interview schedule (see section 2.5.2).

At the analysis stage, it was not possible to access either service user group for consultation due to time restraints, however, several participants were offered the opportunity to read and comment on the analysis section of the report. This is known as 'member validation' (section 4.3.1.1). In addition, the researcher utilised peer supervision with Trainee Clinical Psychologists to ensure that the interpretation truly represented the data set.

2.5.6 Dissemination

Several drafts of this report are to be constructed for different audiences and fed back verbally to all stakeholders if requested. Stakeholders include participants and BRC staff and commissioners. Anonymity will be enhanced by excluding lengthy excerpts and demographic details of participants (Thompson & Chambers, 2011).

2.6 Ethical Considerations

Ethics are the moral principles guiding research. As a Trainee Clinical Psychologist enrolled in a Professional Doctorate Programme, an application for research ethics approval was made to the UEL School of Psychology Ethics Sub-Committee. Approval was granted in April 2015 with minor amendments (appendix F) to be made to the participant documents and the addition of a participant debrief. The study was registered with the University of East London (UEL) Graduate School. NHS approval was not required as the study was carried out in a charitable third sector organisation.

All research performed by Psychologists is subject to scrutiny, the British Psychological Society has set out guidelines for identifying ethical considerations and potential risks; these guidelines are necessary to clarify the conditions under which psychological research can take place (BPS, 2014). All student research should comply with the principles of the Code of Human Research Ethics (BPS, 2014). These principles were retained throughout the process:

- Respect for the autonomy, privacy and dignity of individuals and communities
- Scientific integrity
- Social responsibility
- Maximising benefit and minimising harm

Risks to participants in this research include; inconvenience, invasion of privacy and emotional distress. Some of the participants would be classed as coming from groups that would be widely thought of as 'vulnerable groups', for example, the elderly and asylum seekers. However, Davison (2004) states that *'the capacity for harm is incumbent in any research- vulnerability and conflicting emotions can be linking experiences for both the research informant and the researcher'*. That is, all humans are vulnerable in certain situations or contexts. The potential pitfalls of identifying individuals as 'vulnerable' was acknowledged by the researcher, for example, the impact this attitude could have on

questioning and approach at interview. The guidance contained in British Psychological Society ethics documentation were utilised alongside professional judgement.

2.6.1 Informed Consent

As there was no need for deception in this research study, the researcher was open about the aims and process of the research from the outset. Time was spent time both on the telephone and in person explaining this to each participant. All potential participants were sent a Participant Information Sheet either by post or email. This provided sufficient information for each individual to make a clear informed decision about their participation; it included the aims of the research, method, confidentiality, benefits of the study and participants right to withdraw.

At interview, each participant was asked to re-read the Patient Information Sheet and encouraged to ask any questions they had. Subsequently, if individuals still wished take part, a Participant Consent Form was signed. All participants were given a Patient Information Sheet, containing researcher contact details, to take away with them.

2.6.2 Confidentiality

Information collected during the recruitment and interview stages of the study was kept confidential; in line with requirements of the Data Protection Act (DoH, 1998). The confidentiality protocol was clearly explained in the Participant Information Sheet and Participant Consent Form. At interview participants were informed that the information discussed would be treated confidentially unless the researcher felt it necessary to share information to prevent harm coming to them or to others.

All personal participant information, such as address and telephone number and all audio recordings of interviews were stored on an encrypted memory-stick. Signed Participant Consent Forms were scanned into a computer and stored electronically on the same encrypted memory stick; at this point paper

copies were destroyed. Interviews were anonymised at the time of transcription; removing all identifiable information including names, places and staff names. All participants were given a pseudonym. Transcripts were stored in a separate folder on the same encrypted memory stick and all data will be kept for 3 years.

As participants were recruited by staff from a small population of individuals involved in SUI initiatives, caution was taken when selecting excerpts of the interviews to use in the analysis. Nine of a possible nineteen participants put forward by staff took part in the research study, thus staff may have been able to reconstruct the identities of participants despite the above safeguards. As a result, all references to activities relating to specific types of SUI were minimised as this may have led to participants being identified. In cases where this was not possible I sought consent from the participant.

2.6.3 Right to Withdraw

Participants were informed of their right to withdraw from the study in the Patient Information Sheet, Participant Consent Form and at interview. They were given the opportunity to withdraw completely from the study until January 2016; however, after this time withdrawal was not guaranteed as analysis had begun. No participants requested to withdraw their data.

2.6.4 Debriefing

Any interaction between two individuals can cause harm. The risk that the researcher was most concerned about going into the study was the potential for participants to become distressed while reflecting on their experiences. Whilst the researcher did not directly question participants about the services they received from the BRC or the personal experiences that led them to seek support from the BRC, these experiences often came up in conversation. This could have been distressing for them. If a participant had become distressed during the interview, they would have been offered a break and reminded that they were free to withdraw from the study. This however was not necessary.

The British Psychological Society's Code of Ethics and Conduct (BPS, 2009)

requires researchers to debrief all research participants once data collection is complete. In line with this guidance, standard debriefing questions were added to the interview schedules (appendix D). Time was allocated at the end of each interview to conduct a debriefing conversation; this included reflecting on the interview process and discussing any concerns of the interviewer or interviewee. If the researcher had been concerned that any of the participants were at risk of harm, they would have contacted the local BRC service lead and followed the safeguarding procedure of that service.

2.6.5 Protection of the Researcher

As all interviews were conducted at participant's homes, the researcher followed standard NHS lone working policy. This consisted of:

- Informing their Director of Studies or field supervisor that they would be conducting the interview and providing them with the interview location, plus anticipated start and end times.
- Carrying a mobile phone during the visit.
- Informing the allocated supervisor when the interview was complete and the researcher had left the participant's home.

2.7 Analytic Approach

Data analysis took place over several months. The six-step guide constructed by Braun and Clarke (2006) was used in a non-linear way, moving both forwards and backwards between steps. The six steps are outlined below:

1. Familiarising with the data.

As the researcher conducted all interviews, familiarisation with the data and participants had already begun. Further immersion began with orthographic transcription, containing a verbatim account of all verbal utterances and sounds. All transcripts clearly indicated what is being said and who is speaking. Significant punctuation was added, especially when it could have changed the meaning of the data (Poland, 2002); this left less scope for misinterpretation

further along in the analysis. The researcher transcribed all interviews in close succession; this enabled previous transcriptions to remain fresh in their mind. The next step involved repeated reading of the transcripts and making notes in the margins of my thoughts, reactions and ideas for coding.

2. Generating initial codes.

'Data driven' codes were developed identifying the semantic features of the data set relevant to the research questions and are the most basic elements of raw data. Each transcript was worked through systematically (appendix G), identifying any interesting data and looking for repeated patterns or connections. After reviewing the codes several times, related codes were collated (appendix H-I).

3. Searching for themes.

At this stage, all codes were printed and cut out separately; this enabled the researcher to observe multiple codes at once and sort them into initial 'theme' piles. A theme developed when ideas occurred several times in the text, especially if over several interviews. Mind maps were created to encompass potential main themes and sub-themes.

4. Reviewing themes

Potential themes in the coded data extracts were then reviewed for coherency and refined accordingly; at this point the researcher aimed for internal homogeneity and external heterogeneity (Patton, 1990). Once complete, the themes were reviewed in relation to the entire data set to ensure that they were a true representation and any further data that fit the themes was added.

5. Defining and naming themes

This stage involved refining the themes and identifying any sub-themes, subsequently developing a clear definition and title for these themes. Appendix J lists the refined codes in sub-theme groupings.

6. Producing the report

An account of the interview data and themes identified has been set out in section 3, illustrating each theme with appropriate data extracts.

3. RESULTS

This chapter sets out the main findings of data analysis. A summary of sample characteristics is presented, followed by a thematic map containing an overview of themes and their component sub-themes. Each theme is discussed and illustrated with raw data examples.

3.1 Sample Characteristics

Demographic information of the nine participants is presented in Table 1. To assure anonymity due to the small number of potential participants, only the gender, age and ethnicity of each participant are presented and pseudonyms have been used.

Table 2. Demographic information of individual participants

Name	Gender	Age group	Ethnicity
Bill	Male	65+	White British
Rose	Female	55-64	Black African
Kay	Female	35-44	Black African
Peter	Male	35-44	Black African
Barbara	Female	65+	White British
Sara	Female	35-44	White Middle Eastern
Karen	Female	65+	White British
Jim	Male	55-64	White British
Linda	Female	55-64	White British

3.2 Approaches to Involvement

Study participants were spread across a wide geographical area in England and Wales. Four participants had attended a focus group with the BRC, four were volunteers, and one participant had been involved both as a volunteer and a focus group attendee. All interviews with volunteers covered their experience as a volunteer, plus any opportunities available to them to feedback on the services provided. The entire data set was combined and analysed as one. In all cases, focus group attendance had been a one-off event; participants described meetings in which they all shared their experience of being a service user. During the interviews it emerged that a consultation model had been used; staff invited service users to the BRC office to attend a meeting. They were asked for a narrative of their service use, commonly described as 'we told our stories.' Several attendees were able to identify questions asked, for example "were staff polite?" All focus group attendees had received support from the Independent Living services, part of Health and Social Care.

Volunteer participants were based in the Health and Social Care, International Family Tracing, or Refugee Support services. As part of volunteering, participants described informal requests for feedback from service coordinators on the services provided and potential improvements.

Both focus group attendees and volunteer participants described requests for written feedback by BRC, either by post or in person at volunteer meetings.

3.3 Context

Although not specifically asked at interview, when questioned about how they became involved in SUI initiatives participants described how they came to use BRC services. A summary of this is useful in providing contextual background to the situation participants found themselves in. Notably, all participants explained that their lives would have been significantly worse off if the BRC had not been available to them. Several spoke of psychological difficulties

associated with their personal situation at the time of service use.

Volunteers at Refugee Support and International Family Tracing services described approaching BRC staff to become involved. All of these volunteers were at various stages of seeking asylum, and had used or were using Refugee Support services. Some participants described the process in more detail, but all agreed that the asylum process was both difficult to cope with and could be experienced as very isolating. Participants expressed an opinion that BRC services had made a substantial difference to their lives.

All participants in SUI initiatives in Health and Social Care had used the Home from Hospital service. This service provides practical support to individuals returning home after a hospital stay. Without this service, participants would have endured a prolonged hospital stay. All focus group attendees were invited to attend by telephone or letter; a BRC staff member already known to them made contact. Volunteers from the Health and Social Care service described being invited to become a volunteer by BRC staff.

3.4 Themes

The analysis takes an inductive approach, in which themes and sub-themes were generated from the data. The researcher did not shape the results using existing research and theory, instead taking a 'bottom up' approach. Four overarching themes were identified, each consisting of several sub-themes (Figure 2). For each theme, raw data examples are provided with the pseudonym and transcript location. Words in brackets () replace potentially identifiable information, and those in italics represent the interviewers words.

3.4.1 Theme 1: Motivations for Starting Out

'Motivations for starting out' describes participant's reasons for initially becoming involved in SUI initiatives. Participants spoke of a wide range of reasons for agreeing to participate; the most significant themes were feeling indebted to the BRC, and their proximity to the service user experience. Several

other prominent motivators are covered in the 'personal considerations' sub-theme.

3.4.1.1 Indebted to the British Red Cross

Each individual was in a challenging personal situation at the time of referral and described a sense of relief when offered support from the BRC. Thus it is hardly surprising that participant's most commonly reported reason for becoming involved in SUI initiatives was being appreciative to the BRC for the service they had received.

I was having difficulty because I was depressed, I didn't want to go out. There was quite a long wait for (service), so yea, the Red Cross were wonderful really. I mean, I came out of the hospital on the Thursday, on the Friday they rang me up and on the Monday they were there seeing what shopping I needed, you know. It was good to know that somebody would be coming round. And I didn't have to hang about waiting to see someone. It was all set up very quickly (Jim: 130).

I can't fault the service, it was wonderful and I still have phone calls periodically, which is nice (Karen: 48).

I have been very poorly, but they've been brilliant. They did more than I expected. They don't hang you about (Barbara: 78).

As illustrated above, individuals spoke about a service that was efficient and often exceeded their expectations. The immediacy of the response from the BRC meant that concerns about coping, which may have arisen at the time, were short-lived. The speed of support allowed individuals to focus on their recovery or the asylum process, already unsettling experiences. The BRC was perceived as "going above and beyond" (Bill: 56) in the service they provide to various sub-sections of the population.

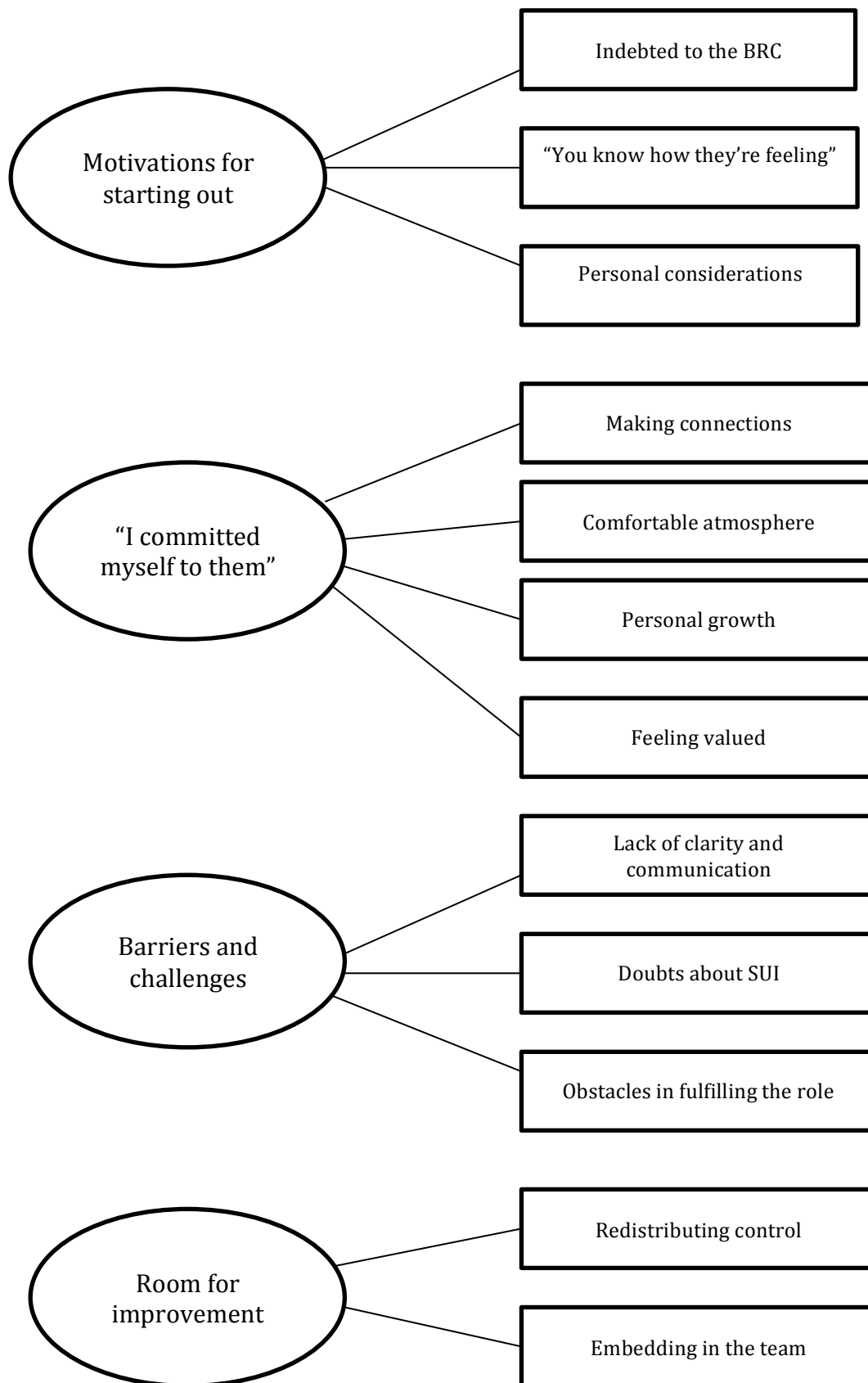


Figure 2. Thematic Map

In Karen's account she explains that she was not just left once her support ended and received telephone calls. This extra service meant that she continued to feel held in mind by BRC. These factors are likely to have led the participants to feel connected to both the staff and the organisation and were evident in several participant accounts.

Participants described being unaware of the services available prior to referral by medical professionals or refugee support services in times of need.

I just thought they were walking an extra mile, taking extra responsibilities. I didn't know RC would be involved in such type of err help or programmes where they, ya know, have a particular work or project which is meant for refugees or asylum seekers (Rose: 91).

As mentioned here by Rose, individuals in the community have a certain idea about what services the BRC offers and vocalised their surprise that the organisation was able to help them. This is especially true in Health and Social Care services, as individuals are likely to assume that the NHS or Social Services would be providing this support. In the initial quote Jim referred to the wait for statutory services and compares this to the service the BRC offers. By publicising the policies and guidelines of statutory services, the UK government and the media create an idea in the general population of what services 'should' provide. As a non-statutory service, perhaps the BRC are able to bypass these unhelpful expectations and thus receive more positive views from the individuals they support.

The BRC was seen as an "informal and friendly" (Bill: 39) organisation that was run by individuals that the participants enjoyed having around. Participants also spoke of staff members being "so polite" (Barbara: 37) and "absolutely lovely" (Karen: 44). All participants described staff positively and strong positive relationships with the staff were central to their experience.

I can't fault them at all. Which is unusual because usually you can find a

weak link. My experience has been wonderful, I couldn't have asked for more. They are all very good, the staff. They are caring people (Bill: 356).

The Red Cross is one place where you can go there and you can be relieved. Just to talk to them and they give you hope (Peter: 228).

As illustrated, service users described genuine gratitude for the organisation, the service they provided and the staff that deliver this service. Consequently participants expressed the view that they would do anything they could to help the BRC and viewed their involvement as 'giving back.' This could mean that their experience of involvement was largely inconsequential, since their ultimate aim was to help the organisation and staff members. This was especially true for focus group attendees, who in their accounts gave a sense that they found their ability to support the BRC reassuring.

So why did you agree to go to that meeting?

Why? Well because they had been so helpful to me, you know and I thought it was sort of a way of showing my appreciation and umm, you know, giving something back really (Jim: 37).

What led you to the decision of saying "yes I'll come and I'll give you your feedback"?

Well, I was asked. I was very grateful for what they'd done for me so if there was anything more I could do to help by way of feedback I was going to do it. That was it really. It's the gratitude (Linda: 298).

3.4.1.2 "You know how they're feeling"

A recurrent focus for participants was the discussion of their proximity to the service user experience. A number of individuals expressed that their drive to contribute to SUI initiatives stemmed from their own experiences as a service user. Their lived experience of 'suffering' and 'hardship' as a service user motivated individuals to help and support others. This was a personal matter for them, thus they chose to contribute their time.

You can't lose as a volunteer. You know how they're feeling so you're happy to help and they are so grateful for you to do it (Linda: 34).

When I got the papers I became free, I had my own home. Whereby I couldn't rely on the Red Cross anymore but I chose not to stop going there and supporting others who were in the same position I was before (Peter: 29).

That's part of the reason why I volunteering. I had many difficulties at this time and I said if I have something to help the new people to avoid to have this difficult, I will help them as a volunteer and I've done that as I can (Sara: 79).

Sara illustrated another key factor of participant's accounts; the ability to offer a new and insightful perspective or offer a solution to a problem that she experienced as a service user. Several participants described an awareness of the unique contribution SUI can make by applying the knowledge of lived experience to service provision. Several individuals therefore expressed the belief that the voice of the service user should be central to services.

Being an asylum seeker myself, there are some things I can see that other staff may not see (Rose: 519).

I mean, unless people ask they're not going to know if they're doing it right or wrong and the only people who can tell them are the people who are being helped (Karen: 204).

Despite holding positive views of the BRC services, participants acknowledged that there were aspects of the services offered that could be altered to make services more accessible and responsive to the needs of service users. Volunteers from Refugee Services explained that a proportion of the refugee community in the UK speak little or no English which can be a huge barrier to

service access. By translating materials and providing support in languages other than English the participants hoped to go some way in making the process easier for non-English speaking service users.

When you see other people and they are struggling and maybe there are other people who cannot speak English. It is hard for them to communicate with others or maybe to ask for help. So, like in our community here there are a lot of people who cannot speak English. They find it difficult to ask for help, so I thought “let me be part of these people who I can offer help to, then at least it can make their life a bit easier when doing the process and everything.” (Kay: 94)

At interview Sara described her own experience of coming to the UK as a refugee who spoke no English and the difficulties she faced. She explained that once she accessed English lessons and learnt the language, she began volunteering so that she could interpret for other refugees in an attempt to ease their struggle.

3.4.1.3 Personal considerations

Several personal considerations were found to be key in the participant's decision on whether to engage in SUI. For a number of participants, one of these was 'passing the time' (Peter: 9). Several participants explained that SUI provided them with an activity that distracted them from the difficult asylum process, kept their brain active or provided them with something novel to do.

For the person who introduced me, they didn't know how to go about it but they just said that RC help people and you can volunteer with them if you want to. Just keep yourself busy. So as for me I thought 'I can't just stay at home' I've been working before and now it's like if I stay home my brain will become dormant. Let me find something to do to keep myself busy (Kay: 43).

Well I like to get out as much as I can, every opportunity. I get bored just

sitting around (Barbara: 324).

So how did you find the whole experience?

Sorry, I can't really answer that because it was just a trip out (Bill: 185).

Significantly, all service user volunteers and focus group attendees were retired or out of work when they began their contribution to SUI. Whilst it is undoubtedly beneficial that these individuals were in the position to attend involvement activities, the idea that SUI was 'something to do' or 'a trip out' can take away from the importance of the activity. Again, these beliefs are likely to have lowered the participant's expectations of the process and outcomes of SUI.

A further important reason for becoming involved in SUI initiatives was the enthusiasm of the participants. The researcher uncovered several personal values that were likely to have impacted on the participant's decision to contribute: kindness and a desire to help others. Several participants explained this themselves.

I just had a passion for helping other people (Kay: 94).

Why did you agree to become involved and what impacted on that decision?

It was just because I like to be helpful, you know, it's that simple. If I could help anybody at any time that is my religion (Bill: 94).

So I, in me and the way I was brought up. I'm not that person who doesn't care "Okay they have given me a cup of tea, who cares; I've had my cup of tea, I'll leave it there" "they have given me some food, who cares, I'll leave the plate there. They'll come and collect it" So, I'm not that kind of a person. I think it's my values. So I just thought, maybe if I help these people, they are helping us and we are letting them down. And they are not complaining, so I thought 'why not give them a hand'

(Rose: 120).

Kay and Bill give a sense that they find helping others to be a rewarding activity, whilst Rose seems to believe that helping others is the right thing to do. Here she describes what she observed as a service user in refugee services: she noticed other individuals accepting help from BRC but being unwilling to help out themselves. She explains that her personal values led her to begin supporting staff, which in turn led her into the volunteering role.

Another consideration for several participants was belief that providing feedback would give them an opportunity to voice ideas for improvement to services being offered.

I also noticed some gaps in the services the RC offers and thought this would be a good space to discuss them (Bill: 126).

I think I must have said I would have liked it to have gone on longer. That is something that could make the service even better (Karen: 134).

Anything that's helpful; that highlights problems, solutions, etc. I'm quite happy to go along with, because unless people have got feedback on something nothing can change (Karen: 331).

Several participants believed that simply by voicing their opinions on services, changes would happen. Whilst Karen suggests that without feedback nothing will change. At interview, improvement suggestions made by participants were primarily for the expansion of successful services already running, providing minimal suggestions for the improvement of current services.

3.4.2 Theme 2: "I committed myself to them"

The statement above (Peter: 17) illustrates the sense of commitment to the BRC felt by participants. The theme describes an array of beneficial experiences participants discovered once they became involved in SUI

initiatives. The most significant factors in the participant's reasons for remaining involved or wishing to remain involved were social connections, a comfortable and welcoming environment, personal growth and feeling valued. These qualities are often found in social and professional environments and provide physical and psychological rewards. Thus for the participants of the study, who spoke openly about the struggles of being either an asylum seeker or retired, they were understandably important.

3.4.2.1 Making connections

Participant's narratives indicated that the social aspect of SUI was a huge benefit; all participants individually commented on various social features of their roles.

Yea it was good. I got to meet different people. And if they had another one I'm sure I'd get to meet different people (Barbara: 330).

It was interesting for me meeting some of the other volunteers and also some of the other users really. You know. Finding out how they got in touch and what their problems had been because, you know, all our problems were different (Jim: 57).

It is rewarding, I do get a lot of fun out of it. I like meeting people, I like talking as you can tell. Errm. I get as much out of it as the people I'm helping (Linda: 144).

For Jim, this experience highlighted an important point; the diversity of the individuals who access BRC services. Despite all being 'users' of the same service, the involvement he participated in allowed him to reflect on these differences between himself and other individuals.

Considering participants were either retired or refugees seeking asylum when they began SUI, social engagement is especially important. Social isolation can be especially high in these subsets of the population and links to poorer

physical and mental health. Hence it is inevitable that participants found SUI uplifting. A number of participants explained that SUI provided them with a new support network at an especially difficult time in their life and even a sense of belonging. This was particularly true for volunteers who had time to build closer relationships with colleagues and service users.

Because I have been doing it some time, most SU's know me. Whenever we are distributing food we joke. There is that openness whereby everybody is free to do the work without hindrances or fear or whatever. We are just used to one another. That is an experience that you don't find anywhere else (Peter: 141).

I find we all have the same objectives or the same goals, the same target, that we help the people. Which in the end is all the same as a volunteer, as a staff; in the end I think we need to help the people. That's it. Because of this, all of them they are very good. I had good relationships with everyone (Sara: 237).

Peter highlighted a unique social element of the BRC services; an environment that felt safe, and where people could be themselves. This statement also suggested that this experience contrasted the world outside of the BRC service, which can be fearful and limited. Sara also recognises the similarities she has to service users, volunteers and staff members. She describes shared goals and conjures up a sense of connectedness and strong working relationships. These beliefs are likely to contribute to a sense of belonging when participating or engaging with BRC services. Across the interviews, there were many further descriptions of trusting and supportive relationships with BRC staff members, and volunteers.

How is it working alongside RC staff?

Yea, it's really good. You feel confident; that you have someone you can turn to if you have any problems. I know they will give me the proper answer and they will give me some help if I'm struggling (Kay: 192).

I have always been told by (staff member) “if there’s anything you’re worried about, ring me” (Linda: 221).

How do you find working alongside Red Cross staff?

They are so good. Its one of the contributing factors which is so moving in me, genuinely it is like they are from the same father, they are just very, very good. Nice people. There are some times that I am going for a while, I am busy at work, they welcome me and show me that they have been missing me there. That encourages me (Peter: 101).

One of the staff saw me and she could tell that something had happened, so she came to me and gave me some tissues and said “ok, just sit there, have a drink of water” and she went into the lady and gave her some water. We gave her some time and then saw how we could help her. So after some minutes she asked me what had happened and she was emotional as well (Kay: 320).

These examples further convey the sense of cohesiveness experienced whilst participating in SUI. Kay describes a challenging incident in which she became emotional after speaking to a distressed service user. This is a powerful illustration of the bonds between staff and volunteers.

3.4.2.2 Comfortable atmosphere

During the interviews, participants often commented on how they perceived the atmosphere in which SUI is operated. The majority of participants mentioned a relaxed and welcoming environment, these perspectives related either to the physical environment or the staff and participants present.

It was quite well organised. They did drinks and cake. It was informal and comfortable setting (Jim: 279).

It was a very friendly atmosphere from the beginning (Bill: 225).

What was it like attending that meeting?

Well, they're lovely. Umm. They're very welcoming, very cheerful, very happy (Karen: 162).

It was unclear why participants specifically referred to the environment, however, comfort has been found to be a predictor of efficient working environments. Physical comfort and relaxation have also been found to impact positively on both physical health and mental health, perhaps individuals have come to relate these factors to beneficial outcomes and thus seek them out.

One participant described the meeting she attended as “unwelcoming” and “clinical”, but this was a clear anomaly. At interview, it appeared that this opinion was associated with the ‘business like’ approach to the focus group and her displeasure with the physical aspects of the environment, not the staff. This participant believed that a relaxed environment “would have got better feedback” (Barbara: 407). These statements provide further support for the key role environment plays in experience.

3.4.2.3 Personal growth

In their accounts, participants described a number of benefits that led to significant personal growth; these predominantly centred on learning and skills development the role provided.

The positives are that you work with Red Cross which is a big organisation, so good experience, you improve your skills, you really know how to deal with the people, how to understand them and how to help them. This has made me more open mind than before and err, it's given me more correct understanding. Sometimes before I was not understanding people. I become more social and more comfortable around other people (Sara: 330).

Sara outlined a number of specific gains, most significantly social skills; she

explained that her interpersonal skills had improved and she had developed a more advanced understanding of diverse individuals in the community. Her ability to communicate more effectively appears to have boosted her confidence and in turn her social life; these factors are likely to have a significant impact on her psychological wellbeing. Similarly, further participants also spoke of improved confidence and self-belief.

Everything has just sort of changed, the experiences have changed.
Because right now I am so confident (Rose: 216).

I have learnt know myself and just to trust myself that I can do this. At the beginning I thought, oh no I can't do this, it is too hard. Or maybe 'I'm not good enough to help other people or to give advise' but in doing so I've built my confidence and knowing that I can do this and I am sure of what I am doing (Kay: 405).

Rose expressed how her experiences as a volunteer have changed her life. Kay reflected on the process of her involvement with the BRC and thought back to a time when she doubted her abilities, these doubts appeared to have been left in the past. These aspects are likely to be hugely beneficial in participant's lives outside of their interactions with the BRC.

Participants commonly acknowledged transferable skills, which enabled them to adapt to new tasks and roles. Several volunteers even found that their developed skills led them to achieve paid employment in a new vocation.

It's really good because I'm working with (company) at my workplace and I can use my RC knowledge there. It's really helpful to people I work with too (Kay: 431).

The experience that I had there helped me for work. I am now working as a (job title). It's similar work, just to support people. The only difference is that I am getting paid, but I am using all the same skills that I use at RC,

which I was taught in RC, it is what I am applying at work now and it's really helpful (Peter: 78)

At interview, the researcher got the sense that both Peter and Kay believed that they did not have the skills and knowledge to attain these roles before becoming a volunteering with the BRC. Both Kay and Peter explained that their developed skills continued to be valuable in paid employment. They were proud of their advancement. For Kay, even her colleagues benefited from her knowledge and she was able to advise them. This was a further rewarding experience for her.

Rose spoke of absorbing as much knowledge and information as she could whilst she is working with the BRC. She saw these skills as transferable to future life aspirations, which were both new and exciting for her.

I wanted to learn more about how it is done as well. How they became involved in such projects. Maybe in the near future I would run my own project (Rose: 137).

Focus group attendees, perhaps due to the brief nature of their involvement, did not identify with the above accounts. Thus the on-going nature of the volunteer role is important in the acquisition of skills.

3.4.2.4 Feeling valued

A dominant narrative throughout all the interviews was the idea that participation in SUI initiatives provided valued experiences. A number of the participants gave a strong sense that their experiences and wishes were heard and paid attention to by other volunteers, focus group attendees and staff.

They asked a lot of relevant questions, made plenty of notes. They were really listening (Bill: 66).

When I went up there I was meeting a lot of new people and I'm sure

they were interested to hear our experience. They were very interested to hear our stories and I felt like they were really listening. (Jim: 200).

In (role) it was established years ago but they listened to me because of my own personal knowledge and experience. It felt great (Rose: 586).

If an individual feels that someone is truly listening to them, this can be a confirmation that their contribution is not going unnoticed and that they are valued. For Bill, the action of someone taking notes on what he was saying gave him the sense that his experiences and opinions were important. This is likely to have been experienced similarly by other individuals involved and above Jim talks of a similar experience. Equally, Rose expressed how 'great' it felt to be listened to by staff, especially as she could draw on her own unique experiences.

Feeling valued is a core emotional need for humans and as such we are likely to seek out situations that contribute to this feeling. If our social or employment environment provides this sense of being valued by others, we are likely to be encouraged to continue to engage. As asylum seekers and retired individuals at the time of commencing involvement, participants did not have a place of work and spoke of being isolated; thus they may not have felt valued or appreciated in other areas of their life. Consequently their participation with the BRC has the potential to provide huge benefits.

Participants who described feeling valued also spoke enthusiastically about the work they were involved in. These individuals commonly described their work as 'rewarding.' Feeling valued can link to a sense of achievement and pride. Both have a positive impact of psychological wellbeing.

I don't worry about not being appreciated; every client makes me feel like I'm worth it. They say thank you the whole time (Linda: 253).

It can be rewarding. It does really help. You can see people really

appreciate it when you give them the food. Yea, it's really helping (Kay: 185).

In their accounts, participants described feeling happier in their role when they believed that they had a choice of which activities they participated in and felt that their wishes were taken into account.

I think maybe you don't think of negative issues if you are happy with what you are doing. If you are being accommodated, you always see the positive side. If I wasn't being accommodated to the extent that I would want to be accommodated then I would see the negative side. Lots of positives (Rose: 409).

That's what's so nice about being a volunteer. If I don't want to do something I don't have to do it. I'm protected and I get to choose what I protect myself from, not just the normal and the obvious. I couldn't be better looked after, that's what I'm saying (Linda: 391).

After being with them I was fully encouraged, nobody pushed me, but I saw the goodness of being with the RC, just to sort people and I really loved it. I am hoping to be there for as long as I can (Peter: 63).

These experiences often result in a stronger commitment to both the organisation and its staff members. Thus individuals who are happy in their role and feeling valued by the organisation would continue to volunteer. Linda summed up her experience of being a volunteer in the following sincere declaration:

It changed my life. I had the epiphany of becoming a volunteer and getting this wonderful life that I've got now. I really can't stress how wonderful it is, I really enjoy life at the moment (Linda: 337).

3.4.3 Theme 3: Barriers and Challenges

Despite the numerous positives covered in the first two themes, barriers to effective involvement exist within the BRC. This theme describes several identified difficulties in achieving successful involvement initiatives.

3.4.3.1 Lack of clarity and communication

The most consistent finding across all interviews was a lack of clarity about the process and purpose of SUI and the lack communication following involvement. This sub-theme focuses on feedback made in its various forms by both volunteers and focus group attendees. Participants, at best, had a vague idea about what the feedback they provided would be used for.

Do you remember what they said to you about the group and err what it was about?

Well they just said would I like to come to a focus group? Umm. Just basically said. Umm. It's a get together of people and you'll have tea and biscuits and it's more like a social event, but with the err Red Cross involved (Barbara: 48).

...(manager) was interested to meet some of the people and hear about their various problems they'd had and how things had been, and how people were now as well, you know, afterwards (Jim: 33).

Do you know what they were going to do with that feedback?

Well I think (manager) was going to take it back and perhaps talk to his other bods about what was what, and you know, he did say it was very helpful. They could think ahead and plan for the future (Karen, 170).

It is fundamental to successful involvement strategies that participants are aware of the numerous benefits of effective SUI and the expectations of them when participating. This allows them to make a fully informed choice to take part. The excerpts above illustrate the lack of clarity participants had when going into the process. This could have been understandably unsettling for

them. Barbara particularly did not understand the importance organisations place on involving service users in participatory activities.

Equally concerning, especially for an organisation hoping to operate a partnership model of involvement, was that none of the participants remembered receiving follow-up information after providing feedback. Not one participant in this study was able to identify points the BRC took on board, changes made to services or opportunities for further involvement. It was common that no contact whatsoever was made with participants after their involvement. This was consistent for both focus group attendees and volunteers.

I think they just wanted to hear our experiences and I think somebody there might have been recording what we said, you know, writing it all down, but umm there was no follow-up really afterwards (Jim: 231).

What happened afterwards? Were you contacted again?

No. Next time I rang up for support, I was thanked for going (Bill: 227).

On the day they just thanked us for coming. I don't think anything else was discussed really. They didn't say, "we'll keep in contact" or anything (Barbara: 302).

So you give the feedback back to (coordinator) and then what do you think (coordinator) does with that feedback?

That I have not. I don't know whether he takes them further. I have not seen any results which came out of the feedback really (Peter: 167).

These accounts demonstrate the above points and highlight that participants were unsure of whether the information they provided was used for anything. It can be noted that the communication between the organisation and participants appears largely one sided; i.e. the BRC invited individuals to participate and they decided whether they would contact them again. These procedures are

likely to perpetuate the power differentials already inherent in the relationships between staff and individuals participating. It also leaves individuals unsure about the next step or whether they will be contacted again. Again, this is likely to be an unsettling experience.

It is also important to note that the majority of participants expressed a desire to receive information on any actions taken as a result of feedback provided.

I think they do as much as they can but I would have liked to have heard what happened. If they gained something really substantial and helpful it would have been nice to know that something has really happened with that forum. Oh yes (Bill: 253).

If you gave feedback like that again, would you like to know what happened as a result?

Yea of course, that is the main point of giving that information, that they will tell us what happens with it. They will tell us "ok, we have noted that many people have noted this that we are not doing right, we might change it to this. What do you think?" We can work on that and see how it goes. (Kay: 273).

I would want staff to tell me direct. Any way. I want to keep up to date (Peter: 335).

These accounts indicate that a follow-up after involvement is something that most participants want to receive. The absence of this follow up left them wondering whether their contribution has made a difference. This again may link to wanting to feel valued. To some individuals getting a follow up on their feedback is the main reason that they provide feedback, but for others it is unimportant.

Several volunteer participants noted that they had noticed changes being made to services since they began involvement; however, they were unclear about

whether the changes were linked to feedback from volunteers or service users.

Did you hear of changes that happened as a result of the feedback?

Actually I didn't remember anything, but they improve things. They improve the service; they change things (Sara: 319).

Do you know anything that has changed as a result of that feedback?

I don't know what has been maintained or changed. They did send something to say thank you for completing the feedback, we will get back to you (Kay: 264).

It may be that the changes discussed above did result from SUI initiatives, but the links could have been made more explicit by staff. By communicating more with the individuals participating, staff could alleviate many of the uncertainties the participants in this study revealed.

3.4.3.2 Doubts about SUI

Several doubts about the effectiveness or purpose of SUI were found amongst participants. Firstly, several participants expressed low expectations of the activities they participated in. Several possible explanations for these low expectations have been mentioned earlier in this chapter, but may also connect to a lack of understanding of the purpose of SUI.

What led you to say yes?

Well, there was no reason not to and I thought 'if (manager) is coming to hear the whys and wherefores, the more he knows the better' so umm, you know, I thought it was a sensible thing to do (Karen: 87).

It was just a matter of, we were all there and we all wanted to help the RC so we all told our little stories. Yea. It wasn't a question of we all personally wanted to gain anything from it (Bill: 190).

These accounts illustrate the lack of expectation expressed during number of

the interviews of the study. This is a concern because lack of motivation to improve services offered or provide suggestions for improvement, is likely to have a negative impact on outcomes. After providing feedback, several participants also questioned the usefulness of SUI.

I can't see that I can help but you never know, do you? If you don't know what's been changed it's hard to know what was helpful (Bill: 305).

In this statement, Bill refers to the lack of follow up received after involvement. At interview it appeared that he would have found a follow-up validating and had he been made aware of points considered and taken forward, he may have been reassured that his input had been useful. This validation perhaps links to wanting to feel valued and heard. It is also possible that his attitude to verbal feedback at the focus group was influenced by an established belief he held about written feedback forms from local BRC services being "a gimmick" sent only as a "polite way of asking for money" (Bill: 310).

Furthermore, a number of participants suggested that the overwhelmingly positive experiences conveyed in this study indicate a sampling bias in the data collected.

I didn't hear any negativity from that group but you'll always get some. Maybe the people that agree to do things like that are the people who have got a good service and want to help RC out (Barbara: 239).

Barbara suggests that perhaps the individuals who agree to participate in SUI initiatives are those who received a good service from the BRC and want to 'give back'. She also picks up on an important point that appears to support this hypothesis; that no matter how good a service is, it is likely that someone will have a complaint or critique. Critiques were not mentioned during any of the interviews conducted in this study. If this suggested bias is present, the feedback being received by the BRC is not representative of the general service user population. In addition, the BRC will not gain all-important suggestions for

improvements.

We have seen previously that participants identify various benefits of engagement in SUI initiatives, so although these attitudes are unlikely to stop individuals from participating, they could impact on whether individuals participated fully and openly.

3.4.3.3 Obstacles in fulfilling the role

This sub-theme covers challenging aspects of the process of SUI. As explained by one of the participants, “although you’re a volunteer and you don’t get paid, you need to be committed. Because there are lots of challenges there” (Kay: 105). The most common challenge reported by participants was difficult interactions with unappreciative or aggressive service users; these interactions could turn a rewarding role, into one that was demanding and less pleasurable.

Most of them you can tell that they do not want to be helped by a woman, but they have no choice (describes the conversation between her and a RC client)... So some of the experiences are more challenging. But I understand from my background, where I came from, where I grew up and my past work experience. I can understand (Rose: 240).

You are offering them help and sometimes because of lack of understanding they can start shouting at you or behaving like maybe you have done something wrong (Kay: 111).

They (service users) start to make trouble for you even in your work. Not people who work there, Clients. Some of them they may not understand or they thought you have to give them more or help me more and they start to get aggressive. Some of them, some of them do not appreciate (Sara: 362).

In these excerpts, both Sara and Kay mentioned that challenges arose when service users lacked understanding. They explained at interview that misunderstandings can happen when it is not clear to service users who the BRC are and what work they do; for example, believing that staff work for the Home Office. This links to a common theme of the data, which identified that communities lacked knowledge of the BRC and the services they provide. Therefore it makes sense that service users become confused. Although tough at the time, participants stated that these challenging interactions lead to improved social skills, such as patience, understanding and the ability to remain calm under pressure.

3.4.4 Theme 4: Room for Improvement

This theme describes potential action the BRC could take in its move towards a partnership model: redistributing control and further embedding SUI into organisational life.

3.4.4.1 Redistributing control

Although negative feedback was minimal, several participants mentioned improvements that they had suggested over the course of their participation in SUI initiatives in the BRC. These interactions had left them feeling powerless.

I just think being a volunteer you have no way of saying something that will be changed. Because you are a volunteer you can say something, and they say “yes we have heard about it, we have noted it” and in my case they don’t change it (Rose: 557).

On this time they said “we have limit, we have some rules, we have some policies, we cannot do more, I’m not sure”. They were listening to me and they discuss with me, but in the end it’s my opinion and they have their view and it was their decision in the end (Sara: 455).

In these accounts, participants explicitly expressed views that as volunteers they have no control over how services are run. From the perspective of these

participants, there is a distinct hierarchy operating within the organisation, with volunteers and service users occupying the bottom rungs. Thus the power over decision-making lies with those at the top, which in these examples are paid staff members and managers. Bill illustrated this when he remarked, “the boss took over. It was his meeting” (Bill: 176).

In circumstances where individuals are asked for feedback, but are left feeling ‘ignored’ when they offer suggestions, they become dissatisfied and frustrated. This dissatisfaction can lead individuals to stop providing feedback completely. This was indeed true for Rose who described her experience of making suggestions of more efficient ways of working as feeling ‘ignored’ and deciding against making suggestions to staff in the future.

Now I stopped. Now I just do what they want me to do even if I feel it is not the right thing (Rose: 544).

Rose believed that the reason why changes do not happen in the way they could was because it is difficult to change established ways of working. The organisation “don’t want to change the culture” because it would be difficult and time consuming. In the previous excerpt, Sara also appeared unconvinced when her attention was drawn to ‘rules’ and ‘policies’. This may well be the case, especially considering the multiple organisational pressures staff members are under.

The service was planned in a certain way and I won’t have a say in it. I can have a say and say “this is not working” but at the end of the day nothing will change (Rose: 552).

This statement gives the impression that feedback was perceived as futile. As previously acknowledged, service user volunteers are appreciated for their unique view and insight into the service user experience, however, in reality they believe that they do not have a say.

..my point it wasn't err discussed because they said "this is our limit, we can't do more" (Sara: 314).

And do you think there is anything that can be done differently when it comes to involvement of volunteers in the future?

Umm, I think if they can allow volunteers to participate in some decision-making, because the volunteers might know some things which cannot be noticed by RC staff (Rose: 510).

If someone that is really in need and they have come to you and they will have help, but you cannot help them. For me it feels that something has to change, just look at their circumstances (Kay: 367).

Kay explains that she wished she was able to have more say in decisions on service provision; here policy again dictates when you can and cannot help someone in need. At interview, the researcher got the sense that this was a distressing experience for her. As mentioned by Rose, one fundamental way to keep service users contributing to SUI initiatives in the meaningful way is to give them more say in the decision-making process. This is an idea central to SUI.

Linda's interview stands apart from the other participants, in that she feels in complete control of the work she does.

I have no reason to stop because I couldn't be looked after more. My concerns could not be taken more into account. It's almost like it's made for me to run. I feel in control of what I do (Linda: 472).

Even in this description, however, Linda does not give a sense that her control goes beyond the coordination of her own involvement or that she has any influence over services in general.

3.4.4.2 Embedding in the team

All service users were asked whether there was anything that the organisation could do improve the process of SUI. A number of responses linked to the process of embedding SUI into the team. Several participants, both focus group attendees and volunteers explained that they would like further opportunities to feed back on the services offered by the BRC. Suggestions emphasised the importance of providing regular opportunities and making feedback a consistent part of the service, rather than a one-off group or providing ad-hoc informal feedback.

It seems like it would be good to do those groups regularly (Jim: 295).

Unfortunately I have never been involved in focus groups. I wouldn't mind. You then get other people's ideas. People see the same things in a different way and they can give feedback in a different way- either positive or negative. I would like to see what other people think. I would like to sit and listen to what other people are saying (Rose: 642).

There was a sense that SUI would be more effective if the BRC invited more service users to feed back.

It would have been nice if there'd been more people there. Not from the Red Cross, but people going to the group. There was only a few of us there so they wouldn't have got a lot of feedback (Barbara: 338).

Tied in with the idea of more regular feedback was hope for improved communication from staff to close the feedback loop and provide those involved with an understanding of how their feedback would be used. This would aid participants in feeling like a valued part of the team. This links to the previous sub-theme.

Providing further training was also suggested several times during the interviews. Volunteers commented that training takes place at the start of their

role, but is infrequently updated and focus group attendees were provided with no training at all. In order for individuals to further understand the process and purpose of SUI and feel confident in their role, this could be improved. Specific ideas for training were suggested.

I think some more training would be good as well. More regular trainings. It can be emotional as well working with these people, so this training on emotional support or whatever that one needs to be like maybe once a year just to help people (Kay: 297).

Kay highlights the need for further training on how to support emotionally distressed service users. She was not the only participant to highlight this. Kay also suggested that the BRC formally acknowledge training offered, for example, by providing a certificate to prove what skills have been developed. This would give them advantage when seeking future employment. Although subjective, these are important considerations for organisations.

4. DISCUSSION

In this chapter the results of the research are considered in relation to the research questions and previous literature in the area. The researcher highlights key implications for the BRC, implications for clinical practice and further research is suggested. The chapter will conclude with a critique of the methodology and the researchers personal reflections from the process.

4.1 Summary of Results

By gaining a clearer picture of the experiences of SUI by those involved, this study aimed to improve understanding of how organisations can better approach SUI and develop meaningful strategies. A task that is especially difficult for those with diverse populations. Thematic analysis revealed four themes, each identifying important areas in the process of SUI; ‘motivations when starting out’, “‘I committed myself to them’”, ‘barriers and challenges’ and ‘room for improvement.’

4.1.1 Situating the Research

This section considered the data in relation to the research questions. As previous literature in charitable organisations is minimal and none has been completed in the BRC, the researcher tentatively situates it in relation to previous literature in other areas. The researcher also utilises theory in attempting to understand the results. Approaching from a critical realist perspective, the connections to theory made in this section are conceivable ways of making sense of the data, but are not believed to be the one correct way of understanding. This study posed the following research questions:

4.1.1.1 Research question 1

What are participant’s experiences of their involvement in British Red Cross service user involvement initiatives?

Significant to all participants and mirroring previous studies (e.g. van der Ham

et al., 2014), was the lack of clarity individuals had on both the purpose of SUI and the use of feedback offered. Whilst focus groups are set up purely for the purpose of collecting feedback, volunteers described sporadic verbal requests and occasional anonymous written feedback. None of the participants received a follow up on their involvement and were not aware of any associated changes made to services; similarly to previous studies (Carr, 2004; Tyler, 2006). For volunteers, the inability to directly see whether changes had happened led to frustration. The lack of follow up for focus group attendees meant that participants could be left wondering whether their contribution had amounted to anything, and feeling disheartened or frustrated. The participant's views mirrored those identified by Carrick, Mitchell & Lloyd (2001), Beresford (2002) and Stringer et al (2008).

Interestingly, both groups revealed the belief that staff and participants had 'shared goals.' This finding differs significantly from previous studies that found participants had difficult relationships with staff (e.g. Crawford et al., 2002) and discrepancies between the views of professionals and service users (Campbell, 2001; Coulter, Peto & Doll, 1994). Having 'shared goals' indicated a sense of cohesion, connectedness, and blurring of the boundaries between staff and SU's. This is likely to link to the type of service the BRC is; voluntary services are viewed in a less authoritarian way than statutory services as they are not government run, thus power differentials between SU's and staff are reduced. As previously published research was predominantly carried out in the public sector this inconsistency seems logical. More specifically, much previous research was conducted in a health setting thus further technical training and language are likely to have increased the power differentials further, this is especially true if staff felt that their expertise were being called into question. A sense of cohesion and shared goals gives services conducting SUI a significant advantage. Further experiences of focus group attendees and service user volunteers are explored separately as they differed slightly and vary contextually.

Focus group:

Participants who had attended focus groups described a 'really pleasant meeting,' at which they provided a narrative of their experience of BRC services. Similarly to Hernandez, Robson and Sampson (2010), contextual factors were found to facilitate participation; participants described transport, refreshments and arrived to a well-organised meeting. For the researcher, the two key aspects of participant's experiences were the social aspect of involvement and feeling valued.

Participants mentioned the social aspect of involvement on many occasions, emphasising the opportunity to meet new people as important and 'interesting.' These statements mirror those of previous research, for example, Huynh (2014). It is important to consider why this aspect was so important. As all focus group attendees were retired and austerity measures have meant that many older adult services have been cut, thus many older adults have fewer sources of social contact and increased levels of isolation and loneliness. Social isolation is linked to feelings of depression, vulnerability and hopelessness (Age UK, 2014; Griffin, 2010). When individuals commented at interview that SUI was 'something to do', it is likely that these individuals have become more isolated than they once were. Feelings of loneliness also tend to lead to higher morbidity and mortality rates (e.g. Brummett et al. 2001). When social isolation is not a problem for individuals, the absence of a diverse social network has been found to associate with health risks (e.g. Barefoot et al. 2005). These figures go some way towards explaining why the social aspect of involvement was such an important feature of involvement to these individuals.

The experience of feeling both heard and appreciated, especially by staff that they both liked and respected, stood out for the focus group attendees in this study. This mapped on to previous findings (e.g. Hernandez, Robson & Sampson, 2010) that emphasised feeling valued and building relationships as key aspects of successful and ongoing involvement. As discussed previously, this is not always the case. Participants referred to these aspects of SUI frequently, which seemed to leave them feeling reassured that their involvement

had been 'useful' and that their experiences and opinions were important. Some older adults are likely to have internalised the Western idea of ageing relating to a 'sick role' where individuals become dependent on others and have restricted opportunities (Townsend, 1981). In this role, health, vitality and positive contribution to society are all minimised and the older generation are often not fully informed or consulted on their wishes. Thus the opportunity to feel heard, appreciated and useful was likely to have been a very powerful experience. Furthermore, this appreciation came from an organisation that they were very grateful to.

Volunteers:

Volunteer participants also identified the social aspect and feeling heard as two key experiences of involvement, however, with the increased involvement of being a volunteer came additional benefits and challenges not experienced by focus group attendees. Positive experiences of involvement seemed to be further emphasised by the volunteer's proximity to the SU experience and thus felt a personal connection to the work. This was especially prominent for volunteers in Refugee Services; we can link this to the growing voice of the refugee movement. As we have seen, successful social movements emerge from a collective desire for advocacy and change; this desire to support others is especially strong when experiences of injustice link to a core aspect of their identity, i.e. being a refugee.

Participants explained that their activities as volunteers were varied, which kept them interested and great rewards were apparent in their verbal accounts.

Interestingly for the researcher, the notion control over their role was a frequently referenced aspect. For refugees, the notion of choice and control can be particularly powerful because the asylum seeking process can leave individuals feeling powerless and dependent (Burnett & Peel, 2001).

For several participants, 'making connections' went beyond the social aspect of volunteering, providing them with deeper relationships with staff and volunteers, and providing them with a sense of belonging. Participants expressed feeling

welcomed and comfortable in their descriptions of SUI. These strengths echoed that of previous studies (e.g. Townley & Kloos, 2011). As many refugees are also socially isolated, it is no wonder that the social aspect of the volunteer role was described so frequently. For these individuals, who may have come to the UK without friends or family, the best mental health outcomes have been found to result from making social connections with people from both the host community and their own country (Watters, 1998). This is not an easy task, especially considering the impact of 'othering' by the media, thus the BRC offers a unique opportunity.

The researcher was struck by the pride with which participants described the skills they developed through their experiences with the organisation, their colleagues and service users. The participants of this study parallel that of previous studies (e.g. Telford & Faulkner, 2004; Waikayi, Fearon, Morris & McLaughlin, 2012). Common declarations amongst participants were improved self-confidence and advanced social skills (Tierney et. al, 2014; Crawford et al., 2002, Muir et al., 2010). The process appeared to be on going and progressive, thus they had further motivation to remain involved. Considering the asylum status of individuals, developing confidence and transferable skills can be vital to their future happiness and success once they are granted 'indefinite leave to remain' and can begin to search for paid employment. Considering the works of Foucault, knowledge can increase a sense of power and agency.

A noteworthy challenge for participants was interactions with unappreciative and aggressive service users; this led to stressful and upsetting experiences, but also strengthened the relationships between staff and volunteers. Whilst the trusting relationships they have built with staff members are crucial to the working environment, stressful work situations have long been acknowledged to have a significant impact on mental health (e.g. Cooper & Marshall, 1976). As individuals in the refugee community often have a limited social network, it is even more important that appropriate support is put in place by the organisation. Without this, the impact of this work can be very destructive. In addition, as volunteers are not paid, they are more likely to disengage if they

are struggling in the role and feel unsupported.

4.1.1.2 Research question 2

What factors influence their participation and continued participation?

Interestingly the participants interviewed explained that their motivations for participating in SUI in BRC in the first instance differed from motivations to remain involved. At interview, the reasons for getting involved that most stood out to the researcher were: feeling indebted to the BRC, proximity to the service user experience, 'something to do', and personal values.

The researcher was moved by participant's expressions of immense gratitude to the BRC for providing a service that had changed their lives for the better. Most significantly, this was a factor of the study that was not identified in any previous studies reviewed. Whilst the experiences of service users were diverse, each participant expressed their appreciation for a service that often exceeded expectations. As a result, they appeared to feel indebted to the organisation and its staff and saw SUI as a way of 'giving back' in any way they could. Considering the context of participants, several explained that they would not have had access to a similar service elsewhere; this is supported by figures indicating that 150,000 older adults in the UK have lost access to vital care services since 2010 (Financial times, 2015). The quality of the service offered should be considered a unique selling point for the organisation, and a crucial facilitator for conducting SUI initiatives.

As all participants had either utilised services or continued to utilise services, they related to the service user experience. This was a personal matter for individuals and knowing how difficult the journey could be motivated them to begin volunteering. Hence central to their involvement was the desire to improve the service user experience by feeding their experiential knowledge back in to the system, and provide the BRC with ideas for improvements. In addition, several participants revealed an awareness of the unique contribution their participation could make to service provision, as noted by Tierney et al.

(2014) and Hossack and Wall (2005).

A number of the participants, both volunteers and focus group attendees, explained that their participation had initially been a way of 'passing the time' which either served as a distraction from their situation or provided them with something novel to do. It is important to consider the contextual circumstances of these individuals and the distressing experiences they are likely to have been going through. Distraction techniques have been established as central to the treatment of low mood and anxiety (e.g. Grewal, Petter & Feinstein, 2012) thus can have a significant impact on mood and psychological wellbeing.

Whilst the above factors are enough to get service users through the door, the positive experiences described in the previous section are necessary to keep them coming back. When individuals find work rewarding and it provides them with areas of on-going personal growth and progressive skills development, it makes sense that they would continue in their participation. The ongoing presence of 'fantastic staff' that participants developed strong and trusting relationships with was a vital aspect in continued participation or willingness to participate. This indicates similarities to therapy, where the key beneficial component of therapy has been understood to be the therapeutic relationship (Lambert & Barley, 2001), and also crucial in encouraging individuals to return even when their experiences have been difficult. Thus their connection to the BRC remained strong and they continue to participate.

Obstacles to continued involvement include the challenging interactions and lack of communication previously described. As unpaid staff, these challenges may cause individuals to withdraw from the volunteer role. Doubts about SUI have seemingly developed over the course of their participation due to their lack of knowledge and understanding about the purpose and benefits of SUI (Carr, 2004). These included low expectations of SUI, questioning the usefulness of their involvement, and even being suspicious of the motives of feedback. All of these experiences were described in previous studies, e.g. Patterson, Trite & Weaver (2014) and Carey (2011). As discussed, providing SU's with further

training and knowledge could indicate that organisations do not value the experience of service use alone, whilst not providing further organisational training could be seen as a way of denying SU's equal status (Lazar, 2005).

Finally, those who contributed wholeheartedly to SUI have identified feeling powerless in their feedback and spoke of wishing for more influence over the decision making process. This could be related to the position of the service users within the initiatives; even when involved, they are not truly heard. This is a vital aspect of meaningful SUI (Arnstein, 1969; Beresford, 2005) but all too commonly reported in the research that change is not happening or not recorded. When individuals are repeatedly give their time and see no changes they are likely to develop 'consultation fatigue' (Beresford, 2002) and disengage.

4.1.1.3 Absence of negative feedback

What struck the researcher during data collection and analysis was the lack of negative feedback about the BRC services or the process of involvement. This mirrors the learning publications outcomes (BRC, 2015). Participants gave factual accounts of their involvement, and volunteers especially, often providing passionate descriptions of their experience with the BRC. As previously illustrated, there are reasons why the participants in this study may have felt a strong connection and sense of gratitude and loyalty to the organisation, for example, a sense of belonging, feeling indebted to BRC. It appeared that the experience of participants was not always positive, yet individuals were always understanding in their accounts. Even when experiencing challenging interactions with service users, participants were able to remain constructive and focus on the interpersonal skills the experience enabled them to develop.

Whilst the ability to stay positive in the face of adversity is a valuable characteristic for these individuals, the lack of constructive criticism during their participation in SUI initiatives has detrimental effects for the BRC. Without suggestions for improvement, staff members are not able to effectively apply the principles of SUI, and consequently no changes resulting from feedback

were reported. The researcher got the sense from participants that the criticisms they did share at interview had not been communicated to the BRC. Ideas for improvement tended to link to requests for additional services rather than suggesting improvements to services already provided. Thus the organisation is not able to learn from the experiential knowledge of the service users they involve. For this reason, whilst this categorically positive feedback may be genuine, it is important to consider other explanations for individual's apprehension to share negative feedback.

Firstly, it is possible participants positive focus could have highlighted a self-selection bias. This bias may have created a situation in which certain aspects of the experience were exaggerated, whilst others minimised. Alternatively, although the researcher clearly stated that they were operating outside of the organisation and impartial, participants may have been apprehensive to share criticisms from fear that staff would discover what they had said. Thus criticising the services may have impacted on their relationships with staff, which the study revealed they deeply valued, or affect their access to services in the future. This would be especially true for focus group attendees. Equally, participants may have been concerned that critique would put the services at risk of losing financial support. Hernandez, Robson & Sampson (2010) previously discovered these fears in service user participants. Additionally, although attempts were made to minimise the impact, relational power imbalances between the researcher and the participants were inevitable and can be incredibly silencing.

In his extensive work in the field of action research, Burns (2007) revealed that it can take over a year to build meaningful relationships with communities and groups. Most of the participants had been in a relationship with the organisation for a relatively short period of time, and despite reporting feeling a connection to staff, were unlikely to have reached the stage where they felt comfortable sharing negative feedback. This is a strong argument for moving away from ad-hoc consultation approaches towards more regular democratic approach.

4.2 Implications of Outcomes

4.2.1 The British Red Cross

The small-scale exploration and evaluation conducted as part of this research revealed a number of meaningful learning points for the BRC. This report is already being shared with managers within the organisation and utilised in the planning of new SUI projects, e.g. refugee focus groups. Evaluation should thus be integrated into the standard model of SUI within the BRC to indicate what they are doing well and areas of improvement. This suggestion extends to all organisations engaging in SUI.

As we have seen, there has been movement around the consumerist paradigm with services voicing their intentions to move towards a partnership or democratic model. The BRC is one such organisation that appears to be passionate about bringing SUI to the heart of their practice and engaging SU's in a meaningful way, but how is the BRC doing on this currently? In answering this question, it is important to re-consider the definition developed by Millar, Chambers, & Giles (2015) in relation to the data obtained:

'An active partnership between service users and (mental health) professionals in decision making regarding the planning, implementation, and evaluation of (mental health) policy, services, education, training and research. This partnership employs a person-centred approach, with bidirectional information flow, power sharing and access to advocacy at a personal, service and/or societal level.'

Whilst focus group attendees in the study were invited to evaluate the service they had accessed, not one of these individuals mentioned service planning or implementation. Volunteer participants also remembered being asked to evaluate current services, and in addition were asked to feed back about the planning and implementation of future services. Unfortunately, for all participants the flow of information was unidirectional, where those participating provided feedback but received little information from the organisation on the

purpose of feedback, its use, or any changes considered or made resulting from their feedback. Advocacy was not evident in any of the participant's accounts.

The participants in the current study revealed that a top-down approach to involvement is being utilised; where managers decided on how feedback is collected and utilised. Although volunteering is often seen as being closer to a partnership way of working, several volunteers explicitly expressed their belief that they have no control over how services run, depicting the image of a distinct hierarchy that they were situated at the bottom of. This belief appeared to stem from providing feedback to staff and observing no changes to service, and their desire to "participate in some decision making". Thus 'power sharing' was not present in this sample. This perhaps links to the idea within organisations that quantifiable data is prioritised, thus the specific knowledge, experience and emotions of service users can be easily discounted (Carr, 2007). Whilst the participants did not describe a service that meets the definition above, this does not rule out the possibility that SUI is being done differently elsewhere in the organisation.

Within health and social care services there have been concerns voiced about whether SU's are qualified to make decisions about service development and provision (McGowan 2010). It makes sense that in a medical setting individuals may need more information on the technical knowledge that influence such decisions, and the NHS guidelines governing service provision and funding. The BRC is different as there are less external restraints and guidelines on how the services are run, thus there is more scope for SU's to make a mark and run services they feel passionately about. Volunteers already run and manage many BRC services.

The BRC does have a robust volunteer representation strategy that includes having volunteers involved at all levels of organisational planning and delivery. Unfortunately as none of the participants in this study were involved beyond service delivery level, the researcher was unable to comment on the success of

this strategy. It is unclear whether service user volunteers make it to these top positions; if they do not, this indicates a link to previous research which found that the majority of service user board members were not demographically typical of the population they set out to represent (e.g. Wright, 2015). Whilst this question of representativeness should be considered, and is a concern that comes up frequently in the literature (e.g. Omeni et al., 2014; Munro, Killoran Ross & Reid, 2006), what is essential is that the service users continue to be involved. Lindow (1991) claims that service users cannot win; when they are seen as having poor psychological or physical health they are incompetent, but once they are 'well' they are no longer representative of the service user population. These beliefs were reflected in the current sample, as the BRC approved inclusion criteria was based on a staff 'assessment of psychological and physical wellbeing'. It is important to consider that no one ever concerns themselves with the representativeness of the professionals within organisations (Telford & Faulkner, 2004).

Participants in the sub-theme 'embedding in the team' suggested some key considerations for future approaches to SUI. As the title suggests, what struck the researcher as important was the need for SUI to feel integrated into the team and less at risk of being removed or neglected. Individuals voiced the importance of regular meetings and opportunities to feed back, thus making feedback from service users a consistent part of the service. In addition, closing of the feedback loop by providing those involved with a clearer understanding of what is expected of them, what will be done with the information they provide, and following up on involvement with verbal or written updates. These changes would alleviate some of the uncertainties and frustrations the current SUI initiatives elicited. Further training was also suggested to provide further skills on how to support individuals or manage aggressive or challenging service user interactions. This training would allow participants to feel more confident in their role and their abilities to cope with the more demanding aspects of involvement.

Although these are valuable suggestions, they all require the input of increased time and resources from BRC, resources they are unlikely to have. Valuing SUI

at the same time as allocating limited resources to its pursuit has long been acknowledged (Bowl, 1996). As noted previously, the recruitment and coordination of any SUI activity can take a significant amount of time and resource, more so developing a systematic strategy for partnership working. Staff members responsible for coordinating SUI often do not have protected time to work on strategy and planning and have to balance it with the other aspects of their role (Crook, Tomlins, Bancroft & Ogi, 2015). As the results of this study illustrates, without the redistribution of resources, partnership working is an unrealistic goal. The organisation will need to invest initially in order to reap the benefits in the future. Thus, the following approaches are suggested for retaining movement around SUI, whilst remaining realistic about the resources available:

- As suggested by the participants, the organisation would improve the process by providing regular feedback opportunities. Staff and volunteers should revisit their procedures on handing out feedback forms; handing them out on a more regular basis and providing online forms. For ease of collation these forms could predominantly consist of structured questions. Collating the feedback forms could be a role for one of the volunteers, thus enabling them to utilise their skills and become further involved. In order to provide a follow up to individuals who have provided this feedback, staff could coordinate quarterly meetings; meaning that the lengthy process of report writing could be avoided.
- Participants commented on the lack of awareness of BRC services in the community. Thus, it is likely that there are further individuals who would like the opportunity to become involved. Advertising at service user events and community drop-ins could provide these individuals an opportunity to make contact beyond their service use.
- To reduce the pressure on staff and minimise the resources required, services in the same geographical area could operate communal SUI initiatives.
- Staff could provide a one-off training to a group of service users keen to participate in ongoing SUI initiatives. The training could inform them on the purpose of SUI and how to conduct focus groups. Alternatively

participants could be provided with research or presentation skills that they could use to lead on research projects or develop training. Once the participants are trained up, staff could provide monthly supervision. In this example less time spent by staff and service users are handed greater power. In addition, focus groups may yield more balanced information in the absence of staff. A successful example of this type of project has been published, in which mental health service users are trained in research methods to undertake their own projects (Wilson, Fothergill & Rees, 2010).

Despite the diversity within the participants, the data revealed that the BRC is creating a culture of SUI in which SU's generally feel heard and valued by the staff they engage with. It is important to note that the BRC provides high quality services and as an organisation is highly regarded amongst service users. Whilst participants seemed pleased to be asked about their experience, they were not socialised into the partnership model. As a result, they lacked the knowledge of what participation would or could be (Carr, 2004; Carrick, Mitchell & Lloyd, 2001) and expectations were low. The BRC is moving in the right direction, but they have a way to go if they wish to succeed in the ambitions of the 2015 strategy.

4.2.1.1 Dissemination

The researcher will construct a short report containing a summary of the findings of this study and recommendations for small steps towards more meaningful engagement; this report is to be disseminated throughout the BRC to staff and senior managers. In addition, the BRC has been asked by the Home Office to take the lead on setting up service user forums aimed at providing a space for refugees to explain the problems they face within the accommodation system. To aid this process, the researcher and her field supervisor will meet with teams to share the findings of this report in a bid to support them with the process of engaging these service users most effectively and productively.

4.2.2 Clinical Practice

This study's results confirm the view that approaching SUI is a very complicated undertaking for an organisation and its staff members (Bennetts, Cross & Bloomer, 2011; Carey, 2011). Thus the critiques in this report are not a reflection on the organisation, instead highlighting the numerous challenges large organisations face when attempting to coordinate SUI. The BRC, as a large organisation with a hugely diverse service user population, is likely to face similar challenges to NHS Trusts and Social Care services. As discussed, there has been increased pressure from the governing bodies of both statutory and charitable organisations to bring service users to the forefront of organisational life. Guidelines like the Good Governance Code (NHEG, 2010) and NHS Performance Framework (DOH, 2012) insist the inclusion of SUI without providing practical support or resources for its implementation.

This study highlights that even when an organisation truly values SUI, and has it at the core of its organisational strategy, going beyond sporadic involvement and a consumerist approach can be difficult objectives to achieve. Within large organisations there are so many stakeholders with competing agendas, i.e. funders, trustees, shareholders, staff, communities, and service users. Within organisations, the economic driving force emphasising competition and saving competes with SUI. Consequently priorities become unclear as staff members become pulled in a number of directions. Thus involvement becomes limited and infrequent, as previously discovered by Felton & Stickley (2004). Despite the importance placed on SUI, the commissioners also want to retain the final authority and operational or professional agendas drive interactions and decisions (Tierney et al, 2014). Consequently participatory parity is not happening. Even within NHS Foundation Trusts where patient, service user or carer governors serve on the board, it is made clear that governors are not "responsible for decisions taken by the board of directors on behalf of the NHS foundation trust. Responsibility for those decisions remains with the board of directors, acting on behalf of the trust" (Monitor, 2014).

Unfortunately, as The Francis Report (Francis, 2013) suggested, letting these agendas take charge has led to dangerous problems. When the culture became 'focussed on doing the system's business, not that of the patients' it led to widespread abuse of power. Top-down management instruction meant that the voice of the service user was lost and focus remained on portraying the service positively. The Francis Report emphasised the necessity of accountability at all stages; putting the needs of the service users at the forefront of everything that is done.

But simply having service users present does not mean that partnership working is occurring, and the power dynamics between staff and service users so often remain. Thus the service user voice continues to get lost (Sabin, O'Brien & Daniels, 2001) as this study revealed. Where involvement strategies yield little influence over the decision-making process, they stay at a level of tokenism (Arnstein, 1969). Services must alert themselves to the risk of engaging service users ineffectively, for example, not following up on feedback. Within the BRC, changes could have been made as the result of participant feedback, but lack of communication from staff left participants questioning the usefulness of their involvement. Problems in SUI arise when service users become disheartened or frustrated and disengage (Johnson, 2006). These feelings could also arise from a lack of clarity in their role in the participation agenda and feelings of powerlessness.

As outlined by Hossack and Wall (2005), some professionals simply do not appreciate the contribution SUI's could provide. Thus even when an organisation prioritises SUI, not every staff member will value its use and the culture does not change. Thus attitudes of clinicians or organisational discourses provide a further level of complexity. Rather than expecting services to change, perhaps taking a more developmental approach would be more manageable. One example would be providing essential training to staff at all levels within organisations on the value of SUI, in a bid to inspire a vested interest in its success. Considering the Stages of Change Model (Prochaska and DiClemente, 1982) can be an important tool for organisations when

embarking on a new SUI project. Many organisations, and indeed staff members, move between the pre-contemplation and contemplation stages a number of times before initiating action. This is an on-going cycle and thus an on-going challenge. Whilst one of the arguments for the inclusion of SUI is that it will improve efficiency within organisations (Boote, Baird & Beecroft, 2010), time and resources are necessary to arrange even the briefest of SUI initiatives.

Another concern is that once SUI is set up, it can be notoriously difficult to encourage participants to provide the constructive feedback organisations need. The current study raised this as a strong concern. Without constructive feedback, organisations can invest a lot of time and money on projects that yield little successful outcomes. If this has been the case within the BRC, it isn't surprising that staff members are not prioritising it. This is especially true when individuals appreciate being involved and have had a positive view of the organisation. Perhaps by regular interaction and the strengthening of relationships over time, participants may have felt more confident in revealing the drawbacks of both the service and their involvement in SUI.

Sharing of knowledge amongst organisations is vital to the effective implementation of SUI initiatives, including the highlighting of good practice and successful approaches as they are discovered. Whilst the researcher acknowledges that SUI is indeed a difficult objective to achieve, it is not impossible. As outlined by Millar, Chambers, & Giles (2015) the potential positive outcomes for both SUI and services are vast. One key professional experience of the researcher was an example of a specialist service with its own budget and staffing. Thus on reflection, to reach it's potential perhaps SUI requires a shift in funding or specifically allocated resources, in addition to cultural appreciation of SUI. This is a further challenge in the current context of dwindling budgets.

4.2.3 Future Research

Whilst the current study offered greater insight into the experiences of individuals participating in SUI initiatives in the BRC, it does not relate these

experiences to outcomes. The collection of outcomes data from staff, participants, and organisational documentation would provide researchers with further insight into the effectiveness of SUI initiatives. It would also enable them to discover whether positive experiences of SUI correlate with more significant outcomes. If this approach is taken, the selection of appropriate data to analyse requires careful consideration. In addition, as the benefits of training participants on the process and outcomes of SUI have been highlighted in this study, perhaps researchers could compare outcomes of involvement with trained individuals to those of untrained individuals.

A further consideration is the assumption that partnership working is the approach to SUI that services should be working towards. This has not been proven, thus an interesting research would be to compare several approaches to SUI on outcomes, service user satisfaction and staff satisfaction.

This study took a predominantly retrospective account of SUI initiatives. As individual's perspectives on involvement are more likely to be positive after the event, a prospective study could provide novel data on the process and experience of SUI. Recruitment of participants could occur before they have begun the process of SUI, and follow their journey throughout the process whilst charting their opinions and experiences over time.

Finally, the present study did not take into account the attitudes of clinicians or the organisational discourses. Whilst the researcher knew of the organisational strategic reviews (BRC, 2009; 2014), further research could uncover what is really being said within the organisation. By exploring the organisational discourses on many levels, including ground level staff, management, and trustees, the researchers could consider their contribution to practice. This is especially key considering relationship with staff was central to the participants experiences.

4.3 Critical Review

4.3.1 Quality of the Research

Yardley's (2000, 2008) principles were used to assess the quality of the study as they are theoretically neutral. As Yardley notes 'it is not necessary or even possible for one study to exhibit all these qualities.' (Yardley, 2008: 248). As such I outline some of the ways in which these criteria have been addressed.

Sensitivity to context:

The researcher completed relevant literature searches before commencing the study (appendix A) plus situating the research data within the current theoretical context earlier in this chapter. At the data collection stage, the researcher posed open questions to allow participants to guide the interview towards topics they valued, plus expressed empathy and interest in these topics. At the data analysis stage, the researcher continued to keep participant's contexts in the forefront of her mind and took care when representing their experiences.

Commitment and rigour:

The researcher consulted a service user group with the interview schedule prior to data collection, and conducted several 'test run' interviews with colleagues, thus ensuring thorough data collection. Accounts of the data collection and analysis stages were provided in chapter 2 and the appendices G-K to indicate the methodological competence of the researcher. As outlined in chapters 1 and 2 of this report, the researcher has had deep connection to the topic of SUI for a number of years, resulting from both personal and professional experiences.

Transparency and coherence:

A critical realist approach emphasises the importance of context on all interactions. At various points in this report, the researcher made explicit reference to her own context and reflexivity. A reflexive diary was kept throughout the process to ensure that these factors were being attended to (appendix K). Power differentials between the researcher and participants were

considered, and acknowledged at various stages in this document. In chapter 2 of this report, a coherent description of the data collection and analysis stages of the study are reported. Data extracts and detail on the various stages of theme production were included (appendices G-J).

Impact and importance:

This research achieved its ambition to further understand the motivations and perspectives of participants engaging in SUI in the BRC, and was the first to take place within the BRC. It adds to a growing research base on SUI and provides areas of thought for large third sector organisations that offer short-term services to a diverse population. Improvements made to SUI initiatives will impact significantly on the lives of both the individuals participating and using the services. The report will be disseminated within the organisation and to the participants of the study. In addition, the researcher hopes to publish within the wider community.

4.3.1.1 Member validation

Member validation (Seale, 1999) was completed to check analysis outcomes with the research participants. Five participants were emailed, of which three accepted, offering them an opportunity read a draft of the analysis section of this report. Due to the nature of the study and emphasis on participation, the researcher felt this an important step in the process as it allowed participants to play a more active role in the research process. Each of these participants was asked to confirm the confidentiality of their data and comment on whether they believed there was a good fit between researcher understandings and their own understandings of their experiences. This aimed to determine that the results were credible and dependable, and correct any potential errors in the researcher's interpretations from the point of view of the participants (Braun & Clarke, 2013).

Participants commented that they had found the analysis section "interesting" and "enjoyable" to read, but gave no feedback beyond this. They voiced no concerns about the conclusions drawn or confidentiality of the excerpts included

from their transcripts. Power is a dynamic that has been referred to throughout this paper and remains a factor at this point. At interview participants termed the researcher an “academic” and “psychologist”, and as such it is likely that they felt hesitant or unable to criticise the analysis.

4.3.1.2 Transferability

The context and demographic information of participants was included in chapter 3, providing the reader with the opportunity to apply the results to others contexts. This allows a level of transferability. The information provided, however, was not highly detailed so as to maintain the confidentiality of the participants.

4.3.2 Sample

As is many qualitative studies, participant numbers were small and patients were diverse. Amongst other differences, the sample varied demographically by age, gender, ethnicity. The researcher travelled over a vast UK area to conduct interviews. Thus the conclusions drawn represent the opinions and attitudes of the heterogeneous participants, allowing for little generalisation. This aspect of the research was carefully considered during construction of the inclusion criteria; the researcher, along with her field supervisor, felt that it was important to be as inclusive as possible when conducting the research. In addition, it was hoped that by using this broad criteria, the study was left open to the discovery of similarities in experiences between these diverse individuals.

In addition, individuals who had taken part in any form of SUI were included in the study, including focus groups, research, volunteering, and consultation. All of these groups met the inclusion criteria. As recruitment went on, however, BRC staff recruited only focus group attendees and volunteers. At the interview stage, it became clear that although both groups described similarities in experience, there were also variations. The sub-theme, ‘obstacles in fulfilling the role’ was entirely based on feedback from volunteers, and ‘doubts about feedback’ was established as a result of content from focus group attendees. Notably, many key features discussed in this chapter were pervasive across

both groups: for example, lack of negative feedback, feeling indebted to the BRC, and lack of clarity and communication. As volunteers are fundamental to organisations like the BRC, especially service user volunteers, it felt important that the researcher include their voices.

In addition, as the researcher was operating from outside of the organisation it was necessary for her to rely on staff to identify and contact potential participants in the first instance. Due to the demographic diversity of the SU populations of the BRC, staff deemed it necessary to consider the social circumstances and physical and psychiatric health of all prospective participants. As a result, staff remained in control of who was approached to participate and recruitment was essentially out of the researchers hands. It was unclear how staff members to decisions about who to include. It is possible that a sampling bias was operating that mirrored the misrepresentation of populations identified as a problem within SUI in general, i.e. approaching only individuals who were 'well enough' or individuals most likely to report positive experiences. Once contacted by the researcher, a self-selection bias may have taken place.

4.3.3 Researcher Reflections

The researcher's influencing factors include their personal context, political position, personal and work experiences; as indicated in chapter 2. Previous experiences had left the researcher both passionate about really hearing the service user voice and frustrated that their input was often absent from important conversations within organisations. After initially meeting with her field supervisor and learning of the centrality of SUI in their corporate strategies, the researcher began the study hopeful about what she would uncover. As she progressed through the interviews, however, the researcher began to realise that the implementation of SUI was not well established. Hearing the familiar accounts of lack of regular feedback and poor communication elicited disappointment. Nevertheless, witnessing the enthusiasm of the participants, it was difficult for the researcher to come away from the interviews feeling negatively towards the BRC. The heartfelt appreciation individuals expressed to

staff and the organisation was incredible.

The researcher found the process of this research both exciting and challenging. At interview she met some fascinating and inspiring individuals, which was a highlight. At times the researcher found it difficult to keep participants on track or stop the interview once all the topic areas had been covered; this was especially true for individuals who were older in age. These experiences left the researcher wondering what other function she may have been serving for these participants. As participants identified at interview, their participation in SUI initiatives was in part related to having 'something to do.' The researcher considered that this research also served the same purpose and provided them with something novel to participate in, perhaps also limiting their expectations.

Once the interviews and analysis were complete, the researcher further reflected on the process, wondering if perhaps she had approached this project a little naïvely. Her experience stemmed from a small service example within a wider specialist services team, and whilst it had been successful, it was by no means 'the norm.' Since this, she has observed nothing similar in NHS services of varying size. It left the researcher questioning whether this service was the anomaly and comparing its success to other services was causing the researcher to become unappreciative of the steps being made in SUI in other services. Or perhaps the partnership model cannot translate effectively to large organisations with such diverse services and users, especially due to their vast number of stakeholders.

As with many topics of research, it felt difficult to capture the complexity of SUI, especially given the limited time and resources afforded to the project. Overall, it provided the researcher with a rewarding and authentic learning experience.

4.4 Conclusion

This study was the first aimed at understanding the motivations and experiences of individuals participating in SUI initiatives in the BRC. This information can be used to aid planning, monitoring and evaluation of SUI initiatives within the organisation in the future. The majority of the descriptions by participants were complimentary about both the BRC and its staff members; moreover respondents had positive experiences of the process of SUI. All participants explained that they would like to continue to be involved in SUI initiatives; however, there were clear areas for improvement for the organisation.

Whilst the BRC does not want to be tokenistic in its approach to SUI, unfortunately tokenism was highlighted in the data. A consultation model remained dominant in the services this study made contact with. In addition, feedback was not gathered in any regular or consistent way, and participants saw no change to services, and received no follow up after providing feedback. Where the BRC engaged individuals in volunteering, which is arguably more of a partnership model, these individuals participated at a service delivery level but did not progress past this. The outcomes revealed the complexity of coordinating SUI initiatives, ultimately supporting the idea that they require clear commitment from both the organisation and its staff members at every level. Thus organisational discourses play an important role in SUI. The necessity of guidelines for organisations to follow and accountability are key to success.

A key learning point is that we have an idealised view of SUI. Many individuals within governmental bodies, individuals active in the SU movement, and staff members believe that if we wish to co-produce it will happen but this is not the case. The BRC have had involving service users at the heart of their corporate strategy since 2010 yet tokenism remains. Thus this research began advocating for improved SUI, but possibly what the researcher is arguing for is activism. If we take Foucault at his word and resist professional power and create greater equality, perhaps activism is the way to approach it. Activism which works to

achieve a critical or counter discourse to the mainstream by connecting individuals and communities who identify, believe and wish to further their own issues and causes, e.g. the refugee communities of the UK (Stewart, 2016).

5. REFERENCES

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6. APPENDICES

Appendix A. Literature Search

The following search terms were used to access the literature surrounding service user involvement. Searches were carried out in December 2015-January 2016.

1. PsychINFO and PsychARTICLES. Date parameters: 1980 to 2016, Language: English.

Search Term 1	Search Term 2	Number of Articles
Service user participation	-	121
Service user participation	Experience	5
Service user participation	Rationale	0
Service user participation	Patient participation	0
Service user participation	Justification	0
Service user participation	Service user perspectives	1
Service user participation	Motivation	0
Service user participation	Why people get involved	0
Service user participation	Reasons	1
Service user participation	Drive	0
Service user participation	Perspective	0
Service user participation	Charitable organisation	0
Service user participation	Willingness	0
Service user participation	Feedback	0
Service user participation	British Red Cross	0
Service user participation	Statutory	1
Service user involvement	-	256
Service user involvement	Experience	72
Service user involvement	Rationale	1
Service user involvement	Patient participation	2
Service user involvement	Justification	0
Service user involvement	Service user perspectives	7

Service user involvement	Motivation	7
Service user involvement	Reasons	12
Service user involvement	Drive	4
Service user involvement	Perspective	29
Service user involvement	Charitable organisation	0
Service user involvement	Willingness	0
Service user involvement	Feedback	9
Service user involvement	British Red Cross	0
Service user involvement	Statutory	5
Involving service users	-	93
Involving service users	Motivation	2
British Red Cross	-	6
Patient participation	-	706

The vast majority of articles from 'patient participation' search were related to service user's involvement in their own care in approaches such as collaborative decision-making, and choice of service, and many overlapped with those of previous searches. Thus it was decided not to combine this search term with further search terms.

2. Scopus. Date parameters: 1980 to 2016, Subject areas: all.

Search Term 1	Search Term 2	Number of Articles
Service user participation	-	73
Service user participation	Experience	25
Service user participation	Rationale	1
Service user participation	Patient participation	8
Service user participation	Justification	0
Service user participation	Service user perspectives	7
Service user participation	Motivation	1
Service user participation	Why people get involved	0
Service user participation	Reasons	1

Service user participation	Drive	2
Service user participation	Perspective	15
Service user participation	Charitable organisation	0
Service user participation	Willingness	2
Service user participation	Feedback	1
Service user participation	British Red Cross	0
Service user participation	Statutory	2
Service user involvement	-	439
Service user involvement	Experience	172
Service user involvement	Rationale	7
Service user involvement	Patient participation	84
Service user involvement	Justification	0
Service user involvement	Service user perspectives	18
Service user involvement	Motivation	9
Service user involvement	Reasons	18
Service user involvement	Drive	7
Service user involvement	Perspective	87
Service user involvement	Charitable organisation	0
Service user involvement	Willingness	0
Service user involvement	Feedback	7
Service user involvement	British Red Cross	0
Service user involvement	Statutory	10
Involving service users	-	141
Involving service users	Motivation	2
British Red Cross	-	29
Patient participation	-	27,417

Where two search terms are noted, the Boolean search word 'AND' was utilised. All article titles were scanned for relevance, and on this basis of title abstracts of relevant articles read. A snowballing effect from relevant articles was utilised, looking for appropriate literature on their reference lists. Health Expectations, an international journal of public participation, along with Google Scholar and grey literature were also examined for relevant documents utilising the above search terms. Relevant articles were located online, via lending services at The University of East London, OpenAthens access, or The British Library.



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London
E15 4LZ

Service user involvement in the British Red Cross: experience and factors affecting willingness to participate.

About me:

My name is Natasha and I am a Doctoral student in Clinical Psychology at University of East London. I am conducting a research study at British Red Cross. I am contacting you because I understand that you have been involved in a service user involvement initiative and I am very interested in hearing from you about your experience of this.

This sheet should provide you with enough information to decide whether you would like to take part in this study. If you have any questions, please contact me on the below telephone number or email address.

Principal Investigator: Natasha Hickin, Trainee Clinical Psychologist

Email: u1331818@uel.ac.uk **Telephone:** 0208 223 4174

About the research:

I will be interviewing individuals who have been involved in service user involvement initiatives in the British Red Cross. I would like to hear about your experience of the involvement you have taken part in, and whether you think it can be improved. Very few studies have gathered this type of information before, and I think that it is very important to get your perspective.

Although the British Red Cross are aware of this research study, I am not a volunteer or staff member, and British Red Cross staff will not be involved in data collection or analysis. British Red Cross staff will receive an anonymised final copy of the completed research paper and will use this information to assess what is going well, and not so well, in their service user initiatives. Taking part in this research will in no way impact on the services you receive or the involvement you still have with the British Red Cross.

What will you have to do?

Attend one interview lasting 60-90 minutes, where I will ask questions about

your experiences. During the interview you can take breaks if you wish or withdraw at any point without providing a reason for doing so. All interviews will be audio-recorded.

Where will the interviews take place?

I can either visit you at home, or arrange to meet you at your nearest British Red Cross office at a time that is convenient for you.

Confidentiality

All information discussed in the interview will be kept confidential, unless I am concerned that you, or someone else, is at risk of harm. In this case I may need to speak to someone else, but I would always discuss this with you first.

All interviews will be audio-recorded; all audio recordings will be stored on an encrypted password protected memory stick. All recordings of interviews will be transferred into written form; at this point they will be made anonymous through the use of a pseudonym, and you will not be identifiable to others. All information collected will be kept in a locked filing cabinet at University of East London, only accessible by the researcher. When the research project is complete and written up, only short extracts of the interviews will be used in the report. This is the version of the report that British Red Cross staff will receive.

Names and contact details, plus anonymised transcripts, will be held electronically on an encrypted memory stick for three years after project completion date (estimated September 2016). Information gathered will be written up for publication in academic journals.

I will share the outcomes and conclusions of the research with all interested participants in whichever way you would prefer; e.g. verbally or written.

Right to withdraw

You are able to withdraw from the research study at any time without disadvantage and having to give any reason. I will begin to analyse the information from our interview soon after the interview is complete. If you would like your data to be withdrawn completely from the study, please contact me within 2 months of your interview date. If you withdraw after this date, I may still use your fully anonymised data in further analysis and project write-up.

For further Information:

My supervisor, Trishna Patel, will be glad to answer your questions about this study at any time. You may contact her on 0208 223 6392.

Complaints procedure:

If you are in any way dissatisfied with the interview process or wish to make a complaint, please contact Mark Finn (University of East London Ethics Committee) on 0208 223 4493 or Trishna Patel (as above).

Appendix C. Participant Consent Form



School of Psychology
Stratford Campus
Water Lane
London
E15 4LZ

Consent to participate in the following study:

“Service User Involvement in the British Red Cross: Experience and Factors Affecting Willingness to Participate”

I have read and understood the research information sheet provided, and asked questions about anything I was unsure of. The researcher (Natasha) has explained what the research involves and I now understand the procedure. I have a copy of the information sheet for my records.

I understand that everything discussed in the interview will be kept confidential. The interview voice recordings will be stored on a password protected memory stick, and only the researcher will have access. At the point of analysis, all data and transcripts will be made anonymous, and only the researcher will know the identity of participants. At no point will the British Red Cross have information on who has participated in the study. All of the information collected will be kept in a secure place, only accessible by the researcher.

By signing this form, I fully consent to participate in the above named study and for my data to be used in an anonymised way. I understand that I am able to withdraw at any time. If I would like my data to be withdrawn completely from the study, I must contact Natasha within 2 months of your interview date. If I withdraw after this date, my anonymised data may still be used in further analysis and project write-up.

Throughout the interview, if I am unclear about what the interviewer is asking me, I will ask for clarification.

Name

Signature Date

Contact number/email

Researcher signature Date

Appendix D. Interview Schedule

Each participant will be given another Participant Information Sheet to read through, discuss, and ask any questions. Only if the participant consents, by signing the consent form, will the interview begin.

The interview will be semi-structured and will roughly follow the below schedule. Prompts and follow up questions will be permitted.

Proposed interview schedule:

Opening: "I am interested in your experience of service user involvement activity in the British Red Cross...
(description of what service user involvement is, check their understanding)
I understand that you were involved in a focus group/as a volunteer/on an interview panel"

How were you approached to become involved in focus group/volunteering?

Why did you agree to become involved?

Can you tell me what it was like?

What did you do/what was involved?

How did you experience working alongside BRC staff and volunteers?

What happened afterwards (prompt: were you contacted again? Have you been to another meeting?)

Do you know what happened/changed as a result of your input?

IF YES: How did you find out about this? Were you satisfied with the result? How would you like to have been informed about this?

IF NO: Would you like to be informed of action taken as a result of feedback? How would you like to be informed?

What do you think about your involvement now looking back?

Is there anything that could be done differently in the future?

Would you consider being involved again?

Is there anything else you would like to add?

Closing: "Thank you very much for coming today"

Followed by **debrief questions**:

What influenced your decision to come?

How have you found this interview process?

Did I influence your responses in any way?

Were there questions that you think I should have asked or that you wish I had asked?

Do you have any concerns or questions about the process?

Appendix E: Support Form

Further Support Options

If at any point after the interview you feel distress or that you need to talk to someone, consider the following options:

- Contact a friend or family member.
- Visit your local GP or A&E Department.
- Contact **Samaritans** on 08457 90 90 90 (24-hour line)
- Contact **Saneline** on 0845 767 8000 (6pm and 11pm daily)

Appendix F. UEL Ethics Committee Approval

NOTICE OF ETHICS REVIEW DECISION

For research involving human participants
BSc/MSc/MA/Professional Doctorates in Clinical, Counselling and Educational Psychology

SUPERVISOR: Trishna Patel

REVIEWER: Luis Jimenez

STUDENT: Natasha Hickin

Title of proposed study: Service user involvement in the British Red Cross: experience and factors affecting willingness to participate.

Course: Professional Doctorate in Clinical Psychology.

DECISION (*Delete as necessary*):

***APPROVED, BUT MINOR CONDITIONS ARE REQUIRED BEFORE THE RESEARCH COMMENCES**

APPROVED: Ethics approval for the above named research study has been granted from the date of approval (see end of this notice) to the date it is submitted for assessment/examination.

APPROVED, BUT MINOR AMENDMENTS ARE REQUIRED BEFORE THE RESEARCH COMMENCES (see Minor Amendments box below): In this circumstance, re-submission of an ethics application is not required but the student must confirm with their supervisor that all minor amendments have been made before the research commences. Students are to do this by filling in the confirmation box below when all amendments have been attended to and emailing a copy of this decision notice to her/his supervisor for their records. The supervisor will then forward the student's confirmation to the School for its records.

NOT APPROVED, MAJOR AMENDMENTS AND RE-SUBMISSION REQUIRED (see Major Amendments box below): In this circumstance, a revised ethics application must be submitted and approved before any research takes place. The revised application will be reviewed by the same reviewer. If in doubt, students should ask their supervisor for support in revising their ethics application.

Minor amendments required (for reviewer):

1. **Invitation Letter** needs some further clarification in some paragraphs:

A) Needs to specify what is your involvement with Red Cross staff (e.g., you only advertise yourself as a doctoral UEL student) but then you say that the information you gather in interviews will be passed on and used by Red Cross Staff to directly assess their user involvement policies. This way of introducing yourself suggests you are not acting only as a UEL student and – given you also mention in your Ethics Form your participants will be recruited through the decisions of the Red Cross Staff selecting who participates in your research and who does not then you need to

consider the implications of this, e.g., explain better in your Invitation letter the extent of and specific uses of the information you collect in your research as this will also have an impact on the extent to which your potential participants (potentially vulnerable participants) can actually be involved in a process of fully informed consent and how you understand and are using confidentiality and anonymity as part of the ethical considerations of conducting your research.
B) clarify in your invitation letter that only fully anonymised research extracts will be used in the written version of your study

2. **Consent Form:** Needs to clarify you will still seek approval to use data in a fully anonymised way for those participants who have told you they are withdrawing from your study
3. Needs to also include a clear **De-Briefing Procedure as an Appendix**. There is attached a document called "further support options" but this is not synonymous nor the same as a "De-Briefing" with your research participants. De Briefing should also explore some of the basic following questions:

. How do you feel having completed the interview?

. Do you have any concerns or questions about the process of the interview or the research in general?

. Do you feel that the questions were biased in any way?

. Do you think that the questions asked were open, enabling you to express yourself freely

. Did I in any way influence your responses?

Do you feel that you were able to talk about areas that are important to you? .

Were there any questions that you think I should have asked or that you wish I had asked?

Do you have any recommendations or observations about what would make this interview more effective?

You can include the further support contact details you include as part of another appendix called "De Briefing Procedure"

Major amendments required (for reviewer):

--

Confirmation of making the above minor amendments (for students):

I have noted and made all the required minor amendments, as stated above, before starting my research and collecting data.

Student's name (Typed name to act as signature): N. Thoburn N. THORBURN (HICKIN)

Student number: 41331818

Date: 20/05/15

ASSESSMENT OF RISK TO RESEACHER (for reviewer)

If the proposed research could expose the researcher to any of kind of emotional, physical or health and safety hazard? Please rate the degree of risk:

☐

HIGH

☐

MEDIUM

☒

LOW

Reviewer comments in relation to researcher risk (if any):

Reviewer : Dr. Luis Jimenez

Date: 20.04.2015

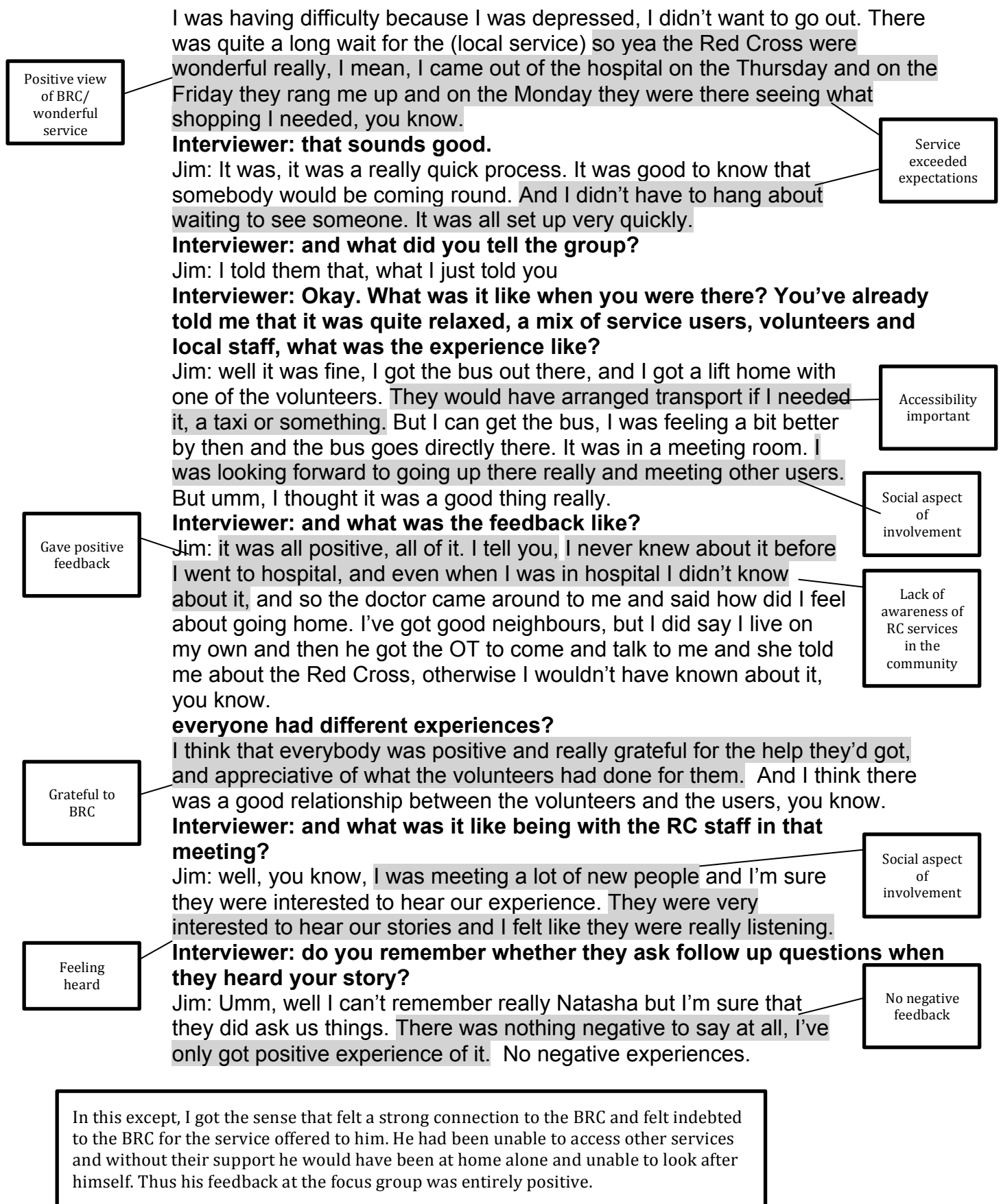
This reviewer has assessed the ethics application for the named research study on behalf of the School of Psychology Research Ethics Committee (moderator of School ethics approvals)

PLEASE NOTE:

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, prior ethics approval from the School of Psychology (acting on behalf of the UEL Research Ethics Committee), and confirmation from students where minor amendments were required, must be obtained before any research takes place.

*For the researcher and participants involved in the above named study to be covered by UEL's insurance and indemnity policy, travel approval from UEL (not the School of Psychology) must be gained if a researcher intends to travel overseas to collect data, even if this involves the researcher travelling to his/her home country to conduct the research. Application details can be found here: <http://www.uel.ac.uk/gradschool/ethics/fieldwork/>

Appendix G: Coded transcript



Appendix H: Initial Codes and Frequencies

The table below displays the initial codes developed from annotating the raw data transcripts. The frequency column indicates the number of participants that mentioned each code.

Initial Codes	Frequency
1. Keen to help	9
2. "I do what I can"	2
3. Informal & friendly atmosphere	1
4. Going above and beyond (RC)	4
5. Vague understanding of the purpose of SUI	5
6. Share ideas for improvement	3
7. Collaborative approach to improvements	1
8. Feeling heard	5
9. Feeling appreciated	8
10. Personal values- helping others	6
11. Giving back to RC	5
12. No negatives about experience	3
13. RC seen as needing help/support	2
14. No negatives about the RC	2
15. Something to do/ keeping busy	6
16. Relaxed environment	4
17. Friendly atmosphere	2
18. Lack of communication after involvement/feedback	5
19. "Fantastic staff"	6
20. Enjoyment	3
21. Manager seen as 'in charge' of meeting	1
22. Well organised	2
23. Suspicious of motives (of feedback)	1
24. Follow up seen as validation	3
25. Questioning usefulness of feedback	1
26. Feedback fatigue	2
27. Expressing positive view of RC	6
28. Caring staff	1
29. Proximity to SU experience/ lived experience	5
30. Lack of awareness of RC services in community	6
31. Transferable skills	4
32. Interesting work	4
33. Exciting work	1
34. Cultural beliefs/values	1
35. Faith directed work	1
36. "It changed my life"	1
37. Built confidence	3
38. Increased aspirations	1
39. Challenging interactions	4
40. Utilises/consolidates current skills	1
41. Develop understanding of other perspectives	6
42. Learn from staff	1
43. Feeling supported by staff	4
44. Choice/being accommodated	4
45. Hostile environment	2
46. Informal supervision available	2
47. Informal feedback sought	4
48. Continual opportunities to feed back	2

49. Believes actions should be communicated to those providing feedback	1
50. Would value follow up	6
51. Wants more influence over changes/decision making	3
52. Feedback is futile	1
53. Feeling powerless	2
54. Difficult to change established ways of working	3
55. Observed changes resulting from feedback	1
56. Happy in the role	5
57. Committed to RC	1
58. Feeling ignored	1
59. Would like further opportunity to feed back	2
60. Varied role	4
61. Sense of purpose	1
62. Skills to offer e.g. language	2
63. Contributing requires commitment	1
64. No negative feedback	4
65. Challenging role	2
66. Psychological impact of asylum process	2
67. Learning and skills development	4
68. Opportunity to reflect	2
69. Relying on others	2
70. Long hours	1
71. Juggling SUI, work and home life	2
72. Quantity of information to learn and remember	3
73. Rewarding work	5
74. Improved communication required	1
75. Further training required	2
76. Infrequent formal feedback opportunities	1
77. Verbal feedback sought	1
78. Written feedback sought	4
79. Unclear on feedback use	6
80. Emotional impact of work	2
81. Trusting relationship with staff	4
82. Lack of communication can lead to challenging interactions	1
83. Would like to do more for SU's	3
84. Improve by providing formal evidence of training	1
85. Website unreliable	1
86. Improved social skills	2
87. RC seen as 'doing their best'	1
88. Improve with more social events	1
89. Social aspect of involvement	7
90. Flexible work	3
91. Welcoming environment	2
92. Sense of belonging	2
93. Questions whether feedback linked to changes	3
94. Community outreach to improve	1
95. BRC provides hope	1
96. BRC services speak for themselves	1
97. Available time impacts on involvement	3
98. Few attendees	2
99. Few follow up questions	1
100. Narrative of service experience offered	4
101. Didn't require follow up after involvement	2
102. Service exceeded expectations	4
103. Grateful for service received	5
104. Biased attendees	2
105. Understands the importance of feedback	3

106. Improve feedback with more attendees	1
107. Clinical environment	1
108. Unwelcoming environment	1
109. Welcoming environment improves attendance	1
110. Uncomfortable environment	1
111. Positive reviews from attendees improves involvement	1
112. Welcoming staff	3
113. Pleasant experience	2
114. Convenience is important	1
115. Relaxed environment improves feedback	4
116. Language as a barrier to service use	1
117. Experienced difficulties as a SU	2
118. Aim to improve SU experience	2
119. Improved accessibility	1
120. Shared goals (staff and SU's)	2
121. Would like to remain involved	6
122. Positive relationship with staff	2
123. Feeling valued	2
124. SUI provides hope for SU	1
125. Training provided	4
126. Regular feedback requested	1
127. Improvements observed	1
128. Experience of working for large organisation	1
129. Unappreciative SU's	3
130. Aggressive SU's	2
131. No changes suggested	2
132. Suggests payment to encourage involvement	1
133. Volunteers leave for paid roles	1
134. Feels held in mind by RC	1
135. Volunteers present- impact on feedback given	1
136. Belief that feedback can lead to changes	2
137. SU voice should be central	3
138. Invaluable service received	5
139. Accessibility important	4
140. Longer notice period to increase involvement	1
141. Regular meetings required/beneficial	2
142. Attending SUI keeps authority connected to ground level services	1
143. Individual experience valued	1
144. "Nobody knows the story better than me"	1
145. No follow up after feedback	3
146. Valued service	2
147. Acknowledging differing circumstances	1
148. Differing attitudes impact on involvement	1
149. More encouragement to become involved beneficial	1
150. RC needs more publicity	3
151. Fun experience	1
152. Cultural considerations	2
153. "Feedback is important"	1
154. Wonderful experience	1
155. Positive staff role model	1
156. Feeling protected	1
157. Low expectations of SUI	3

Appendix I: Examples of Coded Data Extracts

39. Challenging interactions	Rose: Most of them you can tell that they do not want to be helped by a woman, but they have no choice.. (describes the conversation between her and a RC client).. So some of the experiences are more challenging. But I understand from my background, where I came from, where I grew up, and my past work experience. I can understand.
	Rose: Where we are here we are working as different organisations and most of it is referral from (another organisation) to the RC. And you see, there is a lot of hostility between the staff from (other organisation), not volunteers, but the supervisors from the forum. Sometimes you find it very difficult, you can get to work and that day will be so miserable.
	Kay: Although you're a volunteer and you don't get paid, but you need to be committed. Because there are lots of challenges there.
	Kay: you are offering them help, and sometimes because of lack of understanding they can start shouting at you, or behaving like maybe you have done something wrong. So yea, you just need to be calm and try to understand them.
	Kay: I think some more training would be good as well. More regular trainings. It can be emotional as well working with these people so this training on emotional support or whatever; that one needs to be like maybe once a year just to help people.
	Sara: They start to make trouble for you even in your work. Not people who work there. Clients; some of them they may not understand or they thought you have to give them more, or help me more, and they start to get aggressive. Some of them, some of them do not appreciate.
	Linda: I have never had a problem with a client, but sometimes family members think you should be doing more. They might decide that you're not doing enough.

56. Happy in the role	Rose: I have told them that if I get my status I will always stay on working with them even if it is once or twice a week. Because I am really happy working for RC. I would indeed continue.
	Peter: I am happy with it, even in happiness there will be some difficulties.
	Sara: I want to help the people and I like to help the people because I have all this time, all this problems before. Because of that I am really happy when I feel I help somebody.

	Sara: I feel very happy when I find someone is comfortable with me and he take the help.
	Linda (9)I can just say that the way it's run is the perfect way of running it. We're all happy. I guess with volunteers, if staff aren't treated right, there's nothing to stop people wandering off.

103. Grateful for service received	<p><i>Interviewer: and why at that point, when they phoned you, did you decide to urr be involved?</i></p> <p>Barbara: well umm because I think they've done such a good job for me personally that I would go along and see what was what and put any input that I had, umm, if it was asked. Umm, and I basically said that I had a good service from them</p>
	Sara: I was one of these people and I appreciate that RC they help me and now I make volunteer job with RC and I just want to show grateful for these people that they help me.
	Karen: As I said, anything that helps in any way I'm quite happy to do because I was incredibly grateful.
	<p><i>Interviewer: so why did you agree to go to that meeting?</i></p> <p>Jim: why? Well because they had been so helpful to me, you know, and I thought it was sort of a way of showing my appreciation, and umm, you know, giving something back really.</p>
	Jim: I think that everybody was positive and really grateful for the help they'd got and appreciative of what the volunteers had done for them.
	Linda: I was very grateful for what they'd done for me so if there was anything more I could do to help by way of feedback I was going to do it. That was it really. It's the gratitude.

Appendix J: Grouped Final Codes

"You know how they're feeling"	Proximity to SU experience/ lived experience Service user voice should be central Experienced difficulties as a SU Aim to improve service user experience
Personal considerations	Something to do/ keeping busy Personal values- helping others / Keen to help SUI keeps authority connected to ground level services Belief that feedback can lead to changes Share ideas for improvement Understands the importance of feedback
Indebted to the British Red Cross	Service exceeded expectations Grateful for service received Invaluable service received Giving back to BRC Going above and beyond (BRC) The BRC provides hope Positive relationship with staff Lack of awareness of services in the community BRC needs more publicity "I do what I can"
Comfortable Atmosphere	Relaxed environment Welcoming environment Welcoming staff Pleasant experience Relaxed environment improves feedback Informal and friendly
Feeling valued	Feeling heard Feeling appreciated Being accommodated/choice Happy in the role Rewarding work "It changed my life"
Making connections	Social aspect of involvement Feeling supported by staff 'Fantastic' staff Sense of belonging Shared goals (staff and SU's) SUI provides hope for SU Trusting relationship with staff Feels held in mind by RC

Personal growth	<p>Built confidence</p> <p>Developed understanding of other perspectives</p> <p>Improved social skills</p> <p>Opportunity to reflect</p> <p>Transferable skills</p> <p>Training provided</p>
Lack of clarity and communication	<p>Vague understanding of the purpose of SUI</p> <p>No follow-up after providing feedback</p> <p>Would value follow up after involvement</p> <p>Believes actions should be communicated to those providing feedback</p> <p>Questions whether feedback linked to changes</p> <p>Follow up seen as validation</p> <p>Unclear on feedback use</p>
Redistributing control	<p>Wants more influence over changes/decision making</p> <p>Feeling powerless</p> <p>Difficult to change established ways of working</p> <p>Manager seen as 'in charge' of SUI (consultation model)</p> <p>Would like to do more for SU's</p>
Embedding in the team	<p>Improve feedback with more attendees</p> <p>Further training required</p> <p>Would like further opportunity to feed back</p> <p>Improve by providing formal evidence of training</p> <p>Payment to encourage involvement</p> <p>Regular meetings required/beneficial</p>
Doubts about feedback	<p>Suspicious of motives (of feedback)</p> <p>Questioning usefulness of feedback</p> <p>Low expectations of service user involvement</p> <p>Biased attendees</p>
Obstacles in fulfilling the role	<p>Challenging role</p> <p>Juggling SUI, work and home life</p> <p>Quantity of information to learn and remember</p> <p>Challenging interactions</p> <p>Unappreciative SU's</p> <p>Aggressive SU's</p>
Approaches to feedback (Not for themes: context section of results)	<p>Informal feedback sought</p> <p>Continual opportunities to feed back</p> <p>Written feedback sought</p> <p>Narrative of service experience offered</p> <p>Infrequent formal feedback opportunities</p>

Appendix K: Reflective diary extracts

Diary entry after initial interview (Bill):

On first meeting Bill, I was struck by how warm and welcoming he was. I got the sense that he was going out of his way to make me feel comfortable in his home. I felt more relaxed once I met Bill, as in the car I had been feeling quite nervous about starting data collection. It felt strange being in someone's home for an interview, on reflection this may have been linked to an idea I have of what a research interview should be like. The informal setting in his conservatory caught me off guard a little, considering I was armed with my Dictaphone and official paperwork!

Once the interview was underway, I felt pleased that I'd taken the time to consult the service user group and conduct the test runs because using the description of service user involvement at the beginning of the interview put Bill in the right frame of mind to begin. Despite this he took a number of opportunities to wander off topic; for example, talking about his medical conditions. It was difficult to bring him back to the interview. Perhaps due to lack of social contact, he was using the interview as an opportunity to meet someone new and tell them about himself. I thought back to the telephone conversation we had when arranging an interview time, and Bill had commented that he 'never had anything on' and describing the focus group as 'just a trip out.' For this reason, I let him talk briefly before bringing him back to the question I had asked previously.

Another aspect of the interview I picked up on was Bill commenting on me being 'young' and I wondered if these comments were a comparison to his own age, or a questioning of my competence to be conducting the study. In hindsight, the second concern is far more likely to connect to my own self-doubt and lack of confidence in completing research.

I wondered at times whether Bill was holding back, or wanting to portray himself to me in a certain way. He spoke in very positive way about every aspect of his experience of the BRC service and the focus group. I felt a little frustrated when he told me that no one at the focus group had given any suggestions of areas of improvement for the service, especially knowing the time it takes to arrange a focus group. But later linked this to his experiences of written postal feedback that he saw as a way of the BRC asking for money. Perhaps he thought it not worth providing feedback as nothing ever happens with it. He certainly was not able to tell me what the BRC used feedback for. This was disappointing. I was left hoping that future interviews would give me more hopeful overviews of SUI operating at BRC.

Diary entry at time of analysis: code refining

Despite wondering whether the interview data I had collected had provided me with enough information for analysis, and fearing that I might need to approach further staff members for recruitment, I was left with what felt like an overwhelming number of initial codes. Having reviewed the transcripts a number of times, several things struck me about the data:

1. Individual's experiences of the BRC services were very positive and they held the organisation in very high regard- this surprised me at first as it is unusual to hear nothing bad reported. There seemed to be a great connection of these participants to

the organisation to varying degrees. Peter even describing BRC staff as family.

2. The positives of SUI by far outweighed the negatives for these participants, thus the decision to continue to be involved seemed like an easy one.

3. The lack of clarity about service user involvement was worrying. Participants in some cases didn't really understand what experience I was asking about and this left me reiterating the activity I was asking about. To some individuals it seemed like another thing 'to do' or a good way to keep in contact with an organisation they felt highly of.

4. The social aspect and skills development seem key aspects to come out of the data so far.

I continue to review my reflective diary to remain in contact with my initial impressions throughout the process. I felt very aware of my own frustrations that SUI is not being done well enough in this organisation, which has left me disappointed. I hope that the organisation will be able to use this report to highlight the importance of training and communication in SUI. I have now begun the process of refining the codes and collapsing similar codes, this has been challenging. Meeting with other trainees to review progress and discussing each stage with my supervisor has been invaluable.