Service user perspectives of preparation for living in the community following discharge from a secure mental health unit

A thesis submitted in partial fulfilment of the requirements of the University of Brighton for the degree of Doctor of Philosophy

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Deborah Alred

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Author’s declaration

I declare that the research contained in this thesis, unless formally indicated within the text, is the original work of the author. The thesis has not been previously submitted to this or any other university for a degree, and does not incorporate any material already submitted for a degree.

Signed: [Signature]

Date: 9th March 2018
Abstract

Recovery orientated practice is an expectation of current service provision in forensic mental health services. It has been suggested that there are specialist recovery needs of people with mental illness and an offending history; however these have not been explored in research to date. This study aimed to address this gap in knowledge by examining the opportunities and challenges encountered by service users returning to the community following discharge from a forensic mental health unit. It aimed to carry out the study in a way that incorporated the recovery principles of service user involvement, so the specific study question was identified in a service user consultation.

Six service users who had been discharged from a forensic mental health unit and were living in the community were interviewed. They were asked about their preparation for discharge and their experiences of living in the community. Specific recovery tasks for forensic service users were identified, which are either the result of having a history of offending or another aspect of the secure pathway such as length of stay. The research team called these the “Getting Out and Staying Out (GOSO) recovery challenges”. Some of the GOSO challenges have been identified in previous research but the study also identified some novel issues facing service users. This is the first time the recovery tasks have been collated for this group. The findings provide a more comprehensive understanding of recovery for service users with a forensic history.

The GOSO challenges have an application for clinical practice and policy. They provide a structure from which a group intervention or recovery college course can be developed. They offer a framework to support individuals and clinicians to identify recovery goals, taking into account the impact of the offence. They provide a more detailed understanding of the impact of having offended on mental health recovery. They can therefore be used to inform policy and national guidelines. Attitudes to risk management are also challenged as risk reduction through engagement in meaningful activity is highlighted.

The study utilised a participatory methodology grounded in Habermasian critical theory. Two service user researchers (SURs) were employed and trained in research skills. They supported the development of the study protocol including the ethics approval process; they
carried out the interviews and contributed to the data analysis. A three-stage data analysis process was employed utilising a collaborative narrative approach to transcript analysis as well as framework analysis. It was designed to support a shared data analysis process.

Critical or emancipatory research has a dual aim to seek out knowledge and support the flourishing of individuals. Involvement in the study increased the SUR’s confidence and developed their critical and reflective skills. This has resulted in both SURs achieving employment in peer roles and additional research projects.

Participatory research methodology is relatively uncommon in occupational therapy research. The study therefore ends by proposing a model for supporting communicative action within a clinical research setting in order to encourage future participatory studies.
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Chapter 1. Introduction

1.1 Why this study

I have worked as an occupational therapist in secure and forensic mental health services for twenty years. These are specialist services that provide care and treatment for forensic patients. Secure and forensic services have a dual role of providing mental health care and protecting the public by providing effective risk management (Barker, 2012). As a result of these dual tasks the length of stay in hospital for individuals is longer than for people with acute mental health conditions (DoH, 2007a). In their review of secure services the Centre for Mental Health noted that only a third of patients have an admission lasting less than two years and nearly half are admitted for over five years (CMH, 2011). My concern and practice interest has always been how to make use of this increased admission time. How to help patients to develop skills that they will be able to draw upon in the future, so they can make the most of living in the community. Over the years I have observed individuals and talked to them to find out what they needed to prepare them. I have also asked them in various informal surveys and questionnaires within my role as an occupational therapist. When I undertook this study I saw it as an opportunity to look into the patient’s experiences of discharge and living in the community in more detail.

This feels like a particularly apt time for this study to be taking place. For reasons that I explain later, secure and forensic services have experienced a time of tremendous change over the last few years (CMH, 2011). There has been an expansion of services. The service I work in has doubled in size over the last four years and plans are in place to continue this expansion. The physical look of the buildings has changed, with the development of national secure standards (DoH, 2011a; 2011b; 2013; RCP, 2012). This has included raising the height of external fences and developing a sophisticated key management system (DoH, 2011a). This increase in physical security and standardisation of security procedures could easily result in a more restricted philosophy of care and routine, however there has been a step change in how services are delivered (Drennan & Alred, 2012; JCPMH, 2013) which is explained below.

Recovery orientated practice, i.e. practice that puts the individual patient firmly in the centre of service planning and delivery has rapidly emerged as an expectation of service provision (Drennan, Law & Alred, 2013; Jacobson & Curtis, 2000; RCP, 2007; Shepherd, Boardman & Slade, 2008). Services are moving away from a rehabilitation model, services provided by
professionals with consultation of the service user, to a recovery model where patients and staff work in a more collaborative way to meet outcomes identified by the patient (Shepherd, Boardman & Slade, 2008).

Criminologists and clinicians working with offenders in prisons and probation are also taking up this person centred approach. Previously there was an assumption that people often grew out of criminal behaviour (Maruna & LeBel, 2010). However, when asked, offenders described the importance of work, and relationships as motivators for desisting from further offences (Maruna, 2001). This has led to the development of strategies, which assist offenders to work towards the issues they identify as priorities such as housing, work and relationships rather than providing expert programmes focusing on the offence. It sets out a desistance paradigm where the issue of personal agency is given a central position, which mirrors a recovery orientation (Farrall & Calverley, 2006; Gadd & Jefferson, 2007; Maruna, 2001).

The use of person centred approaches are becoming increasingly discussed as a way of addressing both mental health and offence related issues (Maruna, 1999). There is a move away from a “one-size-fits-all” approach to developing an understanding of the particular needs and situation of each individual. Within the current forensic service the lead psychologist and I have co-led the clinical team in exploring this reinterpretation of recovery principles. We have renamed it Secure Recovery to hold in the title the two responsibilities of risk management and recovery. The definition of Secure Recovery is as follows: “Secure Recovery acknowledges the challenges of recovery from difficulties that lead to offending behaviour. This recognises that the careful management of risk is a necessary aspect of recovery in our service but this can happen alongside working towards the restoration of a safe, meaningful and satisfying life.” (Drennan & Alred, 2012, p. x). This has led to a fundamental re-visioning of the service. This has included the development of peer-facilitated interventions, including recovery colleges (Perkins, Repper, Rinaldi & Brown, 2012) and services shaped by service users through patient involvement in planning and design of the service. As an occupational therapist I have been particularly interested in these developments, because of the shared philosophy and roots of occupational therapy and recovery (COT, 2006). I therefore wanted to use the study to develop and inform this work.

Since I have worked in this speciality I have been interested in the transition between a long stay in hospital and the community. How can individuals make a successful life for themselves after a protracted time spent in hospital? How can people make use of the opportunities in the community and what are the barriers to this? How can we ensure that
people do not simply replace sitting in their bedroom in hospital with sitting isolated in their flat in the community? How can we reduce the likelihood of reoffending? By learning more about these issues I can make recommendations that will improve the patient experience.

1.2 A brief introduction to the study

“Getting better and getting out”, is how one service user described recovery to me, the phrase neatly summarises the basis for the study. It was a collaborative, participatory study, which utilised an emancipatory methodology. The study has incorporated service user involvement from the outset, including the development of the question. The study was grounded in recovery practice and utilised qualitative methods. The title of the study was “Service user perspectives of preparation for living in the community following discharge from a secure mental health unit.” Individuals who have been an in-patient on a secure forensic in-patient unit and who had been living in the community for at least six months were interviewed to inform the outcomes of the study. The study makes a significant contribution to the understanding of recovery from mental illness and an offence history.

Participatory research is defined as “systematic inquiry with the collaboration of those affected by the issue being studied, for the purposes of education and of taking action or effecting change” (Mercer et al., 2008, p. 409). In keeping with participatory methodology the study had two aims. The first was to do with the subject matter of the study and the second was to develop research capacity in members of the community under study.

Firstly the study sought to learn from the experience of people who have been in-patients in secure services and who are now living in the community. I anticipated that the study would shed light on how reintegration into the community is defined by the service users and that this would lead to a greater understanding of the opportunities and challenges associated with this. I also sought to gain a service user perspective about the requirements of secure in-patient services to prepare them for living in the community. I hoped to identify some of the challenges encountered on reintegration to the community by patients who had been discharged from secure services and finally I wanted to use the learning from the study to make recommendations for future service developments, including group and individual interventions, which would assist in preparation for discharge.

Secondly the study worked to develop research capacity in members of the community under study. In this case patients who have experienced an in-patient admission to secure services
and who are now living in the community. Two people have been employed by this study as service user researchers (SURs). The study methodology included the provision of training and experience to the SURs so that they could collaborate as co-researchers for the duration of the study. The aim was that at the end of the study they would have the skills, experience and confidence to participate in future research.

My approach to this study in terms of structure and writing style aims to be consistent with the underpinning philosophy and methodology adopted in the study. I therefore employed devices to lead the reader through the information presented. The central focus of the study was recovery. One of the key changes that recovery principles advocate is a reorientation of health services around the individual patient. Throughout the study therefore, when considering different aspects of the study, the patient perspective will be discussed first, before the professional perspective.

How recipients of mental health services are referred to is contested (Simmons et al., 2010). So I will clarify the terms I used in the study. In the thesis I will use the term service user. Service user is consistently the preferred term of those who use the service I work in. At times in the thesis I will differentiate service users in mainstream mental health services from the forensic client group by using the term forensic service user, or service user with a history of offending. I recognise that there is a small number of patients in secure services that may not have been convicted of an offence, however in this study all the participants had a history of offending and it was this offending history which impacted on their recovery. So I have elected to utilise these terms.

Throughout the study I have written using the first person. The dynamic between the presentation of the researcher self in the study context and articulation of their role in shaping the ideas presented are now quite widely recognised as part of the constitution of the research process (Finlay & Gough, 2003). The use of the first person is appropriate and provides a more honest approach to the opinions and decisions discussed in the study (Webb, 1992).

I am using a participatory methodology. Participatory methodology is becoming increasingly used in healthcare (ICPHR 2013a). However detailed strategies for supporting participation are relatively uncommon (ICPHR 2013a). I have therefore taken time to explain the strategies I used in detail and also to reflect on their effectiveness. In order to reflect the participatory nature of the study I have referred to the study within the theses as “the study” or “our study”
I would like to make one final note. I have aimed to protect confidentiality by changing the names of the participants and the recognisable details of their responses. When a unit is named I have replaced the name with the type of unit, e.g. medium secure unit. Nevertheless if you live or work in a secure setting you may recognise the responses and be able to identify the individual due to the fact that the forensic mental health service is a relatively small clinical area. If you do please maintain confidentiality for the participant and the unit, thank you.
Chapter 2. The context

I am the consultant occupational therapist in a Secure and Forensic service working within an NHS Foundation Trust. We provide specialist forensic mental health services. This includes the provision of medium and low secure in-patient beds, two locality-based forensic mental health teams, police custody, liaison and diversion services and specialist mental health services within the two local prisons, we also work into an immigration removal centre. As the consultant occupational therapist, I have a clinical role to support the development of the in-patient therapy and activity programmes. I provide professional leadership to forty-two occupational therapy staff. As a member of the leadership team within the service, I work alongside the other lead professionals and managers to support all members of the multidisciplinary team to provide high quality evidence based therapeutic interventions. My role within the Trust’s leadership team is part of the organisational strategy to move towards a clinical management structure which ensures that efficiency and quality improvement are considered together (Monitor, 2012).

2.1 An introduction to forensic mental health

Secure and forensic services are a very specific and specialist area of mental health care. I am therefore going to spend some time introducing this clinical area by describing the clinical needs of the service users.

Secure and forensic services provide specialist mental healthcare for mentally ill offenders. They provide accommodation, treatment and support for people with severe mental health problems who pose a risk to the public (Durcan, Hoare & Cumming, 2011). The majority of in-service users are detained under the 1983 Mental Health Act Criminal Sections for assessment or treatment (DoH, 1983; Durcan, Hoare & Cumming, 2011). Individuals may have committed an offence while mentally ill and been referred to the secure in-service user setting by the Courts. They may also have become mentally ill during a prison sentence and have been transferred to a secure psychiatric hospital for assessment and treatment (CMH, 2011; JCPMH, 2013). It is estimated that secure services work with between 7,000 and 8,000 people at a time, most of these in medium and low secure settings (DoH, 2007; Durcan, Hoare & Cumming, 2011).

In Appendix I, I have included additional factual information in order to provide a foundational knowledge of the service. It focuses on the legal aspects rather than the experiential pathway
so that the reader understands the process as a whole. It describes the different sections of the Mental Health Act (DoH, 1983) that service users can be detained under and which are referred to in this study. As a specialist area of mental health there are inevitably a number of specific terms and concepts that need to be explained so I have also written a glossary of terms, which can be referred to (Appendix II).

2.2 The service user group

The NHS standard contract for medium and low secure services states that the typical service user admitted to secure and forensic services will have complex mental disorders, with co-morbid difficulties of substance misuse and/or personality disorder, which are linked to offending or seriously irresponsible behaviour (DoH, 2013, p. 1). Most individuals, therefore, are involved with the criminal justice system, the courts and prison system, and many have Ministry of Justice (MoJ) restrictions imposed (DoH, 2013).

The Joint Commissioning Board for Mental Health (JCBMH) identifies four characteristics of service users in medium and low secure settings. They will:

1. Usually have long-standing and complex mental health disorders.
2. Typically require longer-term rehabilitation and support which either cannot be safely or successfully delivered in open mental health units.
3. Be more likely to exhibit behaviour at a level of risk greater than a general mental health service could be expected to safely manage.
4. Receive care, treatment, and interventions based on a recovery approach. (JCPMH, 2013, p. 8)

In the document “Making Recovery a Reality in Forensic Settings” (Drennan & Wooldridge, 2014) a fictional example of a service user, was described. I have quoted it to assist with giving a picture of a representative service user. “Jason was 21 years old when he was convicted of the attempted murder of a stranger woman in an unprovoked knife attack. The attack occurred in a public place. Jason was street homeless at the time. He was arrested and, when interviewed by a psychiatrist, reported hearing voices. Jason also spoke to the doctor about being troubled by violent fantasies. He also reported abusing alcohol and self-harming and feeling, ‘completely mental’. Jason was assessed as suffering from schizoaffective disorder and an emotionally unstable personality disorder. He was not sentenced, but a transfer direction to a high secure hospital was made under a Section 37 Hospital Order (Mental Health Act, 1983) with an additional section 41 Restriction Order” (p. 4). An
The explanation of the Mental Health Act (1983) sections referred to in this quote is set out in Appendix I.

The majority of the service users in the study, including one of the service user researchers, are managed under a Section 41 Restriction Order and are living in the community on a conditional discharge. This means they must comply with the conditions of their discharge and their care plan. This includes meeting with the clinical team and taking medication. It may also mean living in a particular place, or not living in or visiting the area where the offence took place because of potential contact with the victim or victim’s families. The care team must report their progress to the MoJ every three months. If they breach their conditions of discharge they can be immediately recalled to hospital.

I will now describe the physical settings and different levels of security provided by secure in-service user services.

### 2.3 The setting

Secure and forensic in-service user services are provided in three different levels of security: high, medium and low. The different levels of security provision are defined according to three different types of security. Physical: the physical characteristics of the building, Procedural: the policies and procedures which support the safe operation of the service and Relational: the staff knowledge and understanding of the service user (RCP, 2012, 2007).

High secure services are provided for people who, in the opinion of the Secretary of State, require treatment under conditions of high security on account of their dangerous, violent or criminal propensities (DoH, 2006). They are held in the same conditions of security as a category B prison. The Ministry of Justice (MoJ) allocates a security category to prisoners based on their likelihood of escape and their risk of causing harm to others (MoJ, 2011). There are four security categories.

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<th>Category</th>
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<tr>
<td><strong>Category A</strong></td>
<td>Prisoners whose escape would be highly dangerous to the public or the police or the security of the State and for whom the aim must be to make escape impossible.</td>
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<tr>
<td><strong>Category B</strong></td>
<td>Prisoners for whom the very highest conditions of security are not necessary but for whom escape must be made very difficult.</td>
</tr>
<tr>
<td><strong>Category C</strong></td>
<td>Prisoners who cannot be trusted in open conditions but who do not have the resources and will to make a determined escape attempt.</td>
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Category D  Prisoners who present a low risk; can reasonably be trusted in open conditions and for whom open conditions are appropriate.  
(MoJ, 2011, p. 6)

There are three high secure hospitals in the country (Ashworth, Broadmoor and Rampton). They have physical security arrangements which are no less than a Category B prison but they can, adapt procedural and relational security strategies in order to create a Category A environment to treat individuals who would, if they were in a prison setting be in such an environment. High secure care is accessed via assessment in medium secure service settings or through the courts or prisons. People admitted to these settings must present as a grave and immediate danger to the public (DoH, 2010a). According to the NHS figures in 2010 the average length of stay is 7-8 years.

Medium secure services for adults with a mental illness are provided by NHS Trusts or independent sector providers (DoH, 2010a). They have a defined level of security and quality standards with which they must comply (DoH, 2013; JCPMH, 2013; RCP, 2007). The service users in medium secure services move from admission, through interventions to support increased independence and moving on. Medium secure services are provided in a Category C physical environment but with the use of procedural and relational security can provide differing levels of secure care to meet the different and changing needs of service users (these can range from service users transferred from prison who have been charged with serious offences, to service users on a pre-discharge programme involving increasing unescorted community leave) (DoH, 2013). The average length of stay is 18-24 months however some adults require longer periods of in-service care, usually 2-5 years but sometimes longer (DoH, 2010a).

Low secure specifications are defined by the nationally accepted low secure quality standards (RCP, 2012). There are 138 low secure mental health service units in England. The size of unit varies from 12 to 50 beds and a significant number are located within the independent sector (CMH, 2011).

2.4 Summary of the service user pathway

In summary the pathway into secure mental health services begins with a referral through court diversion services, or with transfer from a local acute service, another secure hospital along the secure pathway or as transferred prisoners. Increasingly people are coming into secure services under the Ministry of Justice (Section 37/41 of the Mental Health Act, 1983),
adding a further degree of complexity to their care because of the Ministerial oversight that this requires (Barker, 2012). These individuals have often had difficult and complex developmental histories, previous experience of institutional care, substance misuse problems and a variety of criminal behaviours (Barker, 2012; Drennan & Alred, 2012). The average length of stay is 4 years. Discharge is planned in the Section 117 planning meeting. It is often conditional, the individual is expected to live in a certain place, comply with treatment and meet on at least a weekly basis with the clinical team. The MoJ will continue to monitor progress on a regular basis.

2.5 Current issues in secure and forensic services

Secure and forensic mental health services are one of the developing specialities within healthcare (Boardman & Parsonage, 2007; DoH, 2009). This increase in demand is due to a greater understanding of the complexity and range of mental health needs of the prison population and a consensus that prison may not be an appropriate environment for people with severe mental illness (Owers, 2007). The Bradley Report called for a mandatory 14-day maximum transfer time for prisoners to be admitted to hospital. This has resulted in an increase in the demand for the mental health treatment of prisoners in specialist healthcare settings (DoH, 2009). Another reason for the increase in demand for medium secure beds is the reduction of high secure beds. In the review of security at high secure hospitals (Tilt, Perry & Martin, 2000) it was recommended that a third of the service users no longer needed to be detained in high secure conditions. As a result of this, between 2000 and 2004 the Accelerated Discharge Programme (ADP) led to the movement of 400 patents from high secure to medium secure care (Boardman & Parsonage, 2007; DoH, 2000).

This has led to an increase in demand for local medium secure mental health services (Abbott, 2000). This is resulting in a nationwide expansion of the bed capacity for medium secure beds (Abbott, 2000). In the Trust where I work the number of low and medium secure beds has doubled due to two significant expansion developments. A £16 million project to build 45 extra medium secure beds was opened in January 2012. In addition, following a significant refurbishment, another 20 low secure beds were opened in the summer of 2012. This expansion is being replicated in forensic mental health services across the country so sharing these details does not compromise the anonymity of the service.

The new developments represent a significant investment in secure services at a time when public sector budgets are being reduced. Delivering specialised forensic care in medium secure conditions is expensive and represents a considerable percentage of most NHS
Trusts’ budgets for the treatment of a relatively small number of service users (Cree & Hodgins, 2007). There is therefore an imperative to explore alternative treatment options and approaches, including recovery, within this setting further in order to inform the cost effectiveness and value for money of the opportunities we provide.

The expansion of the service is leading to what can be seen as a rebuilding of a large psychiatric institution (Cree & Hodgins, 2007). It is the responsibility of the service providers to ensure that the benefits of the institution and opportunities it offers are developed while learning from the problems inherent in large institutions of the past in order to develop a service that will meet the needs of a modern mental health service. The study emerges from this context. It is a timely opportunity to review the experiences of service users. It aims to inform these new developments by learning from people who have been in-service users what skills and interventions did, or would have, supported their progress.

2.6 Recovery

The concepts underpinning the recovery movement are increasingly influencing heath care commissioning, planning and delivery (DoH, 2010b, 2011b; JCPMH, 2013; Nice, 2011). They have been incorporated into the Trust expectations (Badu, 2007). The underpinning framework of recovery rather than a psychiatric rehabilitation model lays the foundation for a subtle, but fundamental change in service orientation (Drennan & Alred, 2012). In psychiatric rehabilitation the provider consults and collaborates with the service user, but essentially leads the treatment and sets the priorities. Recovery incorporates a shift to the service user leading the process as far as they can and drawing on service provider resources to do so (Anthony, 1993). It has been referred to as service providers being “on tap not on top” (Shepherd, Boardman & Slade, 2008, p. 2).

Secure services have a dual responsibility of attending to individual’s mental health problems as well as a public protection mandate (Reed, 1992). Secure settings are, by definition, concerned with excluding people from the community and managing the environment in order to reduce risk. At the time that I started this study it was questioned whether recovery principles could therefore be incorporated into a secure setting (Roberts, Dorking, Wooldridge & Hewis, 2008). However it has been demonstrated that there is a role for a recovery perspective within a locked environment (Barker, 2012; Drennan & Alred, 2012; Mezey et al., 2010; RCP, 2007). There may be physical restrictions that limit choice and opportunity in this setting, however the core principle of recovery, of putting the service user at the centre of their own care (Shepherd et al., 2008), is relevant for this group of service
users. Now it is explicitly stated in commissioning guidelines that services should provide care based on recovery principles (JCPMH, 2013).

Recovery principles are gaining prominence as a guiding principle for mental health services both nationally and worldwide (Slade, Williams, Bird, Leamy & Le Boutiller, 2012). Providers of services realise that it is in their interest to have clients recover, not only because the people they service will enjoy better mental health, but because they can focus increasingly limited resources on assisting those most in need (Ralph, 2000). Funders of mental health services are interested in being able to reduce services and costs and legislators want to see the investment in mental health produce successful results (Onken et al., 2002). The Commissioning for Quality and Innovation (CQUIN) programme in forensic services has launched an ambitious programme of service expectations based on recovery principles (DoH, 2013). Developed though a nationwide series of workshops involving commissioners, staff and service users, the Shared Care Pathway CQUIN targets include the implementation of service user defined outcomes and the shared care pathway (Ayub et al., 2013). This has the explicit underpinning assumption that if service users are given opportunities to work on the objectives meaningful to them they will be motivated to engage more with services and therefore improve more quickly and so progress through services to discharge at a more steady pace.

The study can therefore be regarded as both timely and relevant in relation to both the subject manner and the methodology employed. The subject under study addresses of current national and local priorities in identifying, from the service user perspective, what they need to prepare them for community living. This will result in recommendations in service delivery, which will support the shared care pathway. Participatory research methodology will incorporate service user involvement in this study and provide experience and training to develop the service user’s capacity to be involved with future studies. There is an increasing requirement for service user involvement in research and evaluation from the government, research funders and health and social care service users (Hubbard, Wilkinson & Petch, 2004; Involve, 2004).

The study question came out of a service user consultation, which is described in Chapter 4. The subject matter, however, is becoming increasingly relevant to commissioners and planners of forensic services. The drive underpinning the study, which is of key importance to service users, namely the effective use of resources to ensure that they are prepared by secure services to live in the community and so reduce reoffending and readmission rates is
also shared by people who are commissioning and paying for services. This ensured that the study was contemporary and relevant and remained so for the duration of the study.

I have spent some time describing the physical environment, including security. I have done this to set the scene and inform the reader of the specialist nature of the environment. Now I have done so I would like to emphasise that secure services are hospitals, they are not prisons. Their primary purpose is to provide treatment and support recovery (JCPMH, 2013). The intention of the physical, procedural and relational security is to provide a safe environment in which this care and recovery can take place (DoH, 2011b). Often the admission to hospital provides an opportunity for stability and the chance to take stock (Couldrick, 2003). Inside the secure perimeters are found creative, therapeutic spaces where growth and recovery take place even in the most secure environments (Miles et al., 2012; Moore, Lombard, Carthy & Ayres, 2010).
Chapter 3. Literature review

3.1 Introduction

I carried out my literature review in two sections. I started with a broad review of the literature incorporating my areas of interest for the study. This helped to develop an initial conceptual framework for the study. This initial review provided the theoretical foundations of the study (Ravitch & Riggan, 2012). I used this conceptual framework as a basis for a service user consultation. This is described in more detail in Chapter 4. I carried out the consultation in order to involve service users in the development of the study question. Involvement of service users in the development of a study question is recommended in recovery based research (Gillard et al., 2012). It can ensure that the question is relevant to clinical practice by identifying service user priorities (Morgan, 2006). In this way the research question was informed by both the conceptual framework that I was building up from the literature and from the service user group. I was able to balance my research interests and the patient perspectives. The second part of the literature review was informed by the learning from the consultation. I carried out a focused literature review on the areas of interest, which were relevant to the research question, namely transition from hospital to the community and social inclusion. This second review identified where the study was in relation to what is known about the subject and identified the gaps in the literature that the study would seek to address. This learning served to evolve my developing conceptual framework.

3.2 Part one of the literature review

In the first part of the literature review I searched the literature covering forensic occupational therapy, recovery in mental health and recovery in secure settings. I reviewed both UK and international literature. I also reviewed the literature about desistance from offending. This is a related area of interest because of the fact that the patient group are also offenders. I reviewed the formal academic literature, making use of the established academic search tools such as the Cumulative Index of Nursing and Allied Health Literature (CINAHL) and UK PubMed Central. I also reviewed the non peer reviewed literature, termed the grey literature (Strickley & Wright, 2011b). This included government documents and policies, and reports published by relevant organisations such as The Centre for Mental Health, The Kings Fund, Rethink and book chapters. I also reviewed the service user written literature and accounts of mental illness and recovery from mental health problems. These all contributed to a greater
understanding of the context within which the study is situated and served to develop my emerging understanding of this subject.

3.3 Occupational therapy and recovery

I began the literature review by looking at the literature around occupational therapy. There is a close relationship between occupation and recovery, which has been acknowledged by the College of Occupational Therapists who have integrated recovery principles into their Strategy for Occupational Therapy in Mental Health Services 2007-2017, even naming the strategy "Recovering Ordinary Lives" (COT, 2006). Occupation has been found to make a clear contribution to recovery from mental illness (Strickley & Wright, 2011a). When asked, people describe their mental health recovery in terms of what they do: the satisfaction they gain from their occupations, the relationships they have, and the opportunities to contribute to something beyond themselves, whether that is work, helping others or participating in projects that make a contribution to society (Brown & Kandirikirira, 2007; Lapsey, Nikora & Black, 2002; MHF, 2000). The activity itself changes according to the individual; the key requirement identified in recovery literature is that the purpose or outcome of this engagement needs to be meaningful (Brown & Kandirikirira, 2007; Whalley Hammell, 2009). Occupational therapy literature therefore has a contribution to make to the understanding of recovery within secure services. As I am an occupational therapist working within a secure environment I began by reviewing what is known within this body of work.

3.4 Occupational therapy in the secure environment

I begin here by providing a broad overview of occupational therapy in a secure environment before looking at the research in more detail. The process of occupational therapy is encapsulated in the belief that occupation, with its intrinsic power to maintain, restore and transform, is fundamental to the health and wellbeing of all humans (Wilcock, 1998). In 2003 the British Association of Occupational Therapists defined Occupational therapy as a complex intervention (Creek, 2003). The occupational therapy profession is characterised by the principle that each person has intrinsic dignity and worth, the right to autonomy and the capacity for change (Kielhofner, 2009). These values and beliefs inform a practice which is both collaborative and client centred, whereby the occupational therapist enters into a partnership with the individual to address the issues which they prioritise (Creek, 2003; Turner, 2007). Occupational therapy is recognised as a core part of service provision within secure services. The role of the forensic occupational therapist should be no different in
many ways to that of an occupational therapist working in general mental health or other health or social care settings (COT, 2012). The ultimate goal of forensic services is usually for the patient to re-integrate into the community with a comprehensive care and treatment programme, which addresses ongoing needs and risk management (Cronin-Davis, Lang & Molineux, 2004; Hills, 2001). Opinions about how occupational therapy can contribute to this goal have evolved as the speciality has developed. One of the earliest papers suggested that occupational therapists should not focus on treating criminal behaviour, but should assist service users to acquire the competencies and skills related to self-control, decision-making and self-esteem (Farnworth, Morgan & Fernando, 1987). Later work has suggested that the impact of a forensic patient’s pathology must be acknowledged and as a result occupational therapists should be pro-active in addressing how service users’ criminogenic and anti-social occupations impact on their lifestyle and well-being, whether that is in the past, present or future (Cronin-Davis, Lang & Molineux, 2004; Morris, 2012). To date there is no more detailed information about how this can be addressed. Attention is still focused on more conventional occupational therapy interventions aimed at increasing independence in occupational skills. The practice guidelines for occupational therapists in secure hospitals (RCOT, 2017) only recommend considering the life history of service users, including at the time of the offence.

Townsend and Wilcock (2004) have provided a conceptual framework for understanding factors that may influence a patient’s occupational functioning and overall health. Their notion of occupational justice supports the principle that occupations are the practical means through which humans exert citizen empowerment, choice and control. They propose four occupational rights, which are aligned to the concepts of social rights. These are the right to experience occupation as meaningful and enriching; the right to develop through participation in occupational for health and social inclusion; the right to exert individual or population autonomy through choice in occupations and the right to benefit from fair privileges for diverse participation in occupations (Townsend & Wilcock, 2004). Restricted occupational opportunities can lead to the occupational injustices of occupational alienation, the absence of meaning or purpose in the occupations of daily life; occupational deprivation, the denial of access to opportunity and resources to participate in occupation; occupational marginalisation; when people are excluded from occupational choice and occupational imbalance, either when someone is underemployed and has too little to do or is over employed and has too much to do (Townsend & Wilcock, 2004). Although it has been argued that the application of occupational justice concepts are inhibited by a lack of connection with models of practice (Durocher, Gibson & Rappolt, 2014); it has been noted that they have utility in secure settings (Crabtree, Wall & Ohm, 2016).
3.5 Occupational therapy research in forensic settings

An increasing amount of occupational therapy research has been carried out in forensic settings as forensic occupational therapy has become more established (Hitch, Hii & Davey, 2015). The studies have taken place in the UK and Australia. Four early studies focused on the use of time and its impact on the wellbeing of the individuals (Farnworth, Nikitin & Fossey, 2004; Stewart & Craik, 2007; Whiteford, 1997; Whiteford, 2000). I have discussed the findings together because I think that the combination of the findings of the study helps to build a picture of life in the secure environment according to the outcomes of these studies.

The respondents in all studies spent the majority of their time engaged in rest or passive leisure occupations such as watching television, smoking or sleeping. Interviews revealed a range of responses to this. Some valued the pattern of occupation because they were chosen occupations that the individual had some control over and felt that they could succeed in. Others said they were killing time and described current time use as bland (Farnworth, Nikitin & Fossey, 2004). In all four studies the importance of routine was identified, in order to mark time, establish a feeling of control and order within the environment. The importance of predictability was highlighted by the effect that the cancellation of activities had on individuals (Stewart & Craik, 2007). Cancellation of activities led to feelings of powerlessness and dependence on others (Stewart & Craik, 2007). One study showed that individuals only spent 6% of their time in therapy or other planned activities so that any cancellation would have made a big impact on the day. This seems particularly important to some who placed more value on activities organised by others (Farnworth, Nikitin & Fossey, 2004). These above studies also indicated that individuals were most active in the afternoon and early evening.

Craik et al. (2010) carried out a study to explore service user perspectives within and beyond therapeutic programmes in secure settings. This research emphasised occupation in every aspect of their lives, not just within the context of an occupational therapy intervention. The findings showed that there were varied activities available, but access to them was limited; for example, football was available only once a week. Engaging in meaningful occupations gave a sense of achievement, maintaining and promoting health. Many perceived that the environment created barriers to their participation in valued occupations, either due to limitations in access to tools or facilities; for example, a quiet space to study (Farnworth, Nikitin & Fossey, 2004). However in one of the studies (Stewart & Craik, 2007) a respondent stated that he had more opportunities within the secure setting than in the community.
because of participation in organised trips. Although these studies help to set the scene they are all single site studies with a small number of participants: n: 8 (Farnworth, Nikitin & Fossey, 2004), n: 25 (Craik et al., 2010) n: 24 (Whiteford, 1997). The findings may therefore not be generalised to other settings.

From an occupational justice perspective, the two primary occupational injustices in the secure setting seem, from the above studies, to be occupational deprivation and occupational alienation. Some studies have sought to address these by focusing on what interventions occupational therapists provide. These include drama, (Dolling & Day, 2013), use of the Wii Fit, (Bacon, Farnworth & Boyd, 2012), creative and arts activities (Spyby, 2003) and vocational programmes (Garner, 1995; McQueen & Turner, 2012; Stelter & Whisner, 2007). Engagement in these activities was shown to improve relationships, have a positive impact on volition, provide a meaningful occupational intervention and provide a sense of achievement and support learning and development (Bacon, Dolling & Day, 2013; Farnworth & Boyd, 2012).

The studies above seem to give the impression that service users participate in groups or activities when given the opportunity, however two studies that looked at engagement in therapy programmes noticed a different picture. Mason and Adler (2012) looked at the influence of the secure setting on therapeutic group work. They identified two themes, firstly the culture of the environment, which is influenced by the dual expectations of secure settings to balance security and public protection with therapy and, secondly, recovery and the impact of this on opportunity and choice. They concluded that individuals actively disengaged from offence related group work due to issues of trust. Rani and Mulholland (2014) noted a lack of engagement in groupwork. In their study, which considered factors that influenced engagement in activities, Rani and Mulholland (2014) found that involving service users in planning and implementing activities was vital to engagement. This service user involvement also ensured that activities were tailored to meet the changing needs of service users. Bowser (2012) also noted the contribution of service user involvement to ensuring interventions met individual needs. She went on to describe strategies to promote service user involvement at strategic, operational and individual levels of the organisation.

There are some studies with this population that have looked more closely at specific interventions and the role that communication with the service users plays with their engagement in therapy and the outcomes of interventions. One study (Kottorp et al., 2013) used an occupational therapy assessment of activities of daily living (ADL) assessment in a secure setting. Kottorp, et al., (2013) carried out an Assessment of Motor and Process Skills
(AMPS) on 35 service users in a secure unit. They also investigated the patient’s awareness of their ability using the Assessment of Awareness of Ability (A3). They found that the service users showed both ADL motor and process limitations. The level of limitation varied in each patient, however the levels of all the participants were below the ability of an age matched population (Kottorp et al., 2013). They also noticed that the participants showed a limited awareness of these limitations according to the finding of the A3 scores. The implication of this is that if individuals are not aware of their limitations they may not be motivated to become an active participant in planning interventions. A different study which looked at the process of community leave (Walker, Farnworth & Lapinks, 2013) noted that staff and service users had a different understanding of what the aims of taking community leave were. This lack of a shared understanding of the goals of the use of community leave resulted in the recovery potential of community leave not being met. It was suggested that staff training and the development of community leave guidelines were developed (Walker, Farnworth & Lapinks, 2013). Morris (2012) has suggested a way of structuring these conversations when planning occupations in secure settings. She developed a conceptual framework for occupational engagement, which provides a way of helping individuals to develop an understanding of the positive and negative consequences of participation in chosen occupations (Morris, 2012).

It is clear from the studies above that service users in secure settings can benefit from involvement in structured, meaningful activities. However in order to engage with the interventions attention needs to be given to clear communication about the aims of and expectations of any interventions in order to encourage continued involvement and a shared understanding between service user and therapist. This ensures that any interventions address the current needs of the service users. Service user involvement in planning and development is one way to manage this.

3.6 Occupational science

Established definitions of occupation have been developed by studies involving occupational therapists (Corr, Neill & Turner, 2005; Creek, 2003). Occupational science literature is beginning to bring an increasingly complex and detailed understanding of the basic concepts of occupation. Occupational science is a scientific discipline that is defined as the systematic study of the human as an occupational being (Clark et al., 1990). It aims to enhance the practice of occupational therapy through systematic study of the place and potency of occupation (Clark et al., 1990). Occupational science research is increasing our understanding of what occupation means, through research that asks individuals about how
they spend their time (Whalley Hammell, 2009a). The difference now is that occupational scientists are starting with the patient’s views of occupation (Whalley Hammell, 2009a). The outcome of this research is challenging the narrow categorisations of occupation as self-care, productivity and leisure (Law et al., 1990). It suggests this is a culturally-based understanding of occupation, which does not take account of different world views and perspectives (Whalley Hammell 2009b). In addition the aim to try and achieve life balance is also challenged as offering too narrow a perspective. A deeper understanding of individual values and how an individual’s occupational choices reflect their individual and cultural values is suggested (Pentland & McColl, 2008).

Experiencing an activity rather than doing an activity, such as appreciating nature, being alone or being with special people, has been identified as an important component of living well in studies seeking to understand the world view of individuals experiencing occupational challenges. This has been noted in individuals recovering from physical trauma (Whalley Hammell, 2009a) as well as those with severe and persistent mental illness (Nagle, Cook & Polatajko, 2002). It demonstrates how individuals strive for a balance between their activity and their state of physical and mental wellbeing (Eklund, Erlandsson & Persson, 2003; Nagle, Cook & Polatajko, 2002; Whalley Hammell, 2009a). It also shows that people with mental illness need a balance of activities that includes rest and recuperation (Sutton, 2008).

No occupational therapy or occupational science studies to date, have considered the experience of life in the community following a secure admission. This has been identified as an area that needs research in the recently published practice guideline Occupational Therapist’s use of Occupation Focused Practice in Secure Hospitals (COT, 2012).

Occupational scientists are also beginning to consider what has been termed the dark side of occupation (Twinley & Addidle, 2012; Twinley, 2013). It is an acknowledgement that some occupation may not necessarily promote good health but they may provide a sense of well-being (Twinley & Addidle, 2012). This may include violent occupations, although it is acknowledged that violence itself is not an occupation (Aldrich & White, 2012; Morris, 2012). However it is acknowledged that exploring this dark side might encourage a broader, more balanced understanding of human occupation (Twinley, 2013). This is particularly relevant in this setting where individuals may choose occupations that can be antisocial, dangerous or criminal (Cronin-Davis, Lang & Molineux, 2004; Morris, 2012).
3.7 Recovery

The term recovery, as used in current mental health services, is still relatively new. As recently as the year 2000, recovery was not being used as a technical term. In fact in 2011, 60% of literature, both peer reviewed and grey literature, focusing on recovery in mental health had been published since 2007 (Strickley & Wright, 2011b). When I started the PhD there was still a question about the utility of recovery principles in secure mental health settings (O'Hagan, 2003). Now commissioners explicitly request interventions based on recovery-based approaches (JCPMH, 2013). They do not, however, define what recovery-based approaches are.

The concept of recovery from mental illness has been widely discussed, sometimes researched and increasingly used in the development of service policy and provision (Sutton, 2008). Services and organisations are interpreting recovery from their own perspectives. This is resulting in many facets of the concept of recovery. Jacobson and Greenley (2001) have described it as a kaleidoscope and have noted the different aspects of recovery meanings. In addition to recovery-as-experience, (the recovery stories of service users and carers), they have noted recovery-as-evidence, referring to the applied knowledge and scientific evidence of recovery; and recovery-as-model, the service models and specific approaches to treating mental illness. They suggested that when another aspect- recovery-as-ideology - became established in the minds of professionals it became a driving force for mental health system reform. As political factors have entered into the recovery arena they identified a fifth aspect, recovery-as-politics, and a sixth aspect - recovery-as-policy. All of these different ways in which recovery has meaning expand the concept of recovery from simply being an aspect of a patient’s experience, to potentially a form of political struggle with roots in the anti-psychiatry, critical psychiatry and survivor movements; to a set of principles by which mental health services can be modernised and reformed and, as a result, a model for service delivery. However, this tendency to define recovery by focusing on the separate elements moves away from the underlying-philosophy of recovery orientated practice (Gilburt et al., 2013). This has led to objections from the service user movement that recovery has been appropriated, or hijacked, by professional services and concerns that calls for system and service change has been diluted to a mere renaming of services from treatment services to recovery services without the necessary changes to service provision (Allot, Loganathan & Fulford, 2003).

This wider picture about recovery provides the context for this study. However it is beyond the scope of this study to explore in detail all of the facets of recovery. This study will be
focusing on the individual experiences of recovery as related by people living in the community following discharge from secure settings and what that means for the secure services which are trying to support them. It will aim to gain a rounded, inclusive understanding of the individual recovery journey from in-patient services to the community.

3.8 What is recovery?

Recovery from mental illness is a term that originated in the service user movement (Anthony, 1993). It is used to describe how someone can recover their life after experiencing mental illness rather than simply being cured of the symptoms of mental illness. Recovery, then, moves beyond the clinical, professional perspective of mental illness symptom reduction and incorporates the subjective, lived experience of coming to terms with, accommodating and living with mental ill health.

One of the first and enduring definitions of recovery is as follows: “recovery is described as a deeply personal, unique process of changing one's attitudes, values, feelings, goals, skills, and/or roles. It is a way of living a satisfying, hopeful, and contributing life even with limitations caused by illness. Recovery involves the development of new meaning and purpose in one's life as one grows beyond the catastrophic effects of mental illness” (Anthony, 1993).

Another early definition is also influential in the literature. Pat Deegan (1998) is a clinical psychologist who has experienced mental health problems and uses her experience and professional perspective to inform her work: she states: “recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability” (Deegan, 1998).

Recovery is a highly complex and multidimensional concept (Roberts, 2008). In terms of the individual person four aspects of recovery have been identified in the literature; these are set out below.

**Clinical Recovery:** This refers to the absence of the signs and symptoms of these illnesses or diseases (Harding et al., 1987; Harrison et al., 2001; Jobe & Harrow, 2005).

**Functional Recovery:** The restitution of functional capabilities for undertaking life tasks. Mental health service users may still experience hearing voices, have feelings of paranoia, or have urges to self-harm, and may yet lead full and enriching lives. (Lloyd,
Waghorn & Lee Williams, 2008; Mezey & Eastman, 2009; MHF, 2000; Sutton, 2008)

**Social Recovery:** Refers to overcoming social exclusion resulting from discrimination which society directs towards the mentally ill. The impact on service users is devastating and includes ostracisation, loneliness, harassment, and rejection (Braveman & Bass-Haugen, 2009; Mezey & Eastman, 2009; Repper & Perkins, 2008; Sayce, 2001).

**Personal Recovery:** A key feature of personal recovery is the regaining of a positive sense of identity. To do this a person in recovery may need to rediscover a sense of self lost in the course of the illness (Andresen, Oades & Caputi, 2003; Anthony, 1993; Coleman, 1999; CSIP, 2006; Slade, 2009).

### 3.8.1 Patient’s accounts

Service users own stories and accounts have been and continue to be a powerful developer of and source of rationale for key ideas and practices (Deegan, 1998, 2005). Understandings of recovery have been inspired by services users’ accounts of their own recovery journeys. These recovery journeys have occurred with, without or sometimes despite, specific mental health interventions (Anthony, 2000; Coleman, 1999; Trivedi et al., 2007). Although not based on research, the cumulative impact of stories specifically about recovery journeys over the past 20 years has had varied impacts on service users, their families and carers, many professionals and the guiding mental health policies that have emerged in the past few years (Ramon, 2007). While accounts of the lived experience of recovery can be marginalised, within the wider research community because of the higher status accorded to positivistic approaches (Spandler et al., 2007); in the healthcare provider community accounts of recovery are increasingly being published by NHS Trusts and private mental health providers in order to inspire and support those who follow them (DPT, 2009; MCT, 2013; OT, 2013; SLAM, 2013). Academia is beginning to acknowledge the service user perspective in the way the training is delivered. Toronto Ryerson University now provides a “Mad People’s History” course which provides “an overview of the history of madness from the view of people who were, and are deemed mad.” (TRU, 2013) and leads to certificate or degree credits. The service user perspective is becoming increasingly mainstreamed and regarded as central when considering mental health issues.

### 3.8.2 Clarifying the patient group

Davidson et al., (2006) and Pilgrim (2008) provide a helpful way of clarifying the patient group. Davidson et al., (2006, p. 641) differentiates between four different levels of severity
of mental illness and identifies their physical health counterparts as a way of clarifying the different types of mental health recovery journey individuals encounter.

1. People with a single one episode of mental illness and who return to their previous level of functioning following the usual sense of recovery in a primary care setting.

2. People who recover from an acute episode of psychosis but may continue to view themselves as vulnerable to future episodes in ways similar to acute medical conditions such as heart attacks.

3. People who take longer to recover from mental illness, maybe up to 15 years, as with a physical equivalent such as asthma.

4. People with an ongoing severe and enduring mental illness with its counterpart being someone with a permanent disability such as visual, auditory or mobility impairment. They need not regain full function in order to have access to a safe, dignified and full life in the community.

This clarification is useful, it has been noted that recovery terminology is contested because of the way the term recovery implies a return to the way things were to some and learning to accommodate ongoing symptoms to live a meaningful life to others (Wilson, 2007). Davidson’s comparison of physical conditions and the range of outcomes with mental illness incorporate both meanings.

It also helps to define the recovery levels of the people taking part in the study. They are people in the final two levels, level three and four. Some may have taken a long time to recover and some may still be experiencing ongoing symptoms of mental illness.

Pilgrim brings in an additional element, which is relevant to the study. He identifies three notions of recovery in relation to the individual (Pilgrim, 2008):

1. **Bio-medical**, where service users are seen as recovering from biologically determined diseases by treatment.

2. **Social psychiatry**, an approach where supportive and personally tailored skills training enable service users to stay out of hospital and to maximise their ability to socially integrate by complying with service expectations of improvement.

3. **Emancipatory model**, which comes from radical services users who demand freedom from coercive services and the aspiration to be self-determining in life choices and life style. The emphasis is not on patient deficits and professional expertise but, instead, on “experts by experience”; true authority for recovery resides in service users as psychiatric survivors.
I think the clarity that a difference between the social model and the emancipatory model brings is a useful one for the study. However what Pilgrim seems to suggest here is that there is one model for service users who comply with treatment, the social model, and one model for those who chose their own approaches, the emancipatory model. I think this a divisive point of view; it does not acknowledge the contribution that the service users experience can bring. It also suggests that there are three distinct ways of looking at recovery. I would suggest the divisions are a lot more fluid. However it does provide a basis for me to explore how these different aspects of recovery are manifest and how they interconnect through an exploration of the discourses emerging within the study.

As an occupational therapist, my perspective is grounded in social psychiatry principles. Indeed, the outcome of the study for me is to inform the skills training I provide to service users to make them more relevant and effective. However, I regard the emancipatory model as important for building collaborative relationships and supporting service users to become true partners in their care and recovery and in service improvement.

I will be employing SURs and seeking their perspective as experts by experience. The differences in perspective, attitude and interpretation that they bring will be made use of in the study. In the following review of recovery literature there are examples of collaborative working and useful feedback.

3.8.3 The establishment of recovery in clinical practice
Contemporary concepts of recovery emerged principally from the ideological and technological advancements that occurred from the middle of the 20th century (Jacobson, 2004). Prior to then the more common view was that conditions, such as schizophrenia, involved a slow, progressive deterioration from which recovery was not possible (Sutton, 2008). However a number of longitudinal research studies challenged this by showing that people with schizophrenia did recover from mental illness (Harding, Brooks, Ashikaga, Strauss & Breier, 1987; Harrison et al., 2001). In addition the 1950s brought a number of technological advancements including the development of antipsychotic medications. Antipsychotics differed from previous medications in that they were capable of producing improvements in thinking among people with mental illness whereas earlier pharmaceuticals merely had strong sedative effects (Marder et al., 1989).

Ramon (2007) suggests that recovery principles are gaining traction because of four factors. First, de-institutionalisation has led to most people with mental illness living in the community and having more opportunities. Second, users’ first person and expert by experience
knowledge are more valued today than before and they have contributed to an articulation of the recovery concept. Third, the social model of disability, which argues that if a disabled person cannot live an ordinary life, this is the outcome of social barriers rather than an individual’s inability. Fourth the acceptance of the strength model which follows from the social model of disability (Ramon, 2007). I think that there are some additional drivers to the fast implementation of recovery principles across secure mental health services. Firstly, it is not just that expert by experience knowledge is more valued today than before but that service users are ensuring that their voices are heard. One useful tool is the Internet, which has influenced a number of social movements (Laer & Aelst, 2010). The Internet is having an impact as service users have immediate access to information and support from peers. For example the National Service User Network for Mental Health has the explicit aim of connecting people with mental health issues in order to give a stronger voice in shaping policy and services (NSUN, 2013). There are a number of websites that offer advice, and a range of resources for service users both in the UK and across the globe (Wallcraft & Bryant, 2003). They range from small local groups such as Hear Us: Croydon’s Mental Health Service User Group to national groups providing a range of resources on different topics. Mind Freedom, an American based website, is one of the most comprehensive I have found with information on advocacy, arts, genetics, ethics, psychiatric drugs, blogs, diagnosis and many other issues (MFI, 2013). It has been pointed out that when service users discuss mental health experiences they talk about recovery without reference to professional concerns such as symptoms, treatment or illness (Cleary & Dowling, 2009). This perspective is already influencing the language used and how evidence is obtained (NICE, 2011). “No decision about me without me” is stated as the underpinning principle of the government’s mental health strategy (DoH, 2011b, p. 3), which is an explicit undertaking to involve service users at all levels in the planning and delivery of mental health services.

There are still issues with the local variation of funding and therefore the influence local groups have in their area. In their national survey of user groups Wallcraft and Bryant (2003) found a variation in external funding of between £35.00 and £360,000. There is also debate about whether different interest groups, the main ones being around philosophy, ethnicity, gender and sexuality, within the service user movement should join up or work separately to achieve their goals (Wallcraft & Bryant, 2003). However, in my view these discussions are indicative of an increasingly informed and organised patient or expert by experience group.

I think the other main driver for change is economic. The rapid uptake of recovery principles at all levels of mental health care delivery has been noted (Strickley & Wright, 2011a). It is the influence of the financial reality, which is forcing the pace of change. The NHS had a
savings target of £20 billion by 2015, which equates to about 5% of the NHS budget every year (Monitor, 2012). This required a more systematic approach to service planning and delivery to ensure that quality is maintained as cost is reduced. In their strategy document “Liberating the NHS: Equity and Excellence” the government explicitly championed service user involvement to improve the quality and cost effectiveness of services (DoH, 2010b). In secure services national recovery-based initiatives such as My Shared Pathway (Ayub et al., 2013) have been led by commissioners and is an element of the National Secure Services QIPP (Quality Innovation Productivity Prevention) programme (Allen, 2012). My Shared Pathway has an explicit aim to drive cultural change through initiating outcome based collaborative care with service users. The aim being to streamline services and reduce length of stay thereby reducing costs (Ayub & McGann, 2011). It has been developed collaboratively between service users, commissioners and clinical staff. It comprises of a series of booklets to be used by service users and clinicians to provide structure and support collaboration in the care-planning process (Ayub et al., 2013).

The financial imperatives are changing services rapidly. The My Shared Pathway project is an example of the recovery and cost agenda working together to achieve more person centred, better quality outcomes (Ayub et al., 2013). There have been examples of drastic cuts in services in the name of recovery without the necessary process of collaboration and support of the individuals involved, e.g. closure of/reduction in services within mental health day centres (Trivedi et al., 2007). Indeed initially the main issues that service providers consulted service user representatives on and commissioners were what services to cut (Wallcraft & Bryant, 2003). Now there are signs of more strategic thinking with service user groups and representatives at the centre of the planning process. The rapid development of Recovery Colleges over the last couple of years is an example of this (NH, 2013; Perkins et al., 2012; SWLSG, 2013). Mental health service users have been trying to influence the planning and delivery of services for a long time; the first record according to the Survivors History Group is 1772 (SHG, 2013). It seems that now their perspectives coincide with the financial priorities of the government their voices are being heard.

3.9 Research into recovery

When reviewing recovery-based research it is noticeable that researchers have tried to incorporate the recovery principle of “nothing about us without us” (DoH, 2011b). Studies have involved service users, recipients of the service, utilising the expertise of service users within the research methodologies (Larson, 2009). Roberts and Wolfson (2004) suggested that the need to gather and strengthen the evidence base for recovery implies a major area
for collaboration between service users and providers. In this review of the studies below I show how academic research has evolved from a service-based, medically orientated, exploration of the concept to studies that incorporate recovery principles of service user involvement in the design and execution of the research. I note the incremental development of involvement strategies in studies that seek to explore this complex phenomenon.

One of the early studies, which attempted to identify themes of recovery empirically, involved interviewing 46 service users about what supported their recovery and identifying themes that emerged (Sullivan, 1994). In this study there was no service user collaboration. There were some contradictions in Sullivan’s methodology, which illustrate the early stages of recovery inquiry within a medical paradigm. First, the inclusion criteria of participants met the definition of recovery as identified by the goals of the community mental health services. This is a very service orientated perspective. Second, the research was carried out using a qualitative technique, with semi-structured interviews. However, attempts were made in the presentation of the data to begin to bring some quantitative like numerical values to the themes that emerged in order to present the themes in a hierarchy. By presenting the data in chart form the voices of the individuals and their experiences were lost. The themes that emerged from the research, nevertheless, provided the first information about some of the elements of recovery. This included the fact that there were social, spiritual and personal dimensions to an individual’s experience of recovery in addition to the more traditional aspects of adherence to a health management regime.

“Mental Health Recovery: What Helps and What Hinders” (Onken et al., 2002) was a large multisite project carried out in the United States. It involved many stakeholder organisations, mental health authorities and an expert panel made up of researchers, some of whom had personally experienced mental health problems. This was one of the first studies that utilised the lived experience of mental health. It used a qualitative data collection method. A number of focus groups were carried out to interview 115 people in 9 states. A series of workshops and conference calls developed a basic definition and assumptions about recovery upon which the subsequent study was based. These assumptions included the involvement of users at all stages of recovery and the importance of placing understanding of the lived experience of mental health problems at the centre of the study, as well as understanding the variety of contexts in which recovery took place including cultural, social, formal and informal support systems and assistance.

There were some limitations to this study. Groups were disproportionately white and middle aged. What might contribute to their recovery may not be the same as for those from
different age ranges and cultural backgrounds. The focus groups were made up of eight to fifteen people and participants may have felt unable to express opinions as freely as they would have done on a one to one basis. Finally the focus groups were one off events. Participants were trying to encapsulate what may have been years of managing mental health difficulties into one group discussion, so some of the quality of the data may have been lost. However it revealed information about what supports recovery, characterised by interplay between internal and external resources that incorporated:

- **Characteristics of the individual:** A sense of self and self-efficacy, a sense of hope, meaning and purpose, making own decisions
- **Characteristics of the environment:** Basic material resources such as home, income, social relationships, meaningful activities, peer support, formal services, formal staff.
- **Characteristics of the interchange:** Whether it is supportive and consistent. Whether it supports hope, options of choice and flexibility. The important balance between dependence and independence.

This contributed to an understanding of the elements of recovery in more depth. The learning gained from the project has been used to develop a measure of recovery within service settings. This end goal of developing an outcome measure was in mind from the outset of the study, which, though useful clinically, may have influenced the orientation of the research towards mental health provider priorities.

In Scotland a research project, “Recovering Mental Health in Scotland”, commissioned by the Scottish Recovery Network (Brown & Kandirikirira, 2007) took a different approach by learning from the experience of individuals. The study started from the premise that recovery is much more than an absence of symptoms – it is about having the opportunity to live a satisfying and fulfilling life in the presence or absence of symptoms. In this way they moved further from defining recovery in relation to what mental health services could provide. The research team of nine interviewers, who had experience of psychiatric illness, led by two lead researchers carried out intensive narrative interviews with 64 participants. They found that there were consistent internal and external elements that ran through the recovery journeys.

**Internal:** (Individual and self-controlled)
- **Belief in self and developing a positive identity**
- **Knowing that recovery is possible**
- **Having meaningful activities in life**
- **Developing positive relationships with others and your environment**
- **Understanding your illness, mental health and general well-being**
• Actively engaging in strategies to stay well and manage setbacks

**External:** (social or environmental)
- Having friends or family who are supportive but who do not undermine narrators self-determination
- Being told recovery is possible
- Having contributions recognised and valued
- Having formal support that is responsive and reflective of changing needs
- Living and working in a community where other people could see beyond your illness
- Having life choices accepted and validated

(p. 7)

Although the researchers tried to gain a diversity of participants and they had a wider age range of participants than other studies (20-65), the majority of participants were white, the average age was 47 and, as in all previous studies, none had a forensic history.

The National Institute of Health Research (NIHR) funded a five-year programme of research called REFOCUS (Bird et al., 2011). It is a large mixed-methods research programme which is investigating recovery from mental health problems in England (Slade et al., 2011). A conceptual framework of personal recovery was developed following a systematic review and narrative synthesis of recovery models (Boutillier et al., 2011). From this five key recovery processes were identified: Connectedness, Hope and optimism, Identity, Meaning and purpose, and Empowerment. Collectively these form the CHIME framework. Work has since been carried out to test the validity of the conceptual framework. One of these studies involved the use of focus groups with people recovering from mental illness (Bird et al., 2014). This included people with a forensic history but they involved just one percent of the participants. The study demonstrated the CHIME framework was relevant to mental health consumers.

Rethink Mental Illness, is a mental health charity, which has been involved with providing training as part of the REFOCUS programme. In order to inform the training, the Rethink research team utilised an innovative model where they worked in partnership with seven people with lived experience of mental health problems and treatment. They had the title involvement researchers. The involvement researchers interviewed 48 people with similar experiences across England. They also took an active role in the data analysis and co-authored the final report (Ajayi et al., 2009). They reported that involving people with lived experience in a collaborative approach contributed to generating insightful findings. The study demonstrated how personal and contextual circumstances worked together to shape an individual recovery journey. It highlighted three dilemmas central to the recovery process:
1 Acceptance: In order to progress in their recovery individuals need to accept themselves and feel accepted by others.

2 Locus of power and control: Recovery involves gaining back a sense of power and control, often lost in mental illness. This can happen by taking small steps through self-management techniques.

3 Dependence, independence and interdependence: It is essential to recovery for the individual to negotiate a balance between independence and recognising interdependency. Individuals with mental illness often feel dependent on others. (Ajayi et al., 2009)

This study is exploring the experience of people as they have moved from a long-term secure service admission. These three dilemmas offer a useful framework to explore how participants adjust.

3.9.1 Recovery in secure settings

Although it has been suggested that detention and compulsion could be conceptualised as potential routes to personal recovery (Roberts, Dorking, Wooldridge & Hewis, 2008) challenges to implementing recovery-based practice in a secure setting have been noted by practitioners within secure settings (Drennan & Alred, 2012; Mezey & Eastman, 2009).

First, forensic service users are almost invariably detained involuntarily although they may eventually enter into some form of therapeutic alliance with their clinical team. Second, their detained status will limit the opportunities for service users to exert control and choice over their environment. Third, service users spend prolonged periods of time within a secure setting, which can make it difficult to foster hope and optimism. If, as is likely, admissions can be months or years long, how does an individual maintain hope and focus around progressing? Finally, forensic service users are doubly stigmatised: they have committed serious violent offences and they have a severe mental illness (Mezey & Eastman, 2009; Mezey et al., 2010). The therapeutic approach with forensic service users often requires challenging and confronting, rather than affirming or accepting, maladaptive patterns of behaviour or identity, (Mezey & Eastman, 2009; Mezey, MKavuma, Turton, Demetriou & Wright, 2010; Turton et al., 2011). These challenges relate to the limitations imposed by the secure environments, the length of stay and the importance of risk management and assessment. However, in the initial studies exploring the experience of recovery in secure settings for forensic service users the limitations of the environment are less of an impediment to supporting recovery than predicted (Mezey et al., 2010; Turton et al., 2011). Service users have reported that the secure environment provides them with a sense of belonging, acceptance, inclusion and companionship that they have never experienced.
before and that they value the physical and relational security (Mezey et al., 2010). The length of stay is reported, not as a barrier to recovery, but as a help to recovery providing an opportunity to stay put for a while (Mezey et al., 2010).

Recovery informed practice is flourishing in secure settings. I co-edited a book with the lead psychologist in the service. It included chapters written by staff, with patient involvement, from secure services across England, with one chapter written by a Scottish practitioner. It aimed to share some of the recovery based practice taking place across forensic services. The chapters described how different forensic services had approached the introduction and integration of recovery principles into practice from varying perspectives. One focused on staff development and training as a starting point, one began with recovery groups for service users based on self reflection and discussion about what worked, one focused on the organisation of an organisational structure to support recovery.

We suggested that addition to clinical, functional, social and personal recovery the individual needs to recover from the offence they have committed (Drennan & Alred, 2012). We defined offender recovery as “the subjective experience of coming to terms with having offended, perceiving the need to change the personal qualities that resulted in past offending, and accepting the social and personal consequences of having offended” (Drennan & Alred, 2012 p. 15).

The Centre for Mental Health explored the experience of recovery in forensic services. A series of six workshops involving service users and staff were held throughout England. These workshop findings formed the basis of the document (Drennan & Wooldridge, 2014). In this document recovery in forensic services was described as identical to recovery for mental health service users in non-forensic settings. With one crucial difference, the need to for individuals to address the reality of what brought them to forensic services. It was noted in this document that this primarily involved addressing psychological and emotional responses to the offence or the circumstances that led to their admission. The document confirmed that the characteristics of recovery based services within mainstream mental health services should be incorporated into secure services. These included the management of risk, the development of high quality relationships between staff and service users, care planning focusing on an individual’s strengths, and developing a culture of safety (Drennan & Wooldridge, 2014).
3.9.2 Clinical implications of a recovery orientated service

A recovery orientated perspective to providing mental health services requires a fundamental change in culture and practice. It requires a new approach and transformation of clinical customs (Cavanaugh et al., 2009). There will need to be a move away from the dominance of institutional responses, medication and coercive interventions (Slade et al., 2014). Instead, mental health services need to foster hope and a belief in people. They need to be person centred, encouraging service users to set their own personal goals and participate in decision making around their own care in contrast to having clinical goals that are mainly set by professionals (Liberman, 2012: Slade et al., 2014). Bartholomew and Kensler (2010) argue that a reorientation of interventions to demonstrate an overt link between content of therapy and the service user’s own outcomes is a way of operationalising a recovery philosophy. They suggest that supporting service users to reach their goals should be the driving force of the program (Bartholomew & Kensler, 2010, p. 118). In a similar vein Conneeley proposed that clinicians should regard themselves more as collaborators and facilitators rather than imposers of rehabilitation (Conneeley, 2004). However, as researchers have begun to study service user centred working more closely there appear to be challenges for clinicians in implementing this way of working. Armstrong (2008) noted that client centred goal setting is not implemented because clinicians are not sure how to go about it. In forensic services particularly, individuals’ priorities may not necessarily be pro-social, (Cronin-Davis, Lang & Molineux, 2004). As well as training, research has shown that practitioners are concerned that client centred goal setting can be seen as a threat to their professional knowledge and skills (Park, 2009; Sumsion & Smyth, 2000). Time is also noted as a factor preventing collaborative goal setting. Armstrong noted that service users need time to explore and discuss their goals. He states that clinicians may view this as inactive time compared with the utilisation of the professional skills in delivering active therapy (Armstrong, 2008). However he points out this time spent in the initial stages of goal setting is saved later through the benefits of meaningful engagement in interventions (Armstrong, 2008).

At a service-wide level The Centre for Mental Health (2011) is taking a lead in identifying the changes that need to be made at a service provider and organisational level. They have published a series of papers for service users, individual practitioners and service planners which provide practical advice about how to make services more recovery focused (Cavanaugh et al., 2009; CMH, 2003; Repper et al., 2013; Shepherd, Boardman & Slade, 2008). They have also co-ordinated a national programme of support for health organisations seeking to carry out the cultural and structural changes necessary to develop recovery.
promoting organisations called The Implementing Recovery through Organisational Change (IMROC) programme (IMROC, 2011).

3.9.3 Critique of recovery
The main critique about recovery concerns its implementation in practice. In my view debate has moved on in recent years from whether to incorporate recovery services (Resnick, Fontana, Lehman & Rosenheck, 2005) to how to deliver recovery-based services and these concerns reflect that. Some of the concerns are discussed below. Firstly there have been accusations about services simply changing their name from rehabilitation to recovery services and carrying on as before without the fundamental cultural change that a recovery service necessitates (Allot, Loganathan & Fulford, 2003; Borg, 2007; Shepherd, Boardman & Burns, 2011). Secondly it has been noted that some services have appropriated the term recovery, regarding themselves as the experts and not acknowledging the perspective of service users (Trivedi et al., 2007). This has sometimes resulted in services adopting a narrow interpretation of recovery, equating it with getting a job (Keating, 2007). Thirdly, there can be a discrepancy between what the service provider and the patient regard as recovered (Trivedi et al., 2007).

Trivedi (2007) shows how recovery ideas can become distorted when applied inappropriately in practice; he notes that the concept of putting the patient at the centre of decisions regarding their care can be misinterpreted and end with the patient feeling responsible for their care or blamed if they do not recover (Trivedi et al., 2007). Service users have also seen cuts to services in the name of recovery (Trivedi et al., 2007). One concern voiced by service users is a worry that if they recover they may lose the services they rely on (Davidson et al., 2006). Similarly a recovery approach that focuses on the individual alone without considering environmental, material and social circumstances places an added burden of responsibility on the individual (Borg, 2007).

3.10 Desistance from offending
The research into people discharged from secure settings has focused on recidivism rates. There is a dual outcome for forensic services, that of managing patient’s mental health as well as reducing their risk of offending again. It is therefore worth consulting the literature that explores offence behaviour and desistance from offending.

Desistance from crime is defined as the long-term abstinence from criminal behaviour among
those for whom offending had become a pattern of behaviour (McNeill, Farrall, Lightowter & Maruna, 2012, p. 3). It is suggested that there is a difference between primary desistance, a crime-free period, and secondary desistance, meaning a change in the way that an ex-offender sees him or herself (Maruna & Farrall, 2004). Secondary desistance refers to a change in the identity of the offender to a more positive identity; it is about successfully moving beyond the criminal label (McNeill et al., 2011).

Not all researchers agree that this kind of reconstruction of identity is a necessary aspect of desistance for all offenders, (Sampson & Laub, 2003). Bottoms et al., (2004) cite examples where individuals have stopped offending for a period of time without much cognitive change but while they were living in supportive circumstances (Bottoms et al., 2004). McNeill et al., suggests that secondary desistance is more relevant for persistent offenders with deeply entrenched criminal identities (McNeill et al., 2011).

There are three broad understandings of why people desist from, or stop offending which are listed below:

1  Maturational reform; that people stop offending as they get older or “grow out of offending”.
2  Social bonds, or ties to family, employment or educational programmes create a reason to “go straight” without these people who offend have less to lose.
3  Narrative theories which emphasise the individual’s sense of self and identity, reflected in changing motivations, greater concern for others and more consideration of the future.

(Maruna, 1999).

Farrall and Bowling (1999) note that it is the interplay between these factors that supports desistance from offending.

Giordano, Cernkovick and Rudolph (2002) look in more detail at the individual change process necessary to support desistance. They suggest that the individual needs to recognise the need to change and have the opportunities to change so they can begin to see themselves in a new role. The process is complete when old behaviours are no longer seen as desirable or relevant.

Nagin and Paternoster (2000) discuss two processes that influence offending over time: population heterogeneity and state dependence. According to the population heterogeneity model personality characteristics (such as self-control, impulsivity and psychopathic personality) are established early in life and remain stable. These will be the cause of
criminal behaviour rather than any life events. These personality characteristics may influence life events such as unemployment, drug addiction or marital instability but it is the underlying personality rather than the life events which influence criminal behaviour.

A state dependence process suggests that past behaviour influences future events and these events can in turn affect current and future behaviour (Nagin & Patermoster, 2000). Committing a crime can lead to a reduction of restraints and inhibitions about committing a further offence. In addition getting arrested because of criminal behaviour may reduce an individual's future employment prospects, which in turn leads to an increased risk for later crime (Nagin & Patermoster, 2000).

3.10.1 Desistance interventions
Up until recently desistance models such as the Risk-Needs-Responsively (RN) model (Andrews, Bonta & Hodge, 1990) have focused on the criminogenic needs of the individual rather than providing them with the resources to live a better kind of life (Barker, 2012; Ward, Mann & Gannon, 2007). Attention has been focused on the risk behaviour itself, with manualised interventions targeted specifically at the offence characteristic rather than the needs of the individual (Ward, Mann & Gannon, 2007). Ward, Mann and Gannon (2007) argue that this view has often resulted in a one-size-fits-all approach to offence management which does not address the contextual or individual factors related to offending and rehabilitation. There have been calls in offender literature to develop a more integrated holistic approach to offender management rather than focusing on the offender’s risk profile (Maruna, 2001; Ward et al., 2007). It is argued that previous models have not taken account of personal identity and the importance of human needs when determining behaviour. An alternative model, the Good Lives Model (GLM) (Ward, Mann & Gannon, 2007), has been developed and is gaining traction in desistance services. It is a strength-based model, which is concerned with promoting the goals of offenders while managing their risk. This model is also beginning to be of interest to forensic mental health services. Barnao (2013) has made suggestions as to how a GLM approach could be used in a forensic mental health setting. I can see the potential of the use of this model to provide a structure for helping service users to understand themselves better, particularly in relation to the offence. It will also give staff the tools to address patient’s offending behaviour as well as their mental health problems.

The desistance model requires a shift in thinking about offender programmes from focusing on the offence to considering offender’s lives in their full biographical contexts (Lewis, 1990). Maruna and LeBel (2010) describe this as a shift of lenses, which contrasts the desistance model to the correctional model of change, rather like the recovery model of mental health
contrasts with the medical model. Indeed they refer to the recovery model in their work. McNeill (2006, p. 46) suggests how desistance services need to change, in almost a mirror to recovery literature. “Put simply, the implication is that offender management services need to think of themselves less as providers of correctional treatment (that belongs to the expert) and more as supporters of desistance processes (that belong to the desister)”. Self-identity and hope have also been identified as important in the desistance process (Farrall & Calverley, 2006; McNeill, 2002) this is also fundamental to a recovery orientation in mental health (Shepherd, Boardman & Slade, 2008). It is interesting to note the similarities between the desistance process and the recovery process as this study is concerned with both.

3.10.2 Desistance and employment

Finding stable employment is widely recognised as playing a central role in desistance from crime (Baer et al., 2006; Farrall & Calverley, 2006; Visher, Debus & Yahner, 2008)

Sustainable employment reduces the likelihood of an individual re-offending by between one-third and a half (Baer et al., 2006). The impact of the Rehabilitation of Offenders Act (MoJ, 1974) has been noted by some researchers (Hearn, 2010; Niven & Stewart, 2005). The Rehabilitation of Offenders act requires ex-offenders, if asked, to disclose their previous convictions to employers. This requirement lasts until a period of time has passed without further convictions, when they become spent. For those sentenced to over two and a half years the requirement to disclose lasts for the rest of their lives. This requirement affects around 100,000 ex-prisoners yet there is little evidence of training or support in the disclosure process (Seu, 2002). This can affect an individual’s chances of managing the disclosure of the offence so that they are still considered for a job (NACRO, 2007).

Hearn has noted that since the act was passed employers have increasingly demanded information about criminal convictions (Hearn, 2010). As a result of this 85% of ex-prisoners entering new forms of employment or training have secured their opportunities through social networks (Niven & Stewart, 2005; Stewart & Craik, 2007). Research in the US has uncovered a similar trend. A study of 740 ex-prisoners in Illinois found that most ex-prisoners found work through friends and family (Visher, Debus & Yahner, 2008). This informal way of finding employment is not just a more effective way of getting a job, it can also be seen as a response to the way in which labour market processes seek to exclude and marginalise ex-offenders (Hearn, 2010). This may have implications for the participants in this study who have the double stigma of an offence history and mental illness (Drennan & Alred, 2012).
3.10.3 Parallels between recovery and desistance

There are many parallels within recovery literature and the literature around desistance. In the strategies that supports recovery and desistance and the support methods used. In some ways this is not surprising because the aim of both interventions is to support individual change and development. Some of the similarities are noted below:

- Both utilise a strength-based approach (Farrall & Calverley, 2006; Slade, 2009).
- Both focus on the individual rather than either the pathology or the offence. Both approaches place value on the potential of the individual (Maruna, 2001; Shepherd et al., 2008).
- The importance of involvement in meaningful roles in the community such as employment is recognised (McNeill et al., 2002, Strickley & Wright, 2011b).
- Staff role as a supporter and facilitator of the individual’s change rather than a provider of cure or correction.

(McNeill, 2002; Rethink, 2010).

This similarity is reassuring in this study. It implies that although the participant group are people with mental illness and a history of offending, the strategies suggested in recovery literature may also address the risk of reoffending. Indeed new initiatives supporting the reintegration of prisoners on release are drawing on the recovery principle of utilising the lived expertise of peers, in this case ex-prisoners (O’Hara, 2012). In one project they suggest it is the combination of support and practical assistance immediately on release that has reduced the reconviction rate from eighty eight per cent to forty two percent (O’Hara, 2012).

3.11 Conceptual framework following part one of the literature review

Most recovery research to date has been carried out with the general mental health population. Most desistance from offending research has been carried out with the general offender population. The research into what supports recovery for people with mental illness who have offended is limited. This is a gap in the knowledge, which can be addressed by the study. The learning, from both bodies of research, shows remarkable similarities in the conditions that support both mental health recovery and desistance from offending. This suggests that learning which supports mental health recovery may also support a reduction in re-offending.

In summary secure mental health environments provide individuals with a sense of belonging and positive relationships which they may not have experienced before (Mezey et al., 2010).
Positive hopeful relationships are important in supporting recovery (Onken et al., 2002). However these environments are also impoverished places with limited opportunities to develop meaningful routines and participate the activities, which also play an important role in mental health recovery (Stickley & Wright, 2011b). More research is required to understand the impact of the secure environment on recovery more fully.

In addition to the secure environment there are some emerging conversations about specific recovery tasks for people with an offending history (Drennan & Alred, 2012) but these have not been substantiated by research to date. There is a gap in the literature about the more complex challenges facing individuals with an offending history and how they impact on mental health recovery challenges.

The second gap in the literature is related to occupational science. Occupational scientists are developing a more nuanced understanding of occupation (Whalley Hammell, 2009b). Findings have included that people strive for a balance between their activity levels and wellbeing. No study to date has reviewed how people with mental health problems and an offence history understand their occupations. There has been some consideration about the impact of criminogenic and antisocial occupations (Cronin-Davis, Lang & Molineux, 2004) but this has not been studied in research to date.

The first part of the literature review has identified what is known in this area. This demonstrates the relevance of a study with this client group and shows the contribution such a study would make to knowledge. It provides a framework to take to the patient consultation in order to identify a specific question for the study.

3.12 Part two of the literature review

The second part of the literature review followed the patient consultation. The consultation with the service users is described in detail in Chapter 4. Their view was that the study should provide a greater understanding of the demands and challenges facing service users in the community. This could then be used to inform more specific recovery based interventions in in-patient services. There were two broad areas of concern, which emerged from the consultation. These were, firstly, the transition from the hospital to the community. The participants expressed concerns about the adequacy of preparation for leaving hospital, in particular the support during the transition to community living. They highlighted this as crucial to a successful discharge and highlighted it as an important area for research. The second area of concern related to feeling part of the community that they moved to. These
included practical concerns like finding work, or structuring time. They also included feeling part of the community, feeling safe and supported. The consultation therefore prompted a change in emphasis to the study changing the focus of my gaze from recovery in secure settings to the outcomes of secure settings.

I returned to the literature with this change of emphasis in mind. This second part of the literature review looked at these areas to identify how they were understood within the academic and grey literature. From this I identified the gaps in the literature and how the study could contribute to the knowledge base in discharge from a secure setting to the community

3.13 What is known about the experiences of forensic service users living in the community?

The forensic service users’ experiences of discharge into the community have remained largely unexplored to date. A number of follow-up studies have been carried out with service users discharged from secure settings. They have been paper-based and retrospective (Buchanan, 1998; Coid et al., 2007; Lund et al., 2012; Maden et al., 2004; Skipworth et al., 2006). These studies involved the review of a large number of cases (n425, n1344, n152, n135 and n959). One of the primary outcome measures in these studies was the reconviction rate. The outcomes showed a relatively low reconviction rate with offence predictors consistently cited as early onset offending, previous convictions and a co-morbid or primary diagnosis of personality disorder or substance misuse, although one study suggested that the size of the effect of these predictors was weaker than assumed (Buchanan, 1998). Two studies suggested that the most powerful protective factors were Home Office restrictions requiring service users to accept supervision and treatment following discharge (Coid et al., 2007; Skipworth et al., 2006). The cumulative probability of violent convictions increased linearly for service users (Coid et al., 2001) with an increased risk emerging at 6 years post discharge. Coid et al., suggest that reoffending can only be reduced by addressing the changeable factors encountered outside a secure setting, they do not, however offer any indication about what these changeable factors are and only suggest a more prolonged application of restrictions, including enhanced supervision and surveillance as an intervention.

These studies took a bird’s eye view of the total population. They do not explain the individual life stories or experiences behind the statistics. Their recommendations are
therefore broad; they relate to populations not individuals. One study concluded that some degree of reoffending is inevitable and may be attributable to “unknowable” factors, or factors unrelated to the patient’s illness (Skipworth et al., 2006, p. 1008), another study suggested there were “changeable” factors which would have an impact on reoffending in this population (Coid et al., 2001, p. 229). Gaining a clearer perspective of the experience of living in the community following discharge from the patient’s point of view may shed light on some of these unknowable and changeable factors.

Other follow-up studies of people discharged from secure services have involved service users but have focused on the administration of standardised assessments and rating scales (Dorn et al., 2005; Gerber et al., 2003; Hodgins et al., 2007). One study looked at the quality of life among forensic service users living in the community receiving community services (Gerber et al., 2003). Participants were asked to complete a total of 7 measures: The Physical Integration Scale, Social Integration Scale, Psychological Integration Scale, The Rosenberg Self-esteem inventory, The Coping Inventory for Stressful Situations, The Social Problem Behaviour Scale and Hansonn’s client satisfaction questionnaire. The use of the scales allowed for comparison of the results with similar studies of other populations. However, information gained emphasised the perspectives of the researchers and did not provide detailed insight into the experience from the participant point of view. Responses were based on numerical ratings and there are no direct quotes from service users. In the discussion, findings such as a reduction in problem behaviour, and coping with daily issues are attributed to close monitoring and support by the community nurse. However there is no explanation about how this contributes to more settled behaviour or whether the participants utilise other supports. This study found that participants were not well integrated into the community, although they appeared to be satisfied with the quality and frequency of their social contacts. These studies took part outside the UK, in Canada and in North Carolina where the legal systems and community support systems will be slightly different than those within the UK.

One study evaluated a community treatment programme (Luetten, Chrapko & Reddon, 1998). It again focused on reconviction rates as an outcome. The data collection was paper-based, drawing on data from nursing records and clinical files. The community treatment programme involved close supervision and readmission to secure care for short periods at times of crisis. This reduced the reconviction rate. No detail was provided about the occupational life of the individuals and their views were not sought.
Another study compared general adult and forensic service users with schizophrenia living in the community (Hodgins et al., 2007). This was a large-scale study with 248 participants. The study took place in four countries: Canada, Finland, Germany and Sweden. Instruments and sources of information included: historical information, diagnoses, symptoms, medication compliance, alcohol and drug use, aggressive behaviour and obligatory care. Professionals chose the priorities for the study. They gave attention to generalisable facts that could be compared and focused on problem behaviours rather than successes. In this study a participant’s achievement would be indicated by a lack of problem behaviours or compliance with the medication regime. The study did, however, demonstrate that service users at a high risk of violence to themselves or others have rather good outcomes following treatment in forensic services. The study concluded that this was the positive consequence of assessing and managing the risk of violence.

Two recent studies have taken a phenomenological approach with people who have been discharged from secure settings (Lin et al., 2009; Tregoweth, Walton & Reed, 2012). One explored occupational engagement and one looked at the experience of re-entering the workforce. Neither study took place in the UK. There are differences in the legal and support systems in the UK, which may influence experiences of service users. However these are the first studies that have asked the service users themselves.

Lin et al., (2009) found that some of the occupational choices of the participants were dictated by a need to please staff supervising them. They perceived staff as those who controlled their freedom. Participants felt that they needed to demonstrate to the authorities that they were doing well through the occupations in which they engaged (Lin et al., 2009). Self-esteem and motivation were identified as challenges to occupational engagement (Lin et al., 2009). However the occupations they engaged in provided structure and routine, helped shape their identities, made them feel like they were making a contribution and assisted with establishing meaningful relationships.

In the study looking at re-entering the workforce clinical and practical employment supports such as effective medication regimes, building physical stamina and negotiating workplace accommodations were necessary (Tregoweth, Walton & Reed, 2012). Disclosure was a complex issue requiring skilful pre-planned interventions. It has been noted that little is known about service users’ of secure services and the wider outcomes they achieve, for example in helping people into employment (Durcan, Hoare & Cumming, 2011). The study starts to address this.
3.14 Transition

The participants are undergoing a transition from a secure hospital to living in the community. It is therefore useful to learn from some of the theoretical understandings of transitions. Kock, Kralik and Loon (2006) have differentiated the concept of transition from that of change. Transition is the psychological process that takes place to adapt to the change event. Change, substituting one thing for another, can be abrupt. Transitional processes can take time as people slowly disengage from old ways of being, habits and actions (Koch, Kralik & Loon, 2006). The transition process tends to include flow and movement (Meleis & Trangenstein, 1994). This study will be exploring how the participants are managing the transition over a long period of time in hospital to the community. In this next section I will review how transitions are conceptualised in health settings by different professionals and also in offending literature, as prisoners make the transition to community life after a prison sentence.

Transitions in health

Kock and Kralik (2006) are participatory researchers who have carried out a series of studies with people chronic illnesses. In a chapter co-authored with van Loon (Koch, Kralik & Loon, 2006) they define transition as “A process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to disruptive life events” (Koch, Kralik & Loon, 2006, p. 4). From this work they propose an understanding of transition as a pathway, while acknowledging that transition is not a linear process. This pathway incorporates four elements:

**Familiar life**
Prior to the transaction, an experience of living and being in the world. Events are perceived as predictable and are taken for granted.

**Ending**
The ending of this predictable way of living. The circumstances related to the change may be elected or may be forced onto the individual but either way life changes.

**Limbo**
This third stage is the area between the old and new identify. It is characterised by suffering and disempowerment it may be experienced as disorientating.

**Becoming ordinary**
This is the development of a new identify, integrating the changes into daily life.

This four-stage process describes clearly the overview of the experience of transitions.
The life course perspective is a theoretical model, which crosses several disciplines including social work, sociologists, social historians and psychologists. Drawing on theories of developmental psychology, it takes a wider view of transitions and looks at transitions within the context of the way that individual has developed through different periods of their life (Hutchinson, 2003). It refers to the life course as a trajectory, a long-term pattern of both constancy and change, which will involve multiple transitions. In addition to individual pathways it also emphasises the interconnectedness of families when shaping experience (Hutchinson, 2003). The life course perspective model defines transition as “A change in role and status which represents a distinct departure from prior roles and circumstances” (Hutchinson, 2003, p. 12).

Transitions occur within the context of the life course, or trajectory of an individual’s life. A life event is noted as different from a developmental transition, it is a major event involving a relatively sudden change that may result in serious and long lasting events. In addition it defines turning points, a life event or transition that produces an enduring change in the life course trajectory (Hutchinson, 2003).

Other studies have looked at transition in relation to changing states of health, (Meleis et al., 2000). A framework of transition has been developed which describes a three phase transition structure of entry, passage and exit, (Meleis & Trangenstein, 1994). It refers to both the process and the outcome of the complex person-environment interactions that take place. They note that the process of transition can occur with changes in health and illness. In addition individuals experiencing any transition can be more vulnerable to risks that may affect their health. Understanding the transition process can lead to understanding of any potential risks (Meleis et al., 2000). This framework maps out in a more detailed way the elements of transition that can be experienced which can guide clinicians when working with people in transitional states.

There is no theory of transition within occupational science literature although occupational science research has generated some knowledge of transition from an occupational perspective (Crider, Calder, Bunting & Forwell, 2014). Crider et al., carried out an integrative review of the literature on transitions in occupational science. They consolidated this body of knowledge into seven strands of understanding about transition which they proposed could support a theory of life transition from an occupational perspective (Crider et al., 2014). The transitions covered in occupational science literature were mostly individual developmental transitions such as aging (Jonsson, 2011), family developmental transitions and situational
transitions such as retiring or giving up driving. There was only one transition linked to mental health.

From their detailed review and synthesis they identified 7 qualities of transition, which they proposed could be used as a building block for an occupational theory of transition. These were qualities of transition, the experience of transition, roles and transition, environment and transition, occupation and transition, factors facilitating transition and factors that make transition difficult (Crider et al., 2014).

**Transition of prisoners**
Visher and Travis looked at the transition of prisoners from prison to the community (Visher & Travis, 2003). They suggest that these transitions are best understood within a life course perspective framework. This takes into account the individuals’ situation before imprisonment, their experience of prison life and the period after release, both the immediately post release and longer-term settlement (Visher & Travis, 2003). They propose four dimensions that affect re-entry from prison to the community and the reintegration process: Individual characteristics/ circumstances, family, community and state policy (Visher & Travis, 2003). There are similarities here with what the occupational science literature is saying about transitions. Visher and Travis (2003) are looking at the transition process as part of a larger body of work focusing on desistance from offending post release. Visher and Travis noted that most previous studies had failed to take into account the experience of imprisonment and its immediate aftermath. They found that in contrast books and articles written by prisoners themselves suggested these two stages were significant in understanding post prison outcomes and reintegration and as a result they incorporated this into their framework (Visher & Travis, 2003). There is a parallel here with recovery-based practice, utilising the different perspectives between professionals and the people they work with. By taking on the views of the prisoners they are taking a more holistic perspective of the process of transition to the community following prison.

**Transition of people through the forensic mental health system**
Coffey (2012) has compared the transitions of forensic service users with other life transitions. He notes a number of distinctions, firstly transitions for forensic service users are not generally of their choice, they are imposed by others. They are health transitions (JCPMH, 2013), they are not anticipated as part of their life trajectory. Diagnosis and admission leads to a prolonged attempt to return to a form of stability. He notes that the transition from illness to health and into the community, take place in separate institutions. They are hidden and so do not have the same level of public support as other transitions.
such as retiring (Coffey, 2012). He notes that service users have the task of reconciling criminal offending, mental illness and incarceration with the societal needs of normative behaviour (Coffey, 2012). It is not surprising then that discharge from secure services has been found to be very anxiety provoking for service users (Mezey et al., 2010).

The Centre for Mental Health (CMH, 2011) in their report, based on a review of 7 case studies of secure and forensic services in 4 different regions in England, identified seven barriers to transition from in-patient secure services to the community. Most of these were service specific, for example lack of step down facilities, supported community accommodation such as hostels or residential homes that individuals can move onto following discharge from secure care. However, one barrier was patient anxiety about discharge. Service users emphasised the concerns they had about leaving secure services after what will normally have been a long period. Both staff and service users stated that discharge from secure services was so anxiety provoking for service users that it led to a risk of relapse (CMH, 2011). This pre-discharge anxiety has been documented elsewhere (Mezey et al., 2010; Miles et al., 2012).

Michaels and Orentlicher (2004) reviewed the literature on transitions and identified 6 essential core features of person centred approaches to transition planning:

1. holding service users and families at the centre
2. creating a shared vision for the future
3. identifying strengths and support needs
4. building relationships and community connections
5. developing an action plan
6. establishing accountability and follow up

This model of working is an expectation of the Section 117 meeting and care-planning process described earlier (Slay, 2011). This process underpins individual’s care and supports them in their transition to community living.

3.15 Social inclusion

One significant challenge, that service users leaving secure services face, is how to reintegrate into a society following a hospital admission lasting a number of years (Miles et al., 2012). This was a challenge identified in the service user consultation. The literature on social inclusion provides some perspectives that could be utilised in this study. Social inclusion is a well-documented subject (Sen, 2000) although it is a contested term (Peace,
and the versatility of the concept has resulted in the term being used indiscriminately (Sen, 2000). Clarification is therefore required for its utilisation in the study. There are close links between recovery concepts and social inclusion concepts, supported by the political agenda (Ramon, 2007).

People actually diagnosed with a significant mental illness have been described as among the most excluded in society (Sayce, 2001). Burchardt, LeGrand and Piachaud (2002) provide the following definition of social exclusion: “An individual is socially excluded if he or she does not participate in key activities of the society in which he or she lives” (p. 30). The emphasis in this definition is on non-participation arising from constraint, rather than choice (Burchardt, LeGrand & Piachaud, 2002).

In her often-cited text, Silver (1994) suggests three paradigms of social exclusion. These are: solidarity, specialisation and monopoly. Each attributes exclusion to a different cause and is grounded in a different political philosophy. Solidarity is the French concept of social exclusion, which is primarily defined as the breaking of the social bond, both cultural and moral, between the individual and society. In this way the dominant culture is reinforced. In the specialisation paradigm exclusion is based on individual freedom and equality drawing on concepts of liberal citizenship (Kartal, 2001-2002). In this way exclusion reflects discrimination, when individuals are denied access to or participation in particular groups of their choice (Haan, 2000). The final paradigm of social exclusion is monopoly, which arises from the interplay of class, status and political power and serves the interests of the included. Institutions and cultural distinctions not only create boundaries that keep others out against their will, but are also used to perpetuate inequality.

Silver’s definitions as described above provide a useful foundation for understanding the dual aspects of the study; the subject of the study and the way it is being carried out. The study subject will view social exclusion within Silver’s specialisation paradigm. It will seek to identify individual experiences of participation in cultural and social groups and structures of their choice. However by the way I am carrying out the study I am aiming to address the barriers to social inclusion as described in the monopoly paradigm. I am providing training and experience in research techniques, language and strategies to people who are marginalised by their experience of mental illness and offending. How I am designing the study to encourage inclusion will be discussed later.

An interesting perspective on social inclusion comes from Kurzban and Leary (2001) who have considered the evolutionary function of social exclusion. They discuss the influence of
natural selection on relationships and productivity and therefore survival. Starting with the understanding that there is only a finite amount of time they suggest individuals have to make decisions about who they spend their time and resources with. Each selection of a friendship or affiliation constitutes a decision to decline other opportunities. Therefore evolutionary mechanisms have developed which allow individuals to make adaptive decisions. They suggest three factors, which would exclude people from being perceived as a cooperative partner and therefore advantageous to develop alliances with: 1). unpredictable goals and behaviour; 2). a known history of cheating; and 3). evidence of little capital in the form of social or economic factors. People with mental illness are still perceived as a threat. A survey of the British newspapers found that the criminal justice system and the criminal courts were the most common source of stories about mental health, and that messages about the risk of violence posed by people with mental health problems were present in fifteen percent of stories with most implying a high risk (CSIP/Shift, 2006). This perspective may be critical in understanding the participant’s experience of living in the community, these reports convey an inaccurate picture of people with mental health problems resulting in them being ostracised as they try and go about their daily lives (Repper & Perkins, 2003).

3.15.1 Social inclusion and mental illness
The experience of social exclusion for people with mental illness has been described as an enforced lack of participation in key social, cultural and political activities (Morgan et al., 2007). People with mental illness can experience exclusion from material resources, productive activity, often in the form of work or education, social relations, civic participation and health and health services (Boardman, 2011). The relationship between social exclusion and mental ill-health is complex, with many of the elements of exclusion (low income, lack of social networks, joblessness) being in different circumstances both causal factors and consequences of mental ill-health (Repper & Perkins, 2003). Novella (2010) suggests that the shift of mental health care from an asylum-based model to a community model has increased access to mental health care for more individuals in society. However Novella (2010) notes that this process has led to vulnerable individuals becoming increasingly disenfranchised within communities as impersonal organisations are unable to provide the personal support they need.

The social inclusion agenda focuses on the need to support people’s access to a full range of mainstream life opportunities, not just within community-based mental health services (Bates, 2002). Repper and Perkins (2003) argue that many people who are now living in the community with a mental illness are as excluded as ever. People may not necessarily be
able to access opportunities in the community; as Repper and Perkins point out too often individuals will continue to feel and be treated as an outsider (Repper & Perkins, 2003). This lack of improvement could be explained by the continuing media presentation of mental illness as dangerous (Repper & Perkins, 2003). Silver’s (1994) three paradigms of social exclusion also offer some perspectives. First, solidarity, people who have mental illness, particularly if they have also committed an offence, may be perceived as breaking a social bond and therefore will continue to be excluded. Individual examples of people being isolated from their communities for having a mental health problem in Repper and Perkin’s book seem to bear this out (Repper & Perkins, 2003). Second, specialisation, people with mental illness may be denied access to work or social groups of their choice, the recovery research has accounts of this (MHF, 2000) and also individuals limiting their social networks as a protective measure (Whalley Hammell, 2009a; Lin et al., 2009). Third, monopoly, the way that community-based organisations can sustain inequality through rules and strategies to limit participation.

3.15.2 Social inclusion and social capital
Definitions of social inclusion tend to emphasise the development of specific formal roles in the community, for example through work and education (APU/UCLAN, 2005). Social capital refers to more informal roles, relationships and ties, social connections have been found to be important for general wellbeing in the population as a whole (Putnam, 2000).

Two types of network have been identified: homogenous, or bonding networks, which are primarily made up of people from the same background, for example people with mental health problems and an offending history, and heterogeneous (or bridging networks) which primarily consist of people from a cross section of society, for example a political party. I think the conceptual clarity achieved by linking social inclusion with the specific formal roles that people undertake in the community and social capital as the formal and informal networks that people build up will assist with the understanding of the participant responses in the study by beginning to delineate aspects of an individual’s experiences in the community in a terminology which, though still professionally defined, has the potential to clarify responses. As yet we do not know what social capital individuals leaving secure services develop. Research to date has focused solely on the relationship with professional carers (Dorn et al., 2005; Gerber et al., 2003; Hodgins et al., 2007; Luettgen, Chrapko & Reddon, 1998). This study will explore this in more detail.

The social model of disability draws a distinction between the impairment of the person through a diagnosed condition and the impact of the negative societal reaction to the
condition (Beresford, Nettle & Perring, 2010). It is the responses of others, which often have a greater impact on the individual than the original mental health problem (Beresford, Nettle & Perring, 2010). Members of wider society appear to distance themselves from mental health service users, through reluctance to work with them, marry them, live close to them, or have them as friends (Leff & Warner, 2006, p. 3). There are some high profile, well-funded and evidence-based campaigns such as the Time to Change Campaign which emphasises the commonality of mentally illness in the population (Baker, 2011; Evans-Lacko et al., 2013). However the National Mental Health Development Unit presents some stark findings suggesting that there is still some way to go. Seventy one per cent of people with mental health problems stopped doing things they wanted to do because of stigma (NMDHU, 2011). People with mental health problems say that stigma and discrimination affect all parts of their lives: work, education, friendships, community participation, going to the shops, going out to the pub, talking to other people about their mental health problems (NMDHU, 2011).

It is perhaps not surprising that individuals may choose not to participate. Pinfold (2000, p. 206) discussed how the person may negotiate a personally located middle ground that includes and is between dependence and independence, isolation and full participation. This is an interesting point. The study will be able to explore how individuals navigate a social integration that is right for their current circumstances. There may be a need for a positive withdrawal from society where roles and identity are maintained, but without the social demands for full involvement, providing the space and time needed for recovery (Sells et al., 2006). Lin’s (2003) study looking at occupational engagement for forensic service users living in the community noted that participants sought and engaged in positive and meaningful occupation. Some stated their desire for indirect or vicarious social interaction, such as being in a bar or shopping centre where they could observe or be in the presence of others who were interacting but not be directly involved. So time spend on the periphery was important and protective. However contact with others with similar mental health problems are an important and increasingly recognised source of mutual day-to-day help (Abma & Broerse, 2010; Paes, 2008).

3.15.3 Critique of social exclusion

As the concept of social inclusion has increased studies of social variables such as unemployment, housing, income, and education are increasingly discussed under the umbrella of social inclusion (Morgan et al., 2007). It can be too easy to oversimplify the correlation of mental health problems with social exclusion (Wright & Stickley, 2013). Oyen (1997) points out that social exclusion/inclusion is portrayed as a dichotomy. Either you are out or you are in. She goes on to argue that people move in and out of different levels of
social inclusion during a lifespan; that there is a sizable grey zone area between social exclusion and social inclusion where the majority of the population is found. Hickey and du Tolt (2007) have noted that in much of the discourse there is an underlying assumption that social inclusion or integration is good. This can drive inappropriate interventions to addressing exclusion and ignores consideration of the potential of inclusion to be problematic, disempowering or inequitable (Hickey & du Tolt, 2007). Another concern is that the social exclusion debate has the potential to portray the excluded as helpless victims by the lack of focus on choice or agency (Hickey & du Tolt, 2007). It has been argued that social exclusion has a negative impact on health and wellbeing, resulting in an assumption that inclusion in mainstream social settings is important for mental health and well-being (Spandler, 2007). One of the problems with the move to promoting inclusion is that inclusion in practice implicitly assumes that the quality of mainstream society is not only desirable, but also unproblematic and legitimate (Spandler, 2007). Research has also questioned the assumption that inclusion is necessarily lacking or desirable for everyone with mental health difficulties (Secker et al., 2009). Despite its flaws social exclusion can be seen as a helpful term which highlights the marginalisation of people with mental health difficulties because it sustains a focus on the ways in which institutions and cultures operate exclusionary practices (Spandler, 2007).

Ammeraal et al., (2012) suggest that social inclusion is not a process that can easily be taught, written about or understood through texts – booklets, websites etc. – but is a largely experiential learning process, taking place amongst small groups of people over a period of time in a specific context. I disagree with this. While I agree there are attitudinal elements of supporting recovery. There are examples of specific programmes based on social inclusion principles, which have been effective. One example of this is the Individual Placement and Support (IPS) model (CMH, 2009). This advocates an approach of supporting individuals with mental illness into open employment by supporting them firstly to get a job, then working with the individual and employer to make any necessary support and adjustments necessary to ensure the individual stays in work.

3.16 Summary and conclusions

The literature review was carried out in two parts. The first part identified the broad theoretical underpinnings to the study and provided the basis for the service user consultation. The service user consultation identified the service user research priorities and helped to focus the study on the specific area of community living following discharge. I then returned to the literature carry out a more focused search based on the consultation findings.
Below is a summary of the key issues emerging as well as the gaps in understanding that the study will seek to address. The summary is in two parts. The first is related to the subject of the study and the second is concerned with the study design. To aid clarity I have presented this distillation of the findings from the literature review in point form.

Key issues emerging from the literature review and gaps in the literature related to the subject of the study:

a. Valued occupations contribute to mental health recovery (COT, 2006). People strive for a balance between their activity levels and wellbeing (Eklund, Erlandsson & Persson, 2003; Nagle, Cook & Polatajko, 2002; Whalley Hammell, 2014). No study has looked at how individuals with a mental illness and an offending history try to achieve this balance.

b. Occupations may also be criminogenic and antisocial. An exploration of the dark side of occupation and how this influences service user’s decisions has not been addressed in research to date (Twinley & Addiddle, 2012; Twinley, 2013).

c. Concepts of occupational justice (Townsend & Wilcock, 2004) have been noted to have utility in understanding the issues that impact on engagement in occupations for service users in secure settings (Crabtree, Wall & Ohm, 2016).

d. The recovery process first and foremost revolves around genuinely being able to see and believe the person (Deegan, 1998; Kristiansen, 2007) while also addressing their societal situations. No research to date has sought to understand the experience of service users living in the community following discharge from a secure setting.

e. In order to operationalise recovery it is important to link the content of therapy and the service user's own outcomes (Bartholomew & Kensler, 2010). No research to date has explored the service user outcomes in this client group.

f. There are some emerging conversations about offender recovery (Drennan & Alred, 2012) but this have not been explored in research to date.

g. Recovery for forensic service users has been noted to be identical to mental health recovery but with one significant difference, the need to address the reality of what brought them to forensic services (Drennan & Wooldridge, 2014). This has not been confirmed by research, this study will explore this assumption.

h. Studies, with this client group, have focused on clinical or offence outcomes and have not taken into consideration wider social or patient defined outcomes (Dorn, Swartz, Elbogen & Swanson, 2005; Gerber et al., 2003). There is, therefore, a limited picture of the experience of people living in the community following discharge from a secure hospital. It leaves gaps in our knowledge, which has implications both for the risk of the individual in the community and their quality of life.

i. Discharge from secure services has been found to be anxiety provoking for service users (Mezey et al., 2010). Service users have the task of reconciling criminal offending, mental illness and incarceration with the societal needs of normative behaviour (Coffey, 2012). These challenges are also recognised in offender literature (Visher & Travis, 2003). The experience of imprisonment and the consequences of
being imprisoned are significant in understanding prison outcomes and reintegration (Visher & Travis, 2003). This may be the same for the participants; their experience of secure services may impact on their reintegration. This study will help to illuminate this.

j The risk of violent reconviction increases after a six year period (Coid et al., 2001). What contributes to this and what assists individuals to desist from reoffending in this group is not known (Dorn et al., 2005).

k People with mental illness have experienced being excluded from work, education opportunities, social relationships, and civic participation (Boardman, 2011). Research with this client group to date confirms that they experience the same exclusion (Lin et al., 2009; Tregoweth, Walton & Reed, 2012). This study will contribute to this body of knowledge.

l Social capital refers to the informal networks, relationships and social ties that people develop (Putnam, 2000). We do not know what social capital individuals leaving secure services have already or build up. Research to date has noted that this group have limited relationships beyond clinicians and family (Dorn et al., 2005; Gerber et al., 2003; Hodgins et al., 2007; Luettgent, Chrapko & Reddon, 1998). This study will seek to learn more about the variety of relationships, if any, that supports participants.

This review provides a framework of current knowledge and an understanding of how this study can contribute to understandings of the reintegration of forensic service users into the community. We know very little about how those experiencing mental health problems and living with offence histories define what recovery, or a satisfying life post discharge looks like. There is limited research to date into recovery with people with a mental illness and a history of offending. In addition there have been limited recovery-orientated studies with forensic service users living in the community. This study will therefore make a substantial contribution to recovery knowledge and occupational therapy knowledge by seeking to understand the perspectives of forensic service users when they leave the secure environment. In addition it will contribute to our understanding of the impact of forensic care in the community on its recipients.

The design of the study
From this review it is evident that how the study is carried out is as important as what is found.

a Research has previously focused on professional agendas such as reconviction and relapse of mental illness but the importance of understanding the individual perspective and the influences on an individuals' choices which sit outside professional agendas are being recognised (Cold et al., 2007; Maruna, 2001). This study, by seeking the individual perspective, could make a valuable contribution to the knowledge base.
b  It is suggested that critical theories and methods such as participatory action research are employed as a way of working for occupational justice through client centred practice (Townsend & Wilcock, 2004).

c  Researchers examining recovery are beginning to incorporate recovery principles into the way they carry out research studies (Brown & Kandirikirira, 2007; Gillard, Simons, Turner, Lucock & Edwards, 2012; Onken, 2006).

d  The majority of studies reviewed employed people with lived experience of mental health problems. In one investigation service users were employed to sit on the committees which planned the terms of reference of the study and reviewed the data analysis emerging from the study (Onken et al., 2002). In two studies, teams of researchers with experience of mental health problems were provided with training in interview techniques and employed to carry out participant interviews. They were also involved in the data analysis, either in workshops and email discussions to analyse the data (Ajayi et al., 2009) or to comment on the outcomes of the data analysis carried out by professional researchers (Brown & Kandirikirira, 2007). These studies show that the different relationship between staff and service users as identified in recovery practice, that of professionals being on tap not on top (Shepherd, Boardman & Burns, 2011, p. 1) is increasingly prevalent in how research studies are being carried out. This indicates the utility of such an approach in the study.

e  Researchers are utilising strategies that focus on the individual and their experience of the phenomenon under scrutiny. This gives the context of the subject embodied in the life of the individual, it seeks to en Lin et al., 2009; sure that it is not just the impact of professional interventions that are considered but the impact of social, familial and biographical elements are also included in the picture (Brown & Kandirikirira, 2007; Larson, 2009; Lewis, 1990; Onken et al., 2002; Sutton, 2008).
Chapter 4. Methodology

4.1 Introduction

In this chapter I utilise the findings from the literature review and how the decision to undertake a participatory study was reached. I begin by reviewing the worldview of both recovery and occupational therapy. I then discuss methodology and the use of Habermasian critical theory before exploring participatory approaches. I move on to examine the characteristics of a participatory study and discuss some of the practical issues associated with participatory research. The chapter finishes with a description of the service user consultation, which took place in order to identify the specific study focus. I begin, however, by sharing my response to the learning from the literature review and how that influenced my choices of research methodology.

The patient group are living under the influence of two powerful contexts, that of the mental health system and the criminal justice system. These two systems continue to influence care and monitoring in the community (JCPMH, 2013). The impact of this was reinforced by the feedback and opinions stated in the service user consultation, which is described in more detail at the end of this chapter. The population under scrutiny in the study, people with mental illness and an offence history, are a vulnerable group (Neil, 2012). They may have been under the care of the mental health services for a long time. I wanted participation in the study to be a different quality of experience for them, one that was not reminiscent of hospital care. I also aimed to challenge the status quo and assumptions that people with mental illness and an offending history could not participate in a meaningful way with research (Mertens & Wilson, 2012). I wanted the study to be structured in such a way that the values inherent in recovery and occupational therapy practice would be reflected in the methodology. I also believed that this would be taken a step further to relate my methodology and analysis with a critical exploration about how these two systems impacted on the participant experience (Schofield Clark, 2011).

4.2 Recovery world view

Currently in healthcare, including forensic mental health, there is still much emphasis on positivistic research methods, and evidence-based recommendations and techniques (Beresford, 2007). The National Institute of Health and Care Excellence (NICE), formerly the National Institute of Clinical Excellence, the NHS body which reviews evidence to develop
guidelines of practice, recommends the consultation of stakeholders including service user and carer groups but primacy is given to systematic reviews and randomised control trials (DoH, 2011a). However, recovery-based practice challenges these assumptions; it de-emphasises diagnosis in favour of a "person-in-context" approach (Stowers et al., 2009). Recovery ideas have been largely formulated by people who have experienced mental illness (Deegan, 1998; Shepherd, Boardman & Slade, 2008). The recovery process is a unique journey to each individual, which is marked by defining moments or turning points (Brown & Kandirikirira, 2007). Services cannot "do" recovery for individuals; instead they need to focus on creating a climate where the individual’s recovery can be fostered (Shepherd, Boardman & Burns, 2011). Recovery, therefore, is described as a process that supports an individual in his or her personal development (Allot et al., 2003). The underpinning ontology is that individuals learn and develop as a result of their experiences, relationship with their environment and the meanings they ascribe to this.

4.3 Occupational therapy world view

I am an occupational therapist so my professional philosophical position will be influenced by the profession’s philosophical foundation and ethics (Kielhofner, 2009). It is therefore appropriate to explore the occupational therapy worldview. In occupational therapy the underpinning ontology is that we learn not only by experience but by doing; engaging mind and body in occupation (Creek, 2003). It is this observation, that engagement in activity had the potential to transform people, which brought the subject of occupational therapy into existence (Kielhofner, 2009). The roots of occupational therapy are situated in a humanistic perspective of human beings and their relationship with occupation (Creek, 2002). The focus was on occupation, its role in human life and health and its therapeutic potential (Kielhofner, 2009). In the intervening years occupational therapy has drawn much of its knowledge from the social sciences, (Yerxa, 2009) as well as more positivistic medical model knowledge (Kinsella & Whiteford, 2008). This was a response to pressure to develop a theoretical rationale for practice acceptable to the medical perspective (Kielhofner, 2009). In recent years Occupational Science as an academic discipline has begun to integrate these schools of thought back to an exploration of occupation. Wilcox (1998) has articulated this theme by describing the process as doing, being and becoming. This renaissance of occupation has resulted in a shift in orientation toward meaning and an interest in understanding the relationship between what people participate in and their experiences of health and wellbeing (Iwama, 2004).
Occupational therapists refer to the paired concepts of art and science (Turpin, 2007), not wanting to be constrained by either body of knowledge but to draw on both in relation to the people they work with. In isolation, art seems too soft and unquantifiable and science too formulaic and so a balance is sought (Turpin, 2007). Mattingly described occupational therapy as two-body practice distinguishing between a biomedical concern with the physical body and a phenomenological interest in the lived body (1994).

In both recovery and occupational therapy the epistemological position is a constructionist position, which asserts that humans generate knowledge and meaning from their experiences and interactions with the world. The study therefore needs to be situated within a qualitative paradigm. Qualitative methods are considered particularly appropriate for exploring the subjective meanings and perspectives of individuals (Ballinger & Payne, 2000). It is this complexity and subjectivity, seeking to value the individual and contextual experience, and the meaning that individuals give to their relationship with the world, which are valued both in the recovery and occupational therapy worldview. However I was also mindful of the vulnerability of the client group that I wanted to work with in the research and also the potential impact of being under the scrutiny of the two powerful government bodies, the DoH and MoJ. I did not want the study to be experienced as another intrusion but aimed to carry it out in a way where all involved felt that they gained from participation, or at the very least did not feel diminished by the experience. This is in line with other recovery orientated studies (Brown & Kandirikirira, 2007; Onken, 2006). I intended to carry out the study in a way which recognised and sought to address the power differentials between myself, as researcher and clinician, and the research participants (Schofield Clark, 2011). As I read further I realised that this was more consistent with a participatory epistemological position. In the next section I will describe the participatory worldview.

4.4 Participatory worldview

A participatory worldview has a notion of reality as subjective – objective. There is a given reality in which the mind actively participates (Reason, 1994). Merleau-Ponty (1962) described perception as participatory, not simply a sensory phenomenon but a symbiosis. He gives an example of touching; by touching something, the being touching is also being touched. Heron and Reason (1997) described encounters with the world as transactional. Heron states "Worlds and people are what we meet, but the meeting is shaped by our own terms of reference" (Heron, 1996, p. 11). We shape the world in a subjective way; our objectivity is relative to our perspective. Reality is subjective-objective, always called into being and shaped by the participation of the knower in what is known (Reason, 1998). It is
this acknowledgement of the dual nature of knowledge and the embracing of how individuals’ experiences of the world shape their understanding of it that rings true with me. In addition, there is an acknowledgment of the fact that it is dynamic; understandings can be developed and shaped, people learn by experience.

The participatory worldview, incorporating this notion of reality as subjective – objective involves an extended epistemology. A knower, by participating in the known can articulate a world in at least four independent ways:

**Experiential knowing**
- direct encounter, face to face meeting

**Presentational knowing**
- grounded in experiential knowing it is the intuitive resonance with the world, often symbolised in verbal and non-verbal art forms

**Propositional knowing**
- knowing in conceptual terms, a more verbal way of articulating the world and forming theories and concepts

**Practical knowing**
- knowing how to do something, demonstrated in skill and competence

(Heron & Reason, 1997)

Heron and Reason (1997) have called the awareness of the dynamic interplay between these forms of knowing critical subjectivity. Critical subjectivity is different from either the subjectivity of primary experience or the attempted objectivity of the positivistic stance. It accepts that initial experience is our experiential articulation of being in the world and does not attempt to suppress this but rather attends to it as the basis of knowledge. However, initial perceptions are not accepted uncritically. By critically attending to them and bringing in the relationships with and awareness of the other three ways of knowing, initial perceptions can be clarified and grounded as well as being refined. An example of this type of knowing would be the development of the service user researchers within the project. They initially took part in the study because they had an intuitive appreciation that their experience of in-patient services, their experiential knowing, could contribute to service improvement. They have been trained in the techniques and strategies developing propositional knowledge, a theoretical understanding of how to use their experience to contribute. As they took part in the interviews and data analysis, their practical knowledge developed. This development and extension of their original form of knowing is also helping them to reflect on their original experiences. Their sense that their experience could be utilised has now been developed through training and experience so that they can come to the study as informed and active co-researchers.
I therefore began to explore theoretical approaches, which would be consistent with the participatory epistemology. Critical theory aims to not only understand but to change society. It rejects the ideal of value neutrality advocated by positivistic science and instead regards developing theory as a catalyst for human emancipation (Mertens & Wilson, 2012). I am now going to explore the theoretical underpinnings of critical theory in more detail.

4.5 Marx

Marx was the first theorist to link knowledge and a developing understanding with social change. He stated that his chief aim of theorising was to change society, not just interpret it (Marx, 1888). He also challenged the separation of knowledge and experience stating that rational solutions can be found observing and understanding human practice (Marx, 1888). As a result of his observations of the social changes happening across Europe in the 1840s, he developed a theoretical perspective, called historical materialism, which aimed to provide an understanding of society for the explicit purpose of social revolution (Seidman, 2013). He proposed that society was shaped by the economic system which had produced two distinct classes, the bourgeoisie and the proletariat i.e. those who own the means of production and those that sell their labour (Little, 2011). He suggested that the dynamics between these classes shaped the organisation of socioeconomic life, which, in turn, determined the structure and direction of the whole society (Seidman, 2013). He reasoned that the more underprivileged groups understood about their situations the more informed they were to be able to challenge and change their situations (Little, 2011). Following Marx’s death the Frankfurt school was established to provide an institutional context for the development of Marxist ideas (Crotty, 1998). It had to relocate to America for the duration of the Second World War, but became re-established in Frankfurt in the 1950s (Seidman, 2013). It brought together academics with a range of different influences (Little, 2011). From their work a neo-Marxist or post-Marxist model developed which included a mixture of influences from a range of sources (Crotty, 1998). These included music, history, Freud’s psychoanalysis, economics, technology and creative arts (Paddison, 1993). The unifying feature from this eclectic mix was a critical approach to society. The work of these scholars was collectively known as critical theory. Rather than developing a coherent research paradigm, critical theory has a variety and diversity of emphases, a reflection of the multiplicity of influences and perspectives of the academics that developed critical theory (Little, 2011).

Habermas was a second-generation member of the Frankfurt school, becoming the director in 1964. Habermas (Habermas, 1972) is one of the philosophers who has developed thinking about inquiry that is value-laden and which utilises social justice as an underpinning principle.
for research (Mertens & Wilson, 2012). Social Justice is defined as justice in terms of the
distribution of wealth, opportunities and privileges within a society (OED, 2015). As
individuals who have been isolated from society and are now trying to reintegrate into society
following a long-term hospital admission this participant group is vulnerable and socially
excluded in a number of ways, including access to work, housing and social networks
(Repper & Perkins, 2003).

Habermas was critical of science which assumed that studies conducted in controlled
settings was the only way that knowledge could be developed (Williams & Popay, 2011). In
his work 'Knowledge and Human Interests' (1972), he identified three, what he called,
universal human interests, which led to three general forms of knowledge. These are
technical interest, which led to the empirical-analytical sciences, practical cognitive interest,
which led to historical and cultural sciences and emancipatory interests, which led to critical
sciences. He grounded his work in Marxist theory, however one of the key critiques
Habermas had about Marxism is that it failed to distinguish between work and interaction and
so therefore reduced communicative action to instrumental action (Scrambler, 2001). He
noted that this resulted in Marxism being reinterpreted as a mechanistic relationship between
forces and relations of production that undermined its potential as a theory of human
liberation (Scrambler, 2001). He developed a theory of communicative action which has
made a significant contribution to social theory (Kemmis, 2006).

Communicative action is a social action where individuals aim to achieve a shared
understanding and agreement through discussion, and debate (Habermas, 1992). Social
interaction is shaped by an aim to achieve mutual understanding (Bolton, 2014). Habermas
compares communicative action with strategic action (in social situations) and instrumental
action (in non-social situations), where the aim of communication is to achieve a particular
goal whether or not a shared understanding or agreement with the objective is obtained
(Fultner, 2014). The process of communicative action also results in developing social
relationships (Fultner, 2014). Habermas suggests that communicative action is an ideal
model; that deviations from this model can be caused by the repression of discourse caused
by the institutionalisation of power. The model can therefore be used as an instrument for
analysis of power by analysing these variations (Bolton, 2014; Habermas, 1992). I intend for
the study to be characterised by communicative action, though interviews with the
participants and discussions within the research group which I have formed for the study. I
will explain these in more detail later in the chapter. By reviewing the strategies for
communicative action, which I utilise, I will also be able to reflect on how discourse is
supported or suppressed throughout the study.
The opportunities for communicative action will take place in the context of, what Habermas defines, as the ‘life world’ and the ‘systems world’ (Habermas, 1992). These are the two distinct arenas in which people live their lives (Habermas, 1992). The life world is the social space, which is shared with family and friends, the systems world is the professional or administrative space where individuals work or interact with institutional authority. People have started to define themselves by their role within systems as the life world is increasingly dominated by the systems world (Wallerstein & Duran, 2008). This can result in individuals feeling powerless and that their participation will have little impact (Wallerstein & Duran, 2008). At this point in the study I considered the main influence of the systems world as the legal framework under which the participants are being monitored in the community. This appeared the most obvious framework, which influenced their day-to-day decision-making. I anticipated that the participant’s life world would have been significantly affected by their long-term hospital admission. The study sought to explore how the participants were beginning to re-establish a life world in the community, beyond the hospital environment. The life world has been found to be limited following discharge from a secure setting, with the main contact being mental health professionals (Lin, Kirsh, Polatajko & Seto, 2009). These professionals, with one of their roles being the monitoring of risk, may be identified as agents of the systems world. This study intended to note if this was the same for these participants.

An additional perspective of the systems world is offered by Gramsci (1971) in his concept of hegemony. Hegemony is defined as the leadership or dominance of one social group over others (OED, 2015). Gramsci noted that an individual’s social awareness is shaped by different societal institutions such as the newspapers, universities, factories and unions and therefore these institutions have power to exercise hegemony by embedding their guiding assumptions within the foundations of these institutions (Gramsci, 1971). In the case of this study the Ministry of Justice and the Department of Health are both powerful institutions that may shape the participant’s social awareness. These institutions may well be the objects of struggle among powerful agents within society (Baldini Soares, Campos & Yonekura, 2013). A critical methodological approach may help to illuminate this and begin to highlight the patient voice. Gramsci was a philosopher who was imprisoned by Mussolini’s Fascist regime for his political views. He therefore wrote most of his work from within a prison. It is interesting to note, in the light of this study, that individuals can still have an influence on thinking and society from writing from behind a prison wall.

Both Habermas and Gramsci are theorists, they are not researchers, but their ideas have influenced the way researchers have considered and developed research strategies in a
variety of settings. The participatory research methodology, in particular, has been influenced by critical theory and the writings of these two philosophers. In the next section I discuss participatory research.

4.6 Participatory research

Participatory research attempts to develop knowledge about social relations and social change democratically by fostering dialogue and equality between researcher and researched (Penzhorn, 2002). In social and health sciences it is an emerging paradigm (Penzhorn, 2002). There are two broad traditions of participatory research, the northern tradition, which is focused on organisational reform, and the southern tradition, which has more of an emancipatory focus (Minkler & Wallerstein, 2008).

One of the lead proponents of the northern tradition is Kurt Lewin (Wallerstein & Duran, 2008). Generally considered the father of action research, he was a Jewish German social and experimental psychologist, who moved to America in 1933 (Burnes, 2004). He was conducting research in a time of the great social challenges brought about by World War II (Dickens & Watkins, 1999). His concern was with changing social systems (Coghlan & Jacobs, 2005) focusing on addressing conflict, crises, and change, generally within organisations (O'Brien, 1998). Lewin was aware that changing human systems often involved variables that could not be controlled by traditional research methods. This led to his development of action research and the notion that human systems could only be understood and changed if one involved the members of the system in the inquiry process itself (White, 2004). He was an avid proponent of the principle that decisions are best implemented by those who help make them (O'Brien, 1998). Lewin was concerned that research findings should lead to change, stating that the two goals of action research were to involve and improve (Coghlan & Jacobs, 2005; Dickens & Watkins, 1999). He developed a research cycle with 4 stages of problem identification, planning, action and re-evaluation (Dickens & Watkins, 1999; White, 2004). He called this process action research. Participatory research has its roots in Lewin’s work embracing the social change theme that underlines much of his work (Dickens & Watkins, 1999).

The Southern tradition of participatory action research grew from liberation movements within the third world, in particular Latin America (Minkler & Wallerstein, 2008). One of the lead proponents of this was Paolo Freire, a Brazilian educationalist who launched literacy programmes among the peasant peoples of North East Brazil in and around Recife in the early 1960s (Wallerstein & Duran, 2008). His teaching methods were embedded with
empowerment techniques. Freire termed this dual development of knowledge and critical consciousness conscientization (Freire, 1970). This was not just a teaching technique but it reflected Frere’s philosophy of existence. To Freire the purpose of education was human liberation; he viewed people as the subjects of their own learning, not empty vessels to be filled by the knowledge of experts (Freire, 1970). He proposed a listening – dialogue – action approach, beginning with listening to the issues or generative themes of participants in order to create a structured dialogue in which everyone participates as a co-learner to jointly construct a shared social reality. The aim of dialogue is to promote an ongoing interaction between reflection and the actions which people take to promote individual and social change, known as praxis (Minkler & Wallerstein, 2008). People begin to truly shape their knowledge of how the world works through actions and encountering barriers to change, by linking cognitive understanding with the emotional and visceral (Minkler & Wallerstein, 2008).

4.7 Participatory knowledge

Participatory approaches form part of a range of research approaches, which have emerged to challenge positivistic values and assumptions (Crotty, 1998). These approaches include A participatory inquiry paradigm emphasises the primacy of practical knowing (Heron & Reason, 1997). What marks out participatory research from traditional approaches is the emphasis it places on experiential knowledge and the importance of patients developing or being involved in research because of their direct personal experience of the issues under study. This is a direct contradiction of traditional research (Beresford, 2005). In positivistic research, if an individual has direct experience of problems, like use of the mental health system or offending, they are seen as being too close to the problem and cannot claim they are neutral, objective and distant to it. They are therefore likely to be seen as a less reliable and valid source of knowledge. This problem is magnified for mental health patients because their identity is generally devalued and they are frequently treated as though their knowledge is suspect, because they are seen as irrational and lacking reliable perceptions and judgment (Beresford, 2006). The same is true of offenders, because of suspicion of their anti-social motives and concerns about ongoing risk. This devaluing of experiential knowledge contradicts day-to-day experience where people tend to place value on finding out things from those who have direct experience (Beresford, 2006). It negates the understanding at the core of occupational therapy that we learn from doing (COT, 2007; Creek, 2003). These assumptions may be more appropriate in the natural sciences but in this study, which is exploring human experiences and interpretations, it is inhibiting.
4.8 Knowledge generation in participatory research

Knowledge generation in participatory research begins with what people bring to the study as everyday knowledge, their intimate understanding of the environment and the lived experience of the situation under scrutiny (Park, 2006). It then develops that knowledge into a more organised form, turning common sense into good sense (Gramsci, 1971). However it has been argued that participatory research should also have an objective of creating new kinds of human and emancipatory knowledge (Fals-Borda, 1987; Gaventa & Cornwall, 2006). That the epistemological horizons should be broadened to include forms of knowledge associated with various human concerns (Park, 1999; Park, 2006). Park has named these additional forms of knowledge representational, relational and reflective knowledge. He suggests an epistemological framework which draws both on the participatory process and the learning that emerges from this (Park, 2006). I found an understanding of these types of knowledge assisted me to understand the knowledge that was generated throughout the study. These forms of knowledge are described below and are summarised in Table 1.

Representational knowledge has two sub-types: functional and interpretive.

The functional sub-type
This is the most technical form of knowledge. It is the portrayal of a thing, a person, an event or an experience as being related as a variable to some other variable or variables in a functional manner; for example unemployment is related to offending. Co-relational and causal relationships are good examples of this kind of functional representational knowledge. This form of knowledge can allow predictions to be made by showing how events can lead to possible consequences which provide the theoretical possibility of producing desired events or preventing undesired ones. The methodological procedures for the development of functional knowledge conventionally require, in principle, a strict separation of the researcher and the object of inquiry. One of the limitations of representational knowledge in its functional form is that it is unable to identify the meaning that people attach to their experiences (Park, 1999). However, the purpose of participatory enquiry is to enable groups of people to formulate mutually acceptable solutions to their problems (Stringer, 2007); sometimes the knowledge required to make changes is technical and practical so functional knowledge has a place in participatory research.

The interpretive sub-type
Interpretive knowledge arises from the analysis or meaning finding from what people say or write. The researcher making sense of the participant making sense of their experience is the essence of interpretation (Smith, 1996). Hermeneutics, a philosophy and a science of
interpretation, provides guidance about how this form of knowledge supports an understanding of texts, persons, events and situations (Bernstein, 1983; Gadamer, 1975; Palmer, 1969). Although interpretative knowledge is different from the functional version of representational knowledge, it is still representational, in that it is a portrayal of information. In the development of interpretative knowledge the researcher’s previous understandings, through experience and knowledge, are utilised to inform the exploration of the data, not in a superficial mechanistic way but in a way that allows them to understand the complex meaning and influences that people convey (Stringer, 2007).

**Relational knowledge**

In everyday usage, when we say we know someone, we mean this in a very different sense from knowing a fact or a theory or knowing right from wrong; it has a distinctly relational meaning. In participatory research this kind of knowing plays an important role in strengthening community and building trust (Koch & Kralik, 2006; Mercer et al., 2008). It facilitates the sense of involvement and participation in the project that Reason (1994) situated in human inquiry.

While strengthening the ties within the research team through relational knowledge can be an admirable goal in itself, it is also essential in the development of other knowledge as well (Mercer et al., 2008; Park, 2006). Much research activity is carried out in ways that involve some form of human interaction, primarily dialogue. It is a social activity (Koch & Kralik, 2006). This requires that all involved are able to open up and speak frankly and authentically. People who are connected through relational knowledge, are in relationships, can find it easier to become involved with a rigorous, interrogative process, to challenge and explore meanings and ideas in order to achieve a deeper understanding (Stringer, 2007). Without relational knowledge divisions in the research group leading to discord and misunderstandings can occur (Mercer et al., 2008).

**Reflective knowledge**

The concept of reflective knowledge comes from the critical theory tradition, which argues that meaningful human knowledge must not merely understand the world but also change it (Park, 1999). Research teams critically analysing the issue under scrutiny and developing an awareness of the social and political context within which it is situated generate this form of knowledge. Freire termed this dual development of knowledge and critical consciousness conscientization (Freire, 1970). This active engagement in awareness-raising activity demands a conscious reflection by those involved. It is also an outcome of group debate and
discussion with a social emphasis both in the way the knowledge is generated and the practical outcomes (Koch & Kralik, 2006; Park, 2006; Stringer, 2007).

<table>
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<th>Table 1: Forms of knowledge (Park, 2006)</th>
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<td>Form of knowledge</td>
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For me, Heron and Reason describe a clear continuum about how knowledge is developed through experience. This is what the participants in the study share in the interviews. They describe their experiences and responses to these; they share their knowing of life in the community from their own perspectives. However what Parks offers with his descriptions of the additional forms of knowledge are the types of knowledge that emerged from the data analysis and within the research team. It assisted with an understanding of how individual experiential knowledge was developed into an understanding, which can be shared and used to learn more about the general experience of moving on from a secure setting.

### 4.9 Occupational therapy and participatory research

Participatory research is a methodology which is relatively uncommon in occupational therapy research (Whalley Hammell, 2007). I agree with Whalley Hammell when she notes that it seems surprising that a profession which is committed to enabling participation in occupations is not leading the way to engage participants in the occupation of research (Whalley Hammell, 2007). One suggestion is that this may be because researchers are deterred by the additional ethical and methodological considerations associated with participatory methods (Lal, Jarus & Suto, 2012). However, there are some examples of its use by occupational therapists (Cockburn & Trentham, 2002; Smith & Suto, 2014). Usefully for this study Cockburn and Trentham (2002) recommend its use for engaging participants in the community. In their study, exploring spirituality in acute in-patient wards, Smith and Suto (2014) were concerned that they were exploring a potentially sensitive and controversial topic. They therefore used a participatory approach methodology because of the attention given to the development of, what they called equitable and authentic relationships (Smith & Suto, 2014) between researchers and the individuals who would be participating in the study.
The challenges of developing truly equitable and authentic relationships are discussed later in the chapter. However this sensitivity to relationships is one of the reasons I am using a participatory approach. I will discuss this in more detail later in this chapter.

4.10 Critique of participatory approaches

One of the active debates in participatory research literature is about the impact of participatory research. Cleaver (2001) asserts that there is little evidence of the long-term effectiveness of participation in improving the condition of the most vulnerable people or as a strategy for social change. Cooke and Kothari (2001) are theorists who were so concerned about the uptake of participatory research principles without sufficient critique they called their book "Tyranny of Participation". They challenge the intent of participatory approaches of consultation, collaboration and social change. They state that participatory practitioners are more interested in their local projects rather than broader systematic oppression (Cooke & Kothari, 2001). Nawaz agrees that the participatory policy approach is less effective where large scale organisation is necessary (Nawaz, 2013).

Hickey and Mohan (2005) however, point out that when participatory strategies were first employed, researchers argued the importance of a bottom-up, person-centred, process orientated approach to change, as an alternative to a top down technocratic change process. They suggest that these neat divisions have been blurred with the uptake and scaling up of participatory approaches into policy making (Hickey & Mohan, 2005). This is evident in the way initiatives such as the "My Shared Pathway" (Ayub et al., 2013) process has been developed and implemented in secure and forensic services. It is an intervention developed by patients, staff and commissioners through a series of workshops and consultations with all levels of services led at a national level by commissioners.

In relation to empowerment, some participatory researchers (Gaventa & Cornwall, 2006; Hayward, 2000; Hickey & Mohan, 2005) advocate the Foucauldian notion of power wherein power permeates all levels of the system. Foucault, in his lectures at the College de France 1973-1974, suggests that power is not a force (Foucault, 2008), as was described by other theorists (Lukes, 1974), he suggests that power does not exist unless it is put into action. Utilising Foucault's concepts of power, researchers have recognised that change can happen in large scale projects as power relations occur at every level of an organisation and participatory methods can affect change at multiple levels among multiple actors (Gaventa & Cornwall, 2006; Hayward, 2000).
Power relations also need to be considered in relation to the team working within the project, beginning with identifying what participation means to individual participants (Hickey & Mohan, 2005). Without careful consideration of power relations Cleaver asserts that researchers overlook the possible link between inclusion and possible subordination (Cleaver, 2001). In healthcare research tools to facilitate these discussions have been developed. One of these is the Reliability Guidelines for Participatory Research (Mercer et al., 2008), which I discuss in more detail in Chapter 5. This is something that needs to be attended to throughout the project to address the critique that people are different, changing and that individual agency can be suppressed in group work (Cooke & Kothari, 2001).

The other criticisms of participatory research discussed below relate more to how the studies are conducted rather than the impact of the study as a whole. Cleaver (2001) points out that participatory literature assumes that people will be willing to participate. It has over simplified assumptions that people will participate due to the anticipation of benefits and because they perceive it as socially responsible and in the best interests of the community. I question this point of view, certainly in healthcare research; people do participate for a range of personal reasons to do with learning more about their conditions, and sharing their experiences. They also participate to make a contribution to the improvement of services (Koch & Kralik, 2006; MHF, 2000). In addition once taking part people get satisfaction out of developing skills and being involved (Ridge & Ziebland, 2006).

Cleaver also criticises the ways that participatory research is carried out and calls for a more flexible approach to working with communities. He describes the paradox of participatory approaches, which will establish bureaucratic structures, and processes that mimic the structures that participatory approaches question (Cleaver, 2001). This is a good point to be aware of, and in healthcare participatory researchers address this through the description of meetings which are more informal and incorporate learning as well as the research agenda, as well as different data collection and analysis strategies (Koch & Kralik, 2006; Larsen et al., 2012).

Some researchers point out the time that it takes to gain genuine participation (Nawaz, 2013; Ramon, 2000; Schmitttdiel, Grumbach & Selby, 2010). Projects are often time bound by the priorities of funders, and providers. This can lead to participation being compromised. Nawaz (2013) describes this as a tension between output, what funders need and outcome, the quality of involvement. She points out that participants need time and space to decide what they think about the issues put before them. Attention needs to be given to training and support throughout the project (INVOLVE, 2004).
It seems to me that the key to successful participatory research is within the relationships that are developed within the team (Koch & Kralik, 2006; Larsen et al., 2012). They are core to the planning, process and development. If time and attention are given to establishing and maintaining these relationships and if there is true co-ownership of the work, the progress and the outcomes of the study by all then involvement in the study has the potential to be a productive and empowering process which results in outcomes which have a practical benefit. Most of the problems identified above seem to result from a breakdown in relationships, and a shared understanding of the project (Cleaver, 2001; Cooke & Kothari, 2001). As I moved on to develop the strategies I used I was mindful of this in my choices and how I managed the project. This is reflected in the methods I utilised which are discussed in the next chapter.

4.11 What form of participatory research

Having decided to employ a participatory methodology the next decision was what form of participatory study my research would take. Participatory research methods can take on different forms. Some examples include: co-operative enquiry; which involves the researcher as a facilitator, as participant groups identify the specific questions they wish to explore and utilise their knowledge as a group to explore these issues (Baldwin, 2006; Koch & Kralik, 2006); and action research; in which participants take an active role in diagnosing problems and planning action, assisted by researchers, before reaching conclusions and defining new sets of action steps (Chisholm, 2006). I was, however, aware that some pitfalls to involving service users had been identified. Firstly that it took time and resources to establish working relationships and improve service users’ understanding of research so that they could contribute in a meaningful way (Clark, Glasby & Lester, 2004; Faulkner, 2012; Horrocks, Lyons & Hopley, 2010). Secondly there may be issues with encountering attitudes of staff who are not supportive of service user involvement in research (Faulkner, 2012; Staley, 2012). It also takes resources up front to pay people for their involvement (Clark, Glasby & Lester, 2004; Faulkner, 2012). Finally there may be challenges working with people as a result of their ongoing health issues (Staley, 2012). As a result of this it is suggested that researchers need to incorporate a degree of flexibility, which may not always be possible when working within strict timelines (Faulkner, 2012). Although these important considerations are relevant to all participatory research types I elected to carry out what is sometimes referred to as a collaborative enquiry (Sweeny et al., 2012). I elected to employ members of the participant group as peer researchers or service user researchers (SURs). I aimed to provide research training, if necessary. I chose this strategy for the following
reasons: It has been utilised successfully in previous mental health research studies (Brown & Kandirikirira, 2007; Onken, 2006; Rethink, 2010), and in studies that seek to find the views of marginalised groups (Hall, Sadouni & Fuller, 2009). The use of service users in research has been reported to keep the research grounded and focused on the issues important to service users (Clark, Glasby & Lester, 2004; Gillard et al., 2010; Staley, 2012; Trivedi & Wykes, 2002), improve the quality of the research experience for participants (Clark, Glasby & Lester, 2004; Faulkner, 2012), boost recruitment and retention rates and improve the quality of interview data and analysis of data (Faulkner, 2012; Gillard et al., 2010). Personally I was interested in utilising service user expertise within the study and I felt more confident that I could develop the research skills necessary to support collaboration.

4.12 Incorporating participatory strategies into the study

I have described the forms of knowledge that were uncovered in the study. I will now move on to describe in more detail the principles that underlined how that knowledge was achieved. When I began the study I was very clear that I wanted to adopt a way of approaching research that was consistent with the recovery and occupational therapy worldviews that informed my practice and had ignited my interest in research. I wanted to develop a different way of engaging with the participants and SURs in the generation of knowledge. I aimed to develop a research strategy that engaged with and learned from the SURs' and participants' experience. The participatory methodology offered a framework to achieve this. In addition I drew on techniques developed within the feminist emancipatory research tradition and the disability survivor movement to tailor my methods to the specific characteristics of the study.

In this next section I will describe how, it is suggested, that the appropriate environment for the creation of knowledge is developed within a participatory framework. In participatory research the goal is to gain new knowledge that is useful to the group, and to do so in a way that is in the hands of the people who need the knowledge (Letts, 2003). Participatory approaches utilise methods drawn from conventional qualitative research, but they are adapted to reflect the specific aims of the project, the community involved and their perspective (Denzin & Lincoln, 2011; Gaventa & Cornwall 2006). There is no distinct methodology associated with participatory research. However there are some principles that are emerging which encapsulate the main elements of this approach (ICPHR, 2013a; Israel et al., 2008; Mercer et al., 2008). In the following section I will list some of these principles and consider how they were developed in the study.
4.12.1 Principles of participatory research

Descriptions of participatory research are characterised by a list of principles, or characteristics of research rather than a clear description of a method used which may be the case in more biomedical research strategies (ICPHR, 2013a; Israel et al., 1998; Koch & Kralik, 2006; Stringer, 2007). This is because of the emphasis participatory researchers give to designing a study around the specific needs and characteristics of the population or subjects being explored and the individuals involved. In this next section I have listed the characteristics of participatory research noted by Israel (2008). This provides a structure to reflect on some of the principles that underpin the study. It also offers an opportunity to explore some of the tensions and challenges that arise from the use of this methodology. I have begun by writing each of the characteristics identified by Israel (Israel et al., 2008) in italics before reflecting on the relevance to the study.

1. “Community is recognised as a community of identity” (Israel et al., 2008 p. 49). Participatory research builds on the concept of community as part of individual and collective identity (Israel, Schulz, Parker & Becker, 1998). Units of identity are socially constructed dimensions of identity, which are created and recreated through social interactions (Hatch et al., 1993; Steuart, 1993); examples of units of identity are a family or friendship network. In the study the community of identity are service users with a history of mental health problems and offending. Mental health services provided to this group are very separate from those offered to the general mental health population. Therefore the act of identifying a community of identity that is recognised by all involved in the study is straightforward. This community of identity make up the participant group and I am employing two members of this community as co-researchers. The co-researchers chose the job title service user researchers (SURs). This is discussed more fully in Chapter 5.

2. “Participatory research builds on strengths and resources within the community” (Israel et al., 2008 p. 49). In this study, as in other healthcare participatory studies (Koch & Kralik, 2006; Larsen et al., 2012), the main resource that I will be building on is the skills and knowledge of the participants and of the SURs. Participatory research acknowledges the value of lived experience. It regards people as agents, capable of analysing their own situations and designing their own solutions (Cornwall & Jewkes, 1995). In health research the disability survivor movement has led the way in developing emancipatory and user-controlled approaches to research (Beresford, 2005). It has led to healthcare research, which shifts the emphasis to doing research with service users rather than about or for service users (Barber, Boote & Cooper,
2007). Patient involvement in all health research can improve the quality of the research throughout the duration of the study. Wykes (2003) suggests three areas where user involvement may enhance clinical research: improving scientific quality, changing outcome measures and amending the method of research. The patient contribution is valuable beyond study design. Involvement in each stage of the study process can enhance the quality and relevance of the study; in data collection, particularly in carrying out interviews (Harding, 2010), interpretation of results (Allam et al., 2004; Gillard & Clarke, 2010) and data analysis. This different way of doing research has been described as the co-production of knowledge (Nowotny, Scott & Gibbons, 2001). It involves a blurring of the boundaries between researchers and those on the receiving end of scientific inquiry (Nowotny, Scott & Gibbons, 2001). The study is therefore following an increasingly established tradition of service user involvement in research.

“Participatory research facilitates collaborative, equitable partnerships in all research phases and involves an empowering and power sharing process that attends to social inequalities” (Israel et al., 2008 p. 50). In my view this is the core characteristic that participatory research is founded on. These collaborative partnerships begin with the acknowledgement that often socially and economically marginalised communities, in this case forensic service users, have not had the power to identify and share their own experience. Participatory researchers strive to recognise and acknowledge the inequalities that exist between them and the community participants. The researchers then seek to address these inequalities by an explicit focus on the knowledge and expertise brought by community members (Israel et al., 1998; Israel et al., 2008). They also ensure that the research is carried out in a way that empowers the community members through sharing information, devolving decision making power and ensuring community members are supported to participate (Israel et al., 2008; Koch & Kralik, 2006). The partnership, between researcher and community, begins with the development of the research question. This is because participatory research sets out to address concerns identified by community members (ICPHR, 2013a). Following this, control is shared by all parties in each stage of the research process including data collection, interpretation of the findings and application of the findings to address community concerns (ICPHR, 2013a; Israel et al., 2008; Koch & Kralik, 2006). These were my ambitions but there is a gap between ambition and achieving these goals. The feminist research tradition offers strategies, which could address this gap and be applied to the study.
The feminist research tradition is based on an emancipatory type of inquiry, which has shifted over the past forty years from studying women to understanding gender culturally and historically (Sarantakos, 2004). It not only documents aspects of reality but it takes a personal, political and engaging stance to the world (Sarantakos, 2004). Beginning with the standpoint of the participants, feminist research actively seeks to remove the power imbalance between research and subject (Brayton, 1997). Feminist research has developed a number of strategies to achieve this, some of which have been adopted by participatory researchers (Brayton, 1997). These strategies include addressing power imbalances, emphasising co-creation of knowledge and empowering the researched community to have an active role in setting the agenda, by the use of reflexive techniques to attend to the use of language, perceive contradictions and work against oppression (Brayton, 1997; Cook & Fonow, 1990; Sarantakos, 2004). Another aspect of feminist research is the embedding of ethical standards in the research design, particularly in regard to the interpretation of and use of information provided by participants (Arvay, 2003). Researchers return to participants for verification of interpretations, since they are the experts and owners of their own personal experiences (Arvay, 2003; Brayton, 1997). They also involve participants in decisions about how results will be published, providing access to published materials in forms that are accessible to the subjects (Brayton, 1997; Cook & Fonow, 1990).

As a senior clinician within the service I am in a position of power in relation to the SURs. I drew on all the feminist and participatory research principles described above within the study. As a participatory research facilitator my role was to actively encourage critical questioning, raise group process issues and help the team to navigate and negotiate power, institutional and advocacy issues (Cockburn & Trentham, 2002). I was carrying out the study for an academic award, so the timescales for the study and to some extent the process of the study was governed by the structures and demands of the course. However within this context I was able to empower the SURs to have an active role in all aspects of the study through training, reflexive strategies and giving attention to their perspectives. Occupational therapy researchers have argued that their expertise in activity analysis allows them to support lay researchers to take the occupational risks necessary for learning growth and change (Cockburn & Trentham, 2002). I agreed with this. However I needed to be mindful that the power imbalances inherent in the research lead and SUR relationship were going to be difficult to remove completely and that these inequalities were likely to emerge during the process (Israel et al., 2008). Providing
time and attention to regular discussion about the impact of power differentials as a group have been found to assist in recognising, acknowledging and discussing these inequities and how they influence the dynamics and work of the research team (Israel et al., 2008). I incorporated reflective time within each study session from the beginning of the project in order to support routine reflection of these issues within the team as they arose.

“Participatory research proposes co-learning and capacity building among all partners” (Israel et al., 2008 p. 50). The aim of participatory research is to enhance the capacity of all the people involved in the research. It is a process of co-learning, what Habermas (1986) refers to as communicative action. Individuals’ learn together and from each other in a transfer of knowledge, skills and capacity between all partners (Darder, 2002; ICPHR, 2013a; Stringer, 2007). Researchers and participants engage in collective, reflective inquiry in order to understand the situations in which they find themselves and the practices they participate in (Baum, MacDougall & Smith, 2006). The data analysis process involves reflective discussion, the learning arises from the thought and language in which people describe their experiences, how they perceive this and their view of the world (Freire, 1970). This requires the development of self-reflexive critical awareness-in-action (Reason, 1994). Learning comes from a dialectical process between the researcher and the contributors who each bring their own knowledge, experiences and skills (Freire, 1970). I was aware that the environment where reflective discussion takes place needed to be developed and nurtured. Personal relationships within the team need to be fostered (Stringer, 2007). I was a novice researcher, the SURs were new to research and they were also new to working within a structured discussion format. From the outset and throughout the duration of the study the research team met regularly. This was a significant commitment of time however these regular meetings helped to build the relationships between the research team. It built trust and fostered a team space where this reflective inquiry could take place.

“Participatory research integrates and achieves a balance between research and action for the mutual benefit of all partners” (Israel et al., 2008 p. 50). This addresses the priority placed on carrying out research which not only contributes something to what is understood about an issue but also results in tangible, practical recommendations, which benefit the situation the researched community have identified. In other words an intention of participatory research is to study something in order to change and improve it (ICPHR, 2013a). In participatory research there is
an emphasis on not just knowledge generated but its applicability to practice and the action that arises from it. In the study one of the reasons that the SURs became involved with the project was because of their desire to improve services for those patients who were still in hospital. As a clinician this was one of the reasons I began the study. A focus of the study was therefore on the practical implementation of the learning from the study.

“Participatory research disseminates findings and knowledge gained to all partners and involves all partners in the dissemination process” (Israel et al., 2008 p. 51). In participatory research the ownership of the knowledge created is shared and acknowledged between all partners (ICPHR, 2013a). In addition the findings are disseminated in a form and language that is meaningful to the research partners. This means that in addition to traditional forms of knowledge sharing, such as peer-reviewed articles and conference presentations, the outcomes of participatory research are shared in a variety of forms. This has included street theatre, and street fairs (Shah, 2004), press releases and coverage by news media (Farquhar & Wing, 2008), photography and creative arts presentations (Lykes, 2006). Researchers involved with participatory research have described a sense of satisfaction in seeing the impact of their studies from being utilised in different forms (Shepard, Vasquez & Minkler, 2008). In the study I am involving the SURs in conference and team presentations (see Appendix III). We have also presented the findings in the form of a leaflet (Appendix IV), which was co-produced. They will also be involved with co-writing future journal articles.

“Participatory research requires a long-term process and commitment to sustainability” (Israel et al., 2008 p. 52). In order to follow many of the principles outlined above the relationships and commitment from all parties needs to be sustained over a long period (Israel et al., 2008). In the case of the study I needed to be mindful of the longer-term implications of involvement in the study for the two SURs. I had a responsibility to consider their future beyond the end of the study. It would be unethical to simply leave them at the end of the study. I ensured that they engaged with the research community through training and development and by taking part in presentations and research events. I provided them with opportunities to engage with the wider research community so that they had the potential to be involved in additional opportunities following the end of the study.
These research principles provided the foundation of the study planning and development. In addition throughout the study I continually evaluated the principles and how they were being followed. This formal or informal re-evaluation throughout the study duration is recommended to adjust to changes in the partnership working (Israel et al., 2008). It is another characteristic of participatory research (Mercer et al., 2008).

4.13 Summary

To briefly summarise the above I decided to carry out a participatory study with a foundation in Habermasian critical theory. It drew on strategies utilised in feminist research and developed in disability research. The study was grounded in participatory research principles but adapted to suit this particular project in relation to the community under scrutiny, the membership of the research team and the aims of the study. I will describe the methods used in the next chapter.

4.14 Consultation with service users to identify a specific study focus

Once the decision was made to carry out a participatory study, the next stage was to consult with patients representing the group under study to define the specific topic area or question that would be researched. This is in line with emerging recommendations and best practice in research, in both general healthcare (DoH, 2006; Faulkner & Thomas, 2002; UKMHRN, 2005) and forensic practice (Faulkner & Morris, 2003).

The individuals who were invited to the consultation came from the same group as the potential participants. They were individuals who had experienced secure in-patient settings and were now living in the community under the care or supervision of community forensic services. Contributors to the consultation were paid to attend and were also given travel expenses. Potential contributors were invited to attend by members of the community forensic team, they were provided with written information about the consultation event (Appendix V). Initially I planned to co-facilitate the session with the Trust service user involvement and participation worker; however, she could not attend on the day. A room was booked in a central location in a community setting which was not a hospital base. Refreshments were provided. The consultation was structured to provide the contributors with an understanding of the background to the study. I planned to begin by describing what research was and why I was asking for their opinions before moving on to discuss recovery.
The main body of the consultation explored different aspects of recovery in order to identify which areas were worthy of further examination in the research study.

In order to facilitate this and structure the discussion ensuring that all aspects of recovery were considered, I used the 24 elements of recovery identified in the Recovery Enhancing Environment (REE) measure (Ridgway, Press, Allott, & Higginson, 2004). This is a self-report measure that gathers information/data about mental health recovery from 72 people who receive mental health services. This measure was developed from the findings in one of the early Recovery studies (Onken et al., 2002), and was adapted for use in England by Piers Allott and Peter Higginson (Ridgway et al, 2004). It has been found to focus service development and enhance collaborative work with service users, mirroring the principles of recovery it measures. It is recommended for further evaluation and consolidation (Dinniss, Roberts, Hubbard, Hounsell & Webb, 2007). I chose to use this measure because it was grounded in recovery research and because it provided a useful structure for the discussion. I collated the 24 elements into four themes: managing mental illness, relationships, occupational elements of recovery, and personal elements of recovery. I included a fifth theme in addition to highlight the additional recovery tasks that are encountered by the forensic client group (Drennan & Alred, 2012). I named this theme Offender Recovery. Two people attended and contributed actively and comprehensively, using their experiences of a secure setting to inform their responses. The consultation confirmed the additional quality and authenticity that service-user involvement would bring to the study with their specific insider perspectives. They brought detail and experience to the consultation as they shared and compared experiences of different in-patient and prison settings, while considering the most relevant subjects to study for them. The structure of the meeting differed slightly from that planned. I discovered that I needed to provide a description about what recovery was. It was a term unfamiliar to them. This was a reminder about how relatively recently the concept has been taken up in services.

The subject for the study that emerged from the consultation was: “What do you need from in-patient services to prepare you for being in the community?” They also stated, convincingly, that the people best placed to inform the question would be service users who had experienced in-patient settings and were now in the community. They said that current in-patients would not have the perspective and experience of both in-patient and community so would not provide the appropriate perspective. This consultation proved its worth. I now had a study focus that was based in my practice but was relevant to the concerns of the population under scrutiny. It was an authentic question, which had the potential to uncover real issues encountered by service users, and make recommendations to improve the
experiences for future service users.
Chapter 5. Method: Organisation of the study

5.1 Participatory research method

To assist the reader to understand and navigate through the study I have divided the description of the method into three chapters. This chapter is mainly focused on the organisation and support of the SURs. It describes the participatory aspects of the study. In Chapter 6 I describe the study itself, the process of planning, ethics approval and data collection. I describe the data analysis process in Chapter 7.

In this next section I explain how the study was structured to support service user involvement and address the study question as well as contribute to my academic development. I begin this chapter by explaining in more detail why I elected to employ peer researchers before moving on to discuss the practical arrangements that I put in place to support involvement. I also take some time to comment on some critique of the use of peer researchers.

5.2 Peer researchers

Peer researchers are people who are currently or who have recently been receiving services, they share experiences with those who are being interviewed. Because of this they can influence the quality and experience of the interview (Harding, 2010). With a peer interviewer there is an immediate and relaxed manner on the part of the person being interviewed (Harding, 2010). This changes the quality of information received and the engagement levels (Staley, 2012). As the interview progresses a peer interviewer is also less likely to inhibit the natural flow of the interview by requesting translations of jargon particular to the users (Harding, 2010). In this study the peer interviewer, will need to be someone who has experienced a forensic setting and not merely someone who has experience of mental illness. There is a distinct language, culture and experience within secure settings, which can be shocking or alarming to individuals who have not experienced it. A peer reviewer who has experienced secure and forensic settings will understand this, they will not be tempted to ask for inappropriate details, which take away from the information and message the participant is trying to convey. The second advantage that Harding noticed was that with peer interviewers there was a notable levelling of power relations in the interview situation (Harding, 2010). The issue of power relations may be prominent in the participant’s interactions with any interviewers. The employment of a peer researcher is therefore one
way of building rapport and making the individual feel at ease in the interview situation. Involving peer interviewers has sometimes been reported to have a negative impact on data collection (Bryant & Beckett, 2006; Elliott et al., 2002). However, this has been related to the training and confidence of the interviewer, not to the fact that they are a peer.

5.2.1 Mapping out the degree of involvement

Planning the degree of involvement at each stage of the process from the outset is recommended (Mercer et al., 2008). A clear and honest approach can provide confidence in the process and reduce potential for misunderstanding (Faulkner, 2004; Hall, 2009) and ineffective participation (Staley, 2012). It sets the foundation for the project. INVOLVE proposes a simple model of involvement with three dimensions of consultation, collaboration and user control. (INVOLVE, 2004), Hall adds another dimension to acknowledge that sometimes there is no involvement (Hall, 2009). Table 2 maps out the dimensions of involvement. I have ticked what I originally anticipated the involvement of the peer researchers would be. Because the study is being carried out for my academic award it should be noted that there is no aspect of service user involvement which is entirely in the control of the SURs.

<table>
<thead>
<tr>
<th>Service user researcher involvement</th>
<th>None</th>
<th>Consultation</th>
<th>Collaboration</th>
<th>Control</th>
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<tr>
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<tr>
<td>Research Question</td>
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<tr>
<td>Dissemination – conference presentation</td>
<td></td>
<td></td>
<td>✓</td>
<td></td>
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<tr>
<td>Plans for Future</td>
<td></td>
<td>✓</td>
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</tbody>
</table>

Table 2: Degree of involvement grid for study

The main forms of involvement within the study are collaboration and consultation. This project will be contributing to my academic award so it is appropriate that I maintain a lead role in the design and responsibility for carrying out the project. The SURs will, however, be able to have a strong influence on the study. The SURs were initially novice researchers and so their primary participation was consultative. During the study they have received training...
to carry out the specific research tasks, which I will discuss in more detail later. As they became more experienced and grew in confidence, the tasks became more collaborative in nature. With the experience gained in this study SURs will be able to take more responsibility in future research projects.

5.3 Introducing the service user researchers

I employed two SURs as co-researchers in the project. The two service users who participated in the consultation were keen to remain involved with the project. This personal commitment to the outcomes of research is noted in many studies that incorporate service user involvement in research (Faulkner, 2004; Gillard et al., 2010). Two service user researchers were appropriate for the scale of the project. This ensured that the training and support needs were manageable and that each would have sufficient interview experience to develop their skills within the project.

Chris Moxon and Richard Love, the two SURs, have agreed to have their real names used in the study and when they have used their own experiences as part of their reflections they have agreed for these examples to be utilised in the study. I asked them to write some words to introduce themselves and their role in the study.

Chris:
Why did I get involved with the research project? Well it all started with a phone call from my social worker asking me if I would like to meet up with Debbie to talk about my experience in secure hospital. Initially I thought it would be a one off session but once there and Debbie had given us the all over picture what this was about it turned out that this research work was going to be a lengthy project.

To make my decision to get involved easier, I knew Debbie from my stay in hospital, as she was an OT, plus the other service user at the meeting I knew from prison back in 2002. From the very first meeting I had a good feeling about working with Richard and Debbie as we had a good rapport.

At the time of the initial meeting I was working as a picture-framer. I had been doing this for three years and was beginning to be fed up with the work and the travel to the job. So this project came along at the right time. From what Debbie had in mind for us there seemed to be great prospects such as interview training, public speaking and general research skills.

Once this project is over I hope to take on a research project with Richard using the skills we’ve learned.
Richard:
When I saw the advertisement for service user researcher it caught my imagination. I saw it as an opportunity to get involved in something that I could contribute to, because of my experiences in mental health secure services.

The research project is for secure services and thus making a difference to the way the services – secure low, med, high are run for the benefit of the service user and mental health professional. Being paid for this project was a motivator too.

I am really enjoying it. Working for and with Debbie and my co-worker Chris is fulfilling. Chris and I draw on our experiences of being in secure services within the mental health trust.

I myself have had the opportunity to give a talk as well. For me that is just fantastic because public speaking is part of my dream career. We have the opportunity on this project to obtain some valuable skills i.e. how to undertake a research project, how to write a report and how to present it to an audience, how to interview people for research and giving a talk, a speech.

Both the SURs had been living in the community following discharge from secure services for a period of time. They had a commitment to their own future careers to which involvement in the study would contribute. From the outset, involvement in the study aligned with Richard’s goals to support other service users through peer work and motivational speaking. Chris was looking to change his life; feeling limited by his current work and saw involvement as a way of trying something new. Our shared mutual goals of personal development through this project ensured a degree of commitment and personal investment in the project that contributed to the team being very cohesive.

They had both had different experiences of the forensic services because they came from different parts of the county, which were previously different Trusts. However, they had met previously when they were in the healthcare wing of the local prison. This provided an immediate connection and shared experience although their subsequent experiences of mental health services differed.

5.4 The lead researcher role

The role of the researcher in participatory studies has been questioned. Is handing over tasks within the study to service users handing over responsibility for the study? The role of the lead researcher in participatory research studies is significantly different from more conventional qualitative research methodologies. Yoland Wadsworth describes it as a move
from being a researcher to becoming a ‘facilitator of our co-researching’ (Wadsworth, 2011, p. 322). This requires a number of different research skills and tasks, which I will explore later in the chapter.

When the study was presented to Faculty Research Ethics Governance Committee (FREGC) an interesting challenge was posed by one of the reviewers: If the study is being carried out by the service users, and they are carrying out the interviews, then you will not be gaining research skills. I gave the following response: Service user involvement in healthcare research is no longer optional. Funding bodies such as the Mental Health Research Network (MHRN) require evidence of it in research applications. The NHS Research and Development Strategy (DoH, 2006) states the intention to involve service users in research that it undertakes. The Department of Health acknowledged the complexity of supporting service user involvement by committing financial support to INVOLVE, an organisation which was established to support all aspects of service user, carer and stakeholder involvement in health, public health and social care. The form service user involvement takes differs in each study. As has been noted in this study it is proposed that service users, representing the community under study, will undertake the data collection task of carrying out participant interviews. The reasons for doing this are related firstly to the participatory nature of the research methodology, secondly because it is consistent with recovery principles and finally because of the proven impact of using peer researchers on the participant experience of being interviewed and the quality of the data obtained (Harding, 2010; INVOLVE, 2004). The skills needed to support meaningful participation of service users in research are time consuming, varied and complex (Maclean, 2000; Young, 2006). It can be argued that they are essential research skills and tasks to acquire in the current healthcare research environment and that they are appropriate for a doctoral level study.

In the next section I discuss the organisation of the study and demonstrate some of the organisational, logistical and observational skills necessary for a lead researcher within a participatory research project.

5.5 Organisation of the participatory study

In order to support the involvement of SURs in a participatory research project thought needs to be given to a number of issues. If not attended to these can influence continued involvement in the project and the quality of the experience of involvement (Mercer et al., 2008; Staley, 2012). These practical details are discussed below.
The study is a long-term project. If, during the project, one or both, had decided to leave, a recruitment procedure would have been carried out to seek a replacement. The title Service User Researcher (SUR) is a title they chose. Their status in the project is that of researchers employed by me to participate in the project. The roles and responsibilities of all involved with the project have been described and agreed (Appendix VI). The data and findings from the project will remain with me.

The payroll and expenses was managed within the Trust research department and coordinated by the service user involvement and participation worker. When she met the research team for payroll registration she also checked to ensure that payment for their work would not affect their benefits. The SURs were paid in accordance with Trust policy. The funding for the project is being supported by the Trust’s charitable fund.

The Trust service user involvement and participation worker had an additional support role to play. The SURs could contact her if they were having any difficulties with participation with the study. She also had an arbitration role if there were any disagreements within the team.

5.6 Service user researcher development and support

Participatory research is defined by the quality of relationships involved (Faulkner, 2004; INVOLVE, 2004). I supported the development of these by organising regular research team meetings. Time was spent at the beginning of each research team meeting to check in with each SUR, to find out what is going on for them at this time. I also used these meetings to allow the SURs to reflect upon their involvement in the project and to identify their individual training needs or interests. We also had social occasions, as a group, to celebrate birthdays and Christmas. This social element is characteristic of participatory studies. It supports the development of relationships and builds a team culture (Koch & Kralik, 2006; Whitmore & McKee, 2006).

The SURs were provided with training in research skills. Formal training was facilitated and coordinated by the service user involvement and participation worker. I provided informal training within the research sessions. In other studies, which have used peer interviewers, similar care and preparation have been invested (Lapsey et al., 2002). They also had the opportunity to carry out practice interviews with volunteers from a local mental health organisation. The service user involvement and participation worker agreed that they had had sufficient training and were ready to carry out the research interviews.
In addition to training, I organised their attendance at conferences to increase their awareness of the wider research and practice community. They had the opportunity to see and meet other ex-service users involved with consultation and participation work, to begin to see the potential of their developing role. From the outset I also included the SURs in presentations about the study. This has increased their confidence and involvement in the project. One said, "The presentations may be a nervous time but they also produce more knowledge and understanding where we are going with this project" (August 2011).

Reflexivity, the way researchers make visible their individuality and its effects on the research process (Gough, 2003), is also an important research skill for the SURs to learn. As well as discussing it in research meetings, I have asked the SURs for regular reflective accounts and at the end of each session we discuss and write up reflections about that session. As one wrote, "The type of research used is called participatory which is not done just to generate facts, but to develop understanding of oneself and one's context." (December, 2010).

Participatory research is time-consuming and involves different tasks to ensure authentic participation (Maclean, 2000; Young, 2006). However, this investment in time, energy and resources is paid back. It ensures the SURs have the confidence to contribute (Lockey et al., 2004) improves the scientific quality of the research (UKMHRN, 2005; Wykes, 2003), and enhances the experience of participation (INVOLVE, 2004). As a researcher I also discovered another benefit of employing SURs. Getting to know individuals over a longer period of time, I experienced a deeper sense of the daily challenges they encountered as they brought the issues that affected them to discuss at the research meetings. It gave me another, longitudinal, perspective of the issues under scrutiny.

### 5.7 Reliability guidelines for assessing participatory research studies

Our research team undertook a self-assessment using the reliability guidelines for assessing participatory research projects (Mercer et al., 2008). Completion of the self-assessment allowed the SURs and me to take stock and evaluate the progress of the study to date. The self-assessment also brought to light how much the study is influenced by the fact that it is being carried out for an academic award. Decisions about the design of the study are shaped by the SURs but also by the demands and expectations of the academic course. If something is agreed in the research group but is not acceptable to the university then it would need to be reviewed. It also allowed us to discuss how the study is being moulded and
influenced by my learning. As I learn more about research methodology and refine my ideas this influences the research design. I begin each research session by sharing my current thinking and learning about the methodology and how that may shape the design. I also share each stage of the course so that the service users are aware of the academic stage-posts and the pacing of the course. The self-assessment allowed us to discuss this as a group and explore the realities of the course influences on the study.

**Number of participants:**
When considering sampling size in this study I had a number of considerations. Firstly what was recommended as an appropriate size for a qualitative study? Marshall stated that the number is one that adequately answers the research question (Marshall, 1996); however there is no definitive answer for this. In practice the number of required subjects usually becomes obvious as the study progresses, as new categories, themes or explanations stop emerging from the data (data saturation) (Mason, 2010). In his study of sample size and saturation in PhD studies Mason (2010) noted the numbers of participants ranged from 1 to 94. The case for a smaller sample size has also been made (Denzin & Lincoln, 2011).

Denzin and Lincoln (2011) place greater stress on the intensive analysis of a small body of data. Peer researchers have been found to have the most significant impact of the quality of the data analysis (Caldon et al., 2010). Data analysis needs to be carefully structured to ensure true involvement and emersion in the data. This may be a longer process than in traditional data analysis and so it makes sense to have fewer participants to allow for more time to be spent in the careful, group, analysis of each interview. It has been argued that it is the quality of the analysis that is more important to the outcome than the sample number in qualitative studies (Mason, 2010; Silverman, 2010). This focus, then, on quality of analysis rather than number of participants is appropriate.

A final consideration is the interview experience for the SURs. Firstly the sample size will need to be an even number so that they both have the same opportunity to develop interview experience and of sufficient number that they feel they develop their skills.

I therefore elected to aim to have six participants in the study. I planned for each SUR to carry out two interviews for each participant. Therefore there would be a total of twelve interviews. I anticipated that this would support the collection of an appropriate amount of data while allowing capacity within the study timeframe for carefully planned, participatory data analysis process.
Chapter 6. Method: Study design

In this chapter I describe the procedural aspects of the study. This includes ethical considerations, gaining study approval, recruitment of participants and data collection.

6.1 Gaining approval to carry out the study

This study was approved by the University Faculty of Health and Social Science Research Ethics and Governance Committee (FREGC), which is responsible for ensuring the quality and integrity of research proposals, supported by the University, the NHS Research Ethics Committee (REC) which needs to approve any research involving patients or users of the NHS and the Research Approval and Monitoring Committee (RAMC) in order to ensure the study complies with local governance arrangements.

In addition to the ethical consideration for participants, as this was a participatory research design I needed to consider the impact of the study on the service user researchers. I have provided a summary of the ethical considerations identified in (Appendix VII).

6.2 Ethical considerations

Any research that involves human participants will raise complex ethical issues. Research ethics focuses on providing guidelines for researchers, reviewing and evaluating research and establishing enforcement mechanisms to ensure ethical research (Aguinis & Henle, 2002). Guidelines have been published by professional associations, government agencies and universities (Aguinis & Henle, 2002). These guidelines are based on the four general principles of respect for autonomy, beneficence, non-maleficence and justice (Israel & Hay, 2006). In practice these are interpreted in the following ways. The importance of informed consent, where participants should be informed about the nature and consequences of any research they may participate in and that participation is voluntary. There should be no deception or deliberate misinformation in the information that participants are given. Safeguards should be incorporated into the study design to protect participant’s identities and research locations. Finally the importance of accuracy is recognised. Researchers should ensure that the data emerging from studies is internally and externally valid (Christians, 2000).

The above principles are grounded in the value neutral aspirations of biomedical research (Israel & Hay, 2006). However the values incorporated in participatory research raise
important but markedly different ethical issues and obligations for researchers (Israel & Hay, 2006). Participatory research raises specific challenges which are not adequately addressed by the established institutional guidelines (ICPHR, 2013b). The International Collaboration for Participatory Health Research (ICPHR) (2013b) identifies a number of additional issues that need to be considered when carrying out participatory research. These include the ways power and control are negotiated, how the very personal experiences shared by participants are utilised and how the differing needs and expectations of the participants are balanced in the design process. They have published seven ethical principles to consider when conducting participatory research (ICPHR, 2013b). They are intended to work alongside and compliment the established ethical guidelines discussed above.

This code was a useful guide but it did not cover every eventuality and did require consideration as it was applied to our research study. For example guideline three refers to “Promoting democratic participation by encouraging and enabling participants to contribute meaningfully to decision-making and other aspects of the research process according to skill, interest and collective need” (p. 9). I wanted to promote democratic participation of the SURs. That was one of the reasons I adopted a participatory methodology; however putting that ambition into place raised a number of questions. Firstly who assesses the skill levels of the SURs, are they involved with this interpretation of their skill level and what if they disagree? How is the collective need agreed?

An example of a decision that raised a number of ethical issues was the first conference presentation carried out in relation to the study. I was asked to present the study to date at a service user involvement in research conference. This took place about eight weeks after I employed the SURs. The ethical issue was whether to deliver a co-presentation with the SURs. This involved weighing up their novice status in research against the benefits of taking part in a presentation. I needed to balance the possible risk of making vulnerable people more vulnerable by putting them in a situation where they may fail, feel embarrassed or foolish against the potential gains in confidence and sense of what they could contribute by active involvement in the presentation. Making the wrong decision either way may have threatened their involvement in the study or may have had more serious repercussions for their feelings of self worth. If not involved they may have concluded that that their involvement was token, that they sat at the sidelines when the project was shared. However if they were involved before they were ready they may have felt nervous, put under pressure and exposed. I discussed the issue with the service user involvement and participation worker, who was involved in the project, as described in Chapter 5. I also discussed it with my supervisors. Most importantly I discussed it with the two SURs. One had experience of
presentations and the other said it was his ambition to do presentations. They were both nervous but interested in being involved. In research meetings we planned and practiced the presentation so that they felt prepared. The presentation (Alred, Love & Moxon, 2008) was well received and had the effect of introducing the SURs to the research community. In the conference intervals other researchers, commissioners and professionals introduced themselves and congratulated them on their talk. In addition the involvement of the SURs was mentioned in a report of the day published in OT News (Sainty, 2010). The outcome of taking time to consider all aspects of the issues resulted in a positive experience for the SURs and their development as researchers and for the profile of the study within the research community.

I used this approach of consultation, reflection, discussion and use of a reflective log to consider and reflect on the complex ethical issues as they arose throughout the study.
### 6.3 Data Collection Process

The data collection process is described below. It is presented diagrammatically in Figure 1.

#### Figure 1: Data collection process

1. Community Forensic Mental Health Team (CFMHT) identify possible participant
2. Participant given invitation to participate (Appendix VIII)
3. If interested participant given Participant Information Sheet (Appendix IX)
4. Participant gives permission to CFMHT worker
5. Participant’s name and contact details are passed to me, lead researcher
6. Telephone call between myself and participant to arrange interview
7. Letter with interview arrangements and topic outline sent to the participant
8. Consent form completed
9. Interview takes place between the SUR and participant
10. Participant is thanked and paid for their involvement
11. Summary of interview sent to participant
12. Telephone call between myself and participant arrange 2nd interview
13. Second consent form signed
14. Second interview takes place between the SUR and participant
15. The participant is thanked and paid for their involvement
6.3.1 Recruitment strategy
The strategy to recruit the individuals involved close cooperation from the community forensic team. I presented the study at a team meeting so the team members could ask any questions. They were provided with an invitation to participate in the study (Appendix VIII). They were asked to approach individuals who they thought would be willing to participate in the study. If the individuals were interested then staff were asked to explain the study further. Individuals were also given additional written information to help them to consider participation (Appendix IX). If they agreed to take part, participants were asked to contact one of the research team to make arrangements for the interviews to take place.

6.3.2 Interviews
The main data collection method was by one-to-one interviews carried out by the SURs with the participants. During interviews interviewees are encouraged by questions and other verbal and non-verbal methods to produce elaborate and detailed answers (Rapley, 2004), they provide authentic access to the lived experience (Moyle, 2002) and are currently the central resource through which contemporary social science engages with issues that concern it (Atkinson & Silverman, 1997). The purpose of the interview was to gain information about the three main aspects of the question. What was it like being in a secure in-patient facility, what preparations were carried out as the individual made the transition from secure services to the community and what is it like living in the community? The interview structure was developed with the research team (Appendix X). Specific questions about the offence or mental health history were not asked. The focus of the interviews was on the experience of the participants. It was a semi-structured interview, which addressed these three main areas of inquiry. There were prompts listed to identify possible subject areas. Prior to each interview the participants were sent further information about the interview content to allow them to prepare for the interviews and alleviate some anxiety about topics to be covered (Brown & Kandirikirira, 2007).

6.4 Organisation of the interviews
I planned for the interviews to take place in a community setting. Each SUR carried out a one-to-one interview with a study participant. The SURs come from each side of the county so they carried out interviews with participants from the opposite part of the county to ensure that they did not interview anyone they knew. Prior to the interview the participants were asked to sign a consent form (Appendix XI). The interviews were recorded on audiotape. If a participant was not willing to be recorded then I planned to sit in the interview and take notes,
but they all agreed to be recorded. The SURs and I met beforehand to discuss the interview. Following the interview we met again to debrief and to collect immediate impressions of the interview as well as provide support (Johnson & Clarke, 2003; Moyle, 2002). The interview content can be emotional for both interviewer and interviewee so on-tap support and contact details for further assistance was necessary (Miller et al., 2006; Moyle, 2002).

The intention was to provide a welcoming environment, which made the participants comfortable. Participants were offered reimbursements for participating. They were offered travel arrangements and payment based on the Trust policy for payment of service users. The payment of participants provides a monetary value to their expertise, is consistent with Trust policy, and was anticipated to encourage recruitment. This last point can lead to a criticism of coercion if it encourages participants to take part in a study which would not be in their best interests (Cleary, Walter & Matheson, 2008). However, in this study, recruitment was via the clinical teams, who made a judgment before approaching the individual. This added protection for the individual and ensured the payment was a reward rather than an incentive. I transcribed the audiotape following the interviews.

The participants were posted a copy of what they said in the interview. The participants were then invited to meet once more with the interviewers. This member-checking meeting aimed to be a short meeting of half an hour. This meeting gave an opportunity for clarification of any points made in the interview and ascertained that the individual had seen the summary and agreed to the contents being used in the study.

If the individual did not want their responses to be used by the study they were invited to keep their summary but the data was not utilised within the study. If the participant requested that some particular information was not used in the study then that will was removed and the rest of the interview used in the study. If the participant agreed for all the information to be used in the study then it was to be used in the study. Participants agreeing for all or part of their information were asked to complete a re-consent form Appendix XII. They were provided with a copy of their interview transcript and a highlighter pen to the member-checking meeting. Participants were able to indicate which parts of the interview they did not want to be used in the study by highlighting them.

6.4.1 Developing summaries for the participants

After the interviews were transcribed I developed summaries of the interviews for the participants. The raw transcripts included the questions asked by the researcher, hesitations and repetitions as well as incidental comments such as the participant asking for another
drink. I removed these when developing the summary. The summary provided the participants with a coherent format of their experiences on paper. Reading this and seeing it written may assist with their understanding of their experiences. It is a way of giving something back to the participant.

6.4.2 What happened
Six participants participated in the first interview. Four agreed to return for the second, member checking, interview. Two participants did not want to be interviewed a second time. One did not consent to having the information from the first interview used in the study and one did consent to having the information from the first interview used. Therefore a total of 9 transcripts, consisting of two interview transcripts from four participants and one interview transcript from one participant were available for data analysis.

I had originally planned for the interviews to be held in a community setting but the second participant asked to come to the hospital site for his interview. In order to support his wishes I agreed. I then informed the ethics committee, requesting an amendment to the protocol (Appendix XIII) in case any other participants requested this. In the event three out of the six participants opted to be interviewed in the hospital setting.
Chapter 7. Data analysis

In this section I will describe the data analysis strategy employed. I begin by considering the theory about how to develop the conditions in which collaborative data analysis can take place. I then describe the data analysis strategy I employed in detail.

7.1 Conditions necessary for collaborative data analysis

It has been noted that there is more difference between SURs and conventional university researchers in the way they analyse the data from interviews than in the way they carry out interviews (Gillard et al., 2010). I wanted to structure the data analysis so that these important perspectives were utilised. Freire wrote that learning emerges from “dialogue” which he defines as “an encounter, mediated by the world itself, between men and women to name the world (make sense of the world)” (Freire, 1970, p. 88). The data analysis process can be described as a dialogue between the transcripts, the voices of the participants, the service user researchers and myself so as to make sense of the responses in order to inform the study. The features that Freire (1970) identified to support dialogue have been taken up by participatory researchers and adapted to suit the particular circumstances of each study “there is no right way of doing it” (Nind & Vinha, 2012, p. 43). The “right” way is the way that best fosters the relationships that lead to critical reflexive practice that sets the scene for a “horizontal relationship of mutual trust” (Freire, 1970, p. 91). Freire (1970) described the conditions necessary to support dialogue:

**Love:** or a commitment to others and the potential of participation,

**Humility:** the facilitator needs to be open to the contribution others can make,

**Faith:** in people’s ability to engage in the process, to create and recreate understanding from the data,

**Hope:** based on an expectation that change can happen,

**Critical thinking:** which understands reality as a process capable of change rather than static.

Love is an unusual term to find in an academic context. Maybe that is why he uses it. It is a layperson’s word so that in his writing he is making some of the concepts accessible to all. In the literature responding to Freire’s work Schoder noted that the majority of scholars have ignored the term love (Schoder, 2010). Noddings substituted the word caring (Noddings, 1984). She described it as rooted in receptivity, relatedness and responsiveness. More recently researchers have returned to considering the term love (Johnson, 2008; Schoder, 2010).
2010). Schoder (2010) defines it as “a conscious moral appraisal and bestowal of value on a person or thing” (p. 4). In my view in Schoder’s attempt to distil a succinct, formal definition from his comprehensive review of concepts and definitions of love he has lost its essence. Johnson, writing from the standpoint of a Catholic social justice lens, notes that the term love is more acceptable in a spiritual framework (Johnson, 2008). However, she considers the term compassion as more acceptable. Caring and compassion do not convey the warmth and positive regard implied in the term love. They are words that reinforce the power differential between the carer and cared for, being compassionate and the receiver of compassion. Love, in this context is a two way process. All members of the team come to the research with a positive commitment and a belief in the potential in what they are doing.

The role of the researcher is critical in creating the environment for supporting participatory or collaborative data analysis. It does require additional skills compared to more conventional data analysis methods. Involving members of the community under scrutiny as co-researchers in the project changes the role of the researcher. This change has been described as moving from researcher, or director, to facilitator and catalyst (Cornwall & Jewkes, 1995), partners, fellow explorers (Letts, 2003), allies and facilitators (Cockburn & Trentham, 2002), co-learners (MacDonald, 2012) and process facilitator (Fox, Martin & Green, 2007).

### 7.2 Critique of co-production of knowledge

The co-production of knowledge may be a worthy endeavour, but what about the status of the outcomes of the study? Ramcharan et al., (2004) observes that participatory researchers have to choose between achieving rigour in participatory research or inclusion. They argue that aiming for academic rigour will compromise the analytical contribution of lay team members and prioritising inclusion will compromise the theorisation of the data (Ramcharan, Grant & Flunn, 2004). Others disagree with this and acknowledge the contribution that lived experience makes to the knowledge development process (Beresford, 2007; Koch & Kralik, 2006). In his writing Freire advocated using academic knowledge to inform dialogue and data analysis. He suggested that researchers use their understanding of academic knowledge to inform data analysis when developing themes and referred to these as “hinged themes”, bridging the emerging knowledge from the research group with established understanding. The metaphor of a bridge has been used in other collaborative research (Nind & Vinha, 2012). It was used to illustrate how different partners each provide a link to different perspectives and a path to different cultural knowledge. These suggest that inclusive data analysis can be achieved without compromising academic quality. Indeed co-producing
knowledge can go beyond simply adding the service user voices to an academic frame of reference. It conceptualises a creative process of producing new knowledge through collaboration, the exploration and articulation of what different voices mean to each other (Gillard et al., 2012; Sweeny et al., 2012). This is Habermas’ (Habermas, 1986) communicative action in practice.

In this next section I describe how I designed the data analysis process to facilitate communicative action within the research team. How I created the process and environment to foster collaborative data analysis. I explain how I drew on the work of previous participatory researchers and adapted their methods used to the study, and the research team.

7.3 Developing the data analysis strategy

In the data analysis process, more than any other part of the study, I fine-tuned the strategy that I used in response to how the SURs were able to engage with what was being asked of them. I began with a broad outline of how I planned to proceed, but this was adapted as the data analysis process progressed. Because of the close connection between my reflections, and the adjustments I made as a result of these, I will be incorporating my reflections within this description of the data analysis process. In order to provide clarity, I am going to put my reflections in italics so that they can be distinguished from the actual data analysis process described. This strategy of using different fonts to differentiate reflections from the process has been used by Morris (Morris, 2012). Figure 2 provides an overview of the data analysis process.

The data analysis strategies were selected to suit both the study and the characteristics of the team. The following are the main characteristics of the research team that had an influence on how I planned the data analysis.

My research experience: I was still a relative novice to research. I needed a research strategy, which I could clearly explain to the SURs.

The research experience of the SURs: this was their first experience of data analysis so each stage needed to be clear and easily understood.

The size of the research team: our team consisted of three people. The data analysis strategy needed to be suitable to support discussion and teamwork.

Practical issues: some studies have depended at some stages of the data analysis process on email communication (Gillard et al., 2012). The SURs did not have reliable access to the Internet so this was not considered in this study.
I wanted to develop a collaborative, co-sharing approach that could support the SURs to really engage with the data and utilise their experiences to interact with and help to, illuminate what the participants were trying to convey. I also needed to feel able to engage with and explore the data from my clinical and researcher perspectives. These considerations influenced the choice of data analysis methods used.

**Figure 2: The three stage data analysis process**

**Stage one: Familiarisation**
- Step 1 – Read-through of transcript
- Step 2 – Research meeting to discuss transcripts as a group

**Stage two: Framework analysis**
- Step 1 – Initial categorisation of meaning units
- Step 2 – Review and initial discussion about categories
- Step 3&4 – Indexing and charting
- Step 5 – Mapping and interpretation

**Stage three: Abstraction of findings to theoretical knowledge**

7.3.1 **Stage one: Familiarisation**

The first stage of the data analysis was to look at each transcript as a whole. This was the first opportunity for the research team to see the interview data and to gain an initial impression of what the participant was trying to convey. It involved immersion in the data and gaining an overview of the richness, depth and diversity of the data. It also involved making notes and recoding the range of responses (Ritchie & Spencer, 2002). As a participatory research study this initial stage, however, was not solely involved with data analysis. These sessions also served two other functions. The first additional function was the continuing SUR training and reflection about their performance as interviewers. The second additional
function was preparation for the second interview. The additional tasks for this familiarisation phase influenced the method I used to carry it out.

**Step 1 – Read-through of transcript**

In order to support the SUR engagement with the transcripts, I employed a technique described by Arvay in her Collaborative Narrative Approach to transcript analysis (Arvay, 2003). I chose this approach because it would assist the SURs to engage with the transcribed interview in a meaningful way. In order to facilitate this I changed the written transcript into a table format. I then added four columns to the right hand margin following Arvay's procedure (Arvay, 2003). The SURs were asked to read the transcript four times and note down their reflections and observations.

In the first reading the SUR that carried out the interview was asked to read for content. This reading acted as a check for the transcript of the study. If some phrases had been indistinguishable on the recording, or mistakes had been made, then corrections could be carried out, or additions made. In the first interview, for example, the participant's voice occasionally became so quiet on the recording that he was inaudible. The SUR was able to fill in the gaps in what the participant had said.

In the second reading the SURs were asked to consider the interview itself – how did the person interviewing structure the interview? Why did they ask certain questions? Did their decisions influence the response? This second reading acted as a teaching tool. It encouraged the SURs to reflect on their performance as interviewers.

In the third reading they were asked to consider what the participant was trying to convey. This reading focused on the content of the interview and the responses. It began to identify what the participant was contributing to the understanding of the topic.

In the fourth reading they were asked to note their reactions to the content - did they agree? Had they experienced that? How did they feel about the content? What was their response? This was encouraging them to bring their own feelings and perspectives to what the participant was saying.

Table 3 shows a short part of the interview transcript document. This was sent to the SURs for this first stage of analysis.
I also read through the transcripts using the four reading guidelines and noted down my own interactions with the transcript. This structured reading was intended to guide the research team through a reflexive analysis of the transcripts. It resulted in a distilled sub-analysis held by each researcher. I have included a section of one of the reflexive transcripts completed with the comments from the two SURs and myself in (Appendix XIV).

I posted the adapted transcripts to the SURs for them to carry out the readings prior to the team meeting. Each SUR was paid to carry out this work before coming together to look at the transcript as a group. Up until now I had assigned homework tasks. These had generally been to write a reflective account or to read a journal article. I had not given payment for these tasks. However, to emphasise the importance of the task and to ensure that they allowed sufficient time to complete the reading and reflection, payment for two hours work was appropriate.

**Step 2 – Research meeting to discuss transcripts as a group**
Step two was the first team meeting following the interview. I facilitated a dialogue session where all research team members shared their pre-prepared responses to the interview data.
7.3.2 Stage two: Framework analysis

In the second stage of the data analysis process, attention shifted from each individual interview to comparing the interviews with each other. Again, I structured this stage to support the involvement of the SURs. I elected to use framework analysis because it provides a clear and systematic way of applying the principles of qualitative analysis (Gale, Heath, Rashid & Redwood, 2013; Lacey & Luff, 2009). It has also been noted to assist a team approach to data analysis (Gale et al., 2013; Gillard, Simons, Turner, Lucock & Edwards, 2012). Before I go on to explain my strategy I am going to give a brief description of framework analysis.

Framework Analysis

Framework analysis is a qualitative data analysis method which was developed by Jane Ritchie and Liz Spencer (Ritchie & Spencer, 2002). Framework analysis is part of the group of analysis methods termed thematic analysis or qualitative content analysis (Gale et al., 2013). Data is reviewed to identify commonalities and differences before reviewing relationships across the data set. It seeks to develop descriptive or illuminating conclusions clustered around the themes (Gale et al., 2013). The framework approach consists of a series of interconnected stages, which enables the researcher to move forward and backward across the data until a coherent explanation or description emerges (Ritchie, Spencer & O'Connor, 2003). The defining feature of framework analysis is the framework itself. This is a matrix in which the data, in this case interview data, is structured to provide an overview of how themes relate to each other while remaining connected to the source data.

Framework analysis is not aligned with a particular epistemological framework; this means it can be used in inductive or deductive analysis (Smith & Firth, 2011). It is also possible to use a combined approach of using pre-selected themes which can be based on previous literature, the research question, or the lived experience of researchers and an inductive approach, where themes are generated from the data. This allows the opportunity to discover unexpected aspects of the participant’s experience or the way they understand their situation (Srivastava & Thompson, 2009). A number of advantages and disadvantages to using framework analysis have been identified. I have collated them into a table, (Table 4), to aid comparison.
Table 4: Advantages and disadvantages of framework analysis

<table>
<thead>
<tr>
<th>Advantages</th>
<th>Disadvantages</th>
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<tr>
<td>• It can be used to address specific issues identified prior to the study</td>
<td>• There is a temptation to regard the matrix format like a spreadsheet and begin to quantify qualitative data, to develop an argument based on how many people said x.</td>
</tr>
<tr>
<td>• It is primarily based on the observation and accounts of the participants</td>
<td>• It is time intensive</td>
</tr>
<tr>
<td>• It is dynamic and supports the change or addition or amendment throughout the process</td>
<td>• If working in a large team there will need to be time taken in providing training, learning how to code, index and chart data.</td>
</tr>
<tr>
<td>• Comprehensive in nature</td>
<td></td>
</tr>
<tr>
<td>• The access to original textual data demonstrates its transparency, which allows others to formulate judgments</td>
<td></td>
</tr>
<tr>
<td>• It provides systematic and visible stages to the data analysis process</td>
<td></td>
</tr>
<tr>
<td>• It supports team engagement with the data</td>
<td></td>
</tr>
</tbody>
</table>

The reason that the framework method appealed to me was firstly that it built on the pattern of work established in the previous stage, (individual analysis followed by a group analysis of the data) and secondly because the frameworks, or charts were a way of presenting the data clearly. This straightforward presentation of data supported the SURs to engage with the data and use their expertise to interpret it. The way the frameworks or charts were developed also ensured that the participant voice was central to all the discussions.

The Framework Method

The research method itself involves a five-step process of sifting, organising and chartering the collected data in key issues and themes (Ritchie & Spencer, 1994).

Step 1 – Initial categorisation of meaning units

The way I facilitated this stage of the data analysis was to carry out an administrative task in preparation for the first team data analysis session. I read through the transcript and separated each item of information. This identified units of meaning statements, which have discrete meaning when isolated from other information (Stringer, 2007). I then printed out the units of meaning onto paper and cut them out.

In the research team session, I spread out all the units of meaning onto a tabletop. The task of the session was to sort the units of meaning into related groups or categories (Stringer,
The titles for the initial categories we identified from the first interview were the following:

- Therapy treatments
- Attitude through hospital
- Move through hospital
- Medication
- Relationships
- Work
- Activity
- Finance
- Staff relationships
- Attitude
- Disclosure
- The dark side

Step 2 – Review and initial discussion about categories

I led a read-through of each of the categories identified in the first session. This was still part of the preliminary analysis and the aim of this task was to check that we had grouped the meaning units correctly, to continue the process of familiarisation with the data and to discuss initial responses to the data as a team. It was still a process of organising the information for deeper analysis at a later stage. In this session categories were refined; some were merged and additional categories developed. I also made notes of our discussions throughout and ended every research meeting with some reflections so that the learning from these sessions was not lost.

In the initial stages of this task I sometimes became aware of the SURs’ hesitancy to categorise the meaning units. On occasion they seemed to hold back and wait for my lead. Because we had completed this task before I knew that they were aware of the nature of the task so I wondered if it was my presence that was somehow responsible for their reticence. At these times I made an excuse and left them to complete the task on their own. Each time I did this they had finished the categorisation when I returned and we were able to discuss the decisions they had made. Gillard et al., (2012) described a collaborative data analysis process whereby he asked the members of the research team to come to the data analysis meeting with identified categories. In our team I think that the task would have been too daunting for the SURs to carry out alone. However, beginning the task together and giving them periods of time to make the decisions independently of me struck the right balance and gave them the opportunity to make decisions about how data was categorised before we then discussed the decisions as a team. As these discussions progressed the content became more nuanced. In the initial meeting the SURs wanted to focus on positive statements only. Issues which hinted at any conflict, distress or negativity, were quickly assigned to a category called the dark side. As they became more confident at discussing
the data in more detail we were able to return to the category and consider the meaning units in more depth. This led to some of the meaning units being allocated to other categories. They were beginning to recognise the different shades of experience in each category, for example there could be positive and negative experiences of relationships. In addition, new categories were made.

The final set of categories is listed below:

- Attitude through hospital
- Work
- Difference to mainstream
- Relationships with staff
- Offence
- Disclosure
- What to do in the community
- Medication
- Preparation for discharge
- Relationships with other patients
- Relationships with family/friends
- Social inclusion

Steps 3&4 – Indexing and charting

I have merged steps three and four, the indexing and charting stages of the process. This stage moved the data analysis from consideration of individual interviews to a comparison of themes across different participants. It began to pull together key characteristics of the data to map out and interpret the data as a whole (Ritchie & Spencer, 2002). This was a way of beginning to condense all the data down into themes, which were then charted. The indexing and charting process was essentially an administrative process, as a group we had discussed and agreed the themes and their contents in the previous step and so I carried out the task myself.

When developing the charts I elected to employ a modified matrix approach, which was originally described by Averill (2002). This has been used in participatory studies and reported to have supported involvement with the data by SURs (Gillard et al., 2012). In her study she developed descriptive charts or matrix. I adapted Averill’s method by making the decision to use one chart for each category. Beginning with each category I cut and pasted the sentences from each interview into a chart or matrix of that category. Each sentence or phrase was labelled so that I could identify which interview it came from to support navigation through the data, I could easily return to the original transcript. Table 5 shows an example of a section of a chart.

My priority at this stage of the data analysis process was to organise the data into a structure that the SURs would be able to understand so that they could best use their experience to reflect on the patterns and connections emerging from the data. I had noticed in the previous
stage that switching between themes and trying to navigate too much information about
different topics quickly became confusing and the SURs disengaged from the data. They
were finding the data analysis challenging but were keen to persevere to learn from what the
participants were trying to convey. Using one chart for each category meant that the SURs
could take time to look in depth at each aspect of the data.

Table 5: An example of a section of a matrix or chart

<table>
<thead>
<tr>
<th>Category: Relationships with staff</th>
<th>Your reflections</th>
</tr>
</thead>
<tbody>
<tr>
<td>The second thing, which was as important, if not more important was the respect people showed me, the warmth people showed me and the friendship people showed me.1.1</td>
<td></td>
</tr>
<tr>
<td>Treating me like a normal person and reaching out and actually communicating the fact that they wanted to take the time to listen, they cared, and they weren’t about to pull the rug from under my feet; they were going to be supportive, they were going to be caring and they were going to help. 2.2</td>
<td></td>
</tr>
</tbody>
</table>

Step 5 – Mapping and interpretation

This final stage was a repeat of the two-step process of individual reflection on the data followed by group review. Each member of the team was asked to review each chart by reading through and noting any reflections or responses. This could be any patterns, any issues that stand out and any points that evoked a response. This was a condensing reflexive exercise to allow all to review all the responses on each theme with each other to draw out any patterns (Larsen et al., 2012). The SURs were once again paid to spend a couple of hours reflecting on the themes.

We then met as a team to share, and compare, our individual responses and reflections. Each matrix was viewed in turn with the team contrasting the perceptions, accounts or experiences of the participants, searching for patterns and connections. This also involved seeking explanations either explicit or implicit (Ritchie & Spencer, 2002).

In my view these were the key knowledge creation sessions. The SURs were becoming more confident with the data analysis process. They were able to spend time looking at a discrete theme and to write down their own observations. The tone at the beginning of research sessions changed; they wanted to start straightaway rather than having an extended time catching up. They were excited to hear what each other had said and what they had responded to.

As we read through the chart, issues that had caught anyone’s attention were discussed. We were looking for cycles or patterns in the information and how we found these was through a
circular discussion beginning with the data exploring our different perspectives and considering outcomes, always ending with the questions. So what does this mean for patients now? What can we learn that improves services? Each individual’s responses were considered. As these discussions progressed I found that I felt less of a lead researcher and facilitator and more of a co-researcher. Our relationships as a team and the SUR familiarity with the knowledge creation process and resulting confidence meant that I felt able to explore my views with them more openly without feeling that they would automatically defer to me as the professional.

The framework analysis stage resulted in a final distillation of the responses into the key issues emerging from the data. An example of this is in Table 6. This is a section of the disclosure chart. Quotes from the interviews are collated under the disclosure theme. The numbers refer to the interview that the quote came from. In the second column are some of the SUR and my responses to the data and the reflections that emerged from our dialogue. The third column contains the final distillation of the responses resulting in the learning about disclosure.
<table>
<thead>
<tr>
<th>Category: Disclosure</th>
<th>Framework Analysis SUR responses and discussion</th>
<th>Final distillation of responses: Key issues emerging</th>
</tr>
</thead>
<tbody>
<tr>
<td>I heard the other day that I’m obliged to give any potential employer some details as to my forensic history. I’ve been involved in drugs violence and I don’t think people want to hear about that in my opinion. 1.2</td>
<td>True Has only just learned about this – not had a chance to think it through and plan.</td>
<td>Disclosure is an issue to consider with all contacts, not just when looking for employment.</td>
</tr>
<tr>
<td>I said I need a job and he said “what can you do?” and we got talking and within 5 minutes I’d declared all my forensic history to him and then it fizzled out and I got nowhere and I walked away thinking ouch, I didn’t need to tell. 2.1</td>
<td>Learn from mistakes all have experiences of disclosing too quickly – unnecessary disclosure he doesn’t know what the person is going to do – possibly made himself a target.</td>
<td>Disclosure of the offence is more difficult than disclosure of mental illness.</td>
</tr>
<tr>
<td>Not too bothered about disclosing about mental health. It was a bit more difficult about the ABH and assault. 3.1</td>
<td>People more accepting of mental health problems generally the offence is the problem.</td>
<td>Patients need to be prepared so they are less likely to disclose inappropriately</td>
</tr>
<tr>
<td>You don’t want to be open, disclose to everyone, which I did in the beginning. I used to be open and true to people and they didn’t want to know. So I’m at a little bit of a loss at the moment. 5.1</td>
<td>Drip-feed information about yourself to new people – with everyone you meet it is a judgement of how much you say and when.</td>
<td></td>
</tr>
</tbody>
</table>

### 7.3.3 Stage three: Abstraction of findings to theoretical knowledge

Some qualitative researchers call for an intellectually engaged form of analysis that moves beyond just identifying and describing themes within individual studies to discussing the meaning of the data, and exploring how the study findings relate to, context or develop existing theories (Cockburn & Trentham, 2002; Huberman & Miles, 2003; Whalley Hammell, 2009b). I reviewed the initial impressions, patterns and themes developed in collaboration with the SURs in relation to the literature to identify where it was complimentary and where it differed from previous findings. This process helped to move the learning beyond a straightforward recommendation for change to a deeper understanding of the underlying processes. This stage of data analysis is not generally incorporated into descriptions of collaborative study methodologies although other literature is referenced in the reports that are produced (Gillard et al., 2012; Larson, 2009). This is probably because this is a research specialist task.
The SURs and myself also gave a series of talks, sharing the findings with patients and clinicians in order to test out our findings and learn from other perspectives.

*Encouraged by my academic supervisors, I realised that this was the time to finish the frequent data analysis sessions with the SURs and continue to develop a deeper level of analysis utilising the literature. I took the rich textured and in depth experiential perspectives achieved in the matrix discussions and compared it with the existing theories. I began to write up the findings and discussion and in the process of this began to develop a coherent theoretical understanding. As my understanding developed I returned to the SURs to share the learning. I was consulting with them to ensure that the theoretical learning remained grounded in the study findings. It was important to develop the final summary in a way that the SURs could confidently describe and discuss.*

### 7.4 Reflections on the data analysis process

The reflections I shared in italics throughout the description of the data analysis process describe how the data analysis strategy was adapted in the light of the SUR response to the stages of the process. In this next section I reflect in more detail about the way I completed the data analysis.

The data analysis process is the way in which we begin to make sense of what the participants have been trying to convey. Finlay (2003) suggests a number of different levels of reflectivity, which can be utilised to interact with the data:

1. **Introspection:** where individual researchers will seek to relate emerging findings to their personal experiences and thereby enrich or supplement the data.

2. **Inter-subjective reflection:** consideration of how the participant’s encounter with the service user researcher shaped the information provided.

3. **Mutual collaboration:** the research team as data contributors jointly exploring and elaborating emerging insights from the research.

The strategies that I have employed serve to support these multiple levels of reflectivity. In each stage all members of the research team had the opportunity to consider the emerging findings and their responses to them. The first stage of the data analysis process, where the interview transcripts were first reviewed, allowed for a consideration of how the interview shaped the responses from the participants. The final stage of the data analysis process, the
interpretation of the matrices, utilised collaborative dialogue to explore the understandings emerging from the data. This process of exploring and understanding alternative perspectives and standpoints increases the credibility of the interpretations (Paulus, Woodside & Zeigler, 2008). This is because alternative and competing explanations have been discussed before an agreement is reached or occasionally not reached (Sweeny et al., 2012). The SURs and I all focused on the data individually; we were able to consider our own responses and understandings of the data before we met as a group.

7.4.1 Capturing individual and group responses

When analysing data collaboratively it has been acknowledged that there can be a tendency for the group to work towards consensus building (Reit & Boettiger, 2009). This can limit the different points of view that emerge and so may limit the depth and quality of the data analysis (Woodhouse, 1998). However, the process of dialogue and reflection that takes place as consensus is reached can allow for a deepening understanding and knowledge (Gaventa & Cornwall, 2006). In this data analysis process, each of the stages of the data analysis incorporated two different ways in which the researchers examined and engaged with the data, one as an individual and one as a team. The first step in each stage required each individual team member to look at the data and note down their individual responses. In this way there was a written record of individual perspectives, a “distilled sub-analysis” (Larsen, et al., 2012). In the second step in each stage, the same information was examined as a group; responses and reflections arising from these were shared, compared, and discussed. These were rich discussions, which led to increased insight and understandings. These two types of analysis have been described as condensing: introspection and cumulative: intersubjective reflection/mutual collaboration (Larsen, et al., 2012).

It was important for the study to capture both individual perspectives and the consensus for several reasons: Firstly, it is one way of managing power dynamics in the group by ensuring all views are noted and that different perspectives are not marginalised. In some studies this has been managed by ensuring that the SURs always speak first, with the academics holding back (Nind & Vinha, 2012). However, in my view, the use of this technique alone may mean some individual insights are lost in the general discussion, no matter who initiates or leads the discussion. The individual, or condensive, introspection stage of data analysis allows each member of the research team to immerse themselves in the data and note down their own responses and reflections independently of the other research team members. Making notes of their interpretations ensures that they can be referred back to and are not lost as the research group comes together. Secondly: This method contributes to the internal dependability of the study (Bryman, 2004). There will be a record of individual responses to
the data. It will be possible to look back at the responses of each research team member and how these contributed to the team collaboration, or cumulative data analysis.

### 7.4.2 Length of research sessions

It has been noted that time and space is necessary to allow the process of reflexivity to happen (McKay, Ryan & Sumison, 2003). In some projects, the data analysis has taken place in team meetings that last one or two days (Brown & Kandirkirira, 2007; Gillard et al., 2012; Onken et al., 2002). However, my experience of the data analysis sessions was that they are very demanding and intense. The SURs, and I, became tired and lost concentration after a couple of hours. This has been noted by another project, which elected to continue discussion via email and then have smaller meetings (Larsen et al., 2012). The ideal length for our team seemed to be about three hours. This allowed time for a catch-up session at the beginning, to discuss what had been happening since we last met, and any issues that had arisen for the SURs, regular breaks and at least 20 minutes at the end to reflect on the session and complete any administrative tasks, such as planning the next meeting and completing time-sheets to claim payment. A session of this length then allows for 1½ - 2 hours of concentrated work on the project. If the session was shorter, there was not enough time to get absorbed in the data and make some progress, if the session was longer, concentration and attention waned.

### 7.4.3 Organising the data

Initially I tried not to spend time organising the data between sessions in order not to impose my interpretations. However, this unnecessarily impeded the flow of the following data analysis meeting. Straightforward tasks like putting the information into basic order, such as within relationships putting staff, family and friends’ relationship comments in the same place, in order, assisted the service user researchers to engage with the data.

### 7.4.4 Different responses to the data

By comparing my response to the data with the SURs’ responses, I have become increasingly aware how much I view responses through a professional lens. I find that my initial response to the data is as a clinician. I review what the participant is saying through a clinical lens considering, for example, risk implications or clinical issues. For example when participants talked about work the SURs compared those experiences with their own experiences and those of people they knew. They felt compassion for the participants and explored the data for clues to how they could develop to achieve their goals. My initial response was to immediately think about what changes needed to happen on a service wide level. I had quickly lost the experience of the individual. The SURs made sure that the unique
perspective of the individual was maintained. This difference has been noted in other studies. In Cotterell’s study about the experiences and palliative care needs of people with life limiting conditions he noted that he, a palliative care nurse, focused on the professional and the service users focused on the emotional and critical when carrying out analysis (Cotterell, 2008). Gillard et al., (2012), in their study on service users’ experiences of involuntary psychiatric detention, noticed that service user researchers focused on the experiences and feelings surrounding detention and coercion and the university researchers gave attention to process, medication and patient behaviours (Gillard et al., 2012). Gillard argues that neglecting the perspectives of either the service users or the researchers would result in an incomplete picture of the service user’s lived experience (Gillard et al., 2012). From my experience I would agree. The SURs bring richness and depth to the data analysis I would never have been able to achieve alone.

7.4.5 The data analysis sessions

The discussions that took place in the data analysis sessions tended to go in cycles, beginning with reference to the data, which sparked off reflections or discussion about that data. This was often linked with comparison of the experiences of the SURs and any conclusions or learning that could be gained. This often ended with me sharing some learning. The discussion cycle ends with someone making a joke or making some comment about relationships within the team. The section of the discussion, in Table 7 is from one of the first data analysis sessions. It shows how the sessions were being used to gain first impressions and to think about the structure of the interviews and as a training tool. In later sessions the focus is becoming more of the data itself.

You can see the attention moving between the individual and what they are saying, to learning about how to do the interview, to other developing skills of the SURs and the potential of the study. It is also evident how the SURs relate to the experience of the individual in a personal way.

| Richard | It really bugs me it really drains on me the last paragraph. I really |
| Chris | What do you mean? |
| Richard | He's just after a job, "I'll do anything I'll do anything, anything if you just give me a job," It just sounds you know almost soul destroying to be in that place. I so much want to reach out to Tony and guys like Tony and you know that's not it |
| Debbie | What if somebody said that when you were interviewing them? |
| Richard | I wouldn't – years ago I would have gone straight in – boom |
| Chris | Interviewing you are there to gather information you are not there to help |
Table 7: Discussion from data analysis session

structure their lives are you. This is not for him to come along and start gaining like employment and friends and

<table>
<thead>
<tr>
<th>Richard</th>
<th>Sure, sure yeah</th>
</tr>
</thead>
<tbody>
<tr>
<td>Chris</td>
<td>Like me with the gym thing when he asked me about the gym I could have gone off and told him how to lose weight or what things to do but</td>
</tr>
<tr>
<td>Richard</td>
<td>Sure</td>
</tr>
<tr>
<td>Debbie</td>
<td>But one way you could do which would fit both things would be to ask him why</td>
</tr>
<tr>
<td>Richard</td>
<td>Yes</td>
</tr>
<tr>
<td>Debbie</td>
<td>Why does he want a job that doesn’t - any job we might find out – he might be broke, he might have this girlfriend who needs - you know we might find all kinds of reasons why he wants the money and so he’s less fussy about</td>
</tr>
<tr>
<td>Richard</td>
<td>Yes sure</td>
</tr>
<tr>
<td>Debbie</td>
<td>and sometimes if it meets that need</td>
</tr>
<tr>
<td>Richard</td>
<td>Short-term anyway</td>
</tr>
<tr>
<td>Debbie</td>
<td>But it’s really important to ask the whys and the hows – to try and get from them where they are coming from in these things.</td>
</tr>
<tr>
<td>Richard</td>
<td>Yes understand them</td>
</tr>
<tr>
<td>Chris</td>
<td>What did I need to expand on that then or dig more out of him?</td>
</tr>
<tr>
<td>Debbie</td>
<td>Not necessarily not necessarily about the gym but</td>
</tr>
<tr>
<td>Chris</td>
<td>No thinking about the hours, about the work</td>
</tr>
<tr>
<td>Debbie</td>
<td>Finding out about all these things it would be interesting</td>
</tr>
<tr>
<td>Richard</td>
<td>Why do you feel that way – yeah</td>
</tr>
<tr>
<td>Debbie</td>
<td>It’s almost like with every answer they give ask a why so they give a little bit more</td>
</tr>
<tr>
<td>Richard</td>
<td>Right</td>
</tr>
<tr>
<td>Chris</td>
<td>Have you seen these TV programmes where they follow the lives of young kids when they were about 5 back in the 1970s</td>
</tr>
<tr>
<td>Debbie</td>
<td>Oh the 7 Up ones 7, 14</td>
</tr>
<tr>
<td>Chris</td>
<td>Yeah every so many years they go and see them again. A really interesting project would be to interview these people 10 years later, to see what progress they’ve made.</td>
</tr>
<tr>
<td>Richard</td>
<td>Great idea</td>
</tr>
<tr>
<td>Chris</td>
<td>And what they think then of the system they’ve been through 10 years ago or whether they’ve been back in hospital</td>
</tr>
<tr>
<td>Richard</td>
<td>Yeah</td>
</tr>
<tr>
<td>Debbie</td>
<td>It is isn’t it? You are starting to think like researchers now.</td>
</tr>
<tr>
<td>Richard</td>
<td>Wow</td>
</tr>
</tbody>
</table>

The section above gives an example of how the three types of knowledge that Park identifies are developed within the data analysis sessions (Park, 2006). How they emerge and interweave and are dependent on each other.
**Representational knowledge** – what we are finding out about individuals' priorities of work on discharge from hospital.

**Relational knowledge** – The development of skills and confidence of the whole team. It comes from connecting and leads to further connecting. Relational knowledge is needed to create and sustain a community (Park, 2006). This was particularly important at the data analysis stage because this process is challenging. In the section above I am taking on a teaching role because the SURs are still learning interview skills so the relationship is with me as an expert. In later sessions our conversations looked more deeply into what the participant was trying to convey.

**Reflective knowledge** – Participatory research simultaneously addresses questions of community relations and moral consciousness (Park, 2006). In learning about the data the SURs are learning about themselves as developing researchers. The discussion above demonstrates how the SURs are developing as researchers and how they are committed to the potential for change that the study has. At the beginning they discuss how they are aware of their role, to find out more from the participant, to hold back from giving advice but to understand what the participant has to say. At the end of the section they are looking to the future and wanting to see what progress has been achieved. I am facilitating the process by asking questions and providing guidance and encouragement.
Chapter 8. Findings

In this section I will present the findings of our study. I am going to start with a broad-brush summary of the experiences of the participants. With minor variations they all shared a similar basic trajectory that began before admission, continued during admission and remains on discharge. This description gives the reader a context of the general shared experiences of the participants before we move on to explore more specific findings. One of the six participants withdrew from our study so these findings reflect the contribution of the five remaining participants.

Prior to the offence that led to their admission most of the participants described an unstable lifestyle, with individuals feeling mentally unwell for a long period of time. In some cases they tried to hide this, or pretend it was not happening and in others they were receiving treatment for psychiatric illness and had experienced some hospital admissions prior to their most recent admission. Several of the participants used illicit substances, sometimes in an attempt to manage symptoms. A combination of the drug taking and the mental illness affected their mental state, which caused them distress and affected their ability to make decisions. This led to an increasingly disrupted lifestyle which affected schooling or work patterns. In one case the individual became homeless. This is what set the scene to their offence and subsequent involvement with the criminal justice system. Most of the offences, that were disclosed in the interviews, took the form of violent assaults against people that the participants knew, one family member, one supplier of drugs and two people that the participants were acquainted with and were feeling threatened by.

Following their arrest participants with an already diagnosed mental illness were transferred straight to a secure hospital ward. Others were admitted to hospital from prison. The total length of stay in prison and in hospital varied from 4 years to 19 years. Individuals experienced transfer between 3-4 different hospitals and levels of security including prison, high, medium and low secure care. Five participants had been discharged to supported care such as hostel accommodation and spent up to 18 months there. One person was still in a hostel at the time of the interviews, he was about to move to a flat owned by his brother; two participants were living in a supported flat, two living independently in their own flats and one was living with his wife. Out of the five three had moved to another area due to the restrictions imposed by the court and two had moved back to their home area.
When considering the responses as a whole, the overarching impression was of a group of people who were more reflective about their past rather than looking to their future. They were still picking up the pieces of a life disrupted by mental illness and a long hospital admission. They were starting to look tentatively towards a future beyond hospital but this future was still indistinct and uncertain. They felt they had experienced a great deal and it had been a long and difficult journey to discharge. Much of their experience was of survival within a secure and challenging system. The strategies they had developed to cope and progress through the prison and hospital environments were the strategies that stayed with them as they continued to make their way in the world.

8.1 Outline of themes and subthemes

In the next section I share the research team’s findings. The overall themes of getting out and staying out came from the research discussions when analysing the data. The SURs differentiated between what helped participants prepare to leave hospital and what helped them to settle into the community. Getting out and staying out became the organizing themes of the findings. I therefore have presented the findings under these two broad headings.

The sub themes were developed as the research team reviewed the matrixes in the research meetings, as described in Chapter 7. They are the final distillation of the responses of the participants into the key issues that were identified during the data analysis meetings. The participant quotes used are the quotes that particularly drew the attention of the research team during the discussion. This is followed by the impressions and interpretation agreed during the research meetings. All the names used below are pseudonyms; they have been used to protect the anonymity of the participants.
The first theme relates to when the participants were in hospital. It describes the steps individuals took while they were in hospital. It shows the conditions and support the participants identified which helped them to move towards discharge. This is the process of transition from the hospital to the community and the preparation for living beyond the hospital. There are five sub-ordinate themes in getting out: staff acceptance, “showing myself” to the staff team, practical skills, groupwork and activities.

### 8.2.1 Staff acceptance
The key element that set the scene for participants to begin to move on was the staff attitude and approach to the participants. They described the importance of feeling that the staff were
on their side and were aiming to help them. Staff listening to them and accepting what they said was valued. Keith described the experience below:

Keith  “Treating me like a normal person and reaching out and actually communicating the fact that they wanted to take the time to listen, they cared, and they weren’t about to pull the rug from under my feet: they were going to be supportive, they were going to be caring and they were going to help.”

This acceptance by staff allowed participants to begin to accept themselves and to engage in the recovery process. Some of the participants compared the approach of staff with previous experiences. Keith compares approaches that he experienced in prison and in hospital.

Keith  “Really you can’t really underestimate how important it is for people to show you human compassion. For me that was what made me re-evaluate and I started to see myself set against that background I was able to see all the things I needed to change. When I was in prison I didn’t want to change then because the background I was set against was so anti, so aggressive, so uncaring. I was on a survival instinct.”

Keith found the prison environment was harsh and uncaring. He responded to this by saying he was on a “survival instinct”. The heightened sense of anxiety and distress that this implies does not create an environment where personal development and recovery can occur. It is interesting that he notes the fact that when he was transferred from prison to hospital it was the approach of staff that was particularly important. In a more supportive environment, where he was accepted, he describes being able to take a risk and reflect on his own behaviour for the first time.

For some the importance of being accepted despite the crime they committed was particularly important.

Clive  “They forgive you, they don’t judge you, they know exactly what you’ve done.”

Gary  “I thought they might see my offence as a little too much to take on board but they were really good to me.”

These responses hint at their concerns about how the offence will impact on future relationships. They feel tarnished by the fact of the offence and being accepted by people who know about their offence and yet still accept them goes a long way to allowing them to begin to come to terms with the offence themselves.
8.2.2 “Showing myself” to the staff team

“Showing myself” to the staff team refers to the way participants engaged with the staff team and demonstrated that they were complying with the hospital systems. In a secure service staff monitor the patients’ mental health and also the risk patients may pose to themselves or to others.

Gary described this as “showing myself”.

Keith described the importance of engaging with the team as “because then they will be able to see that this guy’s able to take advice, to act on that, to do that in an appropriate way”.

Engaging with the team or showing themselves is the only way that the patients can demonstrate progress. This active engagement and openness with the team is not always easy but it is crucial if people are to move on. Tony implies that he has had some difficulty before learning to engage with the staff team, now he has a view that the staff are there to help.

Tony “Well I’ve learned to go along with them...they were just trying to get me to open up about it you know in order to free it from my mind.”

Keith compared his progress to another patient:

Keith “Just before I left, I bumped into a fellow who I was in admissions with and he had dug his heels in for five years, refused to do therapy and eventually they told him, look if you don’t do therapy you’re not getting out and he decided five years later to start doing therapy, and I was just about to leave, and that really resounded with me, it told me that I had done the right thing.”

This comparison demonstrated to Keith the importance of engagement with the staff team in order to move through the system. This engagement needs to continue over a period of years. Unlike in mainstream services the participants needed to demonstrate their wellness over a period of time. So as well as engaging with the team they needed to consistently demonstrate their progress.

Gary “I played the game, you do have to play the game, do a little bit of work, do a little bit of exercise.”
This slow sense of progress can be difficult for them to cope with and they may experience their movement as being stalled or as unnecessary delays in their advancement towards discharge. Individuals managed this in different ways.

Andrew “I used to take each day as it came and I tried to get a positive out of the day.”

Tony “To be honest with you now that I am out I really didn’t get a lot out... I was an impatient patient.”

The impression given here is that the patients have to harness their resources in order to manage living in the environment and managing day-to-day.

Keith described taking the initiative to progress, to try and ensure that the momentum of his progress was maintained:

Keith “Proactive I would bring it to them, rather than them coming to me.”

8.2.3 Practical skills

The participants described the practical skills development that took place in order to prepare them for living in the community. One step forward, described by them all, were the trips to the community.

Firstly there were general trips to start getting used to environment outside hospital:

Keith “The first time you’re taken to the local village, everybody’s first community trip is there and the reason is because they know the area and it is a controlled experience. They take everybody there on their first trip.”

Tony describes some of his worries on the initial trips.

Tony “Well I was walking on the upper floors of a big shopping mall and I was freaking there I freaked at this guy and I wouldn’t go in the lift I was really worried about crowds of people there, fast moving traffic or heavy traffic.”

The trips were first local then further afield.

Keith “Doing different things all the time, different towns, boot fair, shopping in different places”
Keith continued to negotiate leave with his teams.

Keith  “So I went to my team and said right, my parents are eight miles away can I go to my parents, and the team would sit there and say yeh you can go to your parents….Sometimes they’d say to me you know ‘not just yet’ OK no worries, got to go back to the drawing board, but it was good.”

Tony didn’t feel prepared: “more trips to the community would have made me feel more prepared”.

This progressed to unescorted leave though some preferred the company of staff.

Tony  “Towards the end I had unescorted leave but it was actually nice, beneficial when you had escorts because you had someone to talk to and I quite enjoyed being escorted. Cos when you had all this time to yourself, no one to talk to it was probably a bit more difficult than when you had an escort”

When the place they were going to be discharged to was identified, they had more specific leave.

Keith  “I was trying to familiarise myself with the town, that was when it really started to take shape because this was where I was going to live, this was what would be my locality, and this then really felt, this wasn’t just a pleasure trip this is fundamentally preparatory you know. Um that I guess allowed me to start to put my roots down if you like.”

John  “Before I came out I had trips across here to get used to the place and I was eased into it over a period of months so I think I wasn’t just thrown out and told you’re out now, there’s the accommodation. I came across for a few days, stayed a night, went back, got used to the place. So I think they did it in a thoughtful way they didn’t just – you’re out of hospital.”

As well as preparing by leaving the hospital environment they learned other practical skills.

Clive  “So what you done is went through the hospital and then they processed you, learning to cook, learning to do all these things to look after yourself, hygiene, and that’s where I learnt to really look after myself and get the skills to move into the community I have my own flat now.”

Gary  “You have to make your own way there and back but they sort you out with a bus pass to town and you use the gym there.”
8.2.4 Groupwork

Participants also described the groupwork that they undertook while in hospital.

Keith  “I listened for advice from people and I went to groups which they asked me to go to.”

Tony  “Done drug awareness, victim empathy as well as psychological groups, anger management.”

Group work seemed to be perceived as the work that needed to be completed before people got out. It was not described in as much detail as the community trips. In fact the group interventions were listed off almost as if they were tasks to be achieved before discharge. No learning from them was discussed. Gary says below that groups were regarded as a box ticking exercise.

Gary  “...it was just a case of just ticking the boxes using my leave, cooking for myself, showing myself, of making myself more self sufficient, doing a bit of voluntary work, engaging with a couple of activities a week with the OTs.”

There was some indication that the interventions could be challenging, particularly when dealing with the offence.

Clive  “Victim empathy wasn’t easy ...you’re in a situation you have to accept you are convicted of a crime of assault.”

However the link between therapeutic interventions and moving on was not always clear for participants. They did not connect the content with preparation for discharge beyond the fact that they were demonstrating compliance with the team.

John  “We did group work but it wasn’t geared towards getting out. It was, you know, group sessions of one sort or another.”

The one exception to this was anger management. It was the group that was found most helpful by the participants. Keith noted that it assisted him in his current situation in hospital.

Keith  “I mean there is one which really helped me personally and that was part of the anger management course that I did actually highlighted the importance of what they called assertiveness.”
Tony said anger management helped him manage relationships with his girlfriend once he was back in the community.

Tony “I think anger management helped easing my way round things now ...we are giving us both an opportunity to let off.”

Anger management focused on strategies to help them in their immediate situation and beyond.

8.2.5 Activities

Individuals engaged in a number of activities, again they did not reflect much on these activities but just named them. This may be because they were used to help the participants cope with their admission, with the strain of being in hospital and coping with day-to-day life in hospital.

Keith “There was a DIY shop, where I did picture framing, there was a carpentry shop. Then there was the education centre where I tried music, I tried English, I tried maths I tried computers, so I tried all of these things, I went to the swimming pool I went to the gym. I think the longest period of anything I did was in the metal workshop and in the education centre, but more often than not I was in the education centre.”

Keith “I also got a job as a patient rep. I was a co-chair for the Shared Pathway meeting.”

8.3 Staying out

The second major theme is called staying out. Now the participants are out of hospital they described their lives in the community. This includes the support they received and the strategies they are developing to assist them to live in the community. Staying out represents the overall aim of all the participants, to remain living in the community.
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### 8.3.1 Being out

There was a sense from all participants that they were much happier being out of hospital.

Tony  "Happy that I am in the community"

There was also a general feeling that they had endured a lot to be in the community due to the protracted length of stay and coping with being in hospital. Clive described himself as a survivor.

Clive  "All I can honestly say here in 2015 I've landed and I have survived."

John  "What keeps me out of hospital is a sense of freedom, a sense of my own worth."

The length of stay in hospital was compared to the length of a prison sentence they would have received for the crime.

Gary  "It is a seven year, eight year journey and if I'd gone to court it would have been 3 years sentence."

Andy did describe some anxiety about being in the community but said that was lessening.

Andy  "I tend to hyperventilate sometimes, sometimes I get panic attacks anxious but as time goes past they diminish."
From some there was an impression that they had been spending all their attention to date trying to be discharged and move to where they wanted to be. Once this had been achieved they were unsure what to do next.

**Clive**  "To be honest with you I’m at a little bit of a loss at the moment."

**A new location**
Because of the offence and the impact on victims four of the five participants had to move to a new area.

**Clive**  "The victim didn’t want me to return to the area in case we crossed paths."

**Gary**  "I’m not allowed in certain areas."

Being moved to a new location may well make the transition to the community more difficult because the individual will not have any roots in that area.

### 8.3.2 Support vs. Isolation

The second sub-theme linked to being out notes the support that participants said they received in the community. This assistance came from several sources: the care team and other professional support, from friends and relatives and from others with mental health problems. I have called this sub-theme support vs. isolation because these two words best captured the feeling all participants expressed. While there was some support, individuals experienced a sense of isolation, from others and within the community.

### 8.3.3 a) – Family

**Importance of family relationships**
One theme that came across as important for many of the participants was the importance of family relationships. Family members are playing an active role in supporting the participants in their lives in the community. They are doing this in a number of practical and emotional ways which are described below.

**Structuring time**
Social and recreational activities carried out with family members provided much of the structure to individuals’ weeks:

**Clive**  “*My wife’s life has been a framework for me to fit into.*”
Tony  “I play chess with my Uncle Brian once a week.”

John  “My sister comes across and we go out for a meal and a drink three times a week.”

**Practical support**
Family members provide regular practical support to help individuals cope with community living:

Gary  “Every two weeks my Mum and Dad will come and pick me up and take me to Tesco’s. I will withdraw my money, I’ll spend sixty quid on two weeks’ worth of shopping.”

Gary  “My dad does banking with the job he does at the pub so I tend to give him my slips and my cash and he just goes to the bank and gets them all put through their system so it’s easy, it’s not too bad.”

Keith  “My wife has been such a rock she had the flat ready for me to move into, she goes to work, she provides food on the table.”

In one person’s case they provided accommodation:

John  “I am going to live in my brother’s cottage in the country.”

**Impact of offence**
Gary described his father’s immediate response to hearing that the offence had taken place:

“I phoned them and said I’d been nicked and was in prison and asked them to sort my flat out. He (Gary’s father) just went to my flat, got a suitcase worth of clothes, posted my keys back through the letterbox, phoned up the council and said he is not coming back to his flat sort it out and just left.”

The immediate angry response of his father is clear. As a result of his actions many of Gary’s belongings were lost to him. There are complex issues related to both shame of the offence and the impact that has on relationships as well as blame of family members. The SURs and the patients and teams who responded to the initial outcomes identified these issues. Interestingly, staff groups identified shame as a lead response, while patients talked about blame of family members, which impacted, on relationships. When the offence is committed on a family member these feelings can be magnified. In John’s case the families’ blame was directed at the authorities not John himself; his offence had been carried out in the context of
a long-standing mental illness. The view that the offence might have been prevented if the appropriate help had been made available sooner shifts the blame from the individual family member to the health services:

John  “My brother doesn’t hold the offence against me. He feels that the people at fault were the authorities for not looking after me. If anything if he believes anybody is at fault, he believes it was the authorities, because they knew my situation and they didn’t do anything. He blamed the authorities for not looking after me.”

The impact of the offence on relationships with the family can be complex and distressing. With one of the participants most contact with the family had been severed, Clive said “I’ve got two children in their 30s and seven grandkids. I’m not in touch with them now.”

The importance of family relationships in supporting recovery, and the impact of the offence, will be considered in relation to the literature in the discussion. Restorative justice approaches normally utilised to support victims of crime, and perpetrators, will be considered for their use in addressing some of the complex issues that arise in families in the aftermath of a violent crime.

8.3.4 b) – Friends

Relationships with friends

Out of the five participants, three had been able to maintain some contact with friends from before their admission.

John  “I have a girl who’s a friend so she’s a girl who’s a friend who I’m very close to and she’s got a very nice young daughter who I am very friendly with... She started college this week. I’m in good relationships with them.”

Gary  “By the time I left hospital I got a phone call from a friend, he was very keen on mountain biking, he bought a mountain bike for me, he got it on the cheap, he’s got the same bike himself so he can fix mine pretty cheaply so I am going to pay him over a month in three instalments I’m going out tomorrow for about a 10 mile mountain bike ride.”

With friendships, individuals describe different relationships. In these relationships they can find themselves taking on a supporting role. This contrasts with family relationships where they are on the receiving end of support from the family members:
Tony  “I’ve got a nice girlfriend. Every day, most days. She’s actually, they’re going to, they are going to evict her soon out of her place, I don’t know where she’s going to go, she obviously can’t reside at mine, if needs be I will give some money to go towards a deposit on a flat for her. That’s my plan. I can’t see her go homeless she’s just too lovely for that.”

The participants seemed to be supporting individuals with stressful life events. During the course of our study the SURs managed similarly challenging situations with friends. During one research session one friend phoned and said he was feeling suicidal. For the remainder of the session the SUR was supporting the individual and also linking them into professional support. Eventually they were readmitted. The participants were describing relationships with other people with mental health problems.

8.3.5  c) – Others with mental health problems

Relationships with people with mental health problems

Often people with mental health problems feel more comfortable with others with similar experiences. Tony explained:

Tony  “I feel a lot more at home with my people, people um who have mental health...that’s why I go to church services because I meet mental health service users there and a lot of my friends now they just don’t understand me anymore.”

This preference can be reinforced by feedback from others. Tony reported the following:

Tony  “I got told recently by a friend of mine that people are frightened of me. I can’t work out why, if they are it certainly wasn’t my intention to frighten anyone I mean that’s the last thing I ever do.”

None of the relationships described by the participants were formed in hospital. This is in contrast to both SURs who have close, supportive relationships that were developed during their admission and have been sustained while in the community. They have benefited, and continue to do so, from the continued relationships with people with whom they have a shared experience. They had anticipated this would be the same with the participants.

8.3.6  d) – Community forensic mental health team

Support from the community forensic team

The participants generally valued the professional support they received from the community forensic team.
They are not looking to catch me out
Participants described good relationships with the care team. They saw the care team as on their side, able to help them out.

Clive  "They are so good that I could talk to them about anything. They are not looking to catch me out."

John  "The CPN and people have been looking after me and they've not looked for problems, they've been 'have you got a problem, can we knock it on the head?' They've solved problems, not looked for problems, if you see what I mean. They've been a big help, you know, whenever I get a bit stressed I can talk to them and they put it in order and take one thing at a time and deal with it, they've been very helpful."

They are like a friend or family
The participants have developed close supportive relationships with their community care teams. While maintaining the awareness of the professional nature of the relationships they described close bonds with the community staff.

John  "If you describe what you see as a friend they are defined as a friend, someone who can be helpful at all times, they come under the heading of a friend really. I mean they are CPNs and professional people but they are doing what a friend might do in their place."

Clive  "They listen to me and worry in this world like parents or brother and sisters, official ones."

Keith  "It's been very helpful to have friendly people who are in a professional capacity visiting me on a regular basis."

They seem to regard the staff as supporting them. The staff seem to play an important role as a support and as a sounding board.

They are stern and won't have any nonsense
The care team was seen as taking an active role in closely monitoring what they did and the choices they made to ensure they remained safe and well. Clive put it like this: "They are strict and stern you know won't have any nonsense."
At times this meant pointing out the longer-term implications of choices made. Gary’s friend made him a tempting offer of work for around £100 a day over two years. However he would have to commute to London and work night shifts for the two-year period.

He described the reaction of the care team; “My senior social worker, was worried, ‘If you are working nights what about your sleep?’ Sleep is very important, you know, and she was right.” His CPN was more forthright: “My CPN was like well if you are working all night sleeping all day you’re not going to engage with the team you’ll lose your flat.”

In this example, where Gary is tempted by the attractive offer of work, the team give him a clear message about the possible consequences of his choices to encourage him to reconsider.

All the participants regarded the close and ongoing relationship with the care team as being helpful and supportive. They recognised the role the close monitoring of the care team takes to assist in maintain their status of living in the community and preventing readmission.

**Section 41**
The community team intervention is mandated by the Mental Health Act Section 41, to which most participants were subject. Most thought it had been helpful. Keith noted that his community order had stated that he needed drug testing. This had helped him maintain his drug free status, stating “I think the 41 has been a good thing you know a little bit of drug testing to keep definitely to keep me well.”

There was some misunderstanding about the restrictions of the Section 41. Tony said he found the section 41 a hindrance; “One of the main reasons is I’d like to go abroad for a couple of weeks and just wander around Europe hitchhiking and that you know.” It is possible to leave the country on this section but the individual experienced an ongoing feeling of restriction because of its presence.

**8.3.7 Difference to mainstream**
Both Tony and Clive noted differences between themselves and people with mainstream mental health problems. Tony described a discussion with other mental health service users, which took place at a day service:
Tony  “They were saying that Section 3 was the worst civil section that you could be on so I said that I thought Section 37/41 was the worst you could be on she said that was a forensic section.”

Within a stigmatised group of people, those with mental illness, people with a forensic history can be a stigmatised sub-group. Clive was discharged to a residential unit where he encountered people who had been referred from acute mental health settings:

Clive  “They plonk you in the deep end back into a world where people have still got all them problems and you’ve already dealt with it and you don’t want to deal with it again.”

Clive  “They said oh, I’ve had a hard time I’ve been in hospital for 9 weeks I said look I’ve been in f***ing hospital for years and years mate, you know don’t tell me you’ve had a hard time.”

He described the comparison of the work he had to do during his admission and the people at an earlier stage of their illness. Again, he was unable to relate to them and felt isolated:

Clive  “They haven’t had the background of serious mental illness and to go through the process of getting it cleaned.”

Impact of long duration of admission
The long duration of the admission make people lose touch with friends. When they do meet up again they experience different reactions. As Tony notes, sometimes people have nothing in common:

Tony  “A lot of my friends now they just don’t understand me anymore, they knew me 20 years ago well when I got out I’d been completely renovated for want of a better way of putting it.”

This is common with the march of time and different individuals’ life experiences. Gary’s old friend seems to be more accepting of him. Gary described being conscious of his friend’s new responsibilities:

Gary  “A lad... that I used to know when I was younger, we kind of lost contact for a long time and I saw him in town about a year ago. He said ‘how are you getting on’ I said ‘Well I’ve had Schizophrenia for 10 years’ and he was just like oh yes shit. He’s a good guy, I go out with him sometimes. He said if you ever need anything just come round just ask. He’s a good guy, I try not to bother him too much he’s got a wife and two kids, you know what I mean.”
Gary also talked about this reluctance to contact another friend:

Gary  
“I haven’t heard from Steve in a while, I’d like to hear from Steve. I kind of, I don’t know if I phoned him, I talked to him, but I kind of want him to phone me to be honest, it’s been a long time.”

Clive talked about the loneliness he has experienced and how he is trying to develop friendships:

Clive  
“My social group is zero and friends and family is zero except for a brief call now and then.”

Clive  
“I joined a social group which I found in a newsagents window which was like an old chap with a nice home who was lonely himself and he just got people in a group setting to just chat about anything.”

This is interesting in that it shows that loneliness is not just the province of the mentally ill in the community. Other groups can experience social exclusion and will try and act to address this.

8.3.8  Lifestyle
All participants were aware of the need to structure their time and made a link between filling their time and staying well and also reducing the risk of taking part in behaviours that would be risky for them. Now they were settled, mentally stable and living in the community.

Time to kill
Tony  
“I have a lot of time to kill… I want to get busy again… I want to get my hand in and start doing things, if not I’ll only stay in bed to ridiculous hours you know.”

In Gary’s case the support workers where he lived emphasised the importance of getting out and filling his time.

Gary  
“The worse thing is getting isolated and staying in my flat. If I stay in my flat one of my support workers, says to me ‘If you are in doubt just go out and get in the mix.’ And she is right.”
The benefits of doing something

The participants were able to articulate the importance of being active and doing something to their wellbeing.

Keith  “Time speeds faster when we are doing something… So if you’re just sat there and you’re saying I’m bored and someone’s stood there saying well why don’t you do anything and you say well no I don’t want to do anything I’m bored they say yeh but the reason you’re bored is that you are not doing anything but if you tried doing something you wouldn’t be bored. Yeh, but I can’t be bothered I’m bored. That’s essentially for me what it’s like when you become unmotivated. You become bored, you’re motionless, you’re not applying any momentum to your mind, which is essentially the driving seat to your whole life. That’s where I’m coming from. So I keep on motivating myself.”

Gary  “I find that the weller I am the more I do. That’s kind of how it works.”

Keith describes the importance of activity for him in order to maintain a sense of momentum, whereas Gary has made a connection between feeling well and doing more.

I’m not sure which avenue to go

Although the importance of spending time constructively was acknowledged, participants were less sure about how to fill their days.

Tony  “Well I want to get busy again… I’m thinking of going back to college to try to brush up on my computer skills.”

John  “I’ve a challenge to do my own thing, a day at a time.”

As mentioned above, family members supported four out of the five participants by taking them out and helping them to structure their time by offering leisure or work activities. The participant without active family support did not have as much structure to the week and seemed to have less idea about what to do.

Clive  “I’m not sure which avenue to go. The only thing is there is an adult education centre. But I’ve tried languages, I’m not intelligent enough I’ve got big DVD and CD courses, French and Italian. I can’t pick it all up. You know I try… All I am saying is that I’ve survived the stepping-stones into now. But what’s hitting me now, at 53 is where I go. …What can I do to occupy myself now? Do I go to adult education to keep busy, I’ve picked up the guitar; I’ve got my computer chess set to pass time. I do a little bit of reading; I try and keep myself occupied. I have a love of music so I keep busy but it’s not engaging. I need to do more but I’m not sure which avenue to go.”
Although Clive wants to do something he is not sure what he wants to do or has the opportunity to do, instead he seems to be randomly picking and trying different activities. He does not seem to be getting any active assistance to link him in with any resources that will help him.

Clive  “I mean my team are saying don’t worry about it. The main thing that we’ve all done is you’ve got reasonably well and stable.”

His team does not give the same priority to having something meaningful to do with his time as he does.

**Occupations carried over from hospital**

There were only two mentions of activities started in the hospital that were continued into the community:

Gary  “One thing they did sort out once I left hospital as part of my care package was a membership at the leisure centre.”

For Gary, exercise structured much of his routine, both at home, with friends and also in developing relationships beyond the hospital. He used the gym regularly and was beginning to make connections with people that he has met there.

Gary  “Exercise puts me in a really good mental state, when I go to boxercise, and the endorphins get released and I and I really buzz off of it….I work out in my flat quite a lot. I’ve got weights, I’ve got a punch bag, I do press ups, I do sit ups I do squats… It’s little things like for example I was boxercise a couple of weeks ago, one of the ladies that comes along comes along with another girl, I mentioned that I play badminton and she said well we play badminton after boxercise, she said there is only three of us would you like to join us to make the numbers up so I said to her that I would bring my badminton racket next week.”

Clive has a different activity, bus trips which give him the opportunity to get out and about.

Clive  “I’ve got a free bus pass through mental health so I whiz along the strip of the country seeing things.”
It is not clear why there are not more activities started in hospital that are carried out in the community. Maybe it is opportunity. In the quote below Tony expresses his continuing connection with work he has carried out in hospital.

Tony “Sometimes I get my writing out and I get all excited about it and I don’t know why it is my poetry and my short stories and my pictures and I look through it look through my bits all the work I’ve done in hospital.”

Earlier in this chapter Keith listed a number of practical activities he carried out in hospital and although he has not continued with those specific activities he has continued with a practical frame of mind. “I had to buy a strap for my watch and I phoned the jewellers and said how much is it to put a strap in and they said a fiver… then I got to thinking how much would the tool cost to do it. So I looked on the computer and I got one from eBay for £2.99 so I fitted my strap myself. It only cost three quid and I’ve got a tool to show for it… so I wonder if I can buy a watch repair kit so I’m looking through eBay.”

**Self-generated structuring time**

Two of the participants described beginning to develop activities independently and becoming self-reliant. Keith continued to discuss his watch repair kit.

Keith “Right, so I’ve cottoned onto an idea, I wonder if I can do watch repairs as a hobby so I’ve looked on You Tube and sure enough there’s a lot of videos of people demonstrating how to take certain watch movements apart and putting them back together again, lubricating them, cleaning them, all this. So I put an advert in the local paper saying that I wanted any broken mechanical watches you don’t want because I want to start a new hobby. So I’ve put that there and it’s an embryo at the moment. I’ve not developed it but it’s something that I could do at home, on the dining room table, it’s not going to take a lot of space, it’s not going to take a lot of money. So I’m in the thinking process.”

John also talked about becoming self-reliant and doing the job himself.

John “One of the windows (in my cottage) is closing but I’ve worked out that I need a plane, screwdriver and chisels to fix it so I pushed it back in. Do the job, you see. I could have gone off to my brother and gone ‘can you fix it?’ but that’s the easy way. I can get tools and do it myself.”

**Impact of mental illness**

The participants described the impact of their on-going mental health problems.
Clive  “Sometimes I barely get up I am so knackered and fatigued and worn out from the medication or whatever. Some days I’m up early at the crack and some days I’m sleeping through to midday, some days I can’t be arsed with it, I get a bit down in the dumps with everything. I can do something menial like this interview, I can do an hour. About an hour is enough a little bit longer than an hour… because I’ve been in seeing the psychiatrist for an hour, have the social worker for an hour, everything’s roughly an hour. If it goes on too long I get a little bit tired.”

Tony mentioned that he was sometimes unable to meet the demands of a mental health centre.

Tony  “I am a member of the mental health resource centre. I tend not to attend mainly because of getting up too early and that sessions at the moment go on for a long time.”

Support to establish a routine

Some of the participants did not describe much assistance to help them establish a routine community.

Clive  “My team and I are just working at it at the moment. The usual thing for people in my situation is to go and volunteer in a charity shop. But I can’t see myself in that role.”

Gary is living in a supported flat, which provides more active engagement from the staff. Now he has begun to fill his time independently, and is in less need of all the support offered.

Gary  “The company that manages the flats, they provide me with 11.5 hours of support a week which over three days, but I said on Monday that there’ just too much to do, I’m working in the morning, then I see my parents at lunchtime them I’ve got boxercise in the evening I’ve got a lot on and can afford to lose a couple of hours so they are talking about that now.”

Tony described the resources that the local centre provides to assist him in his creative interests:

Tony  “I’ve got some really nice art work. When I get the opportunity to when I go somewhere like the (local mental health recourse centre) or something and they start doing art work I start to do some of my etches I call them badges they are about that big and they take ½ hour 45 minutes to do just one they are nice you know.”
Tony  “I’ve been dropping by (name) recently it’s a drop in centre.”

**Moving forward**
Gary was the most positive about the direction he was heading and the clearest about what he was hoping to achieve.

Gary  “Continuing to lose weight and achieve improved mental and physical well-being and just make a few more friends and have a few more social activities to be getting on with really.”

The responses above build a picture of the participants working to try and build some meaningful structure and routine into their lives. They recognise the benefits of developing a meaningful and varied routine but they describe a range of barriers and support to access these.

**8.3.9 Work**
Three out of the five participants expressed a desire to gain some paid employment. The two others were not looking for work, because they regarded themselves as retired.

**Desire for work**
There was a desire expressed to obtain employment. However, none of the participants identified what type of employment they would like. The goal seemed to be to have a job in whichever form that would take.

Gary  “Employment would be a nice start.”

Andrew  “I don’t really care what it is.”

Keith was clearer about why he wanted a job but still did not express a preference for the type of work he was looking for.

Keith  “To be self supporting put money and food on the table… It’s the need to provide an income and the desire to have an active life.”

John said he was thinking about retiring.

John  “I am a chartered surveyor and I’ve got to get so many hours’ experience, you do so many lecturers, you have to get 20 hours’ experience and I’m falling short on experience, I could be going to get experience. But I’m 58 now so I
suppose I could retire. I haven’t completely decided yet but maybe I’ll retire, I’m a professional. I’m professionally qualified as a chartered surveyor. I have to make a decision sometime soon.”

**Trying to get work**

Although three of the participants have been trying to get work, only one participant mentioned any of the support services in the community to assist people with mental health problems in gaining employment.

Tony “I went to the recruitment agency and it was closed.”

Keith and Gary described a more active approach to trying to obtain employment.

Keith “I’ve put 33 applications in and I’ve never got even an interview from it.”

Gary “With the cleaning jobs I have been going for, I have probably been going for about half a dozen in the last six months. There is a job that comes up probably once every three, four weeks that I’m able to go for.”

Gary started work between the first and second interview.

Gary “I have got work now. It is only two hours a day, Monday to Friday, ten hours a week.” He noted that this suited him for now but “I’d like to go back to work full time but the only option I’ve got is to go back part time. It’s just not financially possible.”

**Making use of forensic history**

Having been in hospital for a period of time it can be difficult to find employment. However, one avenue open to them is the opportunity to work in a peer role. Keith described when he found out he was able to work as a peer worker.

Keith “Trying to do work as an ex service user really bore fruit when I realised that there was an avenue for me that isn’t necessarily open to everybody in the community.”

He identified work he was carrying out in supporting training and working as a peer in the Royal College of Psychiatrists Quality Network.

Keith “I am working at the hospital where I was a patient previously and I’m doing a recovery focused piece of work talking about my experience of hospital and then my experience getting out of hospital, trying to give people some hope
and encouragement and also informing people about what to expect when they go to medium secure because for many people this is the first time they have been in this situation and they don’t know what to expect and it can become very frightening to put it simply, so, hopefully, through me being able to talk at length about what it’s like to go through hospital and to get out the other side. It’s just a way of giving something back, and it centres on my experiences, it helps me turn my experiences into something positive. Rather than it being a ball and chain it’s now a medium through which I am able to do some work, get a little bit of income, fill my time positively, and who knows what’s going to come as a result of that further down the line.”

He was starting to get more work, making use of his experiences in secure settings. It also gave him an opportunity to give something back, contribute his experiences for the benefits of other patients still in hospital.

8.3.10 Disclosure
Of the three people who were aiming to get employment all discussed disclosure as a barrier to getting employment. Disclosure of the mental illness was not described as an issue. The main concern of the participants was disclosure of the offence they had committed.

Gary “I’m not too bothered about disclosing about mental health. It was a bit more difficult about the ABH and assault.”

None of the participants seemed to have had the opportunity to discuss and think about disclosure. In Tony’s case he was not initially aware of the need to disclose.

Tony “Well I mean from what I heard the other day that I’m obliged to give any potential employer some details as to my forensic history I suppose you want to call it You know I’ve been involved in drugs violence you know and I don’t think people want to hear about that in my opinion….They might be interested in it but I don’t see how that’s going to help me getting a prospective job. Sort of let them know that I’ve got I’ve got half a dozen previous convictions for violence on my record you know.”

Tony is not understanding the need to disclose or the relevance of disclosing to an employer. He has not had the opportunity to discuss and consider disclosure and so it has come as a surprise to him.

There seems to have been little general information given to the participants about disclosure. The participants were told to disclose nothing until they had met potential employers. This advice was not, however initially taken.
Gary  “My CPN and social worker always say to me say nothing but I don’t want to waste anyone’s time from the very beginning so I say something not theft, in a shop obviously, a bit worried about that. So they don’t call me back so I get that quite a lot, it’s a bit of a burden.”

Keith  “My rationale was if I told everybody all the down and dirty from the off, if then I get an interview I’d know that they’d accepted all of that and they thought they’d give me a chance So I tried that for six months and I got nowhere.”

It is at this point that individuals have come to realise the potential barrier that their forensic history may pose.

Keith  “My forensic history is an issue and I do carry that around with me as baggage day-to-day. It kind of explains the reason that I am so keen to work as an ex service user because in that capacity my baggage is accepted and it actually, what’s the word, it’s relevant.”

Gary  “It is quite an obstacle to overcome you don’t realise until you’re sort of in that position.”

All have learned to be open about themselves and have identified openness as the best strategy for progress through and out of hospital. It seems like the skills and attitude that individuals needed to develop to be discharged do not support them when they are living in the community. They have not learned, or been taught, how to judge each situation and to respond to each encounter on its own merit. This has led participants to situations where they are potentially vulnerable.

Keith describes an encounter where very quickly he disclosed everything about himself to a stranger, which reduced his chance of being offered employment and made him potentially vulnerable.

Keith  “It’s a learning process, I mean I saw a mechanic out in the community, I was walking home one day, I said, oh do you need any help, and he said, why’s that and I said because I need a job he said, what can you do and we got talking and within 5 minutes I’d declared all my forensic history to him and then it fizzled out and I got nowhere and I walked away thinking ouch, I didn’t need to tell.”

Tony expresses similar concerns about people that he has shared personal information with.
Tony “I get the impression that certain people would, if they had the opportunity, use the information that I’d given them to put a spanner in the works so to speak.”

Disclosure does not just relate to trying to achieve employment. Clive describes concerns about disclosing information socially.

Clive “I keep to myself a little bit. You don’t want to be open, disclose to everyone, which I did in the beginning. In the beginning I used to be open and true to people and they didn’t want to know. So I’m at a little bit of a loss at the moment.”

Disclosure is a complex issue that individuals need to consider and make decisions about for themselves. There are specific situations, for example employment, where there is a formal expectation that disclosure takes place. However these participants are describing a number of situations where they need to consider what they say to people that they come across in daily life. Their previous experience in hospital is that they need to be open with staff in order to move towards discharge as discussed earlier in the chapter. They seem to be taking this experience to the community with them and being open in situations that could leave them feeling vulnerable.

8.3.11 Avoiding threats
We called the final sub-theme of staying out avoiding threats. These can be threats related to a relapse of the mental illness or related to the offence.

Plonked in the deep end
Clive described being housed following discharge, initially in short-term accommodation, with people at a more acute stage of their illness.

Clive “You go through all that process and right at the end when they have got you well they plonk you in the deep end back into a world where people have still got all them problems and you’ve already dealt with it and you don’t want to deal with it again. You don’t want people fighting in front of you, being drunk, fooling around, it will lead to another breakdown.”

Surrounded by people who were more unsettled he stopped taking his medication became ill and was put on a depot. “You’re getting unwell, we are going to give you a depot.” His care team supported him until he was eligible for council accommodation in his own flat.
Clive “The hospital team, the CPN, the social worker were with me all the way through.”

He then described his reaction to moving into his own flat.

Clive “I moved in had a breakdown, floods of tears because I couldn’t believe the journey I’d been on. I just stood in his empty flat that I knew had been signed over to me. I knew it was my first home for a long, long time.”

This moving account gives a sense of the journey the service users go on and the meaning and value Clive placed on finally having his own front door.

With my history
Tony described being concerned that if he was involved with a fight he would be blamed because of his history.

Tony “I am really dubious about going out at night because if anything does happen with my history it will be me that gets the brunt of it.”

He described a time when this happened to him previously.

Tony “Me and my brother were walking down the road we got attacked by cocaine addicts… they started it you know and even though the police had it on CCTV we got arrested. I was held until Christmas day and they collected me and took me back to hospital which was a shame because as I say that would have been my first Christmas at home for 15 years.”

He has experienced being recalled to hospital and now wants to stay in the community. However he describes feeling vulnerable. He is concerned that he will be blamed if he is involved with an incident because of his history. Tony was one of the participants who moved back to his home area. As result he is concerned about meeting his victims:

Tony “I have a lot of enemies basically… because I’ve robbed so many people and that.”

8.4 Summary
The two themes of getting out and staying out capture the experience of the participants and the journey that they have taken. The participants’ responses provide a window into their
perspectives, of the move through hospital and out to the community. These will be discussed in more detail in the next chapter.
Chapter 9. Discussion

In this chapter I will begin by briefly summarising the main issues highlighted in the literature review. This is to remind the reader about the areas I wanted to explore and knowledge gaps I hoped to address in our study. The methodology used has shaped the way I have structured the discussion so I explain this before going on to explore the significance of the findings in more depth.

Our study set out to explore the experience of service users discharged from a secure in-patient setting, in order to find out more about their recovery. The literature review showed that while a role for recovery based practice within a secure environment has been identified, (Barker, 2012; Drennan & Alred, 2012; Mezey et al., 2010; RCP, 2007) the nature of recovery for mental health service users with an offence history has not been fully explored. This was therefore one of the issues our study aimed to address.

The literature review identified other, related, gaps in the literature. The first gaps were associated with occupation, and the relationship, both positive and negative, between occupations and mental health recovery (Twinley & Addiddle, 2012; Twinley, 2013). It was also suggested that concepts of occupational justice (Townsend & Wilcock, 2004) might be useful in understanding some of the issues that affect participation in occupations.

Some research had been carried out with people who had been discharged from secure settings. However mostly these studies had looked at clinical or offence outcomes and had not explored patient perspectives of discharge (Coid et al., 2007). What was known was that discharge was anxiety provoking but the reasons why were not explored fully (CMH, 2011). However participants had experienced being excluded from work, educational and social opportunities (Boardman, 2011). Our study aimed to continue to build an understanding of life in the community for this group.

Throughout our study the priority of the SURs was to use the learning from our study to improve services for other service users. They were not concerned with the theoretical learning from our study, they wanted to know how the information gained could be applied to help service users and change the way services were delivered. To reflect their priorities throughout this chapter the clinical implications of the findings and possible recommendations are considered alongside the theoretical learning. The close relationship between our study findings and practical implications is a characteristic of participatory
research (Heron & Reason, 1997). It ensures our study is grounded in the aim of improving practice as well as contributing to what is known about recovery for people with mental illness and an offending history.

At the end of this chapter the limitations of our study will be considered, as well as recommendations for future research. I also revisit the decision made in Chapter 6 not to ask the participants details of the offence in the interviews. The methodology, including the impact of using a participatory approach, will be discussed in more detail in Chapter 10.

9.1 The Getting Out and Staying Out Recovery Challenges

As the research team organised the findings under the getting out and staying out headings we began to realise that these headings were not just a useful way of sharing the findings but that they also highlighted some of the issues that service users leaving forensic in-patient services encountered when they returned to the community. The findings from our study were identifying distinct, specific recovery challenges encountered by the participants. We called these the Getting Out and Staying Out (GOSO) Challenges. I will explore these in detail first and discuss how they develop and extend the theoretical understanding of the recovery of service users discharged from a secure setting later in the chapter.

The findings from our study challenge the current understanding of mental health recovery in this client group. They indicate that there are significant additional challenges, which are related to the history of offending and the impact of having been resident in a secure setting. The recovery journey for people discharged from a secure setting has similar characteristics to those with mainstream mental health problems however each element is more complex and multifaceted. These additional complexities can be experienced in a number of ways. There can be further tasks to complete, additional disclosures to make or accommodation of other issues. We named these additional challenges, the GOSO challenges because getting out and staying out were the main goals and concerns of the participants. The responses of the participants indicated that when they were in hospital their decisions were informed by what could help them get out of hospital. Now they were living in the community their everyday decisions were informed by what would help them stay out of hospital. The SURs were pleased with the use of this terminology they said that it captured what the aims of the service should be. For me, as a doctoral researcher, it captured the complex nature of recovery for this client group.
The GOSO challenges are defined as the additional challenges that a forensic service user may need to address as part of their mental health recovery. This can be due to their history of offending or another aspect of the secure pathway such as the hospital length of stay. The research team organised the GOSO challenges into four groups. These are; good relationships, occupation, social inclusion and offence issues. The groups are listed in Table 8. The first three aspects of GOSO: good relationships, occupation and social inclusion have been identified as aspects of mental health recovery in previous recovery research (Lapsey, Nikora & Black, 2002; Onken, 2006); although our research identified additional features that were specific to this client group. The offence aspect of the GOSO challenges is novel.

I will now discuss each GOSO challenge more fully to demonstrate our contribution to knowledge. I will explore them in relation to the literature. I will also consider the implications of each GOSO challenge and how they add to our theoretical understanding of mental health recovery in people with an offending history. Finally I will discuss the clinical implications and recommendations for service delivery.

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9.2 Good Relationships

The importance of supportive relationships has been identified time and again in recovery research (Brown & Kandirikiria, 2007; Onken et al., 2002; Slade et al., 2012). It was also the case in this study. What was new, however, was the finding that the nature of the relationships differed in important ways. The key relationships described by the participants were with staff, family and friends. These will be discussed in detail.

9.2.1 Staff

The responses of the participants noted that their recovery journey began with the warmth and acceptance of the staff. The findings in our study confirm what other studies have noted, that the attitude and approach of staff plays a vital role in supporting recovery (Brown &
Kandirikirira, 2007; Onken et al., 2002). Staff who present as supportive and understanding, are important in mental health recovery (Shepherd, Boardman & Slade, 2008), particularly where there is a consistent approach taken over time (Onken, 2006; Slade, 2009). Staff belief and support for the individual, even if they do not believe in themselves, has allowed individuals to feel hope and given them the courage to take the first step in their recovery journey. This was certainly the case with some of the participants and has been described in other narrative accounts of recovery (Deegan, 2005). Moreover, the approach and attitude of the staff has also been identified as making a key contribution to an individual’s recovery process. Staff who listen to service users with a view of supportive inquiry allow individuals to explore and understand the complex and painful issues they are facing (Lysaker & Yanos, 2009). Service user and staff encounters are characterised in the literature as being supportive and consistent (Onken, 2006) and incorporating a level of collaboration between staff and service user as well as an emotional connection (Moore et al., 2002). This was noted in the participant responses. They also valued the more informally social and practical aspects of the relationships, for example cooking with staff. They spend long periods of time living alongside staff and so for them these day-to-day informal encounters, beyond formal treatment sessions may play a more important role for them.

Repper and Perkins (2003) suggested that in most staff training it is technical competence which is prioritised. However, as they note, these technical skills are most effectively utilised within the context of a supporting, hope-inspiring therapeutic relationship. Based on this knowledge, established learning health organisations are beginning to incorporate personal qualities into the expectations of all roles in the health service who are likely to encounter people with mental health problems (LHP, 2013). Helpful guidance has been published by organisations such as The Centre for Mental Health and Star Wards on such service user and staff encounters (CMH, 2003; Star Wards, 2009).

Although supportive relationships in recovery are important, there are two key differences for relationships in this study. Firstly, in secure services the clinical staff form long-term therapeutic alliances with their service users rather than in acute services where contact with the MDT may be fragmented due to the short in-patient admission times (Kaliski & de Clerq, 2012). Secondly, the participants in this study emphasised the importance of staff acceptance of, not only of their mental health difficulties, but also of their offences. For the participants, it was important to feel that the staff could see the person behind the violent act; this significantly contributed to beginning the process of coming to terms with the reality of the offence. Other literature has further noted the importance of a non-judgmental attitude in relation to the offence (Ferrito, Vetere, Adshead & Moore, 2012). A non-judgmental attitude
was a feature of staff working in secure settings, but it was not necessarily apparent among the staff that worked in the accommodation into which people moved. One of the participants moved to accommodation where staff did not have this additional training and understanding. As a result he described being stigmatised and discriminated against by some of the staff because of his criminal history. This incident shows the importance of forensic services sharing their expertise and perspectives with the clinical teams that they pass the service users on to. As Mezey et al., (2010) have found in forensic settings, intolerant, unkind and insensitive statements from staff can have a powerful negative effect on a service user’s recovery. It is therefore important that staff working in resettlement services have the attitudes towards service users that will help in the recovery process. Forensic services have a responsibility for ensuring that this is the case. This acceptance of the individual, irrespective of the offence they have committed, is not always easy and staff need regular supervision, support and training from staff working in forensic settings in order to help them manage their responses to what can be distressing offences (Davies, 2015; Moore et al., 2012).

The understanding of the importance of relationships to supporting recovery has resulted in the development and publication of measures such as The Recovery-Promoting Relationships Scale (RPRS) (Johnson, 2010) and guidance including The Centre for Mental Health 10 top tips for recovery orientated practice (Shepherd et al., 2008) with a view to develop more recovery orientated interactions. The recovery orientation of both the scale and 10 top tips supports a focus on hope inspiring relationships that acknowledge the service user as a partner. These two documents are written for people with mental health problems, and they do not include the acceptance of the individual in spite of the offence they have carried out. This is not surprising because they are not intended for this particular audience. However the importance of acknowledging the offence and accepting people despite the offence is also not noted in the guidance for staff wishing to achieve constructive alliances in forensic settings (Drennan & Wooldridge, 2014). In the document “Making recovery a reality in forensic settings” (Drennan & Wooldridge, 2014) there is a list of do’s and don’ts for staff wishing to achieve constructive alliances in forensic settings. In these prompts the offence is not mentioned directly. However, close scrutiny of the tips indicates that they are alluded to and appropriate for use by offenders. For example “remain sensitive to the need for confidentiality” (p. 11) suggests that confidentiality may refer to the offence as well as mental health difficulties; “don’t have a closed mind” (p. 11) may suggest the importance of accepting the individual despite their offence. However in our study the participants were more specific about the need for staff acceptance of them as individuals while fully aware of
the offence they had committed. This created an environment where they could begin to learn to accept themselves again.

This understanding of the importance of staff acceptance of the offence is new knowledge emerging from this study. The participants in our study emphasised the importance of staff understanding what they had done and yet still accepting and feeling hope for them. This supported the development of their belief in them, as individuals worthy of respect. It seems that positive, supportive relationships for service users are built on acknowledging the reality of what has gone before. This indicates that building relationships based on holding hope and a positive future can sometimes mean that problems are ignored or minimised. The fact that the service user may well have committed acts that they regret is not acknowledged, possibly due to the concern that this may harm a hope inspiring relationship. The results from this study suggest the opposite could be true. A positive relationship is built on understanding and acknowledging the difficulties the individuals’ face, the acts they have committed and still accepting them for who they are. From our study I suggest that an additional “do” is added to Drennan and Wooldridge’s list (2014). This is that staff are accepting of the individual in clear knowledge of the offence.

‘Showing myself’ to the staff team
The findings revealed another aspect of the participant’s relationship with staff. In order to progress within the hospital, the service users stressed the importance of engaging in a working alliance with the staff. This was described as complying with the expectations of the staff team or ‘showing myself’ to the staff team. This has been identified in some other studies, which have looked at why individuals participate in therapies (Moore et al., 2012; Morris & Moore, 2012). One of the reasons stated is that participation in groups allows individuals to demonstrate progress (Moore et al., 2012; Morris & Moore, 2012). The importance of this was realised by one of the participants when he noted that another service user, who had not engaged with the staff in the same way as him, was still in hospital when he was discharged. The duration of the in-patient stay for the group in this study remains months or even years (JCPMH, 2012). The length of stay is longer for this client group because for service users on some Mental Health Act Sections (DoH, 1983), the Ministry of Justice needs to be satisfied that not only is the individual mentally stable but they no longer pose a risk to themselves or the public (Barker, 2012). The participants have to demonstrate though their behaviour and engaging with the staff team over a sustained period, that they are eligible for discharge.
This engagement with staff also continued into the community. It took on a more central role for participants because of the monitoring role of the community team. The participants described regular, initially weekly meetings with the community staff. They were aware that the role of these meetings was to demonstrate their continued reduced risk and therefore eligibility to remain in the community. The clinical or supervision sessions carried out by the CFMHT involved the service user sharing their activities and their plans with the clinical team. The clinical staff then reviewed, and sanctioned or otherwise the plans of the service user. Foucault describes this as a form of pastoral power (Foucault, 1982). As Hekman (2004) noted, pastoral power entails oversight of the whole individual, encompassing every aspect of his/her life (Hekman, 2004). The participants described discussing relationships, looking for work or education and discussing their money their routines; all aspects of their life with their clinical team. As well as reporting back verbally some were also physically tested for illicit drugs. All participants described their relationships with the community teams positively. Staff were used as a sounding board to problem solve and consider options. The participants seemed to view these meetings as a way of proving their continued suitability to stay in the community, which they were. Most of the participants were discharged under Section 41 of the Mental Health Act (DoH, 2007b). The community staff have a responsibility under the Mental Health Act (DoH, 2007b) to monitor and recall the service users to hospital if it is found that they are not complying with their conditions of discharge, or if they are becoming mentally unwell which may increase their risk of reoffending. I will discuss recall in more detail later in this chapter. Being open with staff is therefore crucial for participants to remain in the community. Community staff are seen to be influential in the many aspects of how the participants choose to spend their time, which is also discussed more fully later in the chapter.

The service user-community staff relationship therefore plays a crucial role in the successful release back into the community. It is surprising therefore that there have been no studies, which have explored this relationship more closely. Studies that have looked at community forensic mental health teams to date have focused on the structure and overall function of the teams (Brett et al., 2012; Green, Carroll & Brett, 2010; Mohan, Slade & Fahy, 2004) or risk assessment (Green, Carroll & Brett, 2010). (Chiringa, Robinson & Clancy, 2014) explored some of the work of a community forensic team, asked service users who had been recalled to hospital about their experience. Participants in this study found supervision to be controlling and disruptive which is contrary to the experience reported in our study. This may confirm the importance of the client-service user relationship to support and maintain individuals in the community. If it is perceived as controlling and unhelpful individuals may be unwilling to engage with the relationship in the same way. Or, alternatively, the participants
may view the relationship in a negative light because of the recall outcome. No studies have focused on the encounter between service users and staff and the implications for continued recovery post discharge. The findings from our study suggest that this relationship has a significant impact on all aspects of individual’s decision-making. Further research into this important relationship is recommended in order to identify what aspects of the relationship can support offence recovery.

9.2.2 Family relationships

The participants in our study highlighted the important contribution of family relationships to their recovery and the significant ongoing support provided by families for the vast majority of participants. Families played a regular active role in their day-to-day routine, such as regular shopping trips. This was a surprise to me; when I have suggested to service users that we seek carers’ views or involvement in initiatives, they have always objected to the suggestion, saying they do not want the families involved. This may be because they want to keep their social world and hospital world apart. However, this may also be because they are concerned about the potential further impositions on their families that increased involvement would bring. Tsang et al., (2002) noted that in forensic services family interventions have been largely neglected. This may be because that up until fairly recently guidelines have focused on the carers of community service users, rather than carers of in-patient users or even restricted service users (Canning, O’Reilly, Wressell, Cannon & Walker, 2009) staff attention may therefore have been focused on these populations. However Castro et al., (2002) found that although contact with family contributed to a shorter length of stay, it did not necessarily result in continued success at follow up. This may be because families are unable to sustain the degree of support or involvement necessary over a prolonged period of time. Interestingly, this result is at odds with the findings from this study, which highlight the significant contribution that family involvement has to the routines and quality of life of the respondents. In our study the participants in contact with family benefited from regular ongoing contact. Family members provided intensive practical and emotional support, e.g. taking them shopping, supporting them financially and going out with them several times a week. The families in our study may be providing support that helps service users to re-establish routines and regain confidence in the social and practical aspects of living in the community. This high level of support from family members may not always be possible which may account for Castro’s findings.

The participants in our study all described a history of mental health problems before the offence. Some of them had already been receiving support from their families to help them cope in the community. The offence itself is often the culmination of a period of instability and
increasing mental health problems (Drennan & Wooldridge, 2014). One carer, John’s brother, blamed mental health services for not listening to the family’s concerns that John was becoming unwell. The experience of expressing concerns about the worsening of mental health problems or threatening behaviour to services, including GPs, mental health services and the police, without an appropriate response has been found to be common in their study of carers of people in secure services (SIMS, 2014). John clearly described the response of anger and frustration expressed by his father as a result of his offence and arrest.

The reactions of the family to the offence and the possible period of increased instability and erratic behaviour as a result of the worsening mental illness might help to explain why there are periods of time during the hospital stay when a service user does not want contact with their family (SIMS, 2014). When I have discussed this aspect of the findings with professionals and service users it was fascinating that all the professional responses considered that this withdrawal from family contact was as the result of service users feeling shame for what they had done, whereas all the service users I discussed it with reported a period of time of blaming relatives for the circumstances that had led to their incarceration. There is little in the literature relating to shame or blame on the part of the offenders, although it is an area which is beginning to be studied (Adshead, Ferrito & Bose, 2015; Ferrito et al., 2012). The exploration of this dynamic is not the focus of this study, but formal approaches, are beginning to address these issues in forensic mental health settings such as restorative approaches (Cook, Drennan & Callanan, 2015) and family interventions (Absalom-Hornby, Gooding & Tarrier, 2011).

Long-term admissions, often in places geographically distant from the family, can contribute to the loss of family ties (Macinnes et al., 2013; SIMS, 2014). In our study individual’s in-patient pathways included admission to hospitals that were up to 200 miles away from their home location. In-patient services have been found to assist with maintaining contact through support (Canning et al., 2009) and more recently through the use of technology such as the internet and Skype (Absalom-Hornby et al., 2011). The participants in our study did not have access to this technology but their descriptions of the active role the family took in supporting them to build a life in the community suggests that any technology that helps service users’ to sustain relationships while they are an in-patient will be beneficial on their eventual discharge.

This study highlighted the key role that carers play in supporting service users when they return to the community. In the responses there were examples of family members providing structure and routine to the week, social contact, occasional work opportunities, practical
assistance with daily living tasks, financial support and help with accommodation. These findings concur with other studies, which emphasise the importance of ongoing support of carers in order to maintain their relationships throughout the long duration of the in-patient stay (SIMS, 2014). The importance of building an alliance with carers is increasingly acknowledged in mental health services (McCann, Lubman & Clark, 2011). The “Triangle of Care” was originally published in, 2010 and was updated in 2013 (Worthington, Rooney & Hannan 2013). This emphasised the importance of developing a therapeutic alliance between carers and staff and identified six recommendations to achieve this. It is a piece of work which has been co-developed with carers (Worthington et al., 2013). The triangle of care has been adopted in some forensic services where carers have responded favourably to the initiatives (SIMS, 2014). These recommendations provide practical guidelines that can support carer involvement and continue to support alliances. They seem to address the issues of concern raised by the forensic carers and will contribute to supporting carers to provide the ongoing care necessary to sustain the service user group.

9.2.3 Friends
The participants described relationships with other service users while they were in hospital. These did not necessarily develop into friendships, and none of the participants were in contact with any one they had met in hospital. This is in contrast to one study which found that hospital friendships continued into the community; participants citing their shared experience over time as one of the ways that cemented their friendship (Forrester-Jones et al., 2012). However in the same study one of the participants noted the importance of keeping a distance from others in order to maintain their own mental health. This may well be the approach that the participants in our study have taken.

Friendships have been found to be positively associated with integration into the community. Individuals have been found to experience a stronger sense of self-esteem from peer friendships (So-Young & Yin-Ling, 2015). This may be because providing support to someone else can forge a more positive sense of identity (Forrester-Jones & Barnes, 2009). In addition friendships tend to be built on a reciprocal basis whereas there may be more unilateral relationships with families who are supporting the individual (So-Young & Yin-Ling, 2015). One of the participants was very conscious of not wanting to make too many demands on his friends.

One of the reasons that has been cited for the limited social network of people with mental illness is the limited opportunity to develop friendships when living in restricted social environments and also the effects of stigma (Forrester-Jones et al., 2011). Some of the
participants were taking active steps to increase their social network by going to the gym and joining local groups. Depending on their circumstances they are getting assistance with this and encouragement to attend. One of the participants gave a good example of beginning to develop relationships through regular use of a leisure centre. This was encouraged by his support team and is an example of the links that can be achieved. The studies all note that social networks are limited by, amongst other things, lack of opportunity (Davis & Brekke, 2013; Forrester-Jones & Barnes, 2009; So-Young & Yin-Ling, 2015). This intervention seemed to support one individual begin to make links.

9.2.4 Summary of Good Relationships
The G in the GOSO challenges stands for good relationships. These are supportive relationships with clinical staff, family and friends. Previous research in mental health has identified the central function of good relationships in promoting and maintaining recovery (Boutillier et al., 2011; Brown & Kandirkirira, 2007; Onken, 2006). Our research has identified the unique characteristics of these relationships in this client group. These may be additional barriers to the relationship or necessary characteristics of the relationship required to support recovery.

Participants were able to move beyond their offence if they felt that they were accepted and valued as a person in spite of what they had done. As one of the SURs said they were not regarded as a bad person because they had done a bad thing. The impact of being accepted by staff helped participants begin the journey of accepting themselves. Relationships with the clinical team were also influenced by the stated need of the participants to demonstrate their engagement and compliance. This is directly related to the dual responsibility of forensic services to address mental health and risk behaviours. What this study highlights is the impact this expectation has on the individual’s decision-making and behaviour. I will explore this further later in the chapter.

Our study showed how important family relationships were for providing practical support, social contacts and a routine for those participants who were still in contact with family. It also confirmed previous studies that have noted the impact of the offence on family relationships (Tsang, Pearson & Yuen, 2002). Our research also confirmed previous studies, which have noted the damaging impact a long-term admission, often in a different part of the country, can have on relationships (Canning et al., 2009).

This study highlighted that the participants had limited social networks beyond clinical staff and family. This endorsed previous studies, which have suggested reasons for this. These
include the effects of stigma and a long-term admission (Forrester-Jones et al., 2011) and lack of opportunity (So-Young & Yin-Ling, 2015). Our participants experienced all these. There was, however, one example of a participant being supported to begin to develop a network. This was achieved through regular trips to the community and a leisure centre, which were accompanied by a support worker.

While the GOSO challenges highlight the specific barriers to recovery that the participants are encountering they are also suggesting ways that specialist services can help the individuals address these. Services have a role in providing appropriate training that emphasises acceptance of the offence as well as understanding mental health issues so that staff can provide the appropriate support. They also have a responsibility to ensure that when service users’ move on to other residential services training is provided so that staff have an awareness of the specialist needs of this group. Family interventions have been described in other studies that this study recommends are adopted more widely to support relationships between service users and their families (Canning et al., 2009; SIMS, 2014; Tsang, Pearson & Yuen, 2002). It is also recommended that interventions to support development of social networks are developed and utilised.

9.3 Occupation

The second set of GOSO challenges relates to how the participants spent their time. They described a long admission in hospital, where the locked setting restricted their movement and structures and routines were largely mapped out for them. This was followed by life in the community where the participants were able to come and go as they wished and were able to make their own decisions about what to do. The different aspects of occupation: how people spend their day, meaningful occupation and work are discussed separately below.

9.3.1 Meaningful occupation

The participants in our study described being prepared for discharge functionally and with the management of their mental illness. However their engagement in meaningful occupation is remarkably similar to the accounts of individuals with mental illness living in the community who do not have a forensic history. One study of people living with schizophrenia found that time use was characterised by isolation, boredom and lack of daily structure (Shimitras, Fossey & Harvey 2003). Some of the participants in this study described an unstructured day, with a lack of routine.
Focusing on participation in mental health, Brown and Stoffel (2011) have found that individuals’ routines involve mainly passive leisure activities, which result in a relatively physically inactive and unhealthy lifestyle. It has been suggested that the reason for these restricted routines is a lack of opportunities for people with mental illness in the community in terms of work, studies, leisure, and social activities (Chesworth et al., 2002; Leufstadius & Eklund, 2008). However, there are examples of studies that have found that individuals actively choose to limit their occupational range in order to maintain their mental health (Eklund, Erlandsson & Persson, 2003; Nagle, Cook & Polatajko, 2002). They sought a balance that was right for them, and which allowed them to both remain well and socially connected (Eklund et al., 2003; Nagle et al., 2002). They therefore valued their lifestyle. The findings indicated, however, that this crucial balance had not yet been achieved for the participants. Many had not yet achieved the balance of meaningful activities and mental health that gives them a sense of contentment with their lifestyles that goes beyond merely being located out of the hospital environment. They want to have more social connections and they are looking to develop a more active and involved daily routine but do not know how to go about this.

Previous studies report that people with mental illness have been found to devote a significant amount of time and energy to do the things that allowed them to remain well and socially connected (Nagle et al., 2002). Our findings suggest that there is the potential for this to be the case with these individuals. Participants said that they wanted a more satisfying lifestyle. However they do not have the knowledge about where to direct this time and energy to achieve this goal. In the findings individuals stated that they do not know how to access assistance. They are aware of the limitations caused by their illness that are both mental and physical. In previous studies interventions that support the individual to achieve the right balance of structure, meaningful activity, and social connection, have been found to be helpful (Brown & Stoffel, 2011; Chesworth et al., 2002; Leufstaduis & Eklund, 2008; Shimitras et al., 2003). This balance is different for each individual. Enhanced self-confidence, competence and subjective wellbeing could be achieved from engagement in occupations, a term called occupational spin off (Rebeiro & Cook, 1999). The participants described some incidents when the benefits of engagement were felt, such as Keith mending a watch and Gary using the gym, however, these were isolated examples. None of the participants described a regular engaging routine, which had the potential to achieve occupational spin off on a consistent basis.

As previously discussed in the literature review the dark side of occupation was considered (Twinley, 2013). These are occupations that may be antisocial dangerous or criminal
(Cronin-Davis, Lang & Molineux, 2004). In the interviews the only reference that was made to these were from participants who were undergoing regular illicit drug tests. They said that it helped them to abstain from drugs. On reflection this is unsurprising. In the participant information (Appendix IX) we informed the participants that their care-coordinators would be informed if they shared information that may imply they or others could be harmed. They may therefore have been reluctant to discuss any issues that may have compromised their current status.

Contrary to previous research that suggested that forensic service users overestimate their capacities to perform tasks (Lindstedt, 2006), the participants in this study stated that they needed support with identifying and engaging with work and leisure activities. However this is not always the support that is provided by clinical services. Chesworth et al., (2002) noted in their study of individuals with enduring mental health problems living in the community, that the support from mental health professionals focused on the reduction of symptoms, often at the expense of assessing social and recreational functioning (Chesworth et al., 2002). This was the case in our study. Our findings are mirrored in another study with this client group; the participants were described as needing support because they were bored and lonely (Chiringa, Robinson & Clancy, 2014). The benefits of occupational spin off (Rebeiro & Cook, 1999) seem not to be fully understood by the CFMHT staff and are therefore not prioritised.

One model of working which provides a bridge of support between hospital and community is being explored in acute mental health services. It utilises the experience of peer workers to assist service users to navigate the transition between hospital and community. The National Institute of Health Research (NIHR) has granted funding of £1.7M for a five-year project for the Enhanced Discharge From Inpatient to Community Mental Health Care (ENRICH) Programme (Foster, Gibson & Marks, 2015). This is a programme of research that will be setting out to manualise, pilot and trial a peer support worker intervention for service users discharged from acute in-patient care. The peer interventions studied will involve working with individuals through the process of discharge to community living. The specific needs of the participants are different in our study because of the longer length of stay and their offending history. However the principle of benefiting from the support of someone who has experienced a similar situation is similar. The responses from participants in our study indicate that individuals are unsure about how to cope with a community transition. Their responses indicated that they have focused for so long on achieving discharge once this is achieved they are tentative about the new challenges of community living. Peer workers could be well placed to provide practical advice, which could complement clinical interventions. Peer workers, however would not provide the occupational expertise
necessary to the community teams. Occupational therapy oversight of the interventions would also be recommended. There may not be funding to introduce occupational therapy staff into the CFMHT but an alternative model of providing specialist expertise to the CFMHT has recently been nationally piloted. In this case it was providing psychology consultation to people working with a specific client group, offenders with personality disorders (Minoudis, Shaw & Crassati, 2012). Initial outcomes from an evaluation of this model of working indicates that team contact with psychologists improved outcomes for personality disordered offenders (Minoudis et al., 2012). In Canada a similar consultation model has also been successfully applied by an occupational therapist working in a mental health team for people with long-term mental health problems (Whalley Hammell, 2008). In her study Reberio (1999) noted that individuals had to spend time and energy navigating community mental health services. Although this was 18 years ago this is the same with the participants in this study. The difference with those on a secure mental health act section is that they are receiving medical and social supervision as it is provided as part of the section requirements. Service users don't need to spend time seeking out mental health support. What is missing is a range of information about work and leisure or accessing local community facilities.

There was a clear message from all the participants that they would like to be doing more with their time, to be engaged in something meaningful to them. Two of the participants in particular had not been given any guidance about how to access any local resources, including those related to education. In discussion with the SURs their response was that this might be a way of indicating that the individual was not ready to engage in meaningful activity and that it was important that they were well enough before starting to do so. If this was the case then it may have been more helpful to discuss this with the individuals. This hesitancy to support individuals to begin to take an active role in the community may be common and may indicate a lack of understanding about the benefits of occupation in supporting health and developing and maintaining links in the community. The findings of our study imply that the CFMHT has a priority to ensure that service users are mentally stable before they begin to involve themselves with activities, with the implication being that activity or employment may be a risk factor. However, increasingly evidence points to the fact that involvement in meaningful activity and the right employment can maintain mental health (Crowther, Marshall, Bond & Huxley, 2001; Evans & Pepper, 2000; Whalley Hammell, 2014).

9.3.2 Work
One striking aspect of the findings of this study was that none of the participants described being given active assistance to support them to achieve employment, although three of the five participants were actively looking for work and another two were interested in the
potential for looking for work but did not know where to start. One person had been told where an employment service was, but had not yet been there on a day when it was open. The participants’ responses gave the impression that they navigated job centres, recruitment websites and other ways of finding employment on their own. They were given basic advice about what type of jobs they could not apply for because of their offence, but were not given active, practical assistance and support to seek and find employment.

This may be because of the additional barrier that an offending history has on finding employment. Previous research has found that having a criminal record reduces the likelihood of a return call from an employer by 50% (Devah, 2003; West, Yanos & Mulay, 2014). One participant who had applied on line for many jobs certainly experienced this; he applied for over thirty jobs, stating his criminal conviction on the application form, and he did not receive any response. The public, and employers, have also been found to discriminate by type of conviction (Devah, 2003, Pager, Western & Sugie, 2009). Employers are far more likely to consider hiring individuals who have been convicted of drug crimes (61.8%) than violent offenders (23.6%) according to (Pager et al., 2009). All the offences carried out by this group were violent offences and the participants experienced the barriers to employment described in other research. One participant noted that it was his impression that it was the criminal record rather than the mental illness that proved the biggest barrier to achieving employment. However, it may not be just the offence that is a barrier to obtaining work. Time in prison has been shown to lead to a reduction in work skills such as formal education and experience and also a reduction of work disciplines such as punctuality or customer relations (Schmitt & Warner, 2010). In their long prison and health admission these skills may have reduced.

Work opportunities may not be routinely offered to people, with a history of mental illness and offending, because there are concerns that the demands of a work environment might worsen the health and increase potential risk factors for this group (Burns et al., 2009; Samele, Keil & Thomas, 2009). Indeed such fears have been cited as a reason why specialist support is not commissioned and provided for this group (Samele, Keil & Thomas, 2009). However research is increasingly demonstrating that work is not only a realistic ambition for mental health service users, it is also an important part of the recovery process (Arbesman & Logsdon, 2011; Boardman, Grove, Perkins & Shepherd, 2003; Burns et al., 2009; Woodside, Schell & Allison-Hedges, 2006). As Marrone and Golowka stated in 1999, “If work makes people with mental illness sick, what do unemployment, poverty and social isolation do?” (Marrone & Golowka, 1999, p 187). The findings from this study indicate that the participants are feeling at a loss for what to do. They feel isolated from the people around
them and unsure about how to spend their time. In addition to supporting mental health recovery work has also been found to reduce reoffending in people on release from prison and aid the transition to community living for offenders (Routh & Hamilton, 2015).

Boardman et al., (2003) noted over a decade ago that there was widespread ignorance about the services and approaches designed to help people with mental illness obtain and sustain employment. The findings from this study indicate that little has changed in the intervening years. Individual Placement and Support (IPS) is a work-based intervention, which has an established evidence base for people with serious mental illness (Burns et al., 2009; CMH, 2009; Crowther et al., 2001; Rinaldi et al., 2008; Samele, Keil & Thomas, 2009). IPS interventions aim to support individuals to apply for real jobs and then support them in their employment (Rinaldi et al., 2008). This focus on seeking employment rather than spending time in work preparation has resulted in a greater likelihood of employment for people with a history of mental health problems (Dunn & Seymour, 2008). Although less research has been carried out with a forensic client group the research that has been undertaken indicated that this group benefit from vocational opportunities (McQueen & Turner, 2012). However it has been noted that employment specialists find working with the forensic service user group more challenging than people with mental illness (Whitley, Kostick & Bush, 2009). The findings from this study indicate the additional complexity of having clients with a mental illness and criminal history could account for these views.

9.3.3 Summary of Occupation
The first O in the GOSO challenges stands for occupation. This refers to both how the participants spend their time and their work choices. The findings of our study corresponded in some ways with those carried out in other studies exploring life in the community for people with mental health problems (Brown & Stoffel, 2011; Eklund, Hermansson & Hakansson, 2011; Shimitras, Fossey & Harvey, 2003). As in these other studies participants were unsure how to spend their time. They did not have a routine and felt isolated and bored. As a result of this they were seeking assistance to find meaningful activities with which to spend their time. They understood the link between a satisfying routine and their continued mental health. The choices that individuals make to balance activity and mental health have been discussed in previous studies (Brown & Stoffel, 2011; Nagle, Cook & Polatajko, 2002). What was different in our study was that four of the participants had moved to new, unfamiliar areas following discharge and were unfamiliar with the local facilities. This meant that they had an additional task of finding out about local amenities. This was another barrier to developing a satisfying routine.
Some of the participants were actively trying to find employment. Previous research has highlighted that an offence history is a barrier to employment (Devah, 2003; West, Yanos & Mulay, 2014). It was the view of the participants in our study that the offence presented more of a barrier to employment than their mental health history.

It was evident from our study that participants required support to assist them to access leisure activities and work opportunities. However the service provided by the clinical team seemed to focus on the reduction of mental health symptoms as noted in Chesworth’s study (2002), and the management of risk. The contribution of work and a satisfying routine to mental wellbeing (Rebeiro & Cook, 1999), and risk reduction (Drennan & Alred, 2012) seem not to be acknowledged or prioritised. I discuss this and its implications for occupational justice later in the chapter.

9.4 Social inclusion

The third of the GOSO challenges is social inclusion. This refers to the social barriers individuals encounter when developing relationships in the community and finding work. These challenges of disclosure and stigma are closely connected. Firstly they concern the complex decisions service users have to consider related to if, when and how to disclose their history of mental illness and offending. The second challenge relates to managing the negative response of others to that information and the implications of that reaction.

9.4.1 Disclosure

The complex issue of disclosure was a key issue raised by one of the SURs at the beginning of our study. Disclosure of both his mental health problem and offence were areas that he managed frequently. He did not think it was properly addressed by services. The findings of our study highlighted that disclosure was an ongoing concern for all the participants. In forensic services disclosure is considered mainly in relation to the legal responsibility of disclosing offences to employers and to other relevant organisations, depending on the nature of the offence. This focus on disclosure for specific formal situations is also reflected in much of the literature (Brohan, Henderson, Slade & Thornicroft, 2014; Hamilton, Pinfold & Rose, 2011). It demonstrates the professional perspective about formal disclosure situations rather than the service user perspective. What was striking in the findings of our study, however, was that while these formal situations were important considerations, especially in relation to employment, it was everyday encounters with people that they met and how to manage these that caused participants most concern. Participants were concerned with how
to manage casual relationships with the people they encountered on an informal day-to-day basis, for example, their neighbours, hairdressers and people from within their church. There were several examples where participants had disclosed information about their mental health or offence history and regretted it, especially in the period immediately post discharge. This left them unsure about what to do next and lacking confidence in their daily interactions with people. It is clear that the participants have not had the opportunity to think through and discuss the issues related to stigma and so have been left to evolve their own understanding of these issues on their own.

9.4.2 Disclosure and employment

The advice, that the participants reported that they were given by their clinical teams, related to disclosure and employment. However even this advice seemed to be inconsistent between participants as not all were given any advice. Members of the community teams gave advice about disclosure. Participants were told not to disclose their mental health or offender history on the job application form but to wait until they had been interviewed, had met potential employers and been able to give a good impression. However, all the participants began their job seeking by being open about their mental health and offender status up front. They therefore had experiences of not being offered interviews, or in one case not receiving any responses from multiple job applications. If participants had been given a chance to consider disclosure and to think through all the issues related to different aspects of disclosure while still an in-patient, they might have entered the community with a more informed approach and be empowered to make disclosure decisions that they felt comfortable with.

9.4.3 Disclosure programme

‘Honest, Open Proud’, formerly known as ‘Coming Out Proud’, is a three-session group programme which has been developed based on a programme of research about stigma and mental illness (Corrigan et al., 2001; Corrigan et al., 2002; Corrigan & Rao, 2012). The aim of the course is to reduce the self-stigma associated with mental illness. Corrigan & Lundin (2015), a researcher and service user team, developed the course. In the materials relating to the course they introduce two “rules”, which govern disclosure. These two rules encapsulate the issues that individuals need to navigate when deciding to disclose: Rule 1) “it is hard to quiet the clanging bell” (Corrigan & Lundin, 2015, p 4), or once disclosure has taken place it is impossible to retract, so that caution and thought is necessary before taking the decision to disclose mental illness. Rule 2) “delayed decision is lost opportunity” (Corrigan & Lundin, 2015, p 4), or in the right circumstances disclosure can help to build relationships and be very supportive. These contradictory positions set the scene for the sessions, which are based on providing information for participants to consider all options
and begin to develop, from an informed position, their views and approach to disclosure. Developed in Chicago, this programme has been trialled in different parts of Europe, Australia and Asia. While this course offers a model of how to support disclosure of mental health problems it does not address the disclosure issues of mentally disordered offenders living in the community. Additional time would be needed to consider the implications of disclosing an offence as well as their mental illness. The programme would need to be adapted to incorporate disclosure of the offence as well as mental illness. A developed version of this programme, which included disclosing the offence, could be provided as an in-patient or within the community. Additional information could include education about the disclosure processes, when disclosure is mandatory, the role of MAPPA, the disclosure and barring process and ways to disclose.

9.4.4 Stigma
The experience of stigma underpinned the participants’ responses throughout. The descriptions of their experiences prior to admission, during their hospital stay and as they tried to make a life for themselves in the community were influenced by the stigma of mental illness and of having offended.

They were aware of the public stigma caused by the perception of people with mental illness as unpredictable and dangerous (Link, Phelan, Bresnahan, Stueve & Pescosolido, 1999; Moldovan, 2007; Schumacher, Corrigan & Dejong, 2003). They related experiences which demonstrated the barriers that arise from this discrimination which has also been noted in other research e.g. the barrier to employment prospects (Henry & Lucca, 2004); impacts on family relations and friendships (Stier & Hinshaw, 2007), limited access to housing and other community resources (Repper & Perkins, 2003).

Previous research has highlighted negative attitudes toward the mentally ill and their presence in the community (Moldovan, 2007). These attitudes have persisted even as tolerance for other stigmatised groups has gradually grown (Stier & Hinshaw, 2007). What is new in this study is that stigma was experienced within the mental health community. Service users with a forensic history experienced a feeling of difference and isolation from those with mainstream mental illness. This may be because individuals with mental illness try to distance themselves from the association between mental illness and violence and people with a forensic history have committed violent offences. People with mental illness in trying to distance themselves from the taint of the association with violence may also shun those that have caused violence. Forensic sections of the Mental Health Act (1983) are different from civil sections, which may mark forensic service users out as different. The hospitals that the
participants are admitted to are also different. Locked units and especially the high security hospitals such as Broadmoor may be regarded by those who have experienced a short stay in a local acute ward as the “real” psychiatric hospitals. In addition to their forensic history four out of the five participants said that they had been diagnosed with paranoid schizophrenia by their responsible clinician. Previous research has shown this diagnosis is perceived as unique in that it is regarded as more shameful than other mental illness diagnoses (Howe, Tickle & Brown, 2014). High profile campaigns to educate the public about mental illness have had some positive effect and the stigma of some illnesses such as depression is reducing (Evans-Lacko et al., 2013).

Previous research highlighted that stigma in the form of criticism and rejection are commonplace in the lives of people with mental illness and has been found to come from communities, families, churches, co-workers and caregivers (Chernomas, Clarke & Chisolm, 2000; Pen & Link, 2011; Stier & Hinshaw, 2007). The responses from this study mirror these results with individuals experiencing criticism and rejection from families, friends and the community. Bizarre behaviour or poor social skills can lead to stigmatising reactions Schumacher et al., (2003). In the responses one participant said that he had been told that he frightened people. This had made him cautious about meeting people and developing new relationships.

Most of the participants in our study were monitored by the community team in line with a community treatment order (CTO). CTOs have been found to contribute to stigma by creating situations where people are likely to feel powerless, devalued and oppressed (Livingstone & Rossiter, 2011). However in our study, as discussed earlier, the participants also valued the support of the care team.

9.4.5 Stigma and offending
This group of participants experiences the stigma of being an offender as well as being mentally ill. One of the participants noted that public responses to the fact that he had a mental illness were positive and accommodating. However, he was concerned about disclosing his offence history. Bodkin and Winnick (2008) found that first time offenders anticipate more rejection upon release than repeat offenders; however, repeat offenders were more concerned about stigma in relation to employment. In this study both first time and repeat offenders anticipated rejection when seeking employment but this might be because of the dual nature of the stigma they were experiencing.
Most of the participants had experienced time in prison and they had all experienced a long length of stay in hospital. Conviction and imprisonment can contribute to an individual’s negative view of the world and subsequent detachment from society (Maruna, 2001). The participants expressed this sense of detachment, although in the responses there seemed to be a more positive view of the world and a desire to be involved in some way. Imprisonment can result in the loss of social networks that can help individuals find work (LeBel, 2012). It can even result in the development of new networks that can lead to future criminal activity (LeBel, 2012; Pager et al., 2009). While the loss of social networks was a feature of the responses, none of the participants had remained in touch with other service users. This was because they were looking forward to forging new relationships away from a hospital identity. This was a surprise to the SURs who had both sustained relationships formed in hospital and found friends who had been through the same experiences and shared the challenges of developing a life in the face of the dual stigma. Strong social bonds to conventional society like family support and stable employment are thought to be important for successful prisoner reintegration (Petersilia, 2004; Visher & Travis, 2003). They have been found to reduce offending by controlling offender behaviour, providing emotional support and helping to transform identity from an offender to a citizen (Sampson et al., 2003). However it is also cautioned that there is also a strong link between antisocial peers and family and offending (LeBel, 2012).

9.4.6 Stigma resistance

The outcomes from this study seem to confirm previous studies which note the relationship between stigma resistance and the duration of hospital admission (Sibitz, Unger, Woppmann, Zidek & Amering, 2011). In this group, admission for a period is inevitable. However, in our study the person with the shortest admission time, in his case four years, seemed to manage to reduce stigma the most. He described relationships, which he found supportive now and had been maintained throughout his admission, whereas, the person who had experienced the longest duration of admission, described experiencing isolation and discrimination. One key strategy mentioned within both the mental health and offending literature is that of supporting and maintaining relationships with friends and family outside of the mental health system so that the individual has a wide enough social network (Corrigan et al., 2001; Maruna, 1999; Petersillia, 2004; Sibitz, Unger, Woppmann, Zidek & Amering, 2011; Visher & Travis, 2003). Certainly the participants with closer family links and a wider social network seemed to have more opportunities and be developing more confidence as they reintegrated into community life. Those without family connections seem isolated. People are less likely to develop stigma resistance when they experience high alienation and
high social withdrawal (Biffu, Dachew & Tiruneh, 2014). Maintaining social connections through family and friends seem to be a way of combating this alienation.

Kondrat and Teater (2009) noted the contribution of narrative approaches that provide opportunities for individuals to re-story their identity and develop their own ways of understanding and describing their experience. This has been found to assist people with mental illness to develop ownership and understanding of their own story separate from the stigmatised illness identity imposed on them by others (Kondrat & Teater, 2009). It is interesting that some of the participants enjoyed the opportunity to tell their story in the interviews. They appreciated seeing their story, in their own words, written down. One participant said it made his experience clear to him. It is an example of how telling their story as part of a research study also contributed to the participants understanding of their experience.

9.4.7 Summary of Social Inclusion
The S in the GOSO challenges stands for social inclusion. The participants encounter significant barriers to social inclusion including the development of social networks and social capital. Once of these barriers is the consideration of disclosure. Professional attention is given to formal disclosure expectations such as when seeking employment (Brohan et al., 2014; Hamilton et al., 2011). Our study highlighted the importance of preparing for disclosure in everyday interactions. These day-to-day interactions such as in the hairdressers or meeting neighbours on the street pose challenges for the participants because they are unprepared. It is these interactions that will contribute to developing informal relationships and networks in the local area. However these are not addressed or prepared for. The participants therefore had to learn these skills in the community through trial and error. This resulted in all the participants disclosing their histories inappropriately and regretting that they had done so. The disclosure programme Honest, Open Proud (Corrigan et al., 2002) is an intervention designed to support disclosure of mental illness. Although it does not address disclosure of offending it may have utility with this group.

The impact of stigma and discrimination is also something that the service users encountered on an everyday basis. The impact of the discrimination of people with mental illness noted in previous research (Henry & Lucca, 2004; Repper & Perkins, 2003; Stier & Hinshaw, 2007) was found in our study. What our study revealed in addition was that the participants also experienced discrimination from within the mental health community. This group were marked out as different within the mental health community because of the
Mental Health Act Sections (DoH, 1983) they were admitted to hospital under, the hospitals they were admitted to and their length of stay as an in-patient.

The participants in this study also encountered discrimination as a result of an offence history. They were more concerned about disclosing their offence history than their mental illness. Offender literature highlights the importance of social bonds such as family relationships in supporting reintegration to the community (Perersilia, 2004; Visher & Travis, 2003). This was the case with the participants with family relationships in this study.

One strategy, which has been demonstrating some utility in developing stigma resistance, is the opportunity for individuals to tell their stories in order build their identities (Kondrat & Teater, 2009). This allows individuals to build a sense of their own identity apart from the stigmatised view imposed by others. This will help to prevent individuals internalising the stigmatising views.

### 9.5 Offence issues

There are some aspects of recovery for the participants which are solely the result of the offence. Although the participants were not directly asked about the offence that brought them to the secure services most of the participants made some reference to the offence during the interview. They did not talk about the specifics of the offence but about the impact of the offence on them. When they talked about the offence they said it was carried out at a time when they were ill. There was a connection with the offence and their illness that is recognised by mental health services that assume that when the mental illness is treated then the risk of reoffending will reduce (Drennan & Alred, 2012). In this way the offence was blamed on the illness and the circumstances that led to it. This gave the impression in the interviews that there was a reduction of personal responsibility for the crime. This may be because they had addressed issues related to the crime in hospital or because this was the case. A previous study acknowledges that recovery from the offence is important and in some ways more challenging than recovery from mental illness (Mezey & Eastman, 2009).

There were three key issues related to the offence that were affecting the participants at this stage of the recovery journey or reintegrating into the community. The first one was the requirement by the courts that they were discharged to a new location. The second one was the awareness of and concern about coming face to face with the victims. The final one was concern about the recall process. I will discuss these more fully below.
9.5.1 Discharge to a new location

Only two of the participants returned to their home area after discharge from the secure services. The others were required by the courts to move to another location when they were discharged to the community. Consequently on leaving hospital individuals had the additional challenge of getting to know a new location. They needed to establish a new lifestyle in surroundings that they did not have a history with or knowledge of apart from when they took part in community familiarisation visits prior to discharge. In addition to this, one of the participants described moving between different community areas as he moved through different types of accommodation until he finally lived in an independent flat. Although he was happy to be finally living independently he was beginning for the third time since discharge to try and familiarise himself with his surroundings. According to this participant moving to an unfamiliar area added additional challenges to the task of reintegrating into the community. Occupational adaptation is defined by Kielhofner as “the construction of a positive identity and achieving occupational competence over time in the context of one’s environment” (Kielhofner, 2008, p. 107). Nayar and Stanley (2015) note that the process of occupational adaptation takes time to develop and that it is influenced by both social relationships and the interactions that people have with their environment. This suggests that familiarity with the environment has an influence on supporting successful integration with the community as well as the more acknowledged benefits of social capital (Bates & Davis, 2004). Having to start again in a new location is an additional task that people recovering from mental illness do not necessarily have to manage. The lack of knowledge about the new area was described by some of the participants as a barrier to engaging in local services, some said they did not know where to start. Feeling socially included involves, trusting and feeling safe, feeling part of the community and having local social connections (Bates & Davis, 2004). One of the participants who was living in a flat with support was assisted by staff to familiarise himself with the local area. They provided eleven hours a week of escorted trips to local shops, and the gym. Through these trips he became familiar with the local area. At the gym he got to know other people. He was being supported in the process of feeling socially included in a new geographical location. This provides an example about how the integration into a community setting can be supported.

9.5.2 Retribution from victims

Concern for retribution from the victims, or meeting the victims of crime was discussed by some of the participants. I could not find any information about the prevalence of revenge attacks in the academic literature, but did find a couple of newspaper articles which described similar revenge incidents by families or friends on perpetrators of crimes (Daily Mail, 2008; Press Association, 2014). One participant had consciously weighed up the
benefits to his reintegration of moving to his own environment and benefiting from the social capital gained by close links with family in order to have richer opportunities for social events and ongoing relationship support with the concerns about being attacked by previous victims. He expressed his feelings of vulnerability and how he avoided certain areas or going out alone at night. Some of the participants stated that one of the benefits of moving away was that they were not likely to meet their victims face to face unexpectedly which they described as a relief to them. The consideration or awareness of the victims and the possibility of bumping into them was an issue that influences the long-term behaviour of the SURs. They have adopted strategies to manage the possible event of meeting the victims or their families. Both said that they did not go to the areas where they are likely to meet victims because of the fear of retribution. One of the SURs said that he always travelled to events by car so that he can leave independently. One of the reasons for this is so that he had an escape if he did meet his victim's family. From the responses of the participants and the SURs it is clear that they experienced a heightened sense of anxiety when going out in the community. They are aware that there are people who will be hostile to them if they meet. This contributes to a feeling of not being safe, and is an additional barrier to navigate, particularly at the time when they first move to the location and are finding their feet in the community. One intervention, which may have the potential to address this issue, is a restorative justice approach. Restorative processes are interventions, which include the victim and the offender (Cook et al., 2015). They give victims the power to meet with their offenders to explain the impact of the crime on them. These meetings hold the offender to account for what they have done, helping them to take responsibility and make amends (Restorative Justice Council, 2016). Restorative justice is established in prisons but has not yet become established in forensic settings (Drennan, Cook & Kiernan, 2015). Three reasons have been suggested for why this intervention has not transferred to secure hospitals: firstly the psychology of shame and remorse, particularly in relation to interventions to address these issues is at an early stage of development, (Adshead et al., 2015; Ferrito et al., 2012). Secondly no specific restorative justice interventions have been developed for this population and thirdly restorative approaches have been developed primarily as an intervention for the victim, although it has been found to have benefits for the offender (Restorative Justice Council, 2016). It is still, therefore, regarded as controversial to initiate a restorative process on behalf of the offender (Drennan, Cook et al., 2015). A group programme for offenders has been developed by Feasey and Williams (2009). It promotes victim awareness and utilises restorative approaches. It is called the Sycamore Tree project and it has been found to have a positive impact on prisoners who have completed the course. Although it may have utility to address some of the other aspects of recovery described in this chapter, it would not address the worries of possible revenge by the victims described by the participants. Only a
restorative process initiated by the victim has the potential to address this directly. There have been no studies on this issue to date, which indicates that this is a new finding emerging from our study. It is an area which merits further exploration.

9.5.3 Threat of recall to hospital
Awareness of the potential of being recalled to hospital and fear of this influenced many of the decisions that some of the participants made. Most of the participants had been discharged under the power of a Mental Health Act Section 41 (DoH, 2007b), which is also called a restriction order. Under this order if individuals fail to comply with the conditions of discharge the Ministry of Justice will be informed and they could be recalled to hospital.

There was some uncertainty, among the participants, about what they needed to do to remain in the community. This seemed to increase their tentativeness to try new activities just in case this increased their risk and therefore the potential of recall, this has been noted elsewhere (Chiringa, Robinson & Clancy, 2014). One of the participants in our study was concerned that with his history he would be recalled if he was the victim of an incident. He said that he would be blamed if anything happened. This made him nervous when he was out at night. This view was echoed by the respondents in Chiringa et al.’s study (2014). They said that the system made them feel like criminals. In our study, however, some conditions of discharge were identified as reassuring; an example of this was having regular testing for drugs, which was perceived as a positive way for participants to demonstrate that they were adhering to the conditions.

A study conducted by Chinga et al., (2014) found that not all participants understood the conditions of their discharge. They recommended that better communication about the conditions may help service users understand and adhere to these conditions. Our study confirms this finding but also notes that if service users understand their conditions of discharge it may help them develop the confidence to understand what they are able to do when out in the community. A lack of understanding about the monitoring process relating to the conditional discharge terms seems to be inhibiting the participants. This is concerning because of the impact it has on the participants confidence and sense of empowerment when they are leaving hospital. In occupational justice terms, this may lead to occupational marginalisation; the participants are excluded from occupational choice because they are not sure what the nature of their conditional discharge is. This limits their opportunities and maintains their isolation within the community. These findings suggest the need for more education to be provided to service users about the conditional discharge process both while still in hospital and on return to the community.
9.5.4 Summary of Offence Issues

The second O of the GOSO challenges refers to the impact of the offence. The fact of the offence has a number of repercussions that can affect the quality of the participants’ experiences when they are discharged. It has both practical and social implications, which are long term in character. Firstly the majority of the participants moved to a new unfamiliar area due to an order of the court. The impact of this has not been explored in research to date; although Bates and Davis (2004) found that familiarity with the environment supports successful reintegration to the community. Our study found that participants were initially unfamiliar with the area. They did not have any points of reference, beyond preparation trips from the hospital prior to discharge. This created an additional barrier to settling into the new area and accessing local amenities. The participants who did return to their area of origin had the benefit of moving to a familiar setting however they expressed their concerned about meeting victims or the families of the victims. Once again, this has not been explored in research to date. The participants described feeling physically vulnerable. This affected their routines in order to avoid potential contact. Restorative justice approaches may assist in some cases (Cook et al., 2015).

Unfamiliarity with the recall process in all the reports from the participants’ means that their community based involvement may be repressed by the concern that the team may not sanction them. This lack of understanding about the recall process is inhibiting the service users. This response has been noted by Chiringa et al., (2014). It indicates the need for education about the recall process prior to discharge.

9.6 Summary of the getting out and staying out challenges

I have provided a summary of the key aspects of the discussion in Table 9. It compares the challenges encountered by people recovering from a mental illness with the additional tasks or barriers encountered by service users with mental illness and an offender history. Seeing the additional tasks mapped out in this way emphasises the significant hurdles encountered by this client group. I would suggest that any service user or practitioner in secure services would recognise these challenges. However this is tacit knowledge, as the range of additional tasks has not been collated in this way before. Other authors have noted one or two additional tasks, which have arisen in relation to their own studies; for example the challenges of work (McQueen, 2011), experiencing stigma (Maruna, 2011) and the impact of relationships (Macinnes et al., 2013). By collating these challenges in this way the scale of
the recovery task for this service user group becomes clearer. The experience of more than
one stigmatising characteristic simultaneously has been found to magnify the experiences of
stigma. The impact of two or more stigmatising attributes has been found to result in an
impact that is more than a sum of its parts (Kidd, Veltman, Gately, Chan & Cohen, 2011). I
suggest this is the case in relation to mental illness and offending. This client group is
encountering multiple additional challenges in all aspects of their life. This has significant
implications for the nature and amount of support which should be offered to these
individuals.
Table 9: A comparison of mental health recovery and recovery from having offended (the GOSO challenges)

<table>
<thead>
<tr>
<th>Good Relationships</th>
<th>Mental Health Recovery</th>
<th>GOSO Challenges</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Staff acceptance</strong></td>
<td>Staff acceptance in spite of mental health difficulties (Onken et al., 2002)</td>
<td>Importance of acceptance of both mental illness and offence (Our study)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Importance of active engagement with the team in order to demonstrate progress (Our Study)</td>
</tr>
<tr>
<td><strong>Family</strong></td>
<td>Fractured relationships/strain on relationships due to burden of illness symptoms (Lin, Kirsh, Polatajko &amp; Seto, 2009)</td>
<td>Shame/maintaining relationships (Our study)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Blame mending fractured relationships caused by burden of illness symptoms and also offence (Our study)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Length and location of stay also impact on family relationships (Canning et al., 2009)</td>
</tr>
<tr>
<td><strong>Friends</strong></td>
<td>Mental health stigma can affect friendships and result in a limited social network (Forrester-Jones et al., 2012)</td>
<td>Length and location of stay can interrupt friendships (Our study)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stigma of mental illness and the offence can limit opportunities to develop relationships (Davis &amp; Brekke, 2013)</td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td>Mental Health Recovery</td>
<td>GOSO Challenges</td>
</tr>
<tr>
<td><strong>Meaningful occupation</strong></td>
<td>Continuity with valued activities encouraged throughout admission (Shimitras et al., 2003)</td>
<td>Need to establish routines, identify valued activities in the community (Lin et al., 2009)</td>
</tr>
<tr>
<td><strong>Work</strong></td>
<td>Employment contributes to mental health recovery (Boardman et al., 2003)</td>
<td>Employment contributes to mental health and reducing risk of reoffending (Samele, Keil &amp; Thomas, 2009)</td>
</tr>
<tr>
<td><strong>Social Inclusion</strong></td>
<td>Mental Health Recovery</td>
<td>GOSO Challenges</td>
</tr>
<tr>
<td><strong>Stigma</strong></td>
<td>Stigma due to mental health (Moldovan, 2007)</td>
<td>Stigma due to mental health and offence history (Drennan &amp; Wooldridge, 2014)</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Stigma within in MH community (Current study)</td>
</tr>
<tr>
<td><strong>Disclosure</strong></td>
<td>Mental health (Venville, Street &amp; Fossey, 2014)</td>
<td>Mental health and offence history (McQueen, 2011)</td>
</tr>
<tr>
<td><strong>Offence Related</strong></td>
<td>Mental Health Recovery</td>
<td>GOSO Challenges</td>
</tr>
<tr>
<td><strong>Discharge to a new location</strong></td>
<td>n/a</td>
<td>Need to become familiar with a new location (Drennan &amp; Alred, 2012)</td>
</tr>
<tr>
<td><strong>Retribution from victims</strong></td>
<td>n/a</td>
<td>Managing additional anxiety related to the possibility of meeting victims (Our study)</td>
</tr>
<tr>
<td><strong>Concern About recall</strong></td>
<td>n/a</td>
<td>Concern about being recalled leads to reduced confidence (Our study)</td>
</tr>
</tbody>
</table>

Seen altogether the additional GOSO challenges facing this client group are clear. The GOSO challenges present the most comprehensive understanding of mental health recovery in offenders to date. They challenge the notion that the only difference between mental health recovery and mental health recovery in offenders is the importance of coming to terms with the offence (Drennan & Wooldridge, 2014). As can be seen from the GOSO challenges...
there are social, functional and offence specific additional facets that need to be addressed by people with mental health problems and an offending history.

9.7 Implications of the GOSO challenges

The GOSO challenges begin to identify and articulate the specialist recovery needs of people in secure services. I began our study by sharing the definition of offender recovery. I return to this now: “the subjective experience of coming to terms with having offended, perceiving the need to change the personal qualities that resulted in past offending, and accepting the social and personal consequences of having offended” (Drennan & Alred, 2012, p. x).

The GOSO challenges begin to contribute to our understanding of what the social and personal consequences of having offended are. They expand our understanding of the preparation; education and support that service users need to support them in their move back to community living.

The learning arising from the GOSO challenges has a number of implications. There are implications for individuals themselves, for how services are planned and delivered and also implication for policies at a regional and national level. In this next section I consider these in turn.

9.7.1 Implications for individuals

The GOSO challenges provide information about the specific recovery challenges facing people with a mental illness and an offence history. An awareness of the GOSO challenges will help individuals to identify the issues they need to address. This may mean additional learning, increasing awareness or participating in specific therapy interventions.

The GOSO challenges could be used as a tool for service users and staff to help them identify the specific offence related challenges that were most relevant to them. I have worked with the SURs to develop a GOSO challenges framework (Table 10). This provides a basic checklist for reflecting on the GOSO challenges. It offers a structure to consider the GOSO challenges in turn. To identify those that particularly relevant to them and which they need to address. In Table 10 is an example of a completed GOSO challenges framework. The research team completed it using the information provided in one of the participant interviews. It shows areas of need for the individual, which could indicate potential areas to concentrate on in future interventions, depending on his priorities. By mapping out the GOSO
needs in this way service users can clearly identify specific areas of need. Being informed allows individuals to develop an understanding of the issues that affect them which, while not easy, can also be empowering (Pilgrim, 2008). Utilising the GOSO challenges in this way may help to enable service users to progress in the offender aspects of their recovery.

### Table 10: GOSO Challenge Framework: Tony

<table>
<thead>
<tr>
<th>GOSO Challenge</th>
<th>Individual situation</th>
<th>Way forward</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Good relationships</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Staff</td>
<td>Good relationship with team</td>
<td></td>
</tr>
<tr>
<td>Family</td>
<td>Family offer opportunities for socialisation</td>
<td></td>
</tr>
<tr>
<td>Friends</td>
<td>Girlfriend – needs support</td>
<td>Peer/support worker to accompany to art sessions and elsewhere to help develop social network</td>
</tr>
<tr>
<td></td>
<td>Limited social network</td>
<td></td>
</tr>
<tr>
<td><strong>Occupation</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Meaningful occupation</td>
<td>Interested in arts</td>
<td>Identify local resources where he can carry out his art. Support/peer worker to accompany him to the gym.</td>
</tr>
<tr>
<td></td>
<td>Has gym membership, has no one to accompany him to the gym so attendance is erratic.</td>
<td></td>
</tr>
<tr>
<td>Work</td>
<td>Would like to work but has not been given support to access work opportunities</td>
<td>Refer to employment support scheme. Accompany him if necessary.</td>
</tr>
<tr>
<td><strong>Social inclusion</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Disclosure</td>
<td>Unfamiliar with disclosure process</td>
<td>Learn more about disclosure through attending disclosure course</td>
</tr>
<tr>
<td>Stigma</td>
<td>Attends mental health centre occasionally but notes he is regarded as different because of his forensic background</td>
<td>Develop links with peers</td>
</tr>
<tr>
<td><strong>Offence related</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Discharge to a new location</td>
<td>Moved back to home location</td>
<td></td>
</tr>
<tr>
<td>Contact with victims</td>
<td>Fear of meeting previous victims in local area limits his movements in the evening</td>
<td>Work with team to look at strategies to feel safe</td>
</tr>
<tr>
<td>Recall process</td>
<td>Fear of being arrested or recalled limits his movements</td>
<td>Education about the recall process</td>
</tr>
</tbody>
</table>

### 9.7.2 Implications for therapeutic interventions

The GOSO challenges offer the most comprehensive understanding of recovery in secure settings to date. They, therefore, have several implications for service planning and delivery for in-patient services, community services and the transition between them. In this section I
am focusing on therapeutic interventions. Firstly I consider what the GOSO challenges teach us about the content of interventions, what additional information service users need to know. However there is also something to learn about how interventions are delivered as well as what is delivered. I will therefore discuss reframing current interventions so that they meet service user defined goals as well as clinically defined goals. I will also consider the impact of co-producing interventions with peer workers. Finally I discuss the timing of interventions.

**The content of therapeutic interventions**

Some of the issues highlighted in the GOSO challenges have been identified in previous studies and interventions are recommended to address them. In particular there are a range of strategies that have been developed to promote family relationships both while the service user is an inpatient and on discharge (Canning et al., 2009; Cook, Drennan & Callanan, 2015; Worthington, Rooney & Hannan, 2013). For some of the other GOSO challenges there are interventions that have been found to have utility in mainstream mental health services but these have not yet been utilised with this client group. An example of this is IPS (Crowther et al., 2001; Samele, Keil & Thomas, 2009) a well-established vocational intervention which may have utility with this client group.

In addition to the above the GOSO challenges highlight a number of different subject areas, which have not been addressed in therapeutic interventions to date. Some of these have the potential to be the basis of group or individual interventions to prepare future service users for living in the community. These subject areas would require some element of education together with the need to provide service users with an opportunity to consider the implications of the subject area for their individual situation. These include disclosure in everyday situations, as well as employment and the process of recall to hospital. Consideration of the GOSO challenges as a whole may also provide the basis for a group intervention.

**GOSO Recovery College Course**

The GOSO challenges have the potential to be used to provide a framework for a recovery college course. Recovery based interventions recommend that interventions are co-planned and co-delivered with people with lived experience (Perkins et al., 2012). They become a co-operative venture, which utilises both the lived experience of the peer and the clinical expertise of the professional. This is the model that has been used in the development of the recovery colleges (Perkins et al., 2012). The GOSO recovery college course will take these concepts a step further. The GOSO recovery college course will be a co-planned and co-
delivered course with the core material being based on research findings, which have been identified in a co-research project. The research team is currently working to develop a GOSO recovery college course. Each of the GOSO challenges will be considered in turn, there will be some element of education and then time given for reflection and discussion. It will be informed by real life examples provided by the peers and utilising some of the research findings.

Reframing current interventions
The interventions that were most clearly remembered by the participants were those, which they understood as relevant to their immediate needs. Their primary need was how does this intervention help me get out of hospital and stay out of hospital. This suggests that the direct link between the interventions provided and their contribution to moving towards discharge and their practical implications for community living need to be more clearly articulated. In this way the goals of both service user and staff will be more explicitly aligned. This confirms the views of Bartholomew and Kensler (2010) who assert that linking service user outcomes and content of therapy is a way of putting recovery into practice. This may result in more active involvement from the service user, which means they may remember and utilise the learning from the groups. Firstly, staff can work with service users to agree the goals of the interventions; the GOSO framework could assist with this. Secondly, peer facilitators could be employed to share their experience of the relevance of the intervention to community living. I shall discuss both more fully below.

Service user-defined goals
One way of raising awareness of the link between the therapy programme and service user priorities is to co-develop explicit goals of therapeutic interventions (Park, 2009). Goal setting is a familiar process for clinicians. However, the literature indicates that documented goals tend to reflect the plans of the clinicians (Eschenfelder, 2005; Palmadottir, 2003; Park, 2009). They do not identify the priorities of the service user group. The findings from our study seem to confirm this. In a study of occupational therapists, the top three barriers to client-centred practice were all related to goal setting (Sumsion & Smyth, 2000). They were: 1) Practitioners and service users identify different goals. 2) Practitioners cannot accept service users’ goals due to their clinicians’ values and beliefs. 3) Practitioners are uncomfortable allowing service users to choose goals (Sumsion & Smyth, 2000, p. 19). Although this study was published 16 years ago the results of more recent studies (Mason & Adler, 2012), including our own, suggest that not much progress has been made.
If the anticipated outcomes of interventions are not shared then service users and staff are in danger of entering interventions with different agendas. In the case of this participant group, facilitators may be attending to content, related to substance misuse or offence related content while the group participants are entering groups with a focus on demonstrating their readiness to engage. This sometimes results in service users feeling coerced into attending groups and describing a predominantly negative experience (Mason & Adler, 2012). This will result in them not benefitting from the opportunities and knowledge the group provides.

**Incorporating service user-defined goals into groupwork**

Group interventions are beginning to be designed to incorporate service user defined goals (Blum et al., 2002). Some clinicians are providing additional individual sessions, which have the explicit aim of supporting participants to consider how the group interventions best fit their individual circumstances and goals (Blum et al., 2002). The Systems Training for Emotional Predictability and Problem Solving (STEPPS) Programme (Blum, Bartels, St. John & Pfohm, 2002) is a treatment programme for people with borderline personality disorder. A unique aspect of this is the use of what is called reinforcers (Harvey, Black & Blum, 2010). These are individuals such as clinical staff or family members who are not involved with the group delivery, but who are given specific training in the content of the group so that they can support the individual by reinforcing the skills learned in the group. They can assist in making the link between group content and the individual’s specific needs. The Recovery Through Activity Programme (Parkinson, 2014), uses the same strategy of having individual sessions planned in parallel to the group programme. However the individual sessions in the ‘Recovery Through Activity Programme’ are carried out by the occupational therapist so that the explicit link between activity and the service users occupational goals can be made. Both of these interventions use individual sessions to support the group process. The conceptual framework for occupational engagement is designed for a secure setting (Morris, 2012). It offers a way in which pro-social occupational choices can be linked to values activities such as leave. Participants could consider how the content relates to their own circumstances; this may ensure that group content is more relevant and utilised. Leave from the unit is the intervention that the participants described most clearly; the responses indicated that it was valued as a marker of progress.

**Use of peer facilitators**

Employing a peer as a co-facilitator for group interventions can emphasise the contribution the group can make to assist someone to get out of hospital and stay out. The use of peers in the co-design and co-delivery of interventions is becoming increasingly established (Mourra, Sledge, Sells, Lawless & Davidson, 2014; Repper et al., 2013; Wold, 2014). Peer
workers provide support to others with similar problems, but who are not as far along with their recovery (Chinman et al., 2014; Mourra et al., 2014). Peer support workers have been shown to address recovery outcomes more successfully than professionally qualified staff (Repper & Carter, 2011). This has been termed a role modelling function (Davidson, Bellamy, Guy & Miller, 2012, p. 123). Peer workers have been found to bring a different range of expertise to the clinical domain, their experiential or life knowledge is not only of mental illness but also how to live with mental illness in daily life; incorporating living on benefits and dealing with stigma and discrimination while understanding and making use of the services that are available (Davidson et al., 2012). This life experience may provide practical examples to participants that they can begin to relate to their own lives. In their review of peer workers, Chinman et al., (2014) concluded that six improvements were found as a result of their employment: a reduced use of in-patient services, a better relationship with service providers, improved engagement in care, higher levels of empowerment, service user activation and hopefulness for recovery. Although Chinman et al.’s (2014) findings do not directly suggest that individuals will be able to make a link between the content of interventions and practical applications, this evidence suggests that might be the case.

The GOSO challenges also identify the value of a support worker or a peer role beyond the impatient setting. It suggests that there may be a role in supporting the transition into the community, in assisting the individual to develop a routine and to manage many aspects of establishing a satisfying lifestyle in the community. This includes developing social networks, becoming familiar with the geography of the local area and the amenities that are available, developing a meaningful routine. This peer role is already showing potential in assisting with the transition of individuals from acute in-patient settings (Foster, Gibson & Marks, 2015)

9.7.3 Risk and occupation

The close monitoring role of the community teams has an influence of the occupations carried out by the participants. If the community staff member does not sanction an activity or work role then they will not do it. It is therefore important that clinical teams understand the risks and benefits of occupation in developing and sustaining a safe and meaningful lifestyle. An over cautious approach can be to stop people involving themselves in activity as a way of avoiding stress and a possible relapse. However, as we see in some of the responses of the participants, the lack of access to meaningful activities is causing the very stress that their clinical supervisors are trying to avoid. Services have tended to err on the side of caution and instinctively play it safe in terms of what clients are supposed to do. However most risk definitions are based on the idea that most humans could (and should) control their future through their activities (Zinn, 2008). Once a risk is identified individuals are encouraged to
respond by doing something about it, for example avoiding, changing behaviour, making choices, or carrying out a particular activity to manage the risk (Zinn, 2008). As Renn noted, if the future was regarded as predetermined, or unaffected by human activities the term risk would not make sense (Renn, 1992). Positive risk management acknowledges that some degree of risk, or challenge, is essential to skill acquisition, self esteem and progress (College of Occupational Therapists, 2006). Positively managing risk does not mean being complacent about risk, but encourages a person-centred approach to evaluate it. Being risk averse can be seen as the lack of hopefulness on the part of practitioners and a barrier to recovery (Deegan, 2001, Perkins & Goddard, 2004).

The World Federation of Occupational Therapists position paper on human rights (WFOT, 2006) refers to human rights in relation to human occupation and participation. It uses the term of “abuses of the right to occupation” (WFOT, 2006, p. 1) noting that these abuses can consist of economic, social or physical exclusion. It says that these abuses may take place “through attitudinal or physical barriers or though control of access to necessary knowledge, skills, resources, or venues where occupation takes place.” (p. 1). With some clinical teams it may be attitudinal barriers that are causing them to restrict access to occupations.

The participants in our study stated that they wanted to be involved with activities, to structure their time. They also indicated that they were aware of their mental health, the contribution a meaningful activity can make to their ongoing mental health and crucially, they had a sophisticated awareness of the amount or level of activity that would be right for them. Without a more complex understanding of risk and how they can manage it, the service users appear to be frozen, afraid to carry out anything that may increase their risk or put them in a vulnerable situation resulting in their re-arrest, recall to hospital or reconviction.

This lack of understanding of the fundamental occupational needs of the participants has serious consequences. This may be one of the “changeable factors” (Coid et al., 2007, p. 229) identified by Coid. Symptom management may be the priority of treatment in the short-term but our findings suggest that in order to sustain a long-term lifestyle in the community, individuals need to feel engaged with the community, to have a satisfying range of activities and feel connected through relationships. This is confirmed by one study which found that spending less time in daily activities resulted in a risk of an adverse daily rhythm which, in turn, could lead to an increase in general symptoms such as anxiety, self blame and difficulties in co-operating with others (Leufstadius & Eklund, 2008). Over time individuals may become increasingly vulnerable to risky behaviours such as illicit drug taking or re-offending. Slade et al., noted that a saying in the recovery approach is “hope, without
opportunity, dies” (Slade, Williams, Bird, Leamy & Le Boutiller, 2012, p. 101). The individuals in our study have hope and a wish to remain in the community. Without the opportunity to utilise the facilities the community offers, hope for them may die and increased the risk of reoffending or the relapse of their mental illness. The question why does the risk of violent reconviction increase after a nine-year period following discharge arose from our literature review. The failure to meet the occupational needs of service users is indicated as one of the reasons in our study.

9.7.4 Occupational Rights
In occupational justice terms the issue for the participants is primarily one of occupational imbalance. The participants are not being exposed to the right to experience occupation as meaningful and enriching. This is having an impact on their wellbeing and mental health, which they are aware of. This occupational injustice cannot only be resolved at a local level. Occupational therapists have been urged to take active roles in exploring the restrictions to participation for people with enduring mental illness in order to support greater access to occupational choices, supports and opportunities (Chugg & Craik, 2002; Rebeiro, 2001) and therefore sustain a healthier lifestyle (Shimitras et al., 2003). However an analysis of risk management and health policies show they are managed through social institutions, which are governed through conceptual practices of power (Smith, 1990). It is clear that the factors that impact on occupation stand outside the immediate control of the individual service user or professional. An understanding of the complex power relations that impact on the individual’s choices is necessary in order to address the issues at the appropriate level (Townsend & Marval, 2013).

The way risk is monitored and managed exerts a powerful influence on the culture, management and everyday practice in forensic services. Risk has historically had a far greater focus than recovery in secure services, mainly because of the nature of the service provision (Barker, 2012). The top down nature of organisational structures matches the pervading concern that mistakes and failures must not occur. This influences policies, and local guidelines, practices, perceptions and behaviours (Barker, 2012). For the last thirty years neo-liberalism has shaped the provision of policy and services in health and social care. It refers to the policy, practices and values that favour market forces, privatisation, individualism, or global deregulation of businesses (Creek, 2002). One of the values underpinning neo-liberal policy is the move away from over interfering government or the nanny state to a promotion of individual self-sufficiency (Pollack, 2010). Government or central intervention is reduced in favour of individual or local self-management (Pollack, 2010). One outcome of this is that attention moves from wider social and systemic issues to
locate problems in the individual (Pollack, 2010). In the case of this study this can be interpreted as the service user is regarded as the cause of potential risk rather than the circumstances in which he finds himself on discharge. A standard feature of neo-liberal modes of governing is a focus on risk. This is closely linked to social exclusion (Rose, 2000), as individuals are excluded from opportunities with the assumption that this will reduce the risks they pose. In forensic services, where the core purpose is the management of risk, this is particularly the case. The developing concept of offender recovery, informed by our study is showing the exact opposite is needed. Individuals require a focus on opportunity to engage with occupations, citizenship and social opportunities at a level that is right for their individual circumstances.

Occupation and participation can depend on social determinants of health such as social networks, work and access to education (Marmot et al., 2012; Raphael & Curry-Stevens, 2009). In the case of the participants, CFMHT staff act as gatekeepers to these opportunities. Power is embedded conceptually in policies, funding and laws that actually regulate what can be done (Smith, 1990). In this way the policies and commissioning guidance for forensic services can serve to continue the exclusion of service users, by focusing on a conceptualisation of risk, which aims to prevent the individual engaging in risky behaviours. This may be effective in the short term however Coid et al.’s study (2007) shows that in the longer term this strategy is less effective. Our study suggests some reasons why. The participants are isolated, lonely, bored and unsatisfied with their routines. An approach focusing on risk prevention serves to perpetuate social exclusion whereas if individuals are going to be risk free in the long term they need the opportunity to develop alternative ways of living. This requires an approach that provides opportunities for occupational enrichment that supports access to occupational opportunities which will facilitate engagement and participation in society, through the development of social networks, civic participation, work and education.

The Quality Standards for Community Forensic Mental Health Team Services (RCP, 2013) show an example of the way standards and policies can limit, or not give enough priority to occupation. There are three standards that specifically relate to access to leisure and activities. These three standards acknowledge the importance of supporting leisure, vocational and educational needs. However two of the standards merely focus on the assessment of these needs to promote an understanding of the user group. The third standard addresses the need to have access to appropriate agencies to provide for leisure, vocational, educational, spiritual and housing needs. In the light of the findings from our study there may not be enough emphasis on the need to engage with these agencies, or
understand the skills necessary to support service users to go to and use community based opportunities. If the CFMHS just has a relationship with an agency as recommended, that does not mean that the service user can access that agency in a way that is meaningful to them, as can be seen from an example from one of the participants. He was given the information about an employment agency, but was not provided with the opening times or support to access it. One participant was told that there were some college courses available but was not informed about the local recovery college which may have had some courses more relevant to his needs. Again he was not supported to find the college to make the first move towards accessing a course. These are both examples of occupational deprivation; the participants were denied detailed information, guidance and support to access the work or educational opportunities. The consequences of not providing the support to access and make use of these resources can be devastating for the individual service user. As our study has shown the participants are left feeling unsure about how to proceed.

9.7.5 Influencing national guidelines
The GOSO challenges have the potential to inform guidelines at a national level. NICE recently published guidelines for the mental health of adults in contact with the criminal justice system, (NG66) (NICE, 2017). Guideline 1.9.2 is written below. It can be seen that although it is recognised that staff should be informed about the stigma and discrimination associated with mental health the discrimination associated with offending is not explicitly mentioned.

Guideline 1.9.2 Commissioners and providers of criminal justice services and healthcare services should educate all staff about:

- The stigma and discrimination associated with mental health problems and associated behaviours, such as self harm
- The need to avoid judgemental attitudes
- The need to avoid using inappropriate terminology

(NICE, 2017)

If they had been written with the GOSO challenges in mind they would have included educating all staff about the stigma and discrimination associated with mental health problems and offending behaviour.

This is the same throughout the document. The impact of having offended on the individual, as emerged in our study, is not mentioned in the guidelines. This is expected because this is new knowledge. However it does demonstrate the utility of the findings from our study at a
national level. The service user understandings will contribute to the professional understandings to create a more comprehensive picture.

9.8 Revisiting the decision not to include details of the offence in the participant interviews

As discussed in Chapter 6 a decision was made at the beginning of our study not to ask the participants about details of the offence that had brought them into contact with secure mental health services. In the event, out of the five study participants, three disclosed their offence within our study and one did not describe the specifics of the offence but did refer to the victim. Only one participant did not refer to the offence. The O in the GOSO challenges refers to the offence specific aspects of offender recovery so it is worth reviewing whether it would have been useful to ask participants about the specifics of their offence. The original decision not to ask about the offence was based on the opinions of the SURs who argued that firstly they felt uncomfortable asking a direct question about the offence, and secondly, that for participants, a question about the offence could not be answered by just a simple factual answer. On reflection I think that not asking about the offence was the right decision for this study. The important learning from the participants’ responses is that it is not the specifics of the offence that is impacting on their reintegration into the community. It is the fact that they have a history of offending. If we had asked about the specific offences in the interview the impact of an offence history, regardless of the particular offence, may have been obscured.

Our study has highlighted an important aspect of recovery work in forensic settings. In national discussions and workshops, which seek to explore recovery in forensic settings such as the Recovery and Outcomes Conferences, and the Centre for Mental Health paper (Drennan & Wooldridge, 2014), discussion of the impact of the offence does not take place. In clinical arenas the offence is addressed directly for example in offence specific groups such as The Firesetting Intervention Programme for Mentally Disordered Offenders (FIT_MO) (Gannon, Lockerbie & Tyler, 2013). Recovery based groups in secure settings focus on mental health recovery; however the offending history is not discussed (Miles et al., 2012; Moore et al., 2012). There is no reason given for this omission. I suspect, however, this is because both service users and clinicians feel uncomfortable about referring to specific offences. The consequence of omitting this subject is that the impact of a history of offending on the individual’s recovery journey is not being acknowledged or thought through. Our study highlights the fact that a history of offending influences all aspects of recovery.
This means that currently an important part of service user’s experience and the challenges they will encounter are not being raised in recovery-based interventions in forensic services. The preparation for community living is incomplete. The GOSO challenges provide a language within which the impact of an offence history on all aspects of recovery can be identified, discussed and reflected on. It suggests a non-threatening way for service users and staff to consider the issues that arise from having an offence history. The GOSO challenges open up a new channel of communication where the reality of the offence and its implications can be discussed without a focus on the details of the offence itself.

9.9 Limitations of our study

There are a number of limitations to this study. These are mainly related to the use of a qualitative methodology. The aim of qualitative research is not to produce objective results that can be directly generalised to other situations, but to open up thinking and shed light on specific aspects of lived experience (Sutton, 2008). As a result of this, smaller numbers of participants are used with a view to gaining a deeper understanding of their individual experiences. This is the challenge of the use of a participatory methodology when seeking to add to the evidence base. Because of the prominence given to larger scale studies in the current dominant scientific paradigm, the practical implication is that this research type is situated at the bottom of the hierarchy of evidence. The strength of qualitative methods is, however, that they allow much more detail about individual’s experiences to be explored (Slade, 2010).

There were 6 participants in this study, although one dropped out. This is a small number, although as discussed in Chapter 5, there is no specific recommended number of participants in a qualitative study (Baker & Edwards, 2010). The participants were all white, British males who lived in one UK coastal county. Because of the small numbers there is a probability that other categories or aspects of recovery in this population may have been identified if there had been more participants. In addition service users from other populations with a similar clinical history, notably women, people with different ethnic backgrounds or groups living in different environments, for example more-urban environments, will have different experiences which will have yielded different outcomes. This study does not profess to provide a comprehensive understanding of recovery for those with mental illness and an offending history and it does not suppose to capture them all. However there is some coherence between these findings and other recovery and forensic research, which lends them credence (Drennan & Wooldridge, 2014; Mason & Adler, 2012).
There are limitations caused by the method of data collection, semi-structured interviews. The tendency of participants to give socially acceptable answers to questions they are asked is known as the social desirability bias (Noiseux et al., 2010). This may limit the breadth of data collected and, consequently, the depth of the analysis. Although I employed the control for this limitation by employing service user researchers to carry out the interviews with the aim of improving the experience of the interview for the participants (Harding, 2010) this may have simply altered the nature of the bias. A socially acceptable response to a fellow peer may be different from a socially acceptable response to a clinical professional.

Data analysis in qualitative research is influenced by the characteristics of the researchers and their personal and professional backgrounds (Whiting, 2002). Another research team with different backgrounds might have identified different themes within the data. However, the data analysis process and emerging findings were discussed with the supervisors and the clinical teams to check for relevance (Donovan & Sanders, 2005).

### 9.10 Suggestions for further research

This is the one of the first studies to explore the perspectives of the service users for this service user group. It has opened up a rich seam of potential directions for future research. Our study has started to raise awareness that the recovery challenges for this service user group are very different from those with mainstream mental illness and is therefore worthy of a specific, specialised research programme approach. This may be argued as one of the main contributions of our study. There is potential for each of the elements of the GOSO challenges or the secure recovery context to be explored in more detail in future research.

I do not claim to have uncovered a definitive list of all the specific recovery challenges instead I believe this study has touched the tip of the iceberg. Future exploratory studies could be carried out to identify the secure offender recovery issues for different groups including women in secure services, different ethnic groups and different populations.

Our study participants were people who had successfully moved from secure services to living in the community. In our study the participants referred to their contemporaries in hospital who had not yet managed to overcome the challenges to recovery. Future research is recommended to explore this group’s experiences in further detail to identify the barriers to recovery in these groups.
The participatory nature of our study means that one of the outcomes of our study is that there are two SURs who have training and experience in research. Some of the participants have also continued to show an interest in the research process. Future studies defined by their interests and research priorities will continue to develop a community of research. The secure services could be seen as a developing a ‘Community of Interest’ (CoI) (Mulivihill, Hart, Northmore, Wolff & Pratt, 2011), which could begin to build alliances with local universities in order have access to more formal research expertise.

9.11 Dissemination of findings

The dissemination of the findings from our study will build upon the series of papers I, and the SURs have presented throughout the duration of the project. These are listed in Appendix III. Our team will continue to contribute to local, national and international conferences.

I have also presented the GOSO challenges in the form of a leaflet (Appendix IV) for service users. The SURs were keen to be able to present the GOSO challenges to other service users in an easily accessible way. The illustrations on the leaflet are by another service user who was keen to be involved with the project and who was pleased to be credited on the leaflet. The leaflet lists the GOSO challenges and suggests that working on the challenges will support service users to get out of hospital and stay out of hospital. It provides the SURs with a document through which they can share the outcomes of the research they have been working on. It also provides service users and staff with a reference point to the GOSO challenges.

In addition to paper presentations I, with the SURs, will be submitting articles to professional and peer related journals. There are different potential audiences for this study:

Firstly other service users both those who have a history of mental illness and offending, and service users recovering from generic mental illness. Service user newsletters like the Recovery and Outcomes Newsletter are published nationally but have a service user readership in mind. Some peer-reviewed journals have been started which encourage co-authorship of articles between peers and professionals, examples include the Journal of Mental Health Training, Education and Practice and Mental Health and Social Inclusion. Secondly there is the occupational therapy community. Outcomes from this study will include both the findings of our study and learning from the methodology used. I would like to share my experience to encourage more occupational therapists to utilise this methodology.
Thirdly there is the professional forensic healthcare community. Again I would like to share the learning from our study and the methodology used. Finally there is the participatory research community I will share the strategies used and the learning from these.

9.12 Conclusion

Our study and the development of the GOSO challenges have extended our understanding around most of the issues that arose from the literature review.

- It has identified a more detailed, nuanced understanding of the experience of service users discharged from a secure setting. This has resulted in a developing understanding of their specific recovery tasks.
- It has extended our knowledge about the recovery experience for mental health service users with an offence history.
- It has identified some of the service user outcomes for this client group.
- It has highlighted the impact that limited access to occupation and work has on the service user's mental health recovery. The concepts of occupational justice provided a useful framework for considering the relationship between occupation and risk.
- It has identified a number of issues that may contribute to the reconviction rate increasing over time.
- It has suggested a number of reasons why discharge can be anxiety provoking for service users.

The only subject raised by the literature review, which did not arise in our study, was the dark side of occupation. The reasons for this were considered earlier in this chapter.

The novel understandings that have emerged from this study come from the issues that impact on the daily life of the participants; the small but significant interactions that take place that can only really be anticipated and described by someone who has experienced them. What was referred to as “changeable factors” (Coid et al., 2007, p. 229) become all too clear to those experiencing the barriers of mental illness and an offending history on a daily basis. Most of the specific tasks of good relationships, meaningful occupation, social inclusion and offender issues, have been identified before. What this study does is collect them to gain a deeper overall understanding of the specific challenges facing this population. These challenges are a result of the environment within which they undertake their recovery journey and the specific recovery tasks, which they need to achieve.
There are obvious similarities between mental health recovery and the recovery experiences of mentally disordered offenders. This has obscured the very real additional challenges and needs of the mentally disordered population. The paper published by The Centre for Mental Health, “Making Recovery a Reality in Forensic Settings” (Drennan & Wooldridge, 2014) suggests that the recovery journey for mentally disordered offenders is mostly identical to the recovery journey for people in non-forensic settings. From this study it can be seen that the lack of clarity about the unique recovery challenges is caused by the superficially similar recovery tasks inherent in recovering from a mental illness and recovering from a mental illness and offence. It can be compared to the famous saying about America and the UK: ‘two countries divided by a common language.’ These are two recovery journeys, which use very similar language and tools but there are significant differences in experience. The differences are subtle and not always observed from the outside but they are experienced as complex and daunting. The offence adds a complexity to every aspect of recovery for the individuals concerned. It can also be difficult to separate out the mental health and offender part of the recovery task. They are not always separate tasks, as has previously been considered; rather they are two aspects of the same recovery task. The GOSO challenges offer a structure and a language where this specialist recovery journey can be considered for the first time.
Chapter 10. Reflections on participatory methodology

In this chapter I begin by discussing how our study builds on what is known about transitions and social inclusion. I then reflect on the impact of the methodology and the participation of the SURs in our study. I would like my learning about the methods used to contribute to the developing body of knowledge by giving guidance to future participatory researchers. To this end in this chapter I have presented a model, grounded in Habermas’ theory of communicative action, for supporting involvement based on my work in this study. I also spend some time with a discussion about the impact of the involvement in our study on both SURs themselves and the wider service. I finish by considering the formation of my researcher identity.

10.1 Transition

In this next section I am going to return to some of the theories of transition reviewed in Chapter 3. I will discuss them in relation to my findings to see how they explain the findings and what our study contributes to the understanding about transition in this client group.

There were two studies, which looked at transition in forensic service users. Coffey (2012) identified several characteristics of transition in this group that were also found in our study. Coffey (2012) focused on admission to hospital. He stated that this transition for forensic service users was not one of their choice, which was the case with our study. However the primary transition the participants are currently going through, re-establishing a life in the community, is a transition chosen by the service users. Coffey also notes that this transition does not have the same level of public support as life transitions such as retiring. This is the case for the participants in our study. The implication of this is that their transition and the difficulties they encounter is not recognised or understood. As a result of this they may be isolated and not receive the support that they need.

In their study looking at discharge from secure services, The Centre for Mental Health noted that discharge from secure services was so anxiety provoking for service users that it led to a risk of relapse (CMH, 2011). There were no details about what caused the anxiety other than the prospect of discharge. The GOSO challenges provide more detailed information about the issues that contribute to this anxiety. The challenges highlight the potential barriers they will encounter to accessing support, finding work or building relationships due to
discrimination, stigma and the need to disclose their offence. Utilising the GOSO framework may allow individuals and clinicians to identify the specific issues that impact on the individual. This may lead to interventions that support the transition process for that individual by providing information, opportunities to reflect or accompanied visits to places of interest.

Kock and Kralik (2006) proposed transition in health as a four-part pathway: familiar life, ending, limbo and becoming ordinary. This model describes the experiences of the participants. The participants in this study all described being in a stage of limbo as they try and move from their old identity as an in-patient to an ordinary life in the community. They described feeling disempowered and disorientated as they adjusted to community life. Meleis (2000) notes that understanding the transition process can lead to an understanding of potential risks. The GOSO challenges provide a tool to aid understanding of some of the issues they need to address as they make this move.

Visher and Travis (2003) identify four dimensions which affect prisoner re-entry into the community: individual characteristics/ circumstances, family, community and state policy (Visher & Travis, 2003). Although they are not directly the same there are some similarities with the GOSO challenges. The GOSO challenges provide a more detailed breakdown of the issues that impact on reintegration with the community. For example one of the four dimensions noted by Visher and Travis (2003) is family. In our study family relationships are recognised as playing a supportive role to reconnect individuals with community. However in the GOSO challenges two other types of relationships also contribute to reintegration: friends and staff. However the four dimensions do confirm the utility of the GOSO challenges to describe and identify and explain the different dimensions or aspects of transition into the community from an offender perspective.

Our study contributes to what is known about transition by confirming some of the findings of previous studies and also adding to the picture of transition in this client group. Previous accounts of transition provide the landscape of the transition process the participants are undertaking. Our study details some of the elements that contribute to their ongoing transition. This includes support needed, knowledge required and issues that need to be reflected on by those undergoing the transition.

10.2 Social inclusion

The experience of the participants was characterised by social exclusion. Individuals described feeling marginalised and socially isolated. The social model of disability draws a
distinction between the impairment of the person through a diagnosed condition and the impact of the negative societal reaction to the condition (Beresford, Nettle & Perring, 2010). It has been found out in previous research that it is the responses of others which often have a greater impact on the individual than the original mental health problem (Beresford, Nettle & Perring, 2010). This was the case with the participants in our study. I am going to draw on Silver’s (1994) three paradigms of social exclusion, which was introduced in the literature review in order to explore the impact of social exclusion on the participants in our study. This reference is old but it is cited and referred to by many researchers when considering social exclusion. The findings showed that the participants are experiencing all three of the paradigms of social exclusion.

The first paradigm identified by Silver (1994) is solidarity. This is defined as the breaking of the social bond, both cultural and moral. The participants had a history of offending, which broke the social bond of being law abiding. This has resulted in the physical exclusion from society in a secure hospital and for some of the participants also in prison. Now that they were living in the community the offence history still has an impact. For some they were still excluded, by order of the courts, from their home community. As discussed in Chapter 9 issues of disclosure of the mental illness and the offending history impacted on the participants’ ability to gain work. They considered that this was because of their offending history. The mental health awareness campaigns cited in the literature review (Baker, 2011; Evans-Lacko et al., 2013) seem to be having an impact. Some of the participants said that they experienced examples of disclosing their mental health problems and being supported as a result. However they had been reluctant to disclose their offending history because of a concern about the response. As a result they were guarded in their interactions because of the additional effort involved with concealing their offending history. This response has been noted in a previous study in people with mental health problems (Rebeiro, 2001). In both her study and mine it results in people avoiding interactions.

The second paradigm identified by Silver (1994) is specialisation, which draws on concepts of individual freedom and equality. Previous research has shown that people with mental health problems experience stigma and discrimination in all parts of their lives: work, education, friendships and community engagement. (NMDHU, 2011). This was the same for the participants in this study.

What our study adds to this understanding of social exclusion is the fact that mental health service users discriminate against people who have been discharged from secure services. People in secure services are detained under the Mental Health Act (DoH, 1983) under
different sections than those with mental health problems. They are admitted to different hospitals, and they stay in hospital for longer lengths of time. This marks them out as dissimilar from the general mental health population. Some others, with a mental illness, discriminate against them as a result of this. Rebeiro’s study (2001) highlighted that for people with mental health problems spending time with their peers in a community setting provided a refuge, a safe space to belong, which was essential to building their confidence in the community. The group in our study did not experience this sense of belonging in community mental health resources, this resulted in self-exclusion from these services. This increased their vulnerability and sense of isolation in the community.

Silver (1994) calls the third paradigm of social exclusion monopoly. This assumes that insiders have a form of monopoly or power over outsiders. That valued resources are restricted by cultural, legal or material boundaries. Social institutions and cultural boundaries perpetuate inequality. One example of this is the attitude of the approach to risk management taken by the planners and clinicians within clinical services. The CFMHT act as gatekeepers to some community facilities. They provide or withhold information and support to access a range of opportunities. They are informed by service and policy attitudes to risk management. This is discussed more fully in Chapter 9. Social exclusion in the community is regarded in some ways as a risk reducer (Rose, 2000). However the service provided is not set up to support individuals overcome the barriers to inclusion. This is a significant transition that the participants are embarking on. Some have minimal practical help, although their progress is monitored and supported by the clinical team. It was significant that the participant who appeared to have progressed the most effectively in his transition was the one who received regular guidance from support workers who accompanied him to social situations. Rather than advice and information he was provided with a support worker who went along with him to use the gym, or go for a coffee. It is this type of regular intervention that may support service users to become more engaged with community resources. Peer support to carry out this intervention has been recommended in mental health services (Repper et al., 2013), and is currently being tested out in research (Foster, Gibson & Marks, 2015). Our study suggests that it could have benefits in this group.

The use of Silver’s three paradigms to analysing the participants’ experience of social exclusion in this way confirms that it is the attitude of others and society that create many of the boundaries experienced by the participants. It demonstrates the ongoing relevance of Silver’s work. This group is among some of the most marginalised people in society. Services to support them need to go beyond monitoring them. In order to fully support them to address the GOSO challenges and integrate into society it is recommended that they are
provided with specialist help in the form of peer support and services that help the individual to access community opportunities.

10.3 Communicative Action

Habermas provides a theoretical framework to understand, describe and reflect on the participatory nature of our study and how knowledge was created or formed within our study team. Habermas proposed that understanding is a social process (Habermas, 1986). His theory of communicative action is based on the assumption that individuals with different perspectives on the same issue can develop a greater understanding with the use of language by asking and answering questions, justifying statements and exploring arguments (Walseth & Schei, 2011). Communicative action is the process of coming to an agreement concerning the interpretation of a situation (Sik, 2015). In this study communicative action took place within the research sessions. The two SURs and myself had different perspectives of the subject, that of patient and clinician. We came together within the research sessions to explore, debate, enquire, reflect on and develop a deeper understanding of the issues related to our study.

According to Habermas, for a mutual understanding to take place decisions have to be rooted in the lifeworld of all the individuals taking part (Habermas, 1987). Lifeworld is a term derived from Husserl; it is the horizon of tacit, everyday knowledge based in the experience of an individual's lived life (Walseth & Schei, 2011). Cultures are shaped when people share the same day-to-day experiential knowledge. These cultures can be within a family, the fans of a football team or, in the case of this study, a group of people with mental health problems and a history of offending. A shared lifeworld acts as a link between the individual and the social community they belong to.

Habermas builds on our understanding of the lifeworld by breaking it down into three different dimensions: the objective, the social and the subjective worlds (Habermas, 1987). These three dimensions resonate with the processes of my research and generation of data. I am going to describe these in turn and illustrate them with examples from our study.

1 Objective World

The objective world involves factual knowledge that can be judged objectively or independently. I identified three aspects of the objective world that required attention within the research meetings: practical issues related to organisation of our study, the
structure and timing of the academic course and, the interview data itself. I will
discuss these in more detail.

The first aspect of the objective world related to the organisation of our study. This
involved addressing issues related to involvement in the project such as queries
about pay, and its affect on benefits. It also involved the development of research
skills and the provision of training. I have discussed the strategies I took to address
these issues in more detail in Chapter 4. Here I want to reflect on the contribution of
this work to achieving mutual understanding. Attending to these practical issues
consistently ensured that the SUR’s felt that their needs were being met. If these real,
hands on, issues were not attended to, the SURs may have been distracted by them,
preoccupied with them and they may have ultimately influenced the SUR’s
willingness to be involved with the project. The practical issues changed throughout
the project. At the beginning the SURs needed reassurance that the payment for
involvement was not going to affect their benefit payments. Later they were related to
training and development. It was also important to give attention to the impact of
involvement on their continued mental health. I anticipated that involvement in an
activity that was meaningful to them would benefit their mental health. The impact of
work on mental health is recognised (Arbesman & Logsdon, 2011). However it can
also be a cause of stress (Burns et al., 2009). I needed to ensure that the demands of
the work were right for them. I did this by regularly seeking their views on the
expectations of the role, the workload and demands of involvement. When our study
was established it was agreed that if any mental health concerns arose as a result of
their involvement we would discuss the impact of working on our study with the
SUR’s care teams. In the event both SURs thrived through involvement in the project.
I did, however, have some contact with the care teams. One of the SURs asked me
to write a report on their involvement in our study to present to a Tribunal, which
reviewed their monitoring under Section 41 of the Mental Health Act (DoH, 1983). I
wrote two such reports for him. The report from the first tribunal noted the benefit of
his involvement and in the second tribunal the Section 41 was removed. This was a
significant achievement and marker of progress for him. His involvement in the
project built his confidence and abilities. It also gave him an opportunity to
demonstrate this.

The second aspect of objective world, which influenced our study, was the structure
and timing of our study and the academic course. Our study had particular stages
and landmarks. These included planning, preparing for and seeking ethics approval,
recruiting participants and interviewing them, analysis of the data from the transcripts, developing findings and preparing reports and presentations of findings. In addition to this our study was being carried out in the context of an academic award. I regularly updated the SURs about the course structure and my latest learning. The SURs also met with my supervisors once every six months. This allowed them to have some contact with the University and ask any questions.

The final aspect of the objective world of our study was the interview data. This is the objective world of the participants as seen in the interview transcripts that the research team analysed. There was a shared sense of ownership and commitment to this data because the SURs had carried out the interviews and so facilitated the collection of the interview responses and I had worked with them in the development of our study. This was the information that the SURs and I aimed to understand and interpret from our different perspectives. This was the core part of the work that we carried out. The data analysis process is described in more detail in Chapter 7.

These three aspects of the objective world: the practical issues, the course landmarks and the participant transcripts provide the framework, the functional, concrete aspects of the lifeworld of our team. They needed to be in place to support communicative action in our study.

2 Social World

The second facet of the Habermas' lifeworld is the social world. This concerns the way that people relate to each other. It involves the rules and norms that govern social interaction. In the early stages of the project as the research team were developing relationships, we got to know each other socially celebrating birthdays and Christmas events. The social elements of participatory research have an important function (Stringer, 2007). Working with people who may not have experience of professional working relationships in a research context is helped by the act of the researcher meeting them in personal contexts, breaking down barriers to communication, and fostering good working relationships based on trust and shared experiences (Koch & Kralik, 2006; Stringer, 2007). In a reflective discussion Richard articulated the link between the social world and the contribution to the project work as follows: ‘I think we’ve got that relationship between the three of us and we enjoy each other’s company and I think because we enjoy it that’s why we’re producing such a high level because we’re enjoying what we’re doing and therefore we seem to have more insight and understanding of how to move the project on’
Having good social relationships within the team develops trust and a supportive environment. It eases the work of the team, making it more enjoyable. It also provides a trusting atmosphere where the important work of debate, questioning and exploration of the subject at hand can take place.

In addition to getting to know each other I was aware of developing a subculture within our research team that was attentive to and addressed power issues within the team. From the outset I encouraged regular discussion about how we worked and interacted as a team. This aimed to ensure that critical review of how we carried out the work became routine and expected so that the SURs would not feel unable to question or query how I approached the sessions. One of the outcomes of this was that the SURs were confident in the contribution that they made as highlighted in this reflection from Chris ‘it weren’t just Debbie sitting down saying right you’ve got to do this that and that. It’s become a free input progression, Richard and I couldn’t develop it ourselves without Debbie, Debbie couldn’t have developed it without us two’ (February, 2016). It is challenging to remove all power imbalances within the team, at the end of the day I am still in a position of power and authority within our study and within the organisation. However this attention to the relationships within the research team and regular reflection about how we worked as a team was one of the strategies I employed to reduce the impact of this power imbalance.

3 Subjective World
The third aspect of Habermas’ lifeworld is the subjective world. The subjective world consists of each individual’s personal intentions, emotions, and drives. Involvement in our study needed to remain relevant to the individuals otherwise their interest would have waned (Mercer et al., 2008). By providing opportunities for regular reflection within the research meetings I was able to learn from the SURs how involvement in the project met their goals. I was able to tweak and adjust the project to support this. One example of this in the project is Richard, who had a particular interest in goal setting and motivation. Early in our study he shared his interest in one particular motivational speaker and expert on organisations, Brian Tracey (Tracy, 2010). I therefore actively incorporated some of Tracey’s principles of goal setting and project management into our study. Our study not only benefitted from this but Richard felt empowered by having something that he valued actively utilised within the project. He said “it was such a sublime moment for me when Debbie picked up on that kind of teaching, because I’ve been passionate about it for over 20 years” (February, 2016).
During the research sessions I also allowed time for the SUR’s to discuss any issues going on in their lives outside of the project. They brought the day-to-day challenges that they faced to the team meetings; this included seeking advice about supporting friends with mental illness, and their ongoing experiences of stigma and discrimination. This provided a dual role of providing ongoing support to the SURs but also informed our study. The issues they were experiencing were similar to the participants. It gave me an appreciation of the ongoing, daily challenges faced by members of this group. Hearing of the issues that the SURs had to consider on a regular basis gave me a sharper appreciation of how the issues that the participants described influenced their decisions on a day-to-day basis.

In practice these three aspects, which constitute the lifeworld, are intertwined but attention needed to be given to each of them in the research sessions. They steered the communication and interaction providing the architecture to our study.

Habermas made a theoretical contribution through developing the theory of communicative action (Habermas, 1987). However he did not suggest how to put this into action. Participatory research literature to date has provided guidelines about the characteristics of participatory research (ICPHR, 2013a; Mercer et al., 2008). However there are no models about how this life world can be considered within the context of a small research team within a clinical setting. This may be because one characteristic of PHR is that the specific strategies used are tailored around the specific research teams and aims of the research. However this lack of detail in how participatory research is carried out and how communicative action can be facilitated may deter potential researchers from utilising this approach. This may be why PR as a methodology is relatively uncommon in occupational therapy research (Whalley Hammell, 2007). Throughout our study I developed a structure to organising the research sessions. This attended to the objective, social and subjective aspects of the lifeworld, and contributed to supporting communicative action throughout the project. I have formed this learning into a model, a practical way to support communicative action within research teams, which may be helpful to future participatory researchers. I describe this in detail below.

10.4 Introducing the GROUP model

I have developed a five-part model based on my experience and observations in this study. I hope that by providing a clear blueprint for conducting research sessions more researchers will feel confident to use this approach. It is grounded in a Habermasian theoretical
approach. I have called it the GROUP model. The five-step group model needs to be followed in each research session. It will ensure the objective, social and subjective aspects of the lifeworld of the participants are addressed and by doing so will foster an environment where communicative action can occur. The GROUP model introduces the different tasks or aspects of communication which need to be in place during every research meeting. It provides a structure for each session which is predictable but which incorporates flexibility to meet the demands of each stage of our study process. GROUP is an acronym with each letter serving as an initial for each of the five stages. I have listed the stages below:

- Gather
- Refocus on project
- Outcomes of session – the work task of the session
- Understanding
- Practical administrative tasks

I will now describe each stage. I will begin by stating which aspects of Habermas’ lifeworld are addressed before going on to describe the characteristics of each stage more fully.

**Gather**
Stage one is called gather: (This stage will address the objective, social, and subjective worlds described by Habermas (1987), depending on what arises). The first part of every research meeting is to welcome all to the meeting. This is followed by providing a space for general feedback about what has happened in people’s lives since the last session. This stage serves several purposes. Firstly it gives the research team members an opportunity to discuss anything that is on their mind. It also has the potential for the team to share practical and emotional support and advice. It contributes to the social cohesion of the group as we learn more about each other. The lead researcher can begin to learn more about the team members’ interests, skills and motivations and the team members can learn about the lead researcher. It is also an opportunity to learn about what other relevant experiences team members have had since the last session; for example if they have had any additional research experience or training. Finally it begins to settle the team members into the communicative space, by bringing the team together.

**Refocus on project**
Stage 2 is called refocus on project. (This stage will address the objective and subjective aspect of the lifeworld as described by Habermas (1987)). This stage moves the team towards the purpose of the meeting. It is important to refocus the research team to the project. This involves recapping on the work, which has been
carried out to date, and identifying the immediate and long term plans for the project. This orientates people to our study and acts as a reminder about what has been done and puts the work of the session ahead within the context of the whole project. It also serves to remind the group why they are involved with the project and their personal goals within it. This stage should involve a discussion with contributions from all members, it is not just the lead researchers providing the information but all participants involved in recalling the project, and their involvement to date. It helps to remind people why they are involved with the project and how involvement meets each individual member’s goals. In the context of a long-term project this regular refocus serves as a reminder to people about why they are there. This maintains enthusiasm and commitment.

**Outcome of the session**

Stage 3 is the outcome of the session. (This stage will address the objective aspect of the lifeworld as described by Habermas (1987)). This is the work of the session itself, the content that has been planned for that day to take the project forward. Depending on the stage of the project this could include role definition, planning, preparing for ethical approval, data analysis or preparing presentations.

**Understanding**

Stage 4 is understanding. (This stage will address the social and subjective aspects of the lifeworld as described by Habermas (1987)). After the task of the session has been completed it is important to reflect as a group about what has happened in the meeting. This involves both what has been done to progress our study and how the team has worked as a group. In particular this is an opportunity to regularly review and discuss issues of power differentials. Did everyone feel heard? Was everyone able to make the contribution they wanted to make? How was the facilitation style of the lead researcher? Was the task explained clearly enough, how could this be improved? Making the discussion about how the group works a routine part of the sessions provides an opportunity for all to become familiar with the concept of reflective practice and gives people an opportunity to learn and develop the confidence to challenge issues as they arise.

Another reason for this discussion is for the lead researcher to develop an understanding about the skills and interests of the team members, by attending to immediate feedback. Future sessions can then be planned to utilise the strengths and interests of the group members. This is an opportunity to tailor the culture of the
team. It is another way to support continued motivation to continue with a long-term project.

**Practical administrative tasks**

Stage 5 is managing practical administrative tasks. (This stage will address the objective aspect of the lifeworld as described by Habermas (1987)). These are the practical arrangements necessary for the project to take place. It can involve the completion of timesheets and booking dates for the next meeting.

Each one of the GROUP stages need to be present in each research meeting. However the time taken with each stage will vary across the course of our study. For example in the initial parts of our study as the team is forming there may be more attention on the first two stages as the team get to know each other and begin to understand the nature of the task. In the data analysis stages, when the SURs had looked at the data at home and were keen to compare their understanding with each other the first two stages were very brief as we focused on the outcome stage. Occasionally the majority of the session focused on the practical administration of our study. On one occasion when one of the SURs arrived to the session in a distressed state the majority of the session was taken up with gather, the first stage, as we provided support for an immediate problem.

The GROUP stages provide a predictable structure and creates an environment where the objective, social and subjective aspects of the lifeworld can be nurtured and addressed. It helps the study leader and the research team members understand and navigate through the study process. It ensures that all aspects of are addressed to support involvement and to achieve the goals of our study.

**10.5 The impact of our study on the SURs and the service**

In this next section I want to reflect on the impact of our study on the SURs and on the wider clinical service where took place. For the SURs participation in our study has had an impact both personally and professionally. The empowering impact on those that participate in participatory research is acknowledged (Koch & Kralik, 2006). However what I did not anticipate was the impact of participation on the service. Our study did not take place in a vacuum. The two SURs were patients within the service and I was a clinician. The participants all came from within the service. One characteristic of PHR is the explicit intention to bring about social change (ICPHR, 2013a). In fact Stoecker (2008) conceptualises participatory research as one part of a wider social change project. As I
reflect on the changes that have occurred as a result of our study I agree with this perspective. I am going to describe the impact of our study on the SURs and the service.

Both of the SURs have developed throughout the project. They have used the learning from the project to gain employment in related roles. They have been employed as peer workers and have acted as advisors on other research projects. They are also both members of the local research group. Richard described the impact that involvement in our study had for him; “My self-esteem and self-confidence is high, from what it was, when we first got together in 2010. I’ve got three or four different hats working for mental health services, and I wouldn’t be here today, doing those things, if it wasn’t for our project, it’s made a great, a massive impact for me and my life.” According to Bradbury and Reason (2008) this demonstrates a mark of quality in a research project. It demonstrates the sustainability of the participatory aspect of the project. The SURs have not only been empowered by participation they have developed skills which has opened up other opportunities for them.

In this next section I will discuss some of the significant attitudinal and structural changes within the service which have been influenced by our study. I want to acknowledge first that I am aware that these changes are not solely due to our study. It is increasingly an expectation from commissioners and national standards that service users take a more active role in aspects of planning and service delivery (JCPMH, 2013; RCP, 2007). However, I believe our study, and the flourishing of the SURs, has gone a long way to demonstrate the potential of utilising the skills of peers to clinicians. Examples of these changes have occurred at the individual clinician and service leadership level.

Firstly, this influence was at the level of local clinicians. The two SURs were both not only well known by the clinical teams, but at the beginning of our study they were both still under their care. At a clinical level the teams could see how participating in the research study contributed to their progress. This is referred to as transformative learning (Park, 2006). In the duration of the project one SUR was discharged from the CFMHT and the other SUR was discharged from being monitored under Section 41 of the Mental Health Act (DoH, 1983). Involvement in our study has changed the way the SURs saw the world and themselves and the clinical teams acknowledged this. It helped to demonstrate the impact of meaningful work (Flanagan, Zeev & Corrigan, 2012) and challenge staff attitudes that associated work with increased risk. This is discussed more fully in Chapter 9.

Secondly this influence was at the more senior manager level. Because of the experience gained as a result of involvement with our study the SURs were asked by other staff to take on involvement work, such as sit on interview panels. They became members of interview
panels alongside senior staff. They used the analytical skills they had learnt and the confidence they had developed to speak up and share their opinions. In these encounters previously sceptical staff could see and experience for themselves the benefit and uniqueness of the service user perspective on real issues. This change in attitude was well described by Chris: “Since I’ve been doing this project with the other things that we done, afterwards I’ve spoken to a doctor that used to be in charge of me. The topic of conversation wasn’t like ‘So Chris, have you taken your meds today?’ it wasn’t like that, it was more like ‘oh did you hear about that happening in the news the other day, about Germany’ or whatever, it makes you feel more at ease, it makes you real, happy for them to treat you like a human being, not just a patient, or ex-patient.” The doctor was now seeing Chris as a colleague, someone who was contributing their expertise as was evidenced by the change in tone of the conversation.

This has smoothed the way for a faster acceptance of other service user led or co-developed initiatives within the service. While the expectations of service user involvement of different types has been an increasing expectation of the service, the obvious benefit of involvement for the SURs and the genuine contribution they have made to service developments or recruitment has caused staff, who may have initially been resistant, to be more supportive in developing these initiatives. This shift in attitude is influencing the way the service is structured. The service recently recruited a service user leader. This is a peer who is employed, and paid, at a senior management level. Their role is to sit on the leadership team as an equal so that service user concerns are considered as a part of all future initiatives. This will mean that there is co-development or involvement of service users at all levels of the service. This role is one of the first of its kind. In this way the service is becoming an innovator in meaningful service user co-delivery of services. Making use of Foucault’s concepts of power, it can be seen how participatory methods can influence change at a range of levels among multiple actors (Gaventa & Cornwall, 2006; Hayward, 2000). The two SURs have demonstrated and embodied the potential that the service user perspective can provide. In a context where increasingly there is an expectation of involvement in service delivery they have been a catalyst for significant service change by demonstrating the benefits of participation at a local level.

10.6 Researcher identity formation

My evolving identity as a researcher has been heavily influenced, and greatly inspired, by authors in the participatory researcher community (Fals Borda, 2006; Farquhar & Wing, 2008; Israel et al., 2008; Koch & Kralik, 2006; Park, 2006). I have been inspired by reading
about their research, the values embodied in participatory research and how researchers tailored their strategies around the particular populations they worked with. Despite the critique of participatory approaches, explored more fully in Chapter 4, in some ways I felt like I was joining and, hopefully, would be contributing to an increasingly established tradition of research. The status of participatory research was confirmed to me when I read that back in 1994 Gibbons et al., had described new traditions of science saying that there was “sufficient empirical evidence to indicate a distinct set of cognitive and social practices” (Gibbons et al., 1994, p. 3). Some of the characteristics of, what they called Mode 2 knowledge development, included developing knowledge that could be applied to address practical concerns, incorporated values of social accountability and reflexivity and involved a wide range of people in knowledge development, not just researchers. These are all characteristics of participatory research.

My developing researcher identity was influenced by the fact that I was a practitioner continuing to work within a clinical context. I was an insider researching within my area of work. In order to develop as a doctoral researcher I needed to position myself reflexively. I initially expected to be able to develop a specific role as a researcher however it proved a complex task to separate out my role as a practitioner and a researcher. Eventually I was able acknowledge that each affected the other. Rather than developing a distinct role I was developing an additional lens through which to observe my practice. But my practice and research complimented and informed each other. Each was enriched by the other. I found that as I developed strategies of facilitating communicative action in my research group I began to apply them to a work arena. My practice observations influenced and informed my reading and my reading informed my practice observations. Drake and Health (2011) have noted, that the impact on undertaking research at doctoral level is more on the person undertaking research than on their workplace (p. 60). I found, however, I was changing but my work was benefitting from my increasingly informed perspective. I was beginning to develop a reflexive stance and learning to question what I was doing in a more research informed way.

I elected to carry out a critical research study, with the aim not just to improve outcomes for service users but to assist the representatives of the client group, the SURs to arrive at a critique of the wider service context (Kemmis, 2006). It took me a long time to tease out and really understand what made our study participatory and what skills I was developing as a participatory researcher. I questioned whether I was just hiding behind my occupational therapy skills, using the development of study skills as a therapeutic activity. I undertook to ensure that my relationship with the SURs was a different type of relationship, a working
relationship not a clinical relationship. The strategies such as the agreement of working roles and the relationship with the Trust research team also helped me to build a distinct working relationship. Although I knew from my reading that the development of a study team was a characteristic part of participatory research, it took time to understand and really appreciate that the relationships built up are as much an outcome of a participatory approach as the knowledge that develops (ICPHR, 2013a). One of the criteria of a successful PhD thesis is that it be rigorously researched and original. I constantly doubted my developing expertise. Were the skills I was developing to involve the SURs in our study rigorous research skills? I spent time questioning whether my work to develop the SURs was a distraction from the ‘proper’ study itself.

As our study progressed I saw the benefits of involvement in participatory research that I had read about come to life as I observed the two SURs develop as a result of their involvement in the project. They embodied the empowerment and confidence that can occur as a result of participation. Over time they developed into co-researchers and they brought their unique insights and perspectives to the work. They also brought an energy and enthusiasm to the meetings. Richard described our working as follows: “we kind of bounce off each other and it brings up serendipitous ideas, you know happy discoveries, because we’ve got a common theme, a common purpose and we bring three different viewpoints to that purpose, and what we do, three minds working together.” This quote describes the participatory research in process. It shows an equal relationship between the researcher and experts by experience as they work together to develop knowledge that will address a common goal. It emphasises the social nature of experience and action (Reason & Bradbury, 2006). I was aware this was both a process and an outcome of the involvement strategies that I had employed.

As my awareness of participatory practices increased I noticed that the involvement of lay people, experts by experience was becoming more common in healthcare generally. Within healthcare there was and is still an emphasis given to evidence based practice. The evidence favoured when developing practice guidelines was still the gold standard of the randomised control trial. However even in this arena NICE guideline development (2014) acknowledged the contributions of other study designs including those based on qualitative methodologies. They also explicitly included the views of people using the services. Representatives from the service user group are now invited to be members of the panel that develop the guidelines and other service users are invited to contribute as part of a consultation process (NICE, 2014). It could be said therefore that they are incorporating a participatory perspective into the guideline development process. This acknowledgement supported my developing confidence in my methodology, and the research skills I was
developing. I could see how my developing research skills and knowledge could be utilised within the wider healthcare arena. I was not just developing academic skills but ways of building a bridge between knowledge and practice. The strategies I had developed to support participation were becoming an increasingly relevant research skill.

As this study comes to an end I have a clearer understanding of participatory research. It is a different form of knowledge generation to traditional research and yet it is still a systematic development of knowing and knowledge. The process of enquiry is as important as the outcomes because participatory research starts with everyday experience. Because it leads to new ways of creating knowledge as well as to new knowledge it has an emancipatory element to it (Kemmis, 2006). The researcher role is that of a facilitator and an expert guide to research methods (Bradbury & Reason, 2008). It opens the door to knowledge and understanding of concerns of individuals as they experience them. It recognises that the issues that affect day-to-day living are worthy of study.
Chapter 11. Conclusion

Although this study was small in scale it has made a contribution to what is known about mental health recovery in service users with an offending history. As has been previously discussed in Chapter 9 the GOSO challenges have contributions to make towards theory, policy and practice. In this section I will list the implications arising from the knowledge developed in our study. I have used bullet points to provide a clear display of the recommendations. This was a participatory study and so I will go on to share the learning related to the methodology used and listing the recommendations for future participatory studies.

11.1 Contribution to theory

Our study has provided a much more detailed understanding of what life in the community is like following discharge from a secure service from the point of view of the service user. It has extended the theoretical understanding of recovery for people with mental illness and an offence history.

- It has contributed to our understanding of the impact of having an offence history on mental health recovery. It has shown that there are broad similarities between the recovery of people with mental illness and those with mental illness and an offence history. However it has also begun to name the differences.
- It has provided a detailed list of some of the additional challenges, the GOSO challenges that forensic service users encounter.
- The research has identified some of the additional support that people with mental illness and an offence history need to prepare them for discharge. This included the nature of relationships with staff. Our study has highlighted the importance of staff acceptance of the mental illness and the offence.
- Our study has confirmed the findings of previous studies (Canning et al., 2009; Macinnes et al., 2013), which notes the negative impact that a long-term stay in hospital can have on relationships. It also identifies the important roles carers can have in supporting this group post discharge. This can include practical help, work and social contacts.
- A previous study noted an increased risk of re-offending in this client group after nine years in the community (Dorn et al., 2005). The GOSO challenges identified in our study suggest a number of possible factors, which may contribute to the service user’s vulnerability to reoffending.
• Previous research has shown that potential discharge may be so anxiety provoking that individuals are at risk of relapse prior to discharge (CMH, 2011). Our study, and the GOSO challenges suggests a number of reasons why this may be the case.

• Our study has shown the additional exclusion that individuals experience in society. This includes discrimination from within the mental health community.

11.2 Contribution to practice

The findings from our study make a number of recommendations for practice. These are listed below.

• Our study identifies the contribution of staff acceptance of the individual in knowledge of the offence as well as mental illness to promoting recovery. It is therefore recommended that staff training is reviewed and modified to take into consideration the importance of acceptance of the offence as well as mental health problem for forging a hope sustaining therapeutic relationship.

• Our study recommends the GOSO challenge framework to support individuals to identify GOSO challenges that are most relevant to their situation. They can help to identify individual identified goals.

• The GOSO challenges provide a structure from which a group intervention or recovery college course can be developed. Each of the GOSO challenges can be explored in more detail so that participants can reflect on the implications for their own circumstances.

• It is recommended that current interventions are reframed so that the goals of the service users and staff are more explicitly aligned. The GOSO challenges may help with this.

• It is also recommended that group interventions are reviewed with a view to providing more peer co-produced and co-delivered interventions. This will make a connection between the issues being addressed and their practical application, which has been shown to contribute to recovery outcomes (Repper & Carter, 2011).

• The findings suggested that the timing of the interventions should be reviewed. It may be more appropriate to carry out some group interventions in a community setting, as recommended in previous research (Petersilia, 2004).

11.3 Contribution to policy

• Attitudes to risk management need to be challenged at a policy level in the light of the findings from our study. The current policy seems to be perpetuating social exclusion and isolation based on the assumption that the service user is the cause of a potential risk rather than the circumstances they encounter on discharge (Pollack, 2010). It is recommended that future policy is informed by an understanding of occupational rights
and the contribution that occupation and a meaningful range of activities makes to reducing risk.

- The findings from this study suggest that the community team staff makeup should be reviewed. The value of support workers, or potentially peer workers, to assist service users in accessing community resources was demonstrated in our study.

- It is recommended that the GOSO challenges are referred to in the development of national guidelines. In this way the impact of having offended on mental health recovery will be taken into consideration.

### 11.4 Contribution to participatory research methods

Participatory research has been described as a research paradigm (ICPHR, 2013a). There are no specific research methods associated with it. Instead researchers develop strategies that are suited to the population they are working with and the nature of the inquiry. I found it useful, when planning the study, to read about the strategies other researchers had employed. The methods I used may therefore be informative to future participatory researchers.

- When service users are involved with research they are more often involved with the planning and data collection than the data analysis process. Reasons for this include that they are not interested in this part of the research process (Minkler & Wallerstein, 2008). The data analysis strategy I developed maintained the interest and involvement of the SURs. The detailed description of the data analysis process offers a strategy for future participatory researchers working with small teams in healthcare settings.

- I based the study on the critical theory of Habermas. In particular his concepts of communicative action (Habermas, 1986). The GROUP model introduces the different tasks or aspects of communication, which need to be in place during every research meeting. It ensures that the objective, social and subjective aspects of the lifeworld of the participants are attended to. This fosters an environment where communicative action can occur.

### 11.5 Development of the SURs

Because of the participatory methodology employed, the research incorporated a second set of objectives related to the development of the SURs. I want to finish by sharing how the SURs have developed as a result of being employed as co-researchers on our study.

- This study has demonstrated how two forensic service users can participate in a challenging project over a long-term period and flourish.

- The two SURs participated in a variety of training activities including research courses, sessions with research experts and interview practice.
• The two SURs now have experience in research and are already being asked to consult about other projects.
• They are both employed in other in-patient and community based services in peer support roles.
• They are both members of the service research steering group. They are contributing to the direction and priority setting of research activity within the service.

11.6 Final reflections

When I began the study I had previous experience of working collaboratively with service users to develop clinical services within clinical practice. I had found this a rewarding and effective way of working and wanted to bring this experience to the research arena. During my time as a researcher I have become convinced of the utility of the service user voice and perspective in research and its genuine contribution to the quality of the outcomes of the research. So much so that I believe and would argue that healthcare research should begin from the standpoint of maximum involvement in research of those affected by the research as an expectation and not as an option. National guidance in research has set an expectation of service user or carer involvement in all research planning and implementation, or at the very least researchers in healthcare are expected to consider involvement and give a rationale about why involvement is inappropriate in a particular study (INVOLVE, 2004).

There are guidelines about how involvement can be supported (INVOLVE, 2004) and some researchers have given detailed examples about how they have involved service users (Koch & Kralik, 2006). Our study contributes to this developing body of knowledge by giving guidance to future participatory researchers.

I am so glad that I chose a participatory methodology. Seeing the principles of participation demonstrated in action through the development in skills and confidence of the SURs sustained me during the times when the project was most challenging. I feel privileged to have worked with two people who embraced the opportunities that involvement brought so fully.

I have developed more of an understanding and appreciation for the many challenges that this client group face and an admiration for how they cope with their experiences. Involvement in this project has made me more aware of the individuals behind the patients, the people grappling with the dual stigmas of mental health and offending and still slowly progressing to regain a life in the community. This has made me a more informed therapist.
as I re-orientate the priorities of my interventions with those of the service users: Getting out and staying out.
Chapter 12. References


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APPENDICIES
APPENDIX I: The legal framework

The legal framework is defined by the Mental Health Act 1983 (DoH 1983), which was updated in 2007 (DoH 2007b). Part 2 of the Act relates to compulsory admission, part 3 of the Act relates to compulsory admission by a criminal court. Most admissions to secure and forensic services are carried out under part 3 of the Act. Patients can be detained under civil sections or under criminal sections (by the courts or after transfer from prison). Criminal sections are sub-divided into restricted and unrestricted sections. With a restricted section the patient can only be granted leave of absence, transfer to another hospital and discharge by the Ministry of Justice (MoJ). The Responsible Clinician (RC) can make these decisions with unrestricted sections. The following are the commonest sections used in secure and forensic services:

- Criminal, unrestricted: section 37
- Criminal, restricted: section 37/41, section 47/49

They are briefly summarised below.

Hospital Treatment Orders
A hospital treatment order, with or without restrictions, diverts the offender from punishment to treatment. The offender does not need to serve a tariff and the period of detention is determined by the disorder and resulting risk of harm (DoH 2008).

Section 37 is a court order imposed instead of a prison sentence, if, at the time, of sentencing the offender is unwell to the degree that they require hospitalisation.

Section 37/41 Restriction Order is a court order, which can only be made by the Crown Court. It can impose a section 37 hospital order together with a section 41 restriction order. The restriction order is imposed to protect the public from serious harm. These restrictions require the responsible clinician (RC) to obtain the Secretary of State’s agreement to certain decisions and so relieve the responsible clinician of ultimate responsibility for protecting the public from further harm (MoJ 2008). These decisions include leave of absence, transfer between hospitals, and discharge, all of which require Ministry of Justice permission.

Hospital Directions
In contrast to hospital treatment orders, a hospital direction accompanies a prison sentence and means that the offender will be managed in the hospital in the same way as a prisoner. The RC can propose transfer to prison to the Secretary of State for Justice at any time before the prisoner’s release date if, in their opinion, no further treatment is necessary (DoH 2008).

Section 47 Transfer Direction This is used by the MoJ to transfer a serving prisoner to hospital. It operates like a section 37. The patient cannot be returned to prison unless he breaches his licence conditions.

Section 47/49 Restriction direction This is a transfer direction under section 47 together with a restriction direction under section 49. The restrictions are the same as those
in section 41. The prisoner can be transferred back to prison at any time, on medical advice or the advice of the Mental Health Review Tribunal (MHRT).

According to the Ministry of Justice figures of 2009 there are about 4000 restricted patients detained in hospital. Over 50% have been convicted of offences of violence against the person, a further 12% convicted of sexual offences and 12% of arson. About 600 are detained in the high secure hospitals; the remaining detained restricted patients are in medium and low secure units, or other National Health Service or private sector hospitals (MoJ 2009).

**Types of Discharge**

**Restricted patients**
Restricted patients are usually conditionally discharged from hospital. This is to ensure that the patient continues to receive the medical treatment they needs, and by so doing to protect the public. A conditional discharge, as the name suggests, means that the patient is discharged according to certain conditions (for example where they live, the treatment they receive and supervision) if they do not follow these the patient risks being recalled to hospital by the Ministry of Justice (MoJ 2009).

There can be the expectation that social and psychiatric supervisors closely supervise patients. The supervisors have a responsibility to keep the Secretary of State informed of their progress and behaviour in the community (MoJ 2008). If the patient’s mental health deteriorates, the clinical supervisor will consider whether it is necessary to arrange for the patient to receive additional outpatient treatment or to be admitted to hospital for treatment, whether voluntarily or by recall. The Ministry of Justice must also be notified as early as possible, (MoJ 2009). The number of conditionally discharged patients under active supervision in the community is around 1500 (MoJ 2009).

**Unrestricted patients**
Civil, and unrestricted criminal, patients are either discharged completely or not; however, the patient can be made subject to a Community Treatment Order (MoJ 2009).

**Section 117**
Section 117 of the Mental Health Act imposes a duty on health and social services to provide aftercare services to certain patients who have been detained under the Mental Health Act (Slay 2011). It states that aftercare services must be provided to patients who have been detained in hospital for treatment under section 3 under a hospital order pursuant to Section 37 (with or without a restriction order) or following transfer from prison under Section 47 or 48 (MoJ 2009).

A section 117 aftercare planning meeting is arranged by the responsible clinician prior to discharge from hospital being considered or implemented (Slay 2011). Aftercare is planned with the patient, their family and carers, as well as professionals looking at both health and social care needs. The care plan approach (CPA) is a way in which mental healthcare is planned and delivered.
The purposes of the Section 117 Mental Health Act are described in the Act's Code of Practice as follows:

- To provide care and treatment to equip patients to cope with life outside of hospital and live there successfully without danger to themselves or others;
- To aid recovery and rehabilitation;
- To minimise the need for repeated admissions (DoH 2008).
# APPENDIX II: Glossary of terms

<table>
<thead>
<tr>
<th>Acronym</th>
<th>Description</th>
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<tbody>
<tr>
<td>CMH</td>
<td>Centre for Mental Health</td>
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<tr>
<td>CPA</td>
<td>Care Plan Approach</td>
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<tr>
<td>CQUIN</td>
<td>Commissioning for Quality and Innovation</td>
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<td>DoH</td>
<td>Department of Health</td>
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<td>GOSO</td>
<td>Getting Out and Staying Out</td>
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<td>ICF</td>
<td>International Classification of Functioning Disability and Health.</td>
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<td>ICPHR</td>
<td>The International Collaboration for Participatory Health Research</td>
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<tr>
<td>JCPMH</td>
<td>Joint Commissioning Panel for Mental Health</td>
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<td>MAPPA</td>
<td>Multi Agency Public Protection Arrangements</td>
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<tr>
<td>MDT</td>
<td>Multidisciplinary team</td>
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<tr>
<td>MoJ</td>
<td>Ministry of Justice</td>
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<td>OT</td>
<td>Occupational Therapist</td>
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<td>PHR</td>
<td>Participative Health Research</td>
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<tr>
<td>RC</td>
<td>Responsible Clinician</td>
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<td>SMI</td>
<td>Serious Mental Illness</td>
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<td>SU</td>
<td>Service User</td>
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<tr>
<td>SUR</td>
<td>Service User Researcher</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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APPENDIX III: Team presentations by SURs and/or myself

Presentations carried out as a team.
In addition, because of these, the SURs have been invited to carry out presentations and seminars independently of our study.

- Academic Meeting: What do service users in secure units need to prepare them for living in the community? April 2015.
- Community Living Forum: What do service users in secure units need to prepare them for living in the community? April 2015.
- Trust Service User Involvement Seminar. “You are the Architect and we are the builders”. Service user involvement in a participatory study. July 2015.
- The Recovery and Outcomes Regional meeting: The GOSO Challenges: Additional recovery challenges. June 2017

Papers that I have presented.

- MPhil/PhD & Professional Doctorate Students Annual Conference: Data analysis and knowledge building in a participatory study. July 2014.
- MPhil/PhD & Professional Doctorate Students Annual Conference: Community living following discharge from a secure unit. July 2015.
APPENDIX IV: GOSO challenges leaflet

Awareness of the GOSO challenges will ensure you are better prepared for life beyond the fence.

What are the GOSO challenges?

The GOSO recovery challenges are a tool designed to help people to their secure settings. This can be anything from their history of offending or another aspect of the secure pathway such as length of stay.

How did we identify these challenges?

We asked people who had been discharged from hospital and were living in the community, what would you have liked to know before you were discharged? What would help people to get out of hospital and stay out of hospital? The GOSO challenges came from what they said.

If living in the community is your goal, considering the GOSO challenges can give you a head start.

This is not a full list. If you have your own additional challenges or would like to know more please contact us.

Richard Love
Richard Love@sussexpartnership.nhs.uk

Deborah Aired
Deborah.aiired@sussexpartnership.nhs.uk

Chris Moxon
Chris.moxon@sussexpartnership.nhs.uk
The Getting Out and Staying Out (GOSO) Recovery Challenges are the additional hurdles that forensic service users may need to address as part of their mental health recovery.

Working on these will help you to get out and stay out of hospital.

**Good Relationships**

- **Staff**
  It is important to develop a positive attitude and genuinely engage with the staff team so that you can demonstrate your progress.

- **Family**
  Family can provide valuable support and practical help throughout your stay and when you leave. Use this time to build bridges and mend relationships.

- **Friends**
  Friends who share interests such as sports can help you when you are discharged. Stay in touch and think about how you can stay involved with shared interests.

**Occupation**

- **Meaningful occupation**
  Reconnecting with or finding out activities that you enjoy and are good at in hospital can help you plan how you will spend your time once you leave.

- **Work**
  Develop work or education skills. Learn how to make use of your experiences in hospital to translate into future opportunities.

**Social Exclusion**

- **Disclosure**
  Think about what you want to say to people about your mental illness and the offence before you leave hospital. You do not need to disclose in social situations but you may choose to.

- **But**
  Remember you do need to disclose your offence in official situations like getting a driving license and applying for work. Learn what disclosures you need to prepare for.

**Stigma**

You may experience stigma due to mental illness and your forensic history. This includes experiencing stigma from others with mental illness. Prepare for this.

**Offence**

- **Offence related**
  You may be restricted from going to certain areas. Plan for this. This could be a fresh start for you.

- **Contact with victims**
  Be prepared for bumping into victims or their families when you are out. Plan what you would do. It probably won’t happen but you will feel more confident.

**Recall**

Understand the recall process and understand what you can do to stay out of hospital.
APPENDIX V: Service user consultation invitation

An invitation to help design a research project.

People who have experienced high medium and or low secure hospital admissions are invited to help plan a research project aimed at learning about and improving services.

Meeting with Debbie Alred, Lead Occupational Therapist and Ruth Chandler, Service User Research Facilitator you will be asked to consider secure mental health services and identify priorities for further study on

21st April from 12.00 – 2.00pm in the community centre.

You will be paid £20.00 and travel expenses.

Possible discussion points are:

What helped and hindered your recovery in the Secure and Forensic Inpatient Services?

What do you do with your time now? Did your time in secure services give you the skills to do what you want to do now?

What do we need to know more about to help future patients in secure services make the most of their in-patient time?

If you willing and able to attend or have any further questions please ring Debbie on:

01323 440022

Thank you for reading and considering this opportunity

Debbie Alred
Community Living Following Discharge from a Secure Mental Health Unit

Service User Researcher Role

Research Tasks

- Use experience to inform discussions
- Use experience to inform interview development
- Carry out interviews
- Reflect and discuss with team interviews in order to learn and develop interview skills
- Contribute to presentations about research

Training and Development Tasks

- Attend research meetings
- Attend training and relevant conferences
- Participate in supervision
- Develop a CPD portfolio
- Reflect on study progress and be involved with ongoing review of progress and role within research
- Participate in data analysis to try and understand what participant was trying to say

Team and Personal Responsibilities

- Work as a team respecting views of other members of the research team
- To keep care coordinator informed of participation
- To monitor own continued mental health and take action if necessary
- Provide constructive feedback to other members
- Maintain confidentiality of participants
- Be respectful of all contributions and views of participants even if not your own
- Maintain communication with research lead, for example always inform research lead if you cannot attend a research meeting

Research Lead Role

- Direct the project
- Structure the research meetings to provide training and development of skills
- Provide individual supervision
• Organise practical aspects of the project – recruit participants, book rooms provide equipment
• Take lead in data analysis
• Incorporate feedback and views of researchers in data analysis
• Write project up
• Communicate with care coordinator

Service User Involvement and Participation Role

• Supervise payment process as per policy
• Signpost to advice on benefits and payments
• Provide training
• Be a link to other service user researchers within the Trust
• Provide a fidelity check if there is a dispute over interpretation of data
• Attend the meetings every four months
• Provide support if Service User Researchers have any concerns about their involvement in the project or any other issues

June 2011
Version 3
APPENDIX VII: Ethical considerations
For participants, service user researchers and myself

Ethical issues for participants
At the heart of our study is the recalling of personal and, at times, painful life experiences so at every stage of the process the individuals involved need to feel supported and not coerced into revealing or sharing information they are not comfortable with. The procedures in place at every stage are designed to ensure that the individuals are able to participate without compromising their continued recovery. I achieved this by consulting with the service user researchers, clinical teams and academic supervisors throughout the design process.

Recruitment
Potential participants were identified and approached by members of their care teams. I discussed our study in detail with the community teams and provided them with an invitation to participate (Appendix VIII) and a more detailed information sheet about our study (Appendix IX). The community staff were then asked to give the invitation to participate in the study to people in their caseload who met the inclusion criteria. If they were interested in learning more, the staff then discussed participation in the study and gave the potential participant the more detailed information sheet. Throughout these discussions the community staff gauged the potential participant’s understanding and appropriateness of participation for that individual.

Potential participants were then given time to reflect on and consider their decision, including discussing it with other people, if they wished. If, following these discussions, the service user was still interested in participating they were invited to contact the lead researcher to ask any more questions, to discuss the study and to make practical arrangements to meet up for the interview. They were asked to sign the consent form prior to the interview.

I am aware that my involvement may affect the decision to participate. The Trust recently merged to become a countywide service. Potential participants in some areas are likely to be past patients of mine; however, potential participants in other areas will not be past patients of mine. My name was on all information so that potential participants were aware of my involvement in the study from the outset.

The interview process
Every attention was given to ensuring that the experience of participation in the study was a pleasant and worthwhile one. They were investing their time and experience so this was respected by creating an atmosphere conducive to supporting their participation.

The interviews were held outside of NHS premises in a local community centre. The reason for this is to acknowledge in the location of the interviews that the service user has moved on from hospital care and is now living independently in the community. When an individual agreed to participate in the study, an appropriate venue at a location easily accessible by the
Managing an ongoing ethical awareness was important when carrying out qualitative interviews that are asking about such personal experiences. Participants were given a preview of general topics to be discussed, with the intention that prior disclosure of topics would reassure participants and that they would be able to prepare for the interviews (Miller et al., 2006). They were encouraged to inform someone, for example their care team, friends or family, when the interview was taking place so that they could gain support from them. The service user researchers conducted the interviews. The lead researcher was present on site to provide additional support and debriefing if required.

If, during the interview, they disclose a criminal offence or information that has the potential of causing harm to themselves or others then the clinical teams would have to be informed. This was made clear in the information given to the participants prior to them giving consent (Appendix IX).

Following the interview, participants were provided with a summary of the transcript of their interview in a format that was straightforward to understand. Taking part in a research interview has been noted by some participants to be a valuable experience which provides individuals with the opportunity to reflect, remember and reinterpret their experience (Carter, Jordens, McGrath & Little, 2008). The participant may not always remember all that is said. A summary in written form provided an opportunity for individuals to continue to reflect and learn from their experience.

A second meeting was planned to allow for any clarification about the interview content. The participant was then asked to sign a second consent form (Appendix XII) agreeing to the interview material to be used in the study. If there were any parts of the interview that, on reflection, the participant did not want included in the study this was be highlighted and removed from the data that is analysed.

Ethical considerations for service user researchers

The service user researchers had ongoing supervision. This allowed space for the service user researchers to discuss their progress, negotiate their roles or involvement and identify difficulties, which could then be addressed. Individuals who have an interest in one specific skill area were encouraged to develop those skills. If more training was required that can be identified, or if someone is having difficulties then they could have been be offered alternative tasks within the project (Miller et al., 2006). At all times the health of the service user researchers was paramount.

The conduct of the interviews was supported. I was on site when the interviews were carried out to provide supervision and practical assistance if necessary. Following the interviews the SURs had the opportunity to debrief and discuss their impressions, observations and emotional reaction to the content of the interview. It was likely that this will be a demanding part of the role so supervision was integral to the research design.
The SURs will have been actively involved with the study for a long time when it ends. Consideration needed to be given to how involvement is ended and how the service user researchers are signposted to further involvement in project work so that they can continue to use the skills they have developed. The service user involvement and participation worker had links with future projects and contact and support will be maintained by the lead researcher to ensure the service user researchers move on from the study and take up further opportunities as they arise.

**Ethical considerations for lead researcher**

The final ethical consideration was for me as lead researcher. The research process can be challenging, isolating and stressful (Roberts 2007). The employment of service user researchers added an extra dimension of complexity to the project. I ensured that I had the necessary support structures in place with the regular use of supervision from the research supervisors. In addition I utilised support within the Trust including practical support from the service user involvement and participation worker, and professional supervision.
APPENDIX VIII: An invitation to participate in a research project

An invitation to participate in a research project.

As someone who has been discharged from a secure psychiatric hospital and is now living in the community you are being invited to participate in a research project aimed at learning about and improving secure in patient services.

The purpose of the study is to learn about people moving into the community following discharge from a secure psychiatric hospital. This will include finding out your views of the preparation you had before discharge and how relevant it was to your experience of community living. At the end of the study we hope to make recommendations that improve preparation for discharge for current and future patients.

Taking part in the study will involve sharing your experiences in an interview with a service user researcher, someone who has themselves been an inpatient in a secure setting and is now living in the community. After the interview you will be sent a summary of what you said, you will then be invited to a second shorter meeting to clarify any issues or make any changes.

If you are interested in finding out more about the study please discuss with one of your care team who will provide you with more detailed information about what participation in the study will involve. In this way you can consider the implications that taking part has for you, what help you would need to participate and ask any further questions before coming to a decision. If you are still interested please contact Deborah Alred. Asking for more information is an opportunity for you to consider participation; it does not mean that you have agreed to anything. You are under no obligation to participate in the study by making an initial inquiry.

Thank you for reading and considering this opportunity.

Deborah Alred

Tel: 01323 440022
Mobile: 07530292594
Email: deborah.alred@nhs.net

Version 2
06.10.12
Participant Information Sheet
Community Living Following Discharge from a Secure Mental Health Unit

Invitation to take part in the research
We would like to invite you to take part a research study. Before you decide we would like you to understand why the research is being done and what it would involve for you. This information sheet has been written by the Lead Researcher, Deborah Alred with assistance from the Service User Researchers, Chris Moxon and Richard Love. We hope answers any questions that you have. If you have further questions we would be happy to discuss them with you. Please also take time to talk to friends, family or your care team about the study if you wish.

Why are we doing the study?
The purpose of the study is to learn more about people moving into the community following discharge from a secure psychiatric hospital. This will include finding out about any preparation before discharge and how relevant it was to your experience of community living. It will also include looking at the impact of your offence on your experiences. At the end of the study we hope to make recommendations that improve preparation for discharge for current and future patients.

Why have I been invited?
You have been invited to participate because you have spent time in a secure psychiatric hospital and are now living in the community.

Do I have to take part?
It is up to you to decide to join the study. We will describe the study and answer any questions. If you agree to take part, we will then ask you to sign a consent form. You are free to withdraw at any time, without giving a reason. The care you receive will not be affected whether you choose to take part or not.

What will happen to me if I take part?
You will take part in a one to one interview with a Service User Researcher, someone who has themselves been an inpatient in a secure setting and is now living in the community.

The interview will be held in a community venue in your area at a time convenient to you. We will send you a list of the possible subjects that may be covered in the discussion so that you have time to think about it beforehand if you choose. The interview will be audio-recorded and will take about 1 to 1½ hours. There will be refreshments available and you will be able to take a break during the interview. Following the meeting a summary of the discussion will be mailed to you.

You will then be invited to a second, shorter interview lasting about ½ hour. This will not be audio recorded. At this meeting you will be invited to make any clarifications to your summary. You will also be invited to consent to your summary being used in the study. If there is anything you said in the interview that you think, on reflection, that you would not want to include in the study you can request that they are removed and they will no longer be utilised in the summary. An updated summary of your interview will be sent to you.
Expenses and payments
You will be paid £20 for taking part in the interview. You will also receive travel expenses.

What are the possible disadvantages and benefits of taking part?
We cannot promise the study will help you personally but the information we get from this study will lead to recommendations that will help the preparation for community living for future in patients. We hope to make participation in this study as positive experience as possible. There are very few disadvantages to taking part apart from using up some of your time. In previous studies some people have found it useful to share their experiences and contribute to the improvement of service for others. However you may find it distressing to recall your time in hospital and some of the experiences you have had. You will be provided with support.

What will happen if I don’t want to carry on with the study?
You are free to withdraw from the study at any time. If you choose to withdraw you will be asked whether you would like us to withdraw the information you have provided up to that time. If you do we will not use the information you have provided if you consent to us using the information to date that will still contribute to the study.

What if there is a problem?
If you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, please contact [REDACTED], the Trust service user involvement and participation worker, her telephone number is: [REDACTED]. This study does not involve any treatment so the risk of anything going wrong is very small. If you have any complaints about the research process please contact my supervisors whose names are at the bottom of the sheet.

Confidentiality
All information about you during the course of the research will be anonymised and kept strictly confidential. The records of the interview and all additional data will be kept securely and computer data pass worded. Transcripts and written information will be anonymised.

Your care coordinator will not be informed about what you say in the interview unless in the course of the interview you share information that suggests you or others could or have been harmed or you reveal you have carried out any further offences.

What will happen to the results of the research study?
The results of the study will be written up and presented. You will be provided with a summary of the study. The study will be presented to the local clinical teams for discussion about how the recommendations can be put into practice. The study will also be written up for publication in professional and service user journals.

Who is organising and funding the research?
The research is being led by Deborah Alred in contribution to a PhD at Brighton University. It is also contributing to the Secure and Forensic Service Secure Recovery Programme. The Trust Charitable Funds Committee is providing the funding for payments of all service user involvement in the project.

Who has reviewed the study?
All research in the NHS is looked at by independent group of people, called a Research Ethics Committee, to protect your interests. This study has been reviewed and given favourable opinion by [REDACTED] Research Ethics Committee.
Further information and contact details
Thank you for reading this information. If you would like to find out more please contact the following people.

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deborah.alred@nhs.net
C/O Deborah Alred

Chris Moxon

Richard Love

If you would like more information about involvement in research please contact:
Rachael Kenny PALS and PPI Manager
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If you are unhappy about any aspect of the study design please contact:
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Eastbourne

If you are unhappy about the way you have been approached or treated in this study please contact:
Ruth Chandler  Service User Involvement and Participation Worker
Research and Development Department
Neville Road Hove
01273 262446
ruth.chandler@sussexpartnership.nhs.uk

Version 2
06.10.12
Interview Schedule

Basic Details:
What led to your admission to a secure unit?
What hospitals did you stay at, what level of security were they and for how long?
What are your interests or hobbies? Did you start them in hospital?

Theme one: What was it like in hospital?
Prompts:
- Describe relationships with other residents
- Describe relationships with staff
- What activities did you do? Do you do them now?
- How did you spend your time?
- What was the ward like?
- What changed over time?
- Could you relax – the atmosphere on the ward
- How did the index offence affect your stay?
- What did you look forward to the most?
- How did you keep in touch with the outside world?
- What groups did you take part in?
- What did you do that helps you now?
- What would have been useful to do that would help you now?

Theme two: Transition: What was your preparation for discharge?
Prompts:
- Describe your experience of escorted/unescorted leaves
- What was your relationship with your staff team like?
- What was the impact of the index offence
- What was your route out – did you have a choice about where to go?
- What role did medication play
- What group work did you do – did it help you? How did it help/not help?
- What about jobs and education
- Did you feel prepared? What helped most?
- What would have made you feel more prepared?
Theme three: What is it like living in the community?

Prompts:

- What helps and hinders life in the community?
- Can you describe a typical day?
- How do you manage benefits/paperwork?
- What opportunities for work/education?
- How about disclosure – what to disclose?
- Compare life now to what it was like before you went in to hospital.
- What is the impact of the index offence today?
- What lessons have been learned?
- What would you like to achieve?
- What are your current obstacles?

Final Question: If you had the power to do so if there was one thing you could change about your preparation for discharge what would it be?

APPENDIX XI: Participant consent form main study

Community Living Following Discharge from a Secure Mental Health Unit Participant Consent Form

Name of Lead Researcher: Deborah Alred

1 I confirm that I have read and understood the information sheet dated 06.10. 2012 (version 2) for the above study. I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.

2 I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason, without my medical care or legal rights being affected.

3 I agree to take part in an interview in which I will be asked about my experience of community living following discharge from a secure mental health unit.

4 I understand that the interview will be audio taped.

5 I understand that I will be sent a summary of what I said in the interview.

6 I understand that I will take part in a second shorter interview where I will have the opportunity to clarify what I said and request that any information I shared is removed from the study if I wish. I will sign a second consent form.

7 I understand that any confidential information will be seen only by the researchers and will not be revealed to anyone else. The only exception to this will be if I share information that suggests myself or others could or have been harmed or I reveal I have carried out further offences, in this case I am aware my care coordinator will be informed.

Signed: ..................................................

Name (please print): ..........................................

Date: ..................................................

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Version 2
06.10.2012
APPENDIX XII: Re-consent form

Community Living Following Discharge from a Secure Mental Health Unit
Re-consent Form

Name of Lead Researcher: Deborah Alred

1 I confirm that the attached summary is of the interview that I took part in on: _______________________________
   Date: _______________________________

2 I confirm that I have read and understood the attached summary of the interview

2a I confirm that I have seen the summary and agree to the contents being used in the study.

   OR

2b I confirm that I have seen the summary and have highlighted the parts of the interview I would like removed from the study. I agree to the rest of the contents being used in the study.

Signed: ______________________________________

Name (please print): _______________________________

Date: _______________________________

When completed: 1 for participant; 1 for researcher site file;

When completed: 1 for participant; 1 for researcher site file; 1 (original) to be kept in medical notes.

Version 1
06.10.2012
APPENDIX XIII: Modification to protocol

The modification to Protocol 1.1 is as follows:

On page 27 the wording has changed from:

The interviews will be held outside of NHS premises in a local community centre. The reason for this is to acknowledge in the location of the interviews that the service user has moved on from hospital care and is now living independently in the community.

to:

The interviews will be held at a location of the participant’s choice. This could be at the hospital where they were an in-patient or outside of NHS premises in a local community centre. The reason for this is to accommodate individual preferences. Some individuals may want to return to the hospital site to visit friends or because it is a familiar location; others may prefer to meet in an environment away from a clinical setting.

Protocol 2 is dated 03.03.14

Version 1
03.03.14
APPENDIX XIV: Example of reflective interview transcript

Participant 4.1 Interview 1 (24-Sep-2014 –first 3 pages only)

This is an example of an interview transcript which is structured to support familiarisation with the interview and reflection about the content using an adapted collaborative narrative approach (Arvay, 2003). The transcript is completed with the three distilled sub analyses, the initial responses from the two service users and myself. These formed the basis of the group reflection and dialogue in relation to this interview. Each individual’s responses are shown in a different colour font, as follows:

(C) Chris
(R) Richard
(D) Debbie

Once again some of the answers in the interview have been slightly altered to protect the anonymity of the participant.

Reflective transcript
This is the first opportunity to read the interview transcript and to interpret it. Please read the transcript from these four different standpoints:

- For content,
- how the interviewer structured the interview,
- what the participant is trying to convey and,
- your reaction.

Write your responses in the columns.
<table>
<thead>
<tr>
<th>Chris</th>
<th>Hello its Chris here and this is the interview with John. Ok we’re going to start with what it was like in hospital. Could you describe your relationship with other patients?</th>
<th>Read for content: are there any corrections.</th>
<th>How did you structure the interview?</th>
<th>What is the participant trying to convey?</th>
<th>What is your reaction to the responses?</th>
</tr>
</thead>
<tbody>
<tr>
<td>John</td>
<td>I've always had a good relationship with staff and patients.</td>
<td></td>
<td>(C) Started with hospital going beginning to end</td>
<td>(R) He seems to be starting from a professional standpoint</td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Could you describe what relationships you had with the staff, what was it like?</td>
<td></td>
<td>(R) Good rapport and sympathy</td>
<td>(C) He got on with everyone – no-one gets on with everyone</td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>It was a good professional relationship, there was no aggravation or no problems</td>
<td></td>
<td>(R) Seem to be grateful for smooth transition whilst in hospital</td>
<td>(D) Bit of a sweeping statement - ? examples</td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>What was the ward like itself?</td>
<td></td>
<td></td>
<td>(D) Sounds resentful –</td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>OK, well managed, well run. I think everybody knew their place it was OK</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>OK brilliant. Could you relax with the atmosphere on the ward?</td>
<td></td>
<td>(D) Good follow up question – Chris has picked up the possibility of tension</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>Read for content: are there any corrections.</td>
<td>How did you structure the interview?</td>
<td>What is the participant trying to convey?</td>
<td>What is your reaction to the responses?</td>
<td></td>
</tr>
<tr>
<td>----------</td>
<td>---------------------------------------------</td>
<td>---------------------------------------</td>
<td>-------------------------------------------</td>
<td>----------------------------------------</td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>You had your one room and washbasin etc and you could always retreat to your room if you felt irritated or annoyed. If things got on top of you, you could always retreat to your room.</td>
<td></td>
<td>(D) The rooms are a haven – what made him irritated or annoyed?</td>
<td>(C) So everything wasn’t as rosy</td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>OK. What did you look forward to the most in you stay in hospital?</td>
<td></td>
<td>(D) Agreeing, using the peer perspective</td>
<td>(C) Realistic</td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>Getting out I suppose</td>
<td></td>
<td>(C) He looked forward to getting out</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Yeh, I can agree with that. Did you take part in many groups?</td>
<td></td>
<td>(C) Didn’t like groups</td>
<td>(C) Groups suit certain people</td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>A few but I tried to stick to myself as much as I could but I did a few groups, yes but I tried to keep it minimal.</td>
<td></td>
<td>(D) see the reason for groups = the contribution to skill development</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Did you index offence affect your stay in hospital?</td>
<td></td>
<td>(D) Links offence with to hospital admission</td>
<td></td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>No</td>
<td></td>
<td>(C) Everything OK</td>
<td>(C) Your stay in hospital is always based around index offence</td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>No? Ok.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>It might have affected the fact that I was in hospital but not on a day-to-day basis.</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Yes, yes. Did you keep in touch with the outside world? By phone or letters or?</td>
<td>Read for content: are there any corrections.</td>
<td>How did you structure the interview?</td>
<td>What is the participant trying to convey?</td>
<td>What is your reaction to the responses?</td>
</tr>
<tr>
<td>-------</td>
<td>------------------------------------------------------------------</td>
<td>---------------------------------</td>
<td>-----------------------------------</td>
<td>----------------------------------------</td>
<td>-----------------------------------</td>
</tr>
<tr>
<td>John</td>
<td>I phone called to my girlfriend and my family so I maintained my which I had before I went into hospital.</td>
<td>(R) It seems positive control guiding and directing the interview in a calm and assertive manner</td>
<td>(C) Has friends and family – important if got (D) Maintenance of important links</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Because that's the most, well it's not the most important thing but that's a key factor</td>
<td>(R) Positive perspective</td>
<td>(D) Relationships have been important to support Chris</td>
<td></td>
<td></td>
</tr>
<tr>
<td>John</td>
<td>No I maintained all my relationships with my friends and family</td>
<td></td>
<td>(D) Seems the same for John</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Chris</td>
<td>Moving onto what was your preparation for discharge, could you describe your experience with escorted and unescorted leaves?</td>
<td></td>
<td>(C) Next stage from hospital</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>