

**Enabling Carers to Administer Depot Injections:
An Action Research Study**

John J Crowley

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Abstract

This study has its origins in a question posed by a patient diagnosed with a psychotic illness, as to why her husband could not administer depot injection. Following local and national discussion the study aims were;

- to explore the elements of risk management involved in enabling carers (supportive persons) to give depot injections
- to develop a training package that may be useful for others to use should such a request be made
- to establish whether enabling supportive persons to give depot injections would have an effect on the relationship between the user (recipient of the medication) and the supportive person (giver of medication)
- to ascertain the views, concerns and attitudes of medical staff (prescribers) and mental health nurses (administrators of depot injections) about enabling carers/relatives (supportive persons) to give depot intramuscular injection medication.

An action research study informed by empowerment theoretical perspectives and influenced by recovery philosophies was used to explore the issues about ‘supportive person’ depot administration. Methods used to collect data included case studies, interviews, observation, reflection and three validated evaluation tools.

Data were analysed through thematic analysis, and alongside establishing data, relating to the study aims, additional themes i.e. stigma, disclosure, concealment and trust evolved from the data.

The study has relevance for clinical practice, policy and service provision. Current government policies promote choice and collaborative working and health and social care staff are encouraged to be responsive to the views of mental health service users and carers in relation to their experiences and expectations of care. Mental health services are being asked to deliver and translate these policies into practice alongside expectations of gainful employment for service users.

ABBREVIATIONS COMMONLY USED IN THIS THESIS

CPN	Community psychiatric nurse
MHN	Mental health nurse
LAI	Long acting injection
Depot medication	Medication administered into muscle by injection as treatment every two to four weeks and released slowly into the body
LTC	Long term conditions
Supportive person	Lay person learning to administer the depot injection. Within this study, supportive person roles included; husband, wife, mother, paid carer and partner
UQM	Understanding of medication questionnaire
DAI	Drug attitude inventory
LQoLQ	Lancashire quality of life questionnaire

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Chapter 1

Introduction

1.0 Background to the study

This study is concerned with the issues that arise when a family member or carer (supportive person) takes on the role of administering an intramuscular depot injection, traditionally administered by a mental health nurse. In this chapter the origins of the study will be discussed within the historical context of asylum closure and the growth of support fora for service users and carers. The origins of the depot injection and skills acquisition utilising Benner's model of skills acquisition are outlined. An overview of the thesis is also provided.

1.1 Origins of the study

The origin of the study was a question posed by a patient, who was prescribed a depot injection for the treatment of psychosis in 2000; 'What stops my husband from giving me my injection?' The patient had, after fifteen years of illness, recently gained paid employment and argued that she lost income when she took time out of employment to visit the depot clinic for her three weekly depot injection. My role at the time was as a full time employee of the mental health Trust, my position being team manager. My response was to explore whether a more flexible service could be offered; perhaps she could receive her injection at a local General Practice (GP) surgery on a weekday evening or at the weekend, for example. But the prospect of teaching a relative to give a depot injection seemed unrealistic and I was even unsure and uncertain of making a first step. There were no examples within local, national and international mental health services that could be used as a role model. Paradoxically, the expressed view of the team and myself was that the patient must be relapsing – the stress of employment being too much. More focus was put on indicators of possible relapse than on answering the patient's question.

The question was repeated by the patient over a period of months and following multi-disciplinary team discussions, of which there were many, the issue was taken to the Trust's research and development meeting. There an audience of thirty practitioners of varying disciplines, including medicine, nursing, psychology and pharmacy offered opinions. No discipline categorically said no to developing the project as long as steps were taken to train, inform, support and monitor the relative. A national and international literature search completed jointly with the pharmacist did not identify any similar projects. Hence, the research is important on both theoretical and practical grounds. The literature on the topic of supportive persons administering depot injections within mental health care is absent.

Drawing on the literature about student nurses and the development of psychomotor skills (Gomez and Gomez 1987; Baillie 2005), together with Trust and professional guidance and peer feedback, a format was established under a practice development model to action the patient's request. Three practice sessions took place and the depot injection was administered by the husband under supervision on the fourth session (Crowley et al 2002). Following this practice development episode, the mental health Trust recommended and supported research to explore the issues involved in more depth. The aims of the research study were:

- to explore the elements of risk management involved in enabling carers (supportive persons) to give depot injections
- to develop a training package that may be useful for others to use should such a request be made
- to establish whether enabling supportive persons to give depot injections would have an effect on the relationship between the user (recipient of the medication) and the supportive person (giver of medication)

This study gained NHS ethical approval in November 2005 through the Local Research Ethics Committee (see appendix 1) (see appendix 2 for research information booklet).

In June 2007 LREC was approached and approved an additional aim:

- to ascertain the views, concerns and attitudes of medical staff (prescribers) and mental health nurses (administrators of depot injections) about enabling carers/relatives (supportive persons) to give depot intramuscular injection medication.

The study aimed to recruit up to 10 supportive person/patient dyads and to undertake a semi-structured interview with 10 practitioners. Within this study, the person who took on the role of administering the depot injection will be referred to within the case studies as husband, wife, mother or paid carer -that being their role within the study dyads. The title 'supportive person' encapsulates all of these roles and is referred to and stated within the research study information booklet. The terms patient, service user and client will be referred to in relation to the person who is receiving the depot injection. The terms community psychiatric nurse (CPN) and mental health nurse will be used interchangeably as discussed in the literature on depot administration.

1.2 Historical background

Between 1960 and the 1980's there was a huge movement of mental health patients out of long term psychiatric institutions in the United Kingdom. This was partially accounted for by the success of the new anti-psychotic agents given by depot injections as treatment for schizophrenia. Accompanying the increased use of the depot injection as a treatment was an awareness of the dangers of institutionalisation within asylum care. Barton (1959) identified institutional neurosis as an illness that struck persons who remained in psychiatric institutions for many years. Wing and Brown's three hospital study (1970) demonstrated that social intervention could have a direct effect on the psychological health and behaviour of the long term mentally ill. This study confirmed that the patient's presentation of a schizophrenic illness was impacted on by institutionalised behaviours and that social and psychological interventions could alter this presentation for the better.

In parallel with asylum closures and the increased use of depot medication, MIND and the National Schizophrenic Fellowship (now renamed Rethink) influenced the development of a user movement in the 1970's to give families and carers a forum to express their views and needs, since the number of patients now living with family members within the community had significantly increased. The user movement challenged the model of care delivered by mental health services, a model which meant that the doctor was very much in control of the patient's life.

The increasing role played by the user movement in health matters led to health professionals generally having to pay more attention to the views of patients and carers.

This received attention in the document '*Working for Patients*' (Department of Health (DH) 1989) which introduced the concept of patients as consumers. This was followed in 1991 by the *Patient Charter* (DH 1991) and *Local Voices* (DH 1992) which stressed the need to ensure that those who seldom have a say in healthcare are heard (NHS Management Executive 1992). Further policies that link with and support user involvement are discussed in table 3.1.

1.3 Long-acting antipsychotic medications and intramuscular injection technique

The development of physical treatment for schizophrenia and psychosis followed the discovery by Charpentier and Laborit in 1953 of effective anti-psychotic agents (Snowden 2007). This led to a spirit of therapeutic optimism that drug treatment was an effective and necessary part of the treatment of schizophrenia and psychosis.

Long acting antipsychotic medication administered by injection (depot medication; also referred to as Long Acting Injection or LAI) was developed in the 1960's to promote adherence in people with long term psychotic illnesses (Simpson, 1984). The late 1960's and early 1970's saw the creation of the community psychiatric nurse (CPN) role and Gillam (2005) suggests that the creation of the CPN was aligned with the creation of the depot injection. Sladden (1979) refers to the *raison d'être* of the CPN as one of depot administrator.

Antipsychotic medication remains a mainstay of treatment for people experiencing serious mental ill health. It is the professional, legal and ethical responsibility of those administering the medication to be suitably skilled in contemporary evidence-based techniques and to be academically equipped to support the medication management of those under their care. Intramuscular injections of antipsychotic medications were developed to allow the medicines to be delivered in a modified way, over time, following administration. This has the advantage of promoting a steady therapeutic concentration of the drug, while minimising some of the side effects and variable effects on symptoms that may result from the peaks and troughs experienced when only tablets are taken. The achievement of a steady therapeutic level from regular injections also affords protection from relapse beyond the injection due date. Peak concentration occurs from seven to ten days after the injection and this is when side effects are also likely to peak (Bazire 2007).

These medications take a long time to be eliminated from the body, so various benefits, and indeed side effects, can persist for some time following the last injection.

All clinicians who prescribe or administer medicines are accountable for the care that they give, and are responsible for undertaking a comprehensive assessment of the patient under their care. It is also their responsibility to ensure there is a valid prescription for the medicine they are administering. As part of their assessment a clinician looking after any patient will need to be aware of other current medications to ensure that medications are not contraindicated (NMC 2010).

Administering intramuscular injections should not be an isolated activity, but rather an important part of a process of medication management requiring thought and professional judgement (NMC 2010). Knowledge and skills in anatomy, physiology, patient assessment, patient preparation and nursing intervention are all essential to fulfilling the role (Shepherd 2002). Core principles of safe practice and an exemplar standard operating procedure for prescribing, preparing and administering injectable medicines are available from the National Patient Safety Agency (2007).

In administering a depot injection, it is recommended to use the 'Z track' technique by immediately before injection, applying a shearing force with the non-dominant hand to the skin, approximately 25mm from the chosen injection site, thus sliding the dermal layer over the muscle. The use of the Z-track method is recommended as it reduces discomfort and prevents seepage back through the needle track (Rodger and King 2000).

When considering sharing or delegating a medical intervention such as the administration of a depot injection it is important to be aware of what is current good practice for the role and the Nursing and Midwifery Council's guidance on delegating this role (NMC 2007). Delegating within this project is to another person, a supportive person who traditionally has no involvement in the role of depot administration.

1.4 Skills development and maintenance

A supportive person learning to administer a depot injection needs to acquire the prerequisite psychomotor skills. Skills can often be divided into domain-general and domain-specific. For example, in the domain of work, some general skills would include time management, teamwork and leadership, and self motivation, whereas domain-specific skills would be useful only for a certain job.

Benner (2001) put forward a model of skills acquisition that distinguishes 'knowing how' from 'knowing that' and her model is used within this study. Benner's theory is based on the difference between practical and theoretical knowledge. Utilizing Dreyfus' (1980) and Kuhn's (1970) published work, Benner argues that there is a difference between 'knowing how' and 'knowing that', and as a consequence knowledge development in a practice discipline depends on developing 'knowing how' through the practice of a discipline. Skills are learned. While individuals may have an aptitude to practise in particular ways – to be more or less reflective, more or less sensitive towards others, or more or less dextrous – skills develop as a result of learning. This applied to the carers in this study.

Benner identified five stages of learning: novice, advanced beginner, competent, proficient and, finally, expert. Novice practitioners mainly employ a 'knowing that' approach and literally work 'by the book', following guidelines which have been set down. As they become more experienced, they replace the 'textbook' approach with experiential 'knowing how' until they reach the level of expert. They only go back to the 'textbook' when they find themselves in unfamiliar situations. The novice will use guidance to problem solve and complete tasks and the techniques they use are usually ones introduced at an early stage in their learning. The novice nurse might hope that practice could be reduced to a simple set of techniques, rules or procedures; experience suggests that it cannot (Benner 2001). A technique is described as a way to proceed or a set of steps that bring about a particular end. For example, there are techniques to use for dressing a wound or administering an intramuscular injection. Procedures are set techniques, sanctioned ways of proceeding that are designed to be safe, effective, efficient and ethical (Kelsey and McEwing 2008). Many care settings operate using manuals, describing procedures and the agreed way to proceed, for example the Royal Marsden clinical skills manual whose injection technique procedure is taught to student

nurses and Hunter's (2008) intramuscular injection technique article, both of which were used within this study (see section 6.5).

Once skills are learnt, they are maintained and developed through regular practice and supervision. This applies to the carers in this research study, who unlike the nurse, are administering an injection only every two or three weeks.

1.5 Thesis structure

This research aimed to understand the issues that arise when family members or carers (supportive persons) administer the depot injection within an action research approach. This thesis gives a detailed account of the research and has been divided into 7 chapters; setting the context, relevant literature, focusing on the research itself and finally analysing, discussing, drawing conclusions and making recommendations for practice, research and policy.

The administration of an intramuscular injection is a routine part of nursing but is a complex medical intervention. A proposal to delegate the role of administration to a supportive person needs to consider the patient's capacity to give consent and an awareness of risk factors. Alongside capacity and risk, chapter 2 covers concepts underpinning the study such as stigma, concealment, disclosure and trust. Chapter 3 discusses key national policies that promote active involvement of patients and carers in health delivery. This policy discussion includes related concepts like the expert patient, carer resilience, the personalisation agenda and the philosophy of recovery. The role and attitudes of the mental health nurse in the administration of the depot injection will be discussed in the light of patient experiences. Chapter 4 links the literature on power, empowerment philosophy, and innovation in practice to this study. Chapter 5 gives details of the methodology, an analysis of action research and the relevance of this approach to this study. Chapter 6 discusses findings from the action research cycles and other data collection approaches. Implications for policy, practice, education and research are discussed in Chapter 7.

Chapter 2

Literature review

2.0 Introduction

This chapter discusses literature on important concepts integral to everyday mental health practice and also concepts that arose as this research study developed. The process through which the literature was identified and accessed is outlined in the next section.

Within psychiatric care, concepts relating to insight, capacity and risk are integral to care delivery and management. Current psychiatric thinking perceives the diagnosis of schizophrenia and psychosis as serious mental illness which can lead to degrees of disordered mental functioning requiring for the most part, treatment with antipsychotic medication. This view is sometimes different from that of the patient and the discrepancy is commonly referred to as a lack of insight. This broad concept 'lack of insight' leads to discussion among mental health practitioners about the patient's capacity and ability to give informed consent. Concepts like capacity, insight and the giving of informed consent are pertinent to this study since they are all relevant when making decisions about having a person other than a mental health nurse administer the prescribed medical intervention such as a depot injection. Insight, informed consent and capacity associated with mental health are integral to discussions about risk and risk management and are explored in this chapter. The concept of risk, its relevance and effects (both actual and potential), on individuals and organisations has become increasingly important in modern society and as such will be comprehensively discussed within this chapter.

People who experience an illness of any description, must at some level, either conscious or unconscious, consider whether they will conceal aspects of this illness from others. Decisions are to be made about whom to conceal illness concerns from, and if patients decide to inform others of their illness, what depth of information, and with whom they will share. A factor in the decision to disclose information to others is the important concept of trust. The concept of trust will be discussed in depth including how it relates to healthcare, nursing, depot medication and the recovery philosophy. The work of Goffman is used to explore and understand stigma and how negative attitudes towards mental illness are viewed by self and others. The impact of negative attitudes will influence the decision to conceal and this chapter will discuss models that help to explain

how and why people conceal and the consequences for them if they do conceal their mental health problems.

2.1 Accessing the literature

Relevant literature has been reviewed throughout this research thesis. This is in keeping with the convention of qualitative research approaches, which is to use literature as a point of reference for grounding, validating and questioning issues raised by the research (Silverman 2000). Actively searching for published studies involved collaborating with librarians and the use of online databases and e-journals, mostly the University of Greenwich and Royal College of Nursing facilities. Databases accessed included EBSCO, Swetswise, CINAHL, MEDLINE and PsycINFO. More specific web based resources related to recovery were searched – (Scottish Recovery Network: www.scottishrecovery.net; and Social Perspectives Network; www.spn.org.uk).

The Boolean searching method, which is a logical combinatorial system strategy for information retrieval (Merriam-Webster 2013), was used. Key search terms used, and combinations of them, endeavoured to reflect different terminologies used in relation to the patient, carer and the administration of depot injection within international mental health care. Key words ‘patient’ ‘service user’, ‘client’, ‘carer’, ‘buddy’, ‘home administration’ and ‘family administration’ were used in combination with ‘anti psychotic medication’, ‘LAI’s,’ depot medication’ ‘intramuscular injection’ and trade names used in the United States and Australia for specific medications. The parameters of the search were English language only and international publications without any defined dates.

In the absence of study-specific published material, I also considered health literature and practice where a family member is involved in care delivery related to medication. For example: diabetes (personal discussions with diabetic team); infertility treatments (personal correspondence and observations of family members administering intramuscular injections); rheumatology (Arthur et al 1999 and personal correspondence); paediatric care (Evans 1994); renal care (personal observations and correspondence) and multiple sclerosis care where a buddy scheme caters for patient

needs. Hand searching of journals was largely restricted to publications relating to mental health as they were published.

The RCN mental health forum disseminated the project and sought contacts. The sponsoring mental health Trust research and development team alongside the Trust librarian were enormously supportive and helpful. This process involved targeting health, social care and policy databases and following up further references from useful papers, key authors and network connections. Books and policy documents have also been used extensively to inform this research as it unfolded. The national media, in particular '*The Guardian*', was used as a source of information about new developments and emerging opinion about choice in healthcare. In addition to national policy, local strategic documents were used to explore how changes impacted on service provision.

The searches did not produce any published work on supportive persons and depot medication administration in mental health.

2.2 Insight

Insight is operationally defined according to five dimensions: the patient's awareness of mental disorder, awareness of the social consequences of disorder, awareness of the need for treatment, awareness of symptoms and attribution of symptoms to disorders (Mintz et al 2003). It is mostly discussed within the context of a psychotic illness but applies to all conditions.

In a classic paper on the subject of insight, Lewis (1934) recognised that schools of philosophy, aesthetics and ethics contribute as much to this field of study as do psychiatric theories. Medical and social models of insight are highly reductionist and loaded in favour of simple concepts such as normal/abnormal and pathological/healthy. Lewis pointed out that patients' insight is judged essentially 'as a result of a psychiatrist realisation of mental illness' and he noted that gross abnormalities of insight are often apparent in physical illness and in neurosis.

The construct of insight in psychosis assumes congruence between patient and clinician views of the meaning of symptoms and experience. Tranulis (2008) argues that current definitions and measures of insight do not give systematic attention to the impact of

interpersonal, cultural and socio-economic contexts. In schizophrenia, patient insight is impaired but a patient may possess clear insight into aspects of their disorder. This insight can be distressing and is associated with depression. This is highly relevant for a patient recovering from an acute phase of psychosis who can enter what is termed recovery phase. Recovery (see section 3.5) refers to a process of acquiring consciousness and awareness of the potential fears, disordered perception and alienation associated with the psychotic process. Linked to this concept of disordered perception are concerns that it interferes with the giving of informed consent.

Sims (1988) argues that insight is highly relevant when considering capacity and consent issues and is important within therapeutic engagement. David (1990) suggests that insight is relevant when individuals decide to pursue and concord with treatment and suggests insight is central to the concept of the 'sick role'. The 'sick role' concept was developed by Parsons (1951) and essentially states that the patient who is sick is exempt from responsibility for the incapacity as long as it is beyond the patient's control. The patient is orientated towards accepting, rejecting or negotiating the treatment options suggested by the doctor and the patient's insight into their illness will play a part in the outcome.

2.3 Informed consent and capacity

People with a diagnosis of schizophrenia are often characterised in the psychiatric literature as globally irrational. This may be because of their status diagnosis where the presence of delusions and hallucinations is seen as constituting irrationality or a lack of mental capacity (Hewitt 2010). Capacity in clinical psychiatry is concerned with the capacity to consent to treatment and failure to comply with treatment may be seen as a lack of insight and thus a sign of irrationality. Culver and Gert (1982) suggest that mental ill health and irrationality are not synonymous as it is the person who is mentally ill, whilst it is beliefs, desires or actions that are irrational.

The concept of informed consent is a central component of the communication between the health practitioner and patient. Health professionals like doctors and nurses are afforded rights, assuming that informed consent has been given, to administer treatments like depot injections which in their professional judgement are likely to benefit patients.

The doctrine of informed consent requires that the patient understands the nature, benefits and risks of the proposed treatment and benefits and risks of alternative choices, including no treatment (Munetz and Roth, 1983). Meisel et al (1977) identified four components of the consent process and these are echoed in the guidance given on consent seeking by the Department of Health (2009a). These components include the precondition of voluntariness, the provision of information, the patient's competency and the active mental process required to make a decision. Mental capacity legislation (DH 2005a) states that within the United Kingdom it must be assumed a person has capacity unless it is established that they lack capacity. A person is not treated as unable to make a decision merely because he or she makes an unwise decision and is deemed to have capacity and be able to make a decision if they are able to do all of the following:

Understand information given to them that is relevant to the decision

Retain that information long enough to be able to make the decision

Use or weigh up the information as part of the decision making process

Communicate their decision- this could be by talking or using sign language and include simple muscle movements like squeezing a hand or blinking an eye

It can be argued however that the real clinical difficulties concerning the nature of consent and psychosis and schizophrenia are not addressed and determining capacity remains essentially a clinical decision based on a relationship between an individual health professional and the patient. The Royal College of Psychiatrists (2009) offers generic guidance about seeking consent and this should include engaging the patient and family and listening to viewpoints. Trust is important in the engagement process and is discussed in sections 2.9-2.9.3. The Good Practice (RCP 2009) document does not give specific guidance on consent seeking with a patient diagnosed with a psychotic disorder.

2.4 The ethics of treating patients with uncertain competencies

Hirsch and Harris (1988) provide a fascinating discussion on the ethics of treating potentially incompetent mental health patients. One proposed argument is that the mental health practitioner continues to use appropriate skills to effectively protect the vulnerable patient, whilst other medical and legal contributors propose involving several

professionals (from different professions) in making difficult judgements about competency. This approach is written into both mental health (MHA 1983/2007) (DH 2007a) and mental capacity legislation in the UK today (DH 2005a). Current contemporary good practice guidance from legal professionals is for health care professionals to adopt a mentality of seeking peer opinion and capacity should be a topic for daily discussion, particularly when working with patients whose competency may be uncertain.

Competency and capacity are relevant issues to this study. All participants were deemed competent at the time of recruitment and the study has built in review processes to monitor competency and revisit consent seeking (See section 5.13.2).

2.5 Risk

Inherent in the discussion about capacity and consent giving are the concepts of risk, risk assessment and risk management. Understanding two principles which underpin Heyman et al's (2010) definition of risk is important and relevant and will be explored more fully within this chapter. These two principles are that only human beings who are cognitively intact and who understand the concept can 'take a risk,' and secondly, that only those observers who have adopted a risk framework can judge others to be 'at risk'.

The concept of risk, its relevance and effects (both actual and potential), on individuals and organisations have become increasingly important in modern society. Risk is a complex and multi-dimensional concept; it is both nebulous and fluid. Definitions and perceptions can vary across and within society or cultures and are frequently historically and event specific (Glover-Thomas 2011; Mitchell and Glendinning 2008). The concept of risk is viewed from differing angles. For example, from 'being at risk' to 'risk taking' to 'taking a risk'; from 'risk manager' to 'managing risk' to 'risk owner'.

Defining risk, within the understanding that it is a fluid and nebulous concept, is not easy. Heyman et al (2010:19) defined risk as 'the projection of uncertain expectation, viewed in terms of randomness, about the occurrence of a negatively valued outcome category within a selected time frame'. The authors state that this definition is offered as a working specification and is not offered as a definitive answer to the conundrum of risk. In an analysis of risk definitions, Heyman et al (2010) identified four components

which are core within and across a range of domains to which risk definitions are applied. These components concern: a categorisation of an event; a value judgement about negativity; expectations about an occurrence and these components being within a temporal framework. These authors differentiate between ‘the negatively valued outcome’ with its focus on adversity, and purposeful risk taking, which entails taking into account the potential benefits as well as adversity. Purposeful risk taking relates to the recovery philosophy (see section 3.5).

The assessment of risk seeks to determine the probability that an adverse event will occur at a given point in time. The changing nature of a patient’s profile means that assessment is an ongoing and evolving process. The Department of Health risk framework (DH 2007b) relates to three areas of risk; violence, self-harm and self-neglect. Further division of the risk concept is whether the risk is deemed to be dynamic, static, acute or chronic (Heyman et al 2010; Glover-Thomas 2011). These authors have classified risk factors into two categories:

1. Static risk factors relating to historical events which cannot be changed or reversed. For example, the age when the first event occurred, the age of the first psychotic episode.
2. Dynamic risk factors that can and often do change over time. For example, substance misuse, changes in mental state and support structures.

Assessing risk and managing risk within a variety of contexts is a key task in mental health care and is a central activity of mental health nurses (DH 2006a; Doyle & Duffy 2006; Coombs et al 2011).

There are a number of theoretical approaches to risk. Lupton (1999) discusses two broad approaches to conceptualising risk, namely the technico-scientific approach and the socio-cultural approach. The technico-scientific approach focuses on calculations of risk probability, measuring hazards and dangers, and this approach is prominent in a number of scientific and social science disciplines. Using this approach, Lupton claims that risk factors can be identified by ‘experts’ and measured by assessment tools.

The socio-cultural approach recognises that risk can sometimes be experienced and viewed objectively; however, greater importance is given to social, cultural and economic structures and processes (Lupton 1999). How risk is viewed and identified is context bound; there is a shared understanding of the value of human subjectivity and as

such lay knowledge and ideas are valued. Lay knowledge and experience as a contribution to understanding risk are further supported by Taylor-Gooby (2006) who suggests that individuals react to and understand risk on both a rational/cognitive and non-rational/affective level.

2.5.1 Risk - policy and legal frameworks

The heightened awareness of risk and uncertainty has become a defining phenomenon of modern society and health care (Alaszewski and Brown 2007). In seeking to counter risks, government policy-makers increase public awareness of these phenomena and add credence to their 'reality' and 'problematic nature' (Broer 2007). In fact, Alaszewski and Brown (2012) suggest that risk is arguably the most high profile example of a symbolic emotive policy concept that has been used as a tool of legitimation, to mobilise consensus around the reconstruction of norms and values. One such intervention was the implementation of community treatment orders under Mental Health Act legislation (MHA 2007a). The Clunis Report (Ritchie 1994) emphasised the threat posed by people with mental illness and recommended the use of risk strategies to identify and manage this dangerousness. Alaszewski and Brown (2012) suggest that the Clunis Report reinforced public perception of the dangerousness of people with mental illness and this influenced the New Labour Government's risk and blame ideology. Frank Dobson (Secretary of State for Health 1997) accepted the media representation of the dangerousness of people with mental illness and the failure of voluntary treatments within the community so the law was amended to introduce compulsory treatment in the community through community treatment orders. This view of dangerousness was opposed by an alliance of voluntary groups, service users and clinicians who argued that people with mental illness were more likely to be the victims of neglect and stigma than the perpetrators of violence. This alliance argued that policy should be addressing identifying and meeting the needs of people with mental illness.

The minimisation of risk related to violence, self-neglect and suicide is recognised by service providers as being of paramount importance in the reduction of costs and as well as avoiding adverse outcomes (DH 2007b; NHS Litigation Authority 2010). NHS policy supports the inextricable link between risk assessment and risk management (Kennedy 2001; DH 2007b). These policies aim to embed risk management into day-to-day clinical

practice rather than being an add-on to patient care, and stipulate the legal requirements for serious untoward incident reporting and ‘learning of lessons’ after incidents.

Conversely, key government policies over the past five years promote choice and responsibility- taking within health and social care and discuss risk within the context of individual choice. Policies which illustrate this are; *Risk, Responsibility and Regulation: Whose risk is it anyway* (Better Regulation Commission 2006); *Making Choices: Taking Risk* (Commission for Social Care Inspection 2006); *Independence, Choice and Risk; A guide to Best Practice in Supported Decision Making* (DH 2007c); *No Health without Mental Health* (DH 2011a).

Concepts like choice and personalised care are linked to the philosophy of recovery, a philosophy that is embedded into current mental health service provision. One principle of the recovery philosophy is the taking of responsibility and control by the patient. A document that argues for the primacy of the recovery approach, *Making Recovery a Reality* (Shepherd et al 2008), criticises mental health services for ‘a preoccupation with managing risk at the expense of learning’. The National Patient Safety Agency guidance (2004) critiques the risk management approach as one where a safe service is one that is ‘preoccupied with failure’. Roychowdhury (2011) suggests that at a basic level, the current focus within mental health on risk is anti-recovery. The dichotomy between recovery orientated approaches and risk management is exemplified by the John Barrett inquiry (NHS London 2006) when the report concluded that too much importance was placed on the patient’s wishes and preferences with correspondingly less emphasis on the principles of sound risk management. Both the Clunis Report and the John Barrett inquiry highlight third party risk, which though rare in occurrence does have catastrophic consequences.

Within mental health care delivery in countries like the United Kingdom, Australia, New Zealand and United States, a self-management programme, the Wellness Recovery Action Planning (WRAP) is promoted and implemented across their health sectors. WRAP was developed for and by people with mental ill health by Mary Copeland and is rooted in the values of the ‘recovery’ movement (Slade 2010; Scott and Wilson 2011). The WRAP programme aims are to promote higher levels of wellness, stability and quality of life; increase understanding of challenges resulting from their mental health problems; decrease stigma and increase the participants' sense of personal responsibility

and empowerment. This self-monitoring and increased personal responsibility promotes the possibility of re-engaging with and re-entering their local community.

Copeland's original work avoids using the word 'risk' and instead talks about challenges and the prevention of suicide. Scott and Wilson (2011) argue that it is understandable that such a programme developed in mental health, because people with mental illness are highly stigmatised (see section 2.6-2.6.3) as 'a risk' and viewed as in need of 'risk management'. By developing their own form of self-monitoring 'at risk' identity, mental health consumers are, paradoxically, able to construct themselves as ideal health citizens and no longer 'a risk'.

The major legislation which guides mental health care currently in England is the 1983 Mental Health Act (amended 2007) (DH 2007a). This legislation solidifies the dominance of risk in current mental health policy by providing a legitimating framework in which risk can be assessed, monitored and managed. The legislation, however, neither defines risk nor delimits the factors relevant to risk, even though a rationale for considering the implementation of a Mental Health Act (DH 2007a) assessment is a concern about the patient's deteriorating mental state which may pose a risk to self or to others. This absence of definition within the legislation, together with no limits on the factors pertaining to risk, means that individual practitioners within mental health have sufficient scope for professional interpretation and discretion to make decisions based on their interpretation of risk (Glover-Thomas 2011). What constitutes a risk to self or others is a matter for decision makers alone. This approach to risk prediction and determination raises some concern as practitioners may operate an 'ad hoc' decision-making system based on experience. An ad hoc decision-making approach occurs within a structure of uncertainty as there is no system of risk assessment and management which is wholly accurate (Bartlett 2010). The language of risk is all pervasive within mental health practice. Risk determines the nature and extent of a patient's engagement with the services and the risk profile determines the level of supervision in the community (MHA 2007, sections 17A-17G).

The implementation of mental health legislation is monitored by The Care Quality Commission (CQC) (DH 2008a). The CQC was established in 2008 as the overarching healthcare regulator and is required to adopt a risk-based approach. The focus on risk is

embedded within the CQC by the formation of 'risk summits' where CQC inspectors, healthcare providers and NHS leads assess the safety of every hospital.

2.5.2 Risk - carers' and patients' views

Users of mental health services have been the subject of a number of studies whose foci are 'risk and dangerousness' (Warner 2006; Kelly and McKenna, 2004; Warner and Gabe 2004). The research was contextualised by official inquiries and media scares involving mental health service users (also referred to as catastrophic or never events) and the perceived danger they posed to members of society. With the advent of epidemiological research, Castel (1991) argues that risk factors within populations have been used to sift out sub-populations for more risk preventative attention. Such preventative measures include the Care Programme Approach (DH 2000a) and the Amended Mental Health Act (DH, 2007a) (Glover-Thomas 2011).

A scoping review by Mitchell and Glendinning (2008) found a dearth of evidence about patients' own experiences of the risks that their illness can bring and how patients are regarded as risk managers in their own right. This dearth of research was deemed to reflect the state's role and preoccupation with risk management rather than an understanding of patients' ideas of risk and their preferred risk management strategies.

There was some evidence on the experiences of informal carers in the field of mental health (Ryan 2002). Ryan's study found that carers had rarely been taught any risk management strategies but some had copied strategies from mental health professionals. Carers did not have a risk language they used within everyday caring but had gained through experience strategies which were effective. Experience featured strongly in the carer's use of and confidence in proactive risk management strategies. The carer intervened when they perceived there was a concern for their family member. This caused them anxiety as they were torn between the control aspects of care and the belief that the person they were caring for should be as independent as possible. The lack of a risk language to utilise in the manner of professionals may be a factor in perceived poor communication between carers and professionals and should be explored by professionals when developing packages of support with users and carers.

Three models of risk management were identified as being used by carers (Ryan 2002). These were classed as being individual, situational and decision-making models. Whilst the patients in Ryan's study did not have a risk management strategy in some risk circumstances, informal carers always employed a strategy. Gaining experience as a carer often resulted in an increased number of strategies to manage risks. These strategies were a combination of passive and active, for example, carers demonstrating submissiveness when the patient became angry as they felt that being assertive would increase the likelihood of violence towards themselves. However, as carers became more experienced in their role as a carer and discussed the issues with other carers, they became more proactive in their strategies. They were able to adjust voice tones and posture to show assertion without appearing aggressive and practised doing this until they felt comfortable about putting it into action. Limit-setting to behaviours was evidenced by discussing worrying behaviours when the patient was calm and would be likely to accept what was being said.

One principle of the recovery philosophy is the taking of responsibility and control by the patient, one such programme being The Expert Patient programme (DH 2006a). This is a programme where patients with long-term conditions are taught to be effective users and consumers of healthcare (DH 2006a). This use of the term 'expert' within the title of the programme indicates a change in relationship between users and providers of healthcare. The policy states that only patients and carers can understand what it is like to live with ill health and risk.

Scott and Wilson (2011) suggest that the move towards Expert Patient programmes and self-management within mental health is particularly fraught. They link this to the recovery philosophy which, currently, is a dominant approach within the delivery of mental health services and refer to the work of Mead and Copeland (2000) about the internal personal resources individuals with mental health problems have and how these resources have been buried over the years by layers of imposed limitation. Recovery is aimed at enabling these individuals to make leaps of faith and to take risks that are not calculated by someone else. The patient needs to be asked about what would enable them to take new risks – the experience which would enable change in the context of assumptions of fragility and limitations.

These policy and philosophy approaches are encouraging the taking of responsibility by patients – patients are believed to want to make choices and to take risks (Commission for Social Care Inspectorate 2006). Yet health professionals retain statutory responsibilities for patient care and to the wider society. Tensions are to be expected when individuals want to self-manage and risk take whilst practitioners have a duty of care. Britain has undertaken considerable changes in the organisation and delivery of mental health services over the past fifty years- mental health care is delivered in many diverse arenas, from the asylum to day centres, acute wards to private homes and to the homeless on the streets. A constant which has moved from the asylum to the new arenas is professional-client interaction (Godin 2006) and this interaction is relevant to the risk debate.

Because of this client-practitioner interaction, mental health care workers have some discretion in current ‘risk thinking’ management because there is local self-governance (Godin 2006). There are opportunities for mental health workers to incorporate into the local risk management culture issues that service users are concerned about. Examples of service user issues which the mental health worker could concern themselves with include; assessing the risk of poverty, the risk of being denied choice in service provision and the risk of being denied therapeutic risk taking. Mental health care workers have an opportunity to engage in, and change the discourse about risk to one that includes service user concerns, which is within their professional role or within their professional caring mission (Godin 2006). An additional service user concern is stigma (Scott and Wilson 2011) and stigma will be discussed in the next section.

2.6 Stigma – the work of Goffman

A person who is deemed to be different, who is sick or handicapped with some affliction may be stigmatised by other members of that society if that affliction is unpleasant for other people. This difference may for example, be because of how they smell, appear or behave. The concept of stigma was developed within sociological literature by Goffman as part of a wider theory about the presentation of self (Goffman 1969) and is defined by Goffman (1963:3) as ‘an attribute that is deeply discrediting’.

Goffman explains that the term stigma originated with the ancient Greeks who used it to refer to marks on the body that represented something bad or immoral about the person

(stig is the stem of stizein which is Greek for 'to prick'). Usually these were marks that were cut or burned into the body of the person to identify the bearer as a slave or criminal or traitor. People who encountered such a person were expected to avoid them.

In contemporary society, Goffman argues that there are three main forms of stigma, namely: abominations of the body, such as physical deformities, blemishes of individual character which may be a mental disorder and, thirdly, the tribal stigmas of race, religion and nationality. Goffman argues that we attribute a wider range of imperfections on the basis of the original abomination and the response of the individual to his or her situation may then be perceived as a direct expression of the defect. Stigma, even though it is imposed on the individual by other people, can have a negative effect on the self-concept of those stigmatised. The stigmatised person is likely to be aware of society's norms and how he or she is falling short of these norms. Consequently, because of the falling short, the individual is likely to feel shame.

Stigma does not always translate into doom and despair. Goffman (1963:11) points out that it may link to positive outcomes. 'He (the stigmatised) may see the trials he has suffered as a blessing in disguise, especially because of what it is felt that suffering can teach one about life and people'. The key issue revolves around how the individual manages and responds to the experience of stigma. Does the stigma result in a stable reduction in self-esteem or is it the catalyst for positive reinterpretation of self?

Goffman (1968) distinguished between those whose stigma is obvious to others, for example, a facial disfigurement, which he refers to as discredited stigma and discreditable stigma when the stigma is not obvious to others and the individual may pass as normal. The discreditable person has a dilemma of whether to reveal his problem by informing others or reveal by bodily signs. The possibility of revelation may lead to high levels of anxiety. Goffman offers another possible scenario for the stigmatised person in that they may reveal their stigma but ensure the stigma does not loom large in the interaction process. An additional aspect of stigma is the impact of the stigma on the person's own identity.

Goffman's principal sociological interest was in the structure of interactions – 'to describe the rules regulating a social interaction is to describe its structure' (Goffman 1967: 144). One of these rules, he claims, has to do with 'maintenance of face', requiring individuals to present and sustain consistent and positive images of self. The challenge

for those with visible marks he suggests is to 'manage impressions' whilst for those with invisible marks it is to 'manage information'. This analysis links to the basis of Goffman's theoretical position relating to stigma which is symbolic interactionism.

2.6.1 Stigma definitions and types

A stigma is defined as the shame or disgrace that is attached to something that is regarded as socially unacceptable and its use connotes a mark of disapproval (Bloomsbury English Dictionary 2nd ed, 2004). Link and Phelan (2001; 363) offer a definition of stigma which is the occurrence of its components, these being labelling, stereotyping, separation, status loss and discrimination. For stigmatisation to occur, power must be exercised by others. Within this literature, the focus will be on the stigma of having a mental illness.

There are different types of stigma discussed within the literature. When the general public endorse specific images of people with an illness, for example, that all people with mental illness are incompetent or all patients with a diagnosis of schizophrenia are dangerous, then this is referred to as a public stigma. This over-simplified conception of a person or a group of people is referred to as a stereotype. If a person attaches shame or disgrace to an aspect of their personal characteristics, and internalises this shame, this is referred to as self-stigma. Self-stigma has two components. Where an aspect of a person's body, for example, a skin mark or obesity, is evident to others, without the person themselves having to disclose this information, this is referred to as a visual stigma. If there are no outward signs of differences that attract public notice and the perceived disgrace can be concealed from the public, for example, mental illness, this is referred to as a concealed stigma (Goffman 1963; Scambler 2006; Thornicroft 2006). Friends and family members, because they associate themselves with a stigmatised individual, can experience what Goffman (1963) defines as courtesy stigma. This is stigma by association.

2.6.2 Stigma and mental illness

The stigma that is attached to mental illness has been defined as a set of negative attitudes toward people with a psychological disorder (Corrigan 2004; Komiti et al 2006). Public stigmatising of people with mental health problems is damaging to individuals with mental illness and is associated with substantial societal burden (Sharac et al 2010). This public stigma is a global phenomenon and persists over time (Schomerus et al 2012). There is a link between public stigma and individual experiences of stigma among people with mental health problems (Evans-Lacko et al 2012). Mental health stigma is pervasive and this stigma is described as a major barrier to seeking professional help (Masuda et al 2009; Vogel et al 2005; Scambler 2006). Scambler (2009) states that within the United States, mental illness is the primary focus of research into stigma and theory generation about stigma. Evans-Lacko et al (2013) found that England's Time to Change¹ programme against stigma and discrimination between 2008 and 2012 did bring about an improvement in attitudes but not in knowledge among the public in England.

The stigma of having a diagnosis of schizophrenia impacts on individuals' lives in differing and profound ways. Corrigan (2005) found that individuals with a diagnosis of schizophrenia belong to one of the most stigmatised groups in our society. Pandya et al (2011) state that a diagnosis of schizophrenia impacts on people's lives in ways that most people would experience as profoundly painful whilst the diagnosis of schizophrenia also has a negative impact on both income and on quality of life (Thorncroft et al 2009; Yanos et al 2008). Social stigma contributes to low income and unemployment among mentally ill people (Markowitz 1998) and people with a mental illness often experience a reduction of social contacts and social rejection which can lead to social isolation (Fieldman and Crandall 2007).

Staff who work within mental healthcare settings are not immune to having negative attitudes towards schizophrenia, but higher rates of negative attitudes towards schizophrenia were found in non-psychiatric settings among the general public (Bjorkman et al 2008; Chin and Balon 2006). Patel et al (2009) also found that nurses view depot medication as stigmatising (see section 3.6 for further discussion on depot medication).

¹ England's Time to Change (TTC) was a 4 year programme against stigma and discrimination towards people with mental health problems. TTC ran between 2008 and 2012 and targeted knowledge, attitudes and behaviour.

2.6.3 Stigma and coping

Individuals who experience stigmatisation can respond and cope with this stigma in a number of ways. In a review of the literature on coping with stigma, Miller and Kaiser (2001) identified concealment as one of the responses that can occur simultaneously with other responses or independently. This tendency to conceal from others is defined as *self-concealment* (Larson and Chastain 1990). Self concealment is a behavioural tendency to keep distressing and potentially embarrassing personal information hidden from others (Cramer and Barry 1999; Larson and Chastain 1990). According to Larson and Chastain, the concealed information has three characteristics – it is private and personal, consciously accessible and actively kept hidden. Thus, self-concealment involves a conscious and active process to hide perceived negative personal information. Because the information is perceived as embarrassing and negative by an individual, it inhibits the seeking of professional help. In other words, it impacts on help seeking behaviours and attitudes.

Individuals with a concealable stigma face challenges in choosing whether, when, how and to whom to disclose their stigma (Greene et al 2003; Kelly and McKillop 1996; Larson and Chastain 1990). Unlike individuals with a visible stigma, individuals with a concealable stigma must face disclosure decisions regularly. In every new situation that is encountered, such individuals must decide who among present company knows of their stigma, who may suspect this stigma and who has no suspicion of the stigma. These challenges have been documented in mental illness (Farina et al 1971; Quinn et al 2004). The ambiguity of social situations, combined with the threat of potential discovery, makes possessing a concealable stigma a difficult and challenging predicament for many individuals.

2.7 Models of self-concealment

The relation between self-concealment and negative psychological outcomes is well established, but the mechanisms behind this association are not well understood (Uysal et al 2010). There are a number of models identified within the literature that assist in the understanding of concealment and its association with poorer wellbeing (Kelly 2002).

One such is the inhibition model. According to this, not talking about certain psychological processes is a form of active inhibition (Pennebaker 1989). It takes physiological effort to consciously restrain thoughts, emotions and behaviours and over time, this physiological work acts as a long term low stressor (Kelly 2002). Over time, these stressors on the body accumulate, leading to physiological and psychological symptoms. If the event that is being concealed is active, in that it is still part of the person, like a diagnosis of mental illness, and more than a one off event that has happened in the past, then there is a risk that the event can be revealed if the keeper is not careful. This adds to the everyday effort to conceal and is a stressor.

Another model is the self-perception model. According to this, self-concealment leads to a self-perception process. For example, ‘because I cannot talk about it, what I am concealing must be really shameful’. This results in negative attributions about the self as well as feelings of shame and guilt (Derlega et al 1993).

A more comprehensive model, a cognitive affective behavioural model, has been espoused by Pachankis (2007). This model, while respecting that everyone is different in their biological makeup, temperament and information processing strategies, attempts to predict the cycle that anyone who is concealing a stigma may encounter. The model proposes that concealing a stigma goes beyond the individual’s global personality traits and that the aspects of any given situation will activate a set of internal cognitive and affective reactions for individuals with concealable stigma. These cognitive and affective responses, which may include, for example, preoccupation with the stigma, feelings of guilt, vigilance and shame are all interlinked. Both cognitive and affective responses, either together or independently, play a part in influencing eventual behavioural responses (Beck 1976). These behavioural responses will in turn impact on the individual within their environment. The cognitive, affective and behavioural responses are influenced by the individual’s evaluation of their surroundings. If an individual doubts their ability to manage or succeed in any given situation, this is likely to impact on their thoughts, feelings and behaviour.

2.7.1 Concealment, stigma and pathology

There is evidence in the literature to suggest that individuals with concealable stigmas have higher rates of psychopathology than the general population (Cochran et al 2003; Gilman et al 2001). Self-concealment is associated with negative psychological outcomes such as anxiety and depression (Kahn and Hessling 2001) and loneliness (Cramer and Lake 1998). On the other hand, concealing a stigma hampers the provision of social support and is related to considerable stressors and psychological challenges (Pachankis 2007). It contributes to low income levels and high unemployment among mentally ill people (Markowitz 1998). Uysal et al (2010) suggest that in the process of self-concealing, self-concealers are less likely to fulfil their personal potential and relatedness. Relatedness involves feeling connected to others in a trusting and supportive way.

Pachankis (2007) suggests that while the source of the stigma itself contributes to this psychopathology, the hidden dimension of stigma impairs the psychological functioning of individuals with concealable stigmas. The ambiguity of social situations combined with the threat of potential discovery makes possessing a concealable stigma a difficult predicament for many individuals. The psychological experience of the individual with a concealable stigma is influenced by how noticeable the stigma is and the power awarded to the stigma by the person. The individualised attributed importance to the stigma is referred to within the literature as stigma salience and refers to the accessibility of stigma-related thoughts and concerns by the individual (Pachankis 2007). A situation in which the individual perceives him or herself to be alone in possessing the stigma may be more likely to lead to negative psychological consequences than situations in which similar others are present. In addition to the absence or presence of similar others, the presence of stigma-related cues within the environment can make one's concealable stigma salient.

Kelly (2002) made a distinction between the act of secret keeping and individuals having an inhibited personality. The author's view was that the process of secret keeping was not problematic, but that individuals with inhibited personalities may be more prone to developing health problems and in her view, self-concealment reflected an inhibited personality.

There are also cultural aspects to self-concealment. In some cultural contexts, excessive self-disclosure is devalued because it is regarded as disruptive to the family honour. For example, Asian college students in the US were found to have a higher tendency towards self-concealment than European students. This is linked to emotional control and the maintenance of individual and family communities (Masude and Boone 2011). Attitudinally, Asian students more negatively evaluated the seeking of psychological help.

2.8 Disclosure and related concepts

Disclosure within health care has been defined as the act of seeking care by revealing personally significant information to others that exposes the bearer to the risk of rejection or negative judgement (Saiki and Lobo 2011). By the time a patient seeks advice from a healthcare provider, they have often been living with the knowledge of a concern, a risk and impairment of their quality of life for a period of time.

Within health care, in the facilitation of people seeking professional help, other key concepts have been discussed. For example, Bell and Duffy (2009) talk about the importance of trust in enabling more open communication within a patient nurse relationship and open communication contributes to the completion of a more inclusive risk assessment (Hupcey et al 2001). The patient having confidence in the service provider's confidentiality code is seen as important in creating a trusting relationship, which will impact on the decision to disclose significant information (Pinch 2000).

Omarzu (2000) developed the disclosure decision model as a framework for understanding disclosure. In this model, antecedents to disclosure were identified as setting a salient goal, having an available and appropriate target to disclose to and consideration of the risks and benefits of disclosure. A review of studies (Saiki and Lobo 2011) suggests that risk in disclosing is felt keenly and competes with the benefits of anticipated help. The need to relieve distress and suffering is a strong motivator to disclose. The need for social support indicates the significance of the act of disclosing beyond simply reporting information. Support and recognition need to follow the disclosure of information. The authors suggest that the implications of patient disclosure

for nursing practice are about the provision of safety, acknowledgement of the significance and sensitivity of disclosed information and acting on the disclosure.

Disclosure is highly relevant to this study and can be understood within the disclosure decision model (Omarzu 2000). The salient goal for the patient was having a supportive person administer depot injection which is a change from the traditional doctor/nurse delivery of a medical intervention. In achieving this goal, the supportive person needs to gain knowledge and skills of injection giving alongside knowledge of the patient's illness and the rationale for medication (See sections 3.7 and 6.5 for further discussion on gaining knowledge and skills). The patient had an appropriate target to disclose to and consider the risks and benefits of disclosing personal information related to their mental illness. Disclosure is identified in the literature as enhancing a more inclusive risk assessment (Hupcey et al 2001) and risk is an important concept within mental health (see section 2.5-2.5.2).

2.8.1 The dilemma of disclosure for clients with mental health needs

Disclosure is a serious dilemma for mental health clients (Corrigan 2005). Self-disclosure is accompanied by risk-taking and may in turn compromise the establishment of trust. Any form of emotional, cognitive or social difficulty disclosed is likely to be recorded and defined within a diagnostic framework (MacCulloch 2012). This diagnostic framework will be considered within the organisational risk management strategy and this can lead to economic and legal agendas becoming part of the individual's life. Examples include discussion about mental health legislation and suitability for employment. Social stigma has a significant impact on the lives of people with a mental disorder and disclosure may lead to stigmatisation and hence may have a negative impact on psychological well-being (Markowitz 1998). Individuals with a concealable stigma such as a mental illness are confronted with the dilemma of disclosure and potentially disclosure could result in child protection issues, social isolation, loss of employment and abandonment by family, friends or neighbours (Corrigan and Kleinlein 2005).

Pandya et al (2011) found that the stigma attached to a diagnosis of schizophrenia impacted on the lives of individuals in a way most people without the diagnosis would report as profoundly painful. The study explored the perceived impact of disclosure by

individuals with a diagnosis of schizophrenia and how such disclosures varied depending on the type of relationship they had with other people. The highest disclosure rate was with doctors and significant others whilst children and employers were lowest. Reactions to their disclosure varied widely. A significant group reported having better treatment by their parents after disclosure to them about their illness. Bos et al (2009) found that persons with a mental disorder selectively disclosed their mental illness. In general, they were open towards their partner and close family members but were closed towards less intimate relationships such as acquaintances and colleagues. If they disclosed to those close to them, they experienced more support and a less stigmatising response.

Both Bos et al (2009) and Pandya et al (2011) found that there were consequences for the patient if they disclosed about their mental illness. Subjects within the Pandya et al study reported having worse treatment for medical problems by their doctors, health providers and by the police after disclosing their diagnosis of schizophrenia. Bos et al (2009) found that disclosure to colleagues related to less support and stronger stigmatising responses. Thus, selective disclosure seems to maximise support and limit stigmatising responses. Within this context, clients with a mental health disorder are in a dilemma – by maintaining selective disclosure, they have to conceal their stigma in certain circumstances, and that concealment may induce stress (Pachankis 2007).

Disclosure of mental health concerns is more likely when trust is present. Lester et al (2005) found that people preferred to consult their GP, a person who was more likely to be in that position for a long time, as this allowed trust to be built up rather than having to retell their story many times with practitioners who frequently change. MacCulloch (2012) articulates that when trust is present, it can open doors for the deep sharing of delicate, vulnerable and sensitive experiences by patients. This sharing within mental health implies that the patient has trust in the ethics, wisdom and skilled judgement of mental health professionals.

A number of reasons for non-disclosure have been identified. These include feeling rushed at appointments, a need to handle the problem oneself, embarrassment and a fear around disclosure (Dew et al 2007). Schuster et al (1996) highlight the risk of confidentiality breaches within trusting relationships when personal information is disclosed.

2.9 The nature of trust

Within the literature on trust, there is a preponderance of accounts coming from the fields of psychology and sociology. In a review of psychology literature, Sellman (2007) categorises the main descriptions of trust as being an attitude of mind, a feature of the psyche and an attribute of individual nature. Erikson (1956) suggests that the concept of trust and trusting starts at the family level and grows to others. Basic trust is the first state of psychosocial development, occurring or failing during the first two years of life. Success results in feelings of security, trust, and optimism, while failure leads towards an orientation of insecurity and mistrust.

Within sociology, the literature on trust is concerned with the position and role of trust in social systems; the main description of trust views it as some form of social contract. Trust is one of several social constructs, a construct being an element of social reality. Other constructs frequently discussed together with trust, are: control, confidence, risk, meaning and power. Trust is naturally attributable to relationships between social actors, both individuals and groups (social systems) (Sztompka 1999).

In both psychology and sociology the degree to which one party trusts another, is a measure of belief in the honesty, fairness, or benevolence of another party. The term "confidence" is more appropriate for a belief in the competence of the other party. A failure in trust may be forgiven more easily if it is interpreted as a failure of competence rather than a lack of benevolence or honesty.

From a philosophical point of view, some argue that trust is more than a relationship of reliance. Philosophers such as Baier (1986) have argued for a difference between trust and reliance by saying that trust can be betrayed, whilst reliance can only be disappointed. McLeod explains Baier's argument by giving the following examples: we can rely on our clock to give the time, but we do not feel betrayed when it breaks, thus, we cannot say that we trusted it; we are not trusting when we are suspicious of the other person, because this is in fact an expression of distrust (McLeod 2006). Thus, trust is different from reliance in the sense that a truster accepts the risk of being betrayed.

Generically, both sociological and psychological approaches view trust as involving competent adults engaging as equal contributors to the construction of individual or social relationships. Pask (1995) suggests that trust is essential to living in a complex

world and moreover an essential component of nursing practice. Baier (1994) observed that trust is often only noticed when it becomes scarce or polluted. The author claims that the inclination of an infant to trust suggests that mistrust is not a default position and that there is a tendency to anticipate goodwill in and towards other people. Hupcey et al (2001) established that people moving towards mistrust when expectations were not being met, changed course as the result of positive trusting interactions. Trust is therefore dynamic and complex. Sellman (2007) claims that the everyday meanings of trust take account of circumstances and suggest that understanding the meaning of trust is contextually bound. This leads to a description of trust as a thick concept: a concept whose application is determined by what the world is like (Austin 2005). Trust is an elementary and basic quality in human beings.

Goudge and Gilson (2005) suggest that the notion of trust can be difficult to define and to investigate. Trust is an everyday concept with implied meaning. Das and Teng (2001; 6) give a definition of trust as 'expectations held by one party that another will behave reliably and predictably'. Radwin and Alster (1999; 328) define trust as 'the confidence that care would be appropriate, reliable and as successful as possible'. They identified key characteristics of trust as: attentiveness, caring, coordination, continuity and competence in the form of professional knowledge and argued that trust results from these trust-engendering care processes. The authors suggest that key characteristics listed are attributes of person-centred care. In contrast, Thom et al (2004) conceptualised trust as a singular concept that is inclusive of trust-engendering processes, namely, interpersonal relationship skills, competency of the practitioner and a duty to the patient.

There are a number of conditions that need to be in place in order for trust to develop (Washington 1990). These include confidence, self-reliance and faith that the world will satisfy needs and provide whatever is necessary. Additionally, Arnold and Boggs (2003) identified the need for good communication, knowledge, respect, honesty and commitment. The preconditions of trust include a need that cannot be met without the help of another person or organisation; a limited focus to the area or behaviour related to the need; a testing of the trustworthiness of the individual concerned; prior knowledge or experience with the other and some assessment of risk of what is at stake, (Hupcey et al 2001). Because of trusting, an individual places him or herself in a dependent and vulnerable situation. Baier (1986;235) declares that 'on first approximation, trust is accepted vulnerability to another's possible, but not expected, ill will towards one'.

What we aim for when we trust is something about a level or ‘the right amount’ of trust. In everyday life, we sometimes trust too much and sometimes trust too little. Sometimes we distrust too much and sometimes distrust too little. Baier (1986) notes the importance of a proper amount of trust or an appropriate amount of trust. There is a tendency to view trust as positive and mistrust as negative. White (1996) points out that an appropriate amount of trust in institutions is something we should encourage as a positive civic duty- because we need institutions to be trustworthy. However, when we trust someone or an institution, we do not always know the value the receiver of the trust places on our trust, and within this scenario is a level of uncertainty and risk taking. Trust that one has developed over a long time and within many contexts, can be destroyed in a single moment (Austin 2005).

Some assessment of the risk (see sections 2.5 - 2.5.2) of what is at stake is a precondition of trust (Hupcey et al 2001). Because of trusting, an individual places him or herself in a dependent and vulnerable situation- a situation where their body is made vulnerable, and personal and private information is shared. Trust and trusting is a calculated risk (Mayer et al 1995), since there is the possibility that the person being trusted may not act appropriately, whilst McAllister (1995) suggests that trust enables one to take a risk. Those who trust, run the risk of letting those they trust near things they care about. Schuster et al (1996) talk about the risk of breaches of confidentiality within a trusting relationship where concealed information can be disclosed. With trust there is always the possibility of disappointment.

2.9.1 Trust and healthcare

Within organisations, between employers and employees, trust is an important concept. Mallock (2002) suggests that trust is the emotional glue that binds leaders and employees together and is a measure of the legitimacy of leadership. A higher degree of trust among employees is profitable, in that teamwork is enhanced and better quality of communication results in greater productivity. Within current public services, audit surveillance is pervasive and occurs at the expense of trusting relationships between professionals and clients (O’Neill 2002; Sellman 2007). Underpinning the institutional need to audit is the lack of trust in the professionals who provide the service rather than an assumption that professionals will protect patients who are vulnerable. Over the past

year, with reports into the care of the older adult² and learning disabilities³, society has a right to question the public sector and its treatment of the vulnerable. Within this context, audit and research is necessary to inspire trust, in the public, in the competency of organisations. Issues of competency, trusting relationships and the care of the vulnerable person relate to this study as a medical intervention was delivered outside traditional service and professional routes where no audit process or research evidence exists.

A dominant assumption in the literature, that trust is something that occurs between equally competent adults, cannot explain trust in nursing because of the unequal power relationship between patients on the one hand and healthcare professions on the other (Sellman 2007). To be in receipt of nursing, generally speaking, is to have a need and to be outside the terrain of everyday routine. In that context, we negotiate trust from the perspective of the patient role and enter into a trusting relationship between those who are vulnerable and those who, if they choose to, exploit that vulnerability.

The development of trust is as important for the nurse to develop as it is for the patient. The nurse must demonstrate the ability to develop trust in order to obtain accurate information from the patient and thereby improve the appropriateness of the intervention (McQueen 2000). Belcher (2009) suggests that through a trusting relationship the patient is encouraged to channel energy into achieving the goal of optimal health instead of wondering about and doubting the reliability of care and information. The expectation that nurses should be trustworthy is given formal expression in the nurse's code of professional practice (NMC 2007). Despite the espoused importance of trust in nursing, the literature on it is sparse (Sellman 2007).

For nurses, it is generally considered that it is desirable to have goodwill towards patients and through this goodwill, expect patients to reveal personal and intimate details about themselves within the caring context. Baier (1986) notes that when we need looking after, we require assistance from others to look after things we most value (intimate and personal information). Implied within this context is both personal and professional trust. Professional trust is inferred as what happens in business-type arrangements. Personal trust comes as part of the choices that are available to us over time with the people

² Francis Report 2013.

³ Winterbourne View care home - Panorama report 2011.

around us. Sellman (2006) suggests that whilst trust is an essential part of nursing, nursing per se cannot be categorised as an example of personal trust, though there are instances where some interventions within nursing approximate personal trust. The examples he espouses are mental health and learning disability, because of the nature of therapeutic relationships built and developed over time.

Despite a lack of clarity in the definition of trust, it is clear from the literature that trust is a major influence on patients' acceptance of care and treatment from health care professionals (Hupcey et al 2001). Thorne and Robinson (1988) suggest that trust was one of the most significant elements in healthcare relationships from the perspective of the critical or chronically ill patient who requires high levels of nursing and medical care. Because chronic illnesses create a climate of vulnerability for the client, the competence of the healthcare professional in relation to the patient and family must be taken into account to build and maintain trustworthy relationships (Rushton et al 2007). For the trusting patient, a trustworthy nurse is vital, especially where the patient has a diminished or compromised capacity to make an assessment of the trustworthiness of others (Sellman 2006) (see section 2.3).

Hall et al (2002) suggest that patients who trust their doctors are more likely to seek care when sick, more likely to provide personal information relevant to an accurate diagnosis, more likely to agree to undergo recommended treatment, more likely to stick with a recommended health regime, and perhaps more likely to experience positive health benefits from the trust itself. On the last point, Hall et al suggest that there is growing evidence that trust in one's physician can have a powerful placebo effect on patients. The doctor is a placebo or a therapeutic agent, regardless of the particular technique used or its independent, biochemical effectiveness. In fact, patients often begin to feel better as soon as they know that they have a physician who is working to help them (Hall et al 2002).

Studies have attempted to measure the relative influence of different dimensions of patient trust. Patients look for their doctors to be competent and honest, to act in their best interests, to treat them with care and respect, to advocate on their behalf where necessary, to avoid conflicts of interest, and to keep their information confidential. Scholars have found that subjects simply lump all of these dimensions together. For example, a doctor who is thought to be low in honesty is presumed to be incompetent and

disloyal, and a competent doctor is presumed to be loyal and likely to keep the patient's confidences. This suggests that patients have a global approach to the assessment of their doctors, rather than a more calculative specific assessment of the doctor's particular strengths and weaknesses (Hall et al 2002).

White (1996) made a distinction between trust in persons and trust in institutions, and family membership falls under both these headings. For some people kinship forms the basis of personal trust. Fukuyama (1995) describes cultural determinants of trust relationships when he suggests that Chinese communities have a tendency for trust to be limited to family members whilst European communities trust family as well as people outside the family.

2.9.2 Trust and collaborative working

Trust, with a definition of the 'expectations held by one party that another will behave reliably and predictably' can take many forms (Das and Teng 2001: 6). Trust when developed, they argue, can replace control as the basis for collaborative working. Collaboration and collaborative working are popular concepts within government and service delivery policies (DH 2008b; DH 2011a) and legal framework (MHA 1983 amended 2007) (DH 2007a). NICE clinical guidelines suggest it is a process that requires the skills of negotiation and shared decision making (NICE 2009) whilst the NMC code of practice (NMC 2007) stipulates that nurses collaborate with patients by listening to and responding to their concerns and preferences. Multi-agency and inter-disciplinary collaborative working practices are popular concepts within health and social care. Ovretveit (1993) suggested three models of collaboration: those imposed by higher authority, which are largely bureaucratic in form; the market model where penalties apply if targets are not achieved and the collaboration through association model. This is based on a belief that collaboration has the potential to deliver solutions to problems which are of mutual concern to persons or organisations and is particularly useful when problems are unclear. The expertise of others is particularly useful. Trust, in the context of collaborative working, is used as a means of dealing with uncertainty and ensuring that those involved in co-operative working practices, behave appropriately.

With much of community mental health being delivered by community teams, there is an expectation that team members trust each other. However, multidisciplinary working

often fails to mitigate the boundaries between professional groups and may even maintain the dominant power relationships (Finn et al 2010). Alongside these challenges of multidisciplinary working, the government policy promotes patients and carers as active partners in care (DH 2008c). The addition of a group, e.g. patients, who are new to health service culture, will add further challenges within multidisciplinary teams.

Newell and Swan (2000) differentiate between three types of trust, specifically in relationship to collaborative working. These types of trust are: *companion trust*- based on judgements of goodwill or personal friendships and continuing reciprocal exchange; *competence trust*- based on perceptions of the other's competence to carry out the tasks that need to be performed and deriving from witnessing this competence first hand and *commitment trust*- based on contractual commitments between the parties, which can act as a more control-based failsafe that will continue to facilitate the collaborative partnership if the other two forms of trust are lacking. The authors see these types of trust as the connection which underpins collaboration with others and the facilitation of sharing knowledge.

2.9.3 Trust within recovery philosophy

Recovery, as a philosophy, is currently at the heart of mental health service delivery within the UK and will be discussed in more detail in section 3.5. This philosophy is underpinned by a belief in the individual living within the limitations of their mental illness and an acceptance that treatment does not always cure (Slade 2009). Seemingly universal in the recovery concept is the notion that critical to one's recovery is a person or persons whom one can trust to "be there" in times of need. People who are recovering talk about the people who believed in them when they did not even believe in themselves, who encouraged their recovery but did not force it, who tried to listen and understand when nothing seemed to be making sense (Anthony 1999). Critical to recovery is regaining the belief that there are options from which one can choose - a belief perhaps even more important to recovery than the particular option one initially chooses. Delivering recovery-focused goals can be integrated with person-centred care.

Skidmore (1994) suggests that by shifting mental health care to community care, the style of intervention required by patients, has to change from a condition-specific approach to that of a person-centred approach. Working within a person-centred approach requires a discussion about responsibility taking by both patient and service provider. Within a community care philosophy, Skidmore (1994) argues that the person with a diagnosis of psychosis, albeit under control, is never really trusted to dispense his/her own medication. If they cannot be trusted, arguably they are not ready for care in the community. Each person's experience has to be judged on an individual basis and not judged by the expectation of the condition. The challenge for practitioners is to make a judgement on to whom responsibility could be transferred. Patients and carers attend CPA meetings or other out-patient meetings- these meetings are formal and highly structured with a tight agenda. The staff are focused on reviewing the medication, the care plan, risk and throughput. It is challenging for service users and carers to build trust in such surroundings, unless evidencing compliance with the care plan. There are no informal opportunities to foster relationships of trust – any contact that enables people to get to know each other and build a sense of commonality and purpose. No other structures exist where service users, carers and practitioners meet whose foci is knowledge and learning transfer rather than the ubiquitous review meeting or ward round. The exception to this is when mental health staff, generally of low status like students and support workers, engage in employment-seeking behaviours or social activities like the football team or dating club with patients. This implies that knowledge and learning transfer takes place between patient and staff of low status which gives an indicator of the organisational and political importance attached to it. Students are a transient group and will move on to other clinical areas and support workers are unlikely to attend or influence decision-making fora where this knowledge can be shared with others in more powerful positions.

In mental health nursing, emphasis is placed on mutual trust in the relationship between patients and nurses as a prerequisite to ensuring that the therapeutic programme will help patients. However, building trust in psychiatry is challenging. This is due to involuntary treatments, unbalanced power structures between staff and patients, severe mental illness itself where belongings are searched and the doors locked, cognitive problems and the use of psychotropic medication. Hem et al (2008) suggest that in acute mental health care, mutual distrust rather than mutual trust is the dominant factor in the relationship

between patients with psychosis and nurses. The work of creating trust is demanding but it is up to doctors and nurses to ensure situations veer towards trust rather than mistrust.

Kai and Crosland (2001) found in a UK qualitative study with 34 clients with enduring mental illness that trust is important in building positive therapeutic relationships. Themes identified in the study emphasised the importance of continuity of care in maintaining trust. Hannigan et al (1997) in another UK qualitative study found that service users felt a trusting clinician-user relationship was central to a good quality service. In a US based study, Mechanic and Meyer (2000) found that clients with a mental illness stressed the importance of trusting the clinician to understand and minimise the side effects of medication more than clients with cancer or Lyme disease. Clients with a mental illness put more emphasis on the importance of confidentiality in their trust in doctors. The same client group reported withholding information on substance misuse; dangerous behaviour and non-adherence to medication (see sections 2.7-2.8.1 on concealment and disclosure). The authors reported that clients with a mental illness diagnosis emphasised the importance of time with the clinician and the importance of continuity of care.

2.10 Conclusion

In this chapter I have discussed the concepts of insight, informed consent and capacity within mental health care. I have defined risk and discussed it within policy and legal frameworks and how it relates to the carer and patient view. Stigma is discussed through the work of Goffman and its association with mental illness and coping. Concealment and disclosure and how they impact on mental health are explored as is an in-depth discussion on trust as it relates to healthcare, collaborative working and the recovery philosophy.

The ability of the patient with a diagnosis of schizophrenia and psychosis to give informed consent is primarily one for the clinician who is engaged with the patient to judge. There is legal and professional guidance to support and inform the clinician in making a judgement related to consent seeking and this is likely to be influenced by the practitioner's values. A challenge for the mental health practitioner is how global inferences and assumptions about and related to a diagnosis of schizophrenia impact on

their decision making. This study worked with participants who had capacity as assessed by mental health practitioners (see section 5.13.2).

The delivery of mental health services has changed significantly over the past 50 years – from the dominant asylum to multiple venues within institutions and the community and this change has necessitated a review and an understanding of risk. Risk is a highly emotive concept and potentially the premise of negativity in mental health obstructs rational debate about it within the caring context. The definitions of risk push the concept towards negatively valued outcomes whilst the recovery philosophy promotes positive risk-taking where patients are guided to have choice and to take risks. Government policies about personalised budgets, the expert patient and devolved budgets suggest a transfer of risk away from the provider of services towards the patient and family. Tensions exist between the enactment of these policies' philosophies (aligned with recovery philosophy) and a risk-averse approach. It is relevant to note that the Department of Health risk framework (2007b) relates to three areas of risk; namely violence, self-harm and self-neglect – not to choice giving.

The enactment of choice policies links to the dynamic risk classification (Heyman et al, 2010; Glover-Thomas, 2011) in that dynamic risk factors can and do change over time, an example being support structures. This study will add to the literature related to risk and support the structures deemed necessary to support the family and patient when they take on the administration role. The study has the potential to develop the literature related to the mental health nurse and a nurse's central activity of assessing and managing risk (DH 2006a; Doyle & Duffy 2006; Coombs et al 2011). The administration of the depot injection, a traditional role of the nurse, was an interaction through which assessment of the patients' mental state could be undertaken and within this study, this interaction opportunity changed through delegating this role. There is no explicit reference in the literature on how empowering patients and supportive persons may have implications for the delivery of services and its subsequent success or failure within a risk aware culture.

There appears to be a dearth of evidence about patients' own experiences of being risk managers in their own right. This suggests a preoccupation with service risk management rather than understanding individual patients' views of risk and their management strategies. With the move to community-based care delivery, carers and families are

integral to the management of risk. The literature suggests that carers had rarely been taught any risk management strategies by mental health professionals but some had copied strategies from them. This finding is relevant to this study in that understanding risk associated with the supportive person taking on the role is a stated aim of the research (see section 1.1). The patients', supportive persons', providers' and practitioners' understanding of risk will be developed. The absence of a health professional involved in the delivery of the depot injection is relevant to this study as the limited literature on carers and their development of risk management strategies suggests the carer copies strategies from mental health professionals.

Relating insight and informed consent within a risk averse culture is a challenge for the mental health practitioner, particularly in the promotion and deliverance of service user choice expectations. These expectations have to be considered within service provider expectations and societal demands. Enabling and promoting choice necessitates an analysis and discussion about information sharing with relevant parties, all of which are relevant to this study. There are potential risks and benefits to disclosing information about a mental illness, particularly in relationship to stigma and the formation of trusting relationships.

A person who is deemed to be different or handicapped with some affliction may be stigmatised by other members of society, and by association, so may members of the person's family. A potential impact of stigma associated with mental illness is decision-making by the patient about disclosing or concealing all, or some, of their illness details. There is a relationship between self-concealment and negative psychological outcomes and a number of models are identified in the literature to understand this process (Kelly 2002). Seeking care by revealing personal significant information exposes the person to the potential for emotional betterment as well as the risk of rejection. Disclosure to mental health professionals is likely to be recorded and defined within a diagnostic framework, this then being considered within organisational risk management strategies. There is an onus on health professionals to manage this disclosure in a safe and confidential way. The literature suggests that patients disclose information about their illness to doctors, family members and significant others and gain support as a consequence. This is relevant to this research study and an important factor in enabling people to disclose personal information is trust.

From the nursing literature, trust is weighted towards the patient trusting the practitioner for care. For example, the patient requires confidence that care will be delivered, and in the practitioner's professional knowledge (Radwin and Alster 1999) and duty to the patient (Thom et al 2004). A precondition for trust is a need that cannot be met without the help of another person or organisation. Within mental health, there are specific challenges to the formation of trust. These are about the diagnosis of psychosis, the cognitive impact of such an illness, the use of psychotropic medication and the patient's understanding and management of the diagnostic stigma. Within acute mental health care, mutual distrust rather than mutual trust may be more dominant.

What is of interest to this study is exploring and understanding the facets of mistrust evident in practice and whether mistrust influenced the referral of participants to the study and the sharing of a traditional nursing role, i.e. the administration of a depot injection. Relating to Newell and Swan's (2000) three types of trust, this study contributes to the literature about competency trust – the carrying out of tasks that need to be performed and whose performers have no track record of doing such an activity. Additionally, enacting recovery-orientated service change and its relationship with commitment trust would benefit from literature development. There is no explicit reference in the literature on how empowering patients and supportive persons may have implications for the delivery of services and their subsequent success or failure within a trusting framework. Involving the patient and their family in the delivery of care is integral to current good practice and national policy and this will be discussed in the next chapter.

Chapter 3

Integrated Working

3.0 Introduction

The implementation of deinstitutionalisation from large asylums in the 1980's laid the foundation for a new vision of service delivery for people who have mental illnesses (Anthony 1993). The state asylum, whilst possibly meeting the complex needs and wants of this mental health client group, for example, residential, vocational, social and educational needs, also met the needs of society by hiding mental illness. The meeting of these complex needs within a community setting would require a new way of thinking about services, and about the people served, and this would lay the foundation of the 'recovery' vision. Within the UK, alongside the deinstitutionalisation process, developments in recovery have been traced to anti-discriminatory and disability legislation (Allot et al 2003) and initiatives in support of the Expert Patient programme (DH 2001c).

Since the 1980's, governments have promoted the active involvement of patients in their own health care and this philosophy has been articulated through health and social care policies. Such policies have promoted concepts like the Expert Patient, the personalisation agenda and the philosophy of recovery. Within this chapter, the philosophy of user involvement will be briefly alluded to with in-depth discussion about key government policies which relate to patient, family and carer involvement. Table 3.1 outlines key government policies with an associated statement of key concepts related to patient and carer involvement. Building on key policy aims, an in-depth discussion about personalisation and the recovery philosophy is provided. The key policy goal of choice and involvement is relevant to this study, and to understand how choice might be delivered in practice, it is necessary to have an understanding of the role of the practitioner. The role and attitudes of the mental health nurse in the administration of the depot injection will be discussed as will the learning of skills and the family as caregivers. Care giving can be demanding and understanding resilience is important in understanding carers' coping responses.

3.1 The philosophy of user involvement

The ontology of illness and illness experiences have been historically tied to the objectification of disease and illness and this has particularly embedded itself since the 1980's with biomedical advances and economic policies (Hafferty 2006). The medicalisation of madness has evolved into the culture of diagnostic manuals (DSM) and pharmaceuticals (Conrad 2005; Mayes and Horwitz 2005). In contrast, Habermas (1971) espouses a critical philosophy (see section 4.4.1) which aligns itself to user perspectives, particularly in relation to practice philosophy. Within critical philosophy, domination and control emanate from the traditional concept of medical power and the linking of mental health problems to deviancy. This deviancy requires controlling. Critical philosophy calls for equalisation, mutual understanding and sharing as the fundamental base of human relationships. These sentiments are embraced in user perspectives so that the rights of users are protected, and the user's voice has equal weight within the caring paradigm. The user perspective founded upon critical philosophy shifts power from the professionals to the users of mental health services.

Aligned with critical philosophy, Strickley (2006) advocates critical realism as the basis upon which service users can usurp the power of control within mental health care. Critical realism claims that there is a reality ('out there' in the physical world) that is separate from our descriptions of it. Unlike positivism, there are no universal claims in critical theory, but knowledge is a social and historical product and specific to a time and place. Change through the perspective of critical realism is advocated not through a traditional hierarchy of power relationship but through emancipatory action projects outside of the existing power structures. Current government health and social care policies which promote service user and carer involvement in their care are discussed in the next section.

3.2 Policy and user involvement

The World Health Organisation (WHO) has encouraged service development that is better tailored to people's needs. The WHO Mental Action Plan for Europe (2005) acknowledges that a lack of empowerment of users and carers and poor advocacy will hinder the delivery of care (European Commission 2005). A number of trends, pressures

and policy shifts can be identified that are promoting greater patient involvement in health care delivery through consultations, treatments and continuing care. In England, user involvement gathered pace following the NHS and Community Care Act (1990) (DH 1990) which introduced a market-based approach to health and social care in the 1990's. Chapter 10 of the NHS Plan (DH 2000b) was devoted to how user involvement in the NHS could bring about 'a patient-centred service'. The involvement of service users is now a legal requirement, outlined in Section 11 of the Health and Social Care Act (DH 2001d). The NHS Constitution (DH 2010a) promises patients that they will be offered information about options for treating their conditions and the risks attached to each of these options, together with the right to be involved in decisions about their care.

The National Service Framework for Mental Health (DH 1999) states that one of its core values is user and carer involvement and refers to involvement of service users 14 times. Within *Strengthening Accountability* (DH 2003a), involvement is mentioned at least 160 times. What involvement actually means is not defined. Different language is used to denote involvement within these policy documents. For example, 'informed choice', 'engagement' 'user perspective' 'participation' 'consultation' and 'partnership working' (DH 2003a). An evaluation by the National Institute for Mental Health England (NIMHE 2004) recommended that a new post of National Director for User Involvement be established to ensure that user involvement structures are even more strongly embedded in services. This post was not established and NIMHE has now been abolished. Policies also state that patients, across all medical specialities, should have more choice and control over the services they receive as well as having an impact on those services themselves. Both statutory and independent sources of funding for mental health services and research now require evidence of user involvement (National Health and Medical Research Council 2002; Department of Health 2006c; National Institute of Health Research 2011).

Current government policy continues to promote involvement. The current coalition government states that it aims to put patients at the heart of the NHS and states its aim to 'champion patient and carer involvement' (DH 2010b; 3; 13). In its *Vision for Adult Social Care* (DH 2010b) the coalition government confirmed its commitment to the personalisation agenda, claiming people not service providers or systems should hold the choice and control about their care. Personal budgets and direct payments are a powerful way to give people control (DH 2010c; 15). However, it is important to consider the

origins of direct payments legalised through the Community Care (Direct Payment Act) 1996. The context in which this act was passed was one where scarce resources were being targeted to those most in need, (Glendinning et al 2000); the need for shorter stays in hospital resulting in more complex health needs in the community and care remained service and crisis led rather than promoting independence and social inclusion (Glasby and Littlechild 2006). The Independent Living Movement was influential in the direct payment lobby whose participants were mostly young disabled people who wanted choice and flexibility rather than services provided by health and social care organisations. One view is that the introduction of direct payment was the backdoor to privatisation and the erosion of traditional public services and transferring the philosophy of direct payment to the older person and persons with long term serious mental illnesses may be more challenging.

Borg et al (2009) state that user perspective and user involvement are not single concepts but encompass meanings at several levels. Terms like user involvement, user participation, user perspective, user control and user empowerment seem to refer to differing ideas regarding users' roles in the receipt of care as well as in the development of mental health services. The authors suggest that 'participation' is less engaging and influencing than 'control' and 'empowerment' whilst 'involvement' is passive and 'perspective' is all encompassing.

There is much discussion within the literature concerning the nature of user involvement. One such approach is the use of a hierarchy of involvement, illustrated by the Assessment Quality Improvement tool developed by the Northern Centre for Mental Health (2003). The levels of the hierarchy are: 'no involvement', 'passive involvement', 'token involvement', 'collaboration and partnership'. This is similar to the continuum offered by Hickey and Kipping (1998), who define involvement at the highest level as encompassing an equal relationship between service users and providers in which decisions are made jointly.

Service user representation at committee level has been described as a mechanism that serves to add legitimacy to stakeholders' plans (Repper et al 2001). This reinforces Bramwell and Williams' (1993) suggestion that service providers are simply searching for service users who fit into their structures. Campbell (2002; 30) refers to representativeness as a 'suffocating blanket'. There is also a danger of the evolution of

the 'lay professional', who might become socialised away from a genuinely lay perspective (Boote et al 2002). These complex, and at times irreconcilable, issues of roles are considered by some as excuses so that service user involvement remains nonexistent, or at least at a tokenistic level (Crepaz-Keay et al 1997). Allott and Holmes (1993) suggest that while tokenism is unacceptable, it may be interpreted in a positive way. Tokenism means that at least the concept of service user involvement has been recognized.

Within the literature there are two approaches to involvement of service users. There is the 'top down' approach, which embodies the interest of the state, service systems, policy documents and legislation, and the 'bottom up' approach embodying service user organisations and advocacy services (Beresford 2003; Rush 2004). The former approach, sometimes referred to as the stakeholder approach, is where service users are involved in the governing body of organisations without having the final say on decisions. The latter prioritises peoples' autonomy, inclusion and human rights and is based on the belief that people should have more control and a bigger input into state organisations (Beresford 2003; Rush 2004). Within these two perspectives, are two polemic representations of power, one representation of power being the managerialist approach, suggesting power over service users and the other the democratic approach, suggesting service users' lack of power (Hui and Stickley 2007). Both representations suggest imbalances in power and as such the efficacy of involvement is called into question.

Encouraging service users to be involved in the planning of healthcare is assumed to improve standards (DH 2003a). Although studies have explored the potential benefits of patient and public involvement in improving health service design and shaping priorities there is still limited empirical evidence to support the effectiveness of these initiatives (Fudge et al 2008; Challans 2006; Nilsen et al 2006). Structural barriers to public participation have been highlighted and include uncertainty over the practicalities of promoting patient involvement (Anderson et al 2006), the precise role the public should play, poorly resourced integration into systems for service improvement and professional attitudes to patient involvement (Brooks 2008; Gagliardi et al 2007; Thompson 2007). A commonly cited concern is that patients' knowledge and awareness focus predominantly on their personal elements of care, with few patients having the awareness or motivation to understand the broader perspectives required for involvement in strategic health service planning.

There is some evidence that user involvement in mental health leads to improved patient satisfaction, higher quality of care, greater treatment compliance and a safer environment for patients and providers (Eisen et al 2000; van Os et al 2002; Hamann et al 2003). However, because of a lack of a uniform definition and validated measuring instruments it is difficult to make objective statements about user involvement. Crawford et al (2002) in a systematic review showed that involving mental health service users was not unequivocally clear, although the review showed that active involvement of patients in services contributed to changes in those services. Examples given within the review were advocacy services, employment and crisis services. Involvement of users led to cultural changes in that providers of services became more open about involving patients. User involvement did lead to improved self-esteem in patients. Crawford et al (2002) comment on the fact that the majority of papers reviewed were case studies and this may reflect the difficulties in defining and measuring involvement.

Bradshaw (2008) suggests that policy intent to involve service users is concerned with their well-being; their involvement however, is also used as a tool to drive market solutions into the delivery of more efficient healthcare. In a traditional hierarchical organisation like the NHS, there will always be a tension between the beneficence of user involvement and the power of clinical judgement and this adds to an overall ambiguity for all parties (Fournier 2005). Crawford et al (2002) argue that the ultimate determinants of health transformation remain with health professionals and managers.

Although the term 'patient led NHS' (DH 2005b) was a policy initiative by the Labour Government in 2005, Hui and Stickley (2007) argue that the concept of a patient led health service is an oxymoron, given that the power balance is predominantly with the health organisations. Within mental health services specifically, people's minds are deemed to be disordered, thereby affecting their views, ideas and judgements (Beresford 2003). Placing such patients, within the NHS, in the lead, implies an element of risk as the patients' capabilities will be questioned. Additionally, within mental health, there is considerable imbalance of power that sits in favour of health professionals (Kumar 2000) and professionals must surrender some of their power in order to pass it on to service users (Gillespie 2000).

In summarising the rhetoric of 'involvement' within government policies, service users report feeling ignored and disempowered. Maguire (2005; 18) reports that 'the bottom

line is that service users are being sold a solution and not involved in the creation of one'. An example of solutions being offered is the Payment by Results policy (PbR) (DH 2010d). The PbR policy operates through an assessment process leading to allocation of the patient to a care cluster and hence determines the care package individuals receive from services. Denham-Vaughan and Clark (2012) suggest that the assessment process in mental health needs to be critically reviewed towards recovery orientated conversations with the aim of having more co-produced understandings between practitioners and service users. Support from friends and family which may be significant in a person's recovery is not measured within the PbR framework. This has implications for this research study in two respects. One, service managers will focus on payment as that is what they will be measured by and secondly, the service's interest in innovation that involves family support is unlikely to be prioritised.

PbR supports greater patient empowerment through the giving of a menu of options about care planning, one such option being the setting of personal health budgets. Personal health budgets are to be rolled out more widely within the NHS (DH 2013a) following an evaluative period – an evaluation which shows that patients with continuing healthcare and mental health needs benefitted most from personal health budgets. The issue for the service user is who defines the menu of options offered within the PbR framework and it is difficult to ascertain this data.

However, while the literature is growing fast on different methods of involvement, little attention has been given so far to the role which patients themselves wish to play, nor the conceptual meanings behind involvement or participation (Thompson 2007). Bradshaw (2008) suggests that as far as service user involvement is concerned, the task for policy makers and managers is to move from aspiration to reality. The author suggests that that whilst the service is a public good, the position of service users within it has been one of subservience.

Some of the key policies and guidelines that have influenced patient involvement in health care delivery in the UK over the past 12 years are summarised in the following table and policy implementation will be discussed in the next section:

Table 3.1 –UK policies which inform patient involvement

Policy	Key statement of direction/intent
The NHS Plan (DH 2000b)	Set up empowerment mechanisms. Increase patient information, informed choice and consultation regarding individual health care and health services
Expert Patient programme (DH 2001c)	Provide training for patients with chronic health conditions to enable them to become equal partners in their care
Now I feel tall – what a Patient Led NHS Feels Like (DH 2005b)	Moving from an NHS that does things to and for people to one which is patient led
Essence of Care. Benchmarks for promoting health (DH 2006b)	Individuals and communities to be empowered to make informed decisions about their health and wellbeing
A stronger local voice (DH 2006d)	Aim to revitalise community empowerment by establishing local involvement networks to influence health and social care services
Schizophrenia – guidelines (NICE 2009)	People with schizophrenia should have the opportunity to make informed decisions, including advance decisions and advance statements, about their care and treatment, in partnership with their healthcare professionals
Payment by Results PbR (DH 2010d)	Personalisation and PbR are both about the individual. They move away from focussing on what care organisations traditionally provide to what people need in their particular circumstances. By breaking funding down to an individual level, they give the opportunity for more service user decisions over the care they access. The two policies also offer the opportunity to combine separate funding streams to meet individual needs

No health without mental health (DH 2011a)	<p>This mental health strategy looks to communities, as well as the state, to promote independence and choice and the recovery philosophy is integral. It sets out how the government, working with all sectors of the community and taking a life course approach, will:</p> <ul style="list-style-type: none"> • improve the mental health and wellbeing of the population and keep people well • improve outcomes for people with mental health problems through high-quality services that are equally accessible to all • personalise the production and delivery of services and support
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3.3 Policy implementation

Power is a key factor in health policy implementation (Eramus and Gilson 2008) and is discussed further in section 4.2. They suggest that the practice of power can generate misunderstandings between providers and patients and impacts on the way providers reformulate policies as they are implemented. Elmore (1978) in discussing bottom-up theories of policy implementation highlights the need for discretionary power because it is not possible for decision makers to foresee all possible circumstances to which the policy might relate. Discretionary power is viewed as giving organisations and professionals some discretion as to how they implement a policy, and is important in healthcare as it enables providers to respond to varying patient circumstances.

Aligned with discretionary power is the power of language used within policies. The language of policy and the meanings people give to that language become policy, and influence the response to policy translation. Alaszewski and Brown (2012) suggest that perlocutionary language is one method of engineering certain psychological reactions across the public sphere. By perlocutionary language they mean the impact the speaker's communication has on the emotions and responses of the listener. This invites public

opinions to attach themselves to the policy despite a gap between the rhetoric and substance of the policy. Local organisations will be pressured to implement but with local discretion as to how this is evidenced. Some examples include the offering of choice and patient participation in care planning. Policy language is not only constructed by politicians but also by professionals and managers. Professionals, particularly doctors, have power because their professionalism and expert judgement is trusted. This power will be supported by the 'normal way of doing things' which is embedded in organisational culture. Alaszewski and Brown (2012) suggest that some of the factors which influence policy outcomes relate to those with power; the groups with veto power, the most resources, those that are media confident and those with good evidence to support their claims.

From a professional perspective within health and social care, enhancing practice to account for the views, wishes and involvement of users is seen as a measure of 'best practice'. Oliviere (2001) highlights how professionals may present barriers to user involvement by declaring that patients need protecting. Whilst user involvement and participation between professionals and service users in mental health have been the vision for the last decades, there is evidence that the vision remains rhetoric rather than reality in many clinical settings (Rose 2003; Beresford 2005; Hansen et al 2004).

Shaw et al (2008) suggest that within the NHS policy needs to be viewed through three layers of meaning as these will impact on implementation uptake; those meanings which are overt and explicit in the policy document; those which reflect the rhetoric of the policy environment and the government's intentions; those which reflect the ideology, usually implicit, underpinning policies at the local and national level. One such example is user involvement. Borg et al (2009) state that user perspective and user involvement are not single concepts but encompass meanings at several levels.

For some regulatory policies, for example Health and Safety policies, Barrett (2004) states that compliance may be an essential requirement. Other public policies are couched in more discretionary terms and the objective may be to encourage innovative courses of action within the policy framework. Within policies where discretionary terms are used, and where innovative potentially risky solutions are proffered, Williams (1971) suggests that to allay public concern, it is likely the innovative solutions will be tempered by tight

administrative and procedural controls. One policy that warrants closer scrutiny as it promotes service user empowerment is policy that promotes the personalisation agenda.

3.4 Personalisation

Personalisation is a way of treating service users as empowered individuals with strengths, preferences and their own network of resources (Carr 2010). The personalisation agenda was set out in '*Our Health, Our Care, Our Say*' (DH 2007d). It was a move away from a traditional service-led approach to service delivery to a more personalised system of providing care and aimed at social care, housing, leisure, transport and health (DH 2007d).

Key policy tenets are:

- Reducing dependency
- Service users, families, and carers assessing their own needs and choosing how those needs are met
- Improving access to public services
- Shifting the focus to proactive, preventative models of care
- Supporting carers
- Empowering the workforce to be more innovative

The latter two points are discussed further in this thesis, in section 3.8 and chapter 4 respectively. Raven (2010) states that as public sector workers are now expected to be collaborators in care rather than mere providers, practitioners will need to be supported and trained in regard to how they see their professional roles so that they may take on a less formulaic style of working. Attitudes towards being collaborators are as important as the skills and knowledge to deliver care.

Morgan (2009) suggests that for personalisation to be a success within the mental health arena there would need to be a fundamental shift in the way professional roles are regarded and how service users are perceived. However, there has been little guidance on how this might be achieved. Equally, it is a major change for service users who will need support and encouragement to take part in these changes. A current philosophy driving

mental health service delivery is the recovery philosophy (see section 3.5) and this supports elements of the personalisation agenda. An element of the personalisation agenda is the use of personal budgets. Personal budgets were introduced in 2008 as part of the policy process to give people greater control over how they receive their social care support needs. These budgets are in addition to mental health services and support, and by April 2013 all councils should be offering personal budgets to those who are eligible.

As discussed in section 3.2, the widespread use of individual budgets and direct payments as a means of empowering service users is hailed as evidence of successful campaigns by disability movements over the past decades (Barnes and Cotterell 2012). There are concerns however about their introduction within the context of a reduction in state spending (Boxall et al 2009) and about the impact of personalisation more generally on the collective responsibility and the delivery of social care. Evans and Jones (2012) demonstrate that user involvement goes well beyond the individual level. Many of the initiatives developed within health and social care were based on opportunities for service users to come together to take part in planning, evaluating and commissioning through user-defined quality criteria. It is unknown what impact a more personalised approach to service delivery will have on user involvement, since it has been at its strongest when built on collective action among service users.

However, service user groups have the same power issues (see section 4.2) as any other type of organisation (Mead et al 2001) and members can be oppressed by other group members. Service user run organisations may adopt the same nondemocratic hierarchical structures found in other mental health organisations. In addition, many people with severe mental illness do not participate in mutual support groups. Davidson et al (1999) found that approximately one third of people with mental illness participate in such activities and many of these individuals do not continue long term.

Whilst individual service users can take advantage of limited choice in health and social care, individuals cannot tackle wider social exclusion or inequalities of service provision in this way. This suggests that broader based collective action continues to be an important aspect of user involvement. Two assumptions underpin the policy development related to the patient as a decision maker and beneficiary of choice making. The first is that the patient has capacity to make decisions about how, when and where they receive

treatment and that such choice is in their long term interest. The patient must be fully informed of the choices and this depends on both their capacity to understand the choices available and the communication skills of the practitioner. Choice is not necessarily conducive to improving outcomes and this in particular relates to patients with chronic conditions where choice may damage continuity of care (Ferlie et al 2006).

The second assumption is that service users actually desire choice. Coulter (2005) points out that whilst there is not unanimous support for choice, particularly from patients with chronic conditions, the most important issue for patients is the availability of good quality services when needed. Choice might imply that there is differentiation in quality between services and confidence in the standardised quality of services may be compromised.

3.5 Recovery philosophy

Recovery orientated approaches are at the forefront of mental health service delivery and care today (Shepherd et al 2008; Slade 2009) (see section 2.9.3 for a discussion on trust within recovery philosophy). The concept of recovery in mental health emerged as deinstitutionalisation took place, resulting in more patients with serious mental health needs living outside the asylum and within the community. This resulted in more contact and involvement of family members. Alongside this and partially as a result of more patients living in the community, user/consumer movements became more organised, knowledgeable and influential. Deinstitutionalisation also resulted in more focused rehabilitation initiatives which, combined with the user movements, promoted a drive for more service user and family involvement (Slade 2009; Warner 2009).

Anthony (1993; 11) defines recovery as;

‘a deeply personal unique process of changing one’s values, attitude, feelings, goals and skills and or roles. It is a way of living a satisfying hopeful and contributing life even with the limitations caused by illnesses. Recovery involves the development of new meaning and purpose in one’s life as one grows beyond the catastrophic effects of mental illness.’

Implicit in this definition of recovery is a highly personalised process of coming to terms with one's own life experiences and redefinition of identity from patienthood to citizenship. This process involves lifelong learning and relearning. A similar point is made by Deegan (1993; 8) when she states that 'any person with a severe mental illness can grow beyond the limits imposed by his or her illness'. Everyone's journey is different and no one can do the recovering for others. Both Anthony (1993) and Deegan (1993) defined recovery from their personal service user experiences.

If, as Deegan implies, developmental and lifelong learning is a core part of recovery, then this understanding has significant implications for mental health survivors (Ryan et al 2012). The experience of mental illness can and usually does profoundly affect an individual's sense of self and of personal identity. One of the necessary conditions of recovery is that it occurs in the context in which the recovering individual is fully included and able to engage in employment, choice making and meaningful activities.

The concept of recovery is conceptually distinct from any medical definition of remission of symptoms (Tew et al 2012). It emphasises rebuilding a worthwhile life and central to this is reclaiming valued social roles and a positive self-identity. Social recovery, such as entering mainstream employment, has been shown to lead towards a reduction of symptoms for many patients (Burns et al 2009).

Leamy et al (2011) in a systematic review proposed a conceptual framework of five interlinking recovery processes:

- Empowerment and reclaiming control over one's life
- Rebuilding positive personal and social identities (including dealing with the impact of stigma and discrimination)
- Connectedness (including both personal and family relationships, and wider aspects of social inclusion)
- Hope and optimism about the future
- Finding meaning and purpose in life

Overall, all of these processes link with the social aspects of people's experiences, but in particular the first three are social in their conception.

Liberman (2008) offers a definition of recovery from a rehabilitative clinician's point of view as comprising a two year period when there is:

- Remission of symptoms
- Engagement in productive activity like work or school
- Independent management of day- to- day needs
- Cordial family relations
- Recreational activities
- Satisfying peer relationships

Liberman suggests that alongside these objective observations there is a subjective component to the process of recovery from schizophrenia that includes such considerations as hope, empowerment, self-help, peer support and coping with the effects of stigma. Subjectively the recovery experience is being enabled to take personal responsibility for one's life and being empowered with skills, support and respect to make decisions that offer satisfaction and meaning in daily life.

In a review of the concept of recovery, Warner (2009) states that employment is significant in enabling more meaningful lives to be lived by patients with a diagnosis of schizophrenia. In addition to employment, user /consumer driven services that focus on empowering the person (See chapter 4) and reducing internalised stigma (see sections 2.6-2.6.3) are also important.

There are some challenges to the concept of recovery such as negative attitudes of professionals that make recovery orientated care difficult to achieve (Happell 2008). Some professionals fear that encouraging hope of recovery for everyone with severe mental illness is false and idealistic. This may be based on the misunderstanding that arises from equating recovery with cure (SCIE 2007). Others believe that recovery-orientated care can only be implemented through the introduction of new services which will add to the burden of professionals and resources (Davidson et al 2006). Slade (2009) disagrees with this and pointed out that current services can be recovery-orientated through reframing from the professionals' (treatment) perspective to the person's (recovery) perspective. Recovery-orientated services place the individual in the centre and heed their perspective and wishes.

Service users can also misuse the concept of recovery or feel threatened by it. Some may use services to appear to be 'recovered' to get out of the system even though they have not recovered in any meaningful sense. Others are concerned that the adoption of the recovery approach will lead to services being taken away or that it may threaten their established coping strategies (Shepherd et al 2008).

The recovery paradigm in mental health also acknowledges families as important players in the recovery process. Families are often at the centre of peoples' social worlds, providing them with primary support networks (Piat et al 2011; 50) For the recovery philosophy to achieve its purpose, patients need to have more choice and say in their treatment and family members need to be involved in a collaborative working relationship with mental health practitioners.

Ramon (2009) states that to embrace recovery philosophy, services and practitioners have to move beyond reactive practice whose focus are immediate needs and risk. This will require a change in attitudes, values and approaches by both service providers and practitioners. The collaborative working relationship and change in values will, in particular, relate to the mental health nurse within this study as they are the administrators of depot injections.

3.6 Depot injection and the role of the mental health nurse

Nurses are the professional group in closest contact with the service users over the period of time, sometimes a lengthy period of time, of their illness and wellness. This contact provides an opportunity for the mental health nurse to become involved in many areas of the service users and their families lives (Repper 2000). The mental health nurse is currently the key administrator of the depot injection and the person most likely to be involved in the teaching and support of others taking on that role.

The prescription by psychiatrists of depot antipsychotic medication shows wide regional and international variation (Walburn et al 2001; Patel and David 2005). Underlying this variation is a number of possible rationales. One is that the use of LAI medication gives the service provider an opportunity to readily identify non-adherence and thereby provide effective follow up (Love and Conley 2004). Another view is that the use of LAI

medication moves service users towards a coercive option and removes true patient choice. Besenius et al (2010) in a systematic review of health professionals' attitudes to depot injections state that there is a scarcity of studies carried out to explore this issue. There is also a dearth of studies that explore the attitudes of service users towards the receipt of depot injections. This thesis adds to this small body of work.

There are a number of reviews and studies that are related and highlight some important issues. A review of the literature about depot medication identified that factors which hampered the use of depot injection were patient preference, presumed adherence to oral medication, cost, an inability to stop promptly and side effects (Patel et al 2009; Harris et al 2007). Within the UK mental health services depot medication is commonly perceived by professionals as the 'last resort' (Besenius et al 2010). They reported that patients are prescribed depot antipsychotic medication because mental health professionals do not trust them to adhere to oral medication (see sections 2.9 - 2.9.3 for discussion on trust).

The attitudes of the health professionals play a crucial and influential role in service users' uptake of antipsychotic medication (Day et al 2005). Differences were identified between nurses' and medical staff's attitudes towards depot medication; medical staff taking a more paternalistic stance, whilst nurses were more likely to note patient -specific behaviours like weight gain and patient preferences (Lambert et al 2003). Walburn et al (2001) found in a review of UK published studies that in five out of six studies comparing oral and intramuscular administration routes, service users opted for depot administration over oral administration. The key reasons given were convenience and control over timing. The studies found that there was an aspect of stigma associated with having a depot injection but this may not come from the service user but from the health professional. The nurses' values and beliefs about injection-giving came from their early experiences with acute mental health settings and the administration of depot injection within the acute service is seen as a negative experience by both nurse and service user.

Patel et al (2003) found that the depot injection, whilst being seen as old fashioned and stigmatising, was as efficacious as oral medication; nevertheless it was seen as less acceptable to patients and their relatives. This study found that there was a positive correlation between attitudes towards depot medication and knowledge of the practitioner, and nurses felt they did not get enough training. Patel and David (2005)

found that differences in the knowledge and education of the health professional impacted on their decision about depot injection/ oral medication preferences.

Svedberg et al (2000) in a study exploring feelings and experiences of community mental health nurses, found that the nurses perceived depot injections to impact on the patient's autonomy and rights to self-determination but also on the nurse's autonomy. The nurses perceived that they had little choice but to administer the injection and had no involvement in the prescribing process. However, Svedberg and Lutzen (2001) found that if the injection-giving nurse was the patient's key worker, the nurse was more involved in assisting the patient to understand the meaning of the depot injection and its benefits. These authors report that it is vital that service users are involved in the decision-making about the mode of antipsychotic medication administration. Part of that decision-making is the provision of information and nurses are seen as key providers of that information. In response to the literature about attitudes and medication information, the Drug Attitude Inventory (See section 5.14.2) and the Understanding of Medication Questionnaire (See section 5.14.4) were used within this study.

The NMC (2007) states that the enablement of individual patients' strengths is a role for the mental health nurse within recovery orientated services. This is further supported by the key government policy *No health without mental health* (DH 2011a). The NMC (2007) standards promote the taking of an emancipatory stance by mental health nurses in the process of clinical decision-making within recovery and personalised approaches to care. The mental health nurse should challenge the workplace culture to promote these approaches. This necessitates the nurse informing and involving relatives as they are key to the success of both recovery and personalisation approaches and in the acceptance of the depot medication. Involving relatives in the acceptance of depot medication may involve the relative in taking on the role of administration and this involves the learning of requisite skills which is discussed in the next section.

3.7 Teaching and learning psychomotor skills

Skills can be classified in terms of cognitive skills (requiring reasoning ability), psychomotor skills (deft control of instruments or materials), interpersonal skills (working with others), and transferable skills (those learned in one context, but usable in

others later on). Within nursing a skill is defined as a learned ability to practise in particular ways, they are learned and the amount of practice and the nature of practice can influence performance (Quinn and Hughes 2007). While individuals may have an aptitude to practise in particular ways i.e. to be more or less reflective, more or less sensitive towards others, or more or less dextrous, skills develop as a result of learning and practice.

A discrete skill is defined by a beginning and end and often very brief in duration i.e. kicking a ball. When discrete skills are amalgamated together into more complicated actions they are called serial skills, i.e. driving a car with manual gears (Schmidt and Wrisberg 2008). These skill sequences suggest that the order of the elements is in some sense crucial to a successful performance. During the learning of serial skills, beginners initially focus on each element separately. Later after considerable practice they are able to combine elements to form a unified sequence. Accomplished performers are able to control the entire action almost as if it were a single discrete movement (see section 1.4).

Motor skills can be viewed as a task or an act and because each task has unique characteristics, one skill can be distinguished from another. Three characteristics used to classify skills are the way the task is organised, the relative importance of motor and cognitive elements and the level of environmental predictability during performance (Schmidt and Wrisberg 2008). In learning a new skill, it is likely some element of transfer will occur from previously learned skills. The frequency and distribution of practice sessions can affect the learning of motor skills and serial skills are best learnt with spaced out sessions as one prolonged session can induce boredom and fatigue (Quinn and Hughes 2007). Motor skills require practice because of the importance of kinaesthetic feedback from the learner's own body; it takes time to produce skilled efficient movements and feedback on performance is essential.

There are some fundamental differences between the concepts of motor performance and motor learning (Schmidt and Wrisberg 2008). Motor performance is always observable and is influenced by many factors such as motivation, focus and physical fitness. Motor learning is an internal process or state that reflects a person's current capability for producing a particular movement and can be assessed by observing peoples' motor performance noting the changes that occur systematically with additional practice.

Internal factors such as fatigue, anxiety or confidence, and being observed can impair performance so it is prudent to observe performance on a number of occasions.

In order to obtain as much information as possible about a performance or learning situation, three components need to be considered, namely person, task and environment (Schmidt and Wrisberg 2008). All three are relevant to this study. The most important component of a motor performance is the person performing the skill and if essential perceptual - motor abilities are present in the individual, a person should be able to achieve a high level of performance. Practice, however has to be tailored to the individual doing the learning. Practicing the same combinations of tasks will lead to a speeded up response as long as feedback is received and understood. Within this study, the supportive person is practicing and learning the skills of injection administration for one person only, and unlike the nurse, will not be administering injections to other people. All supportive persons within this study were car drivers, users of mobile phones and had employment history as examples of established abilities so some components of these skills will have influenced the learning and competency of IM injection giving. The environment where the task is performed is important. Within this study, the home environment had some stability and familiarity; it had also potential emotional associations, disclosure threats and time management challenges. Both of these positions can influence the performance of a task.

Benner (2001) put forward a model of skills acquisition that identified five stages of learning: novice, advanced beginner, competent, proficient and, finally, expert (See section 1.4). Within this study, the supportive person may become expert in the administration of a depot injection within their own environment and to one person. However, with the IM injection administration being periodic, i.e. two or three weekly, in the absence of regular practice, the supportive person may stay at the level of competent practitioner within their unique context. The literature on skills development in nursing students and attaining competencies emphasises the importance of the nurse being able to anticipate, and adapt to changing environments (Christensen and Hewitt-Taylor 2006; Robertson-Malt et al 2007). The home context in this study is fundamentally stable so the supportive person's environmental changes are more predictable.

The Nursing and Midwifery Council's (NMC's) *Standards for Medicines Management* (2010) state that administration of medicines 'is not solely a mechanistic task to be

performed in strict compliance with the written prescription'. Therefore, the administration of intramuscular (IM) injections requires the healthcare practitioner to possess the knowledge and rationale of the guiding principles that underpin these clinical skills. It is essential that all aspects of these techniques, namely, anatomy, physiology, patient assessment, preparation and nursing interventions are evidence based so that the nurse can perform safe and accountable practice (Shepherd 2002; NMC 2010). Similar expectations are required of any person taking on that role and family as care givers will be discussed in the next section.

3.8 Family caregivers

Over the past 50 years in the UK, the policy of deinstitutionalisation has placed increasing emphasis on the role of relatives in providing care for people with severe mental health disorders. The family is now one of the most significant psychosocial supports (Mohr 2000; Clarke et al 2006) and their involvement is important in determining the client's quality of life. The person with mental ill-health has greatly improved prospects of recovery and staying well if they have relatives or friends who support them. 'Informal care' is playing an increasing important part in the development and evaluation of treatment programmes and health policies. Improvements in the human and legal rights afforded to clients with mental health problems have led to a global trend to provide care in the least restrictive environment, preferably the client's home (DH 2007a).

There is a great deal of discourse about the experience of care giving by family members in the literature. Themes identified from the discourse include; carer needs and burden (Lloyd and Carson 2005; Kuipers et al 2006); information sharing and confidentiality (Pinfold et al 2007; Gray et al 2008); participation in decision making (Roulstone and Hudson 2007) and relationships with practitioners (Krupnik et al 2005; Clarke 2006; Wilkinson and McAndrew 2008). These issues will be discussed in the following paragraphs.

During the asylum era of care in mental health, the term 'relative' had greater universal relevance because of the family's role in negotiating hospital care. The term 'carer' first appeared in the community care discussions in the 1970's and was not enshrined in law until the NHS and Community Care Act 1990 (Twigg, 1994). The term 'carer' has gradually taken the place of the term 'relative'. Relatives were not consulted about the

policy shift from hospital to community care although the asylum closures had huge implications for families (Ramon 1995).

Watson (2008) and Ray (1989) define caring as a value and an attitude that has become a will, an intention or a commitment that manifests itself in concrete acts. Eriksson (2007) argues that caring relationships form the meaningful context of caring, and that caring originates from the ethos of love, responsibility and sacrifice. Within mental health legislation the words 'cared for' are not defined but understood to be clear everyday words. 'Caring for' is a matter of judgement and could include shopping, cooking or providing other care (D mental patient: Habeas corpus 2000).

Non-professional carers represent a substantial part of the health economy in most countries (Lefley 1997). These carers are partners, parents, siblings or friends and are often driven by a sense of social duty towards the person they care for. Carers need to be valued and seen as partners in the caring experience (Wynaden 2007). Whilst policies may refer to this level of engagement with carers, it is the clinician who determines how carers are received at the point of contact. Kruijver et al (2000) stated that positive engagement and communication have long been identified as influencing health outcomes; more emphasis needs to be placed on the importance of this partnership to the mental health outcomes for the patient and their family.

It is estimated that one and a half million people care for someone with a mental illness in the UK (Symington 2010). UK health policies acknowledge the role of carers within health services and require health and social care professionals to provide support. However, the type of support is not clearly defined. What is defined is the legal requirement to undertake an assessment of carers' needs (DH 2008c; DH 2009b). The current law treats carers differently to the people that they support. Carers do not have a legal right to receive support – local authorities only have a power to provide carers' services. The current draft Care and Support Bill – the law for carers (DH 2012a) is aimed at giving carers the same legal status as those they care for. The bill also sets out in law that carers should have a personal budget as part of their care and support plan.

Family caregivers have come to the fore for two major reasons within health (Farran et al 2004). One is the number of persons who are living with long term conditions and the other is changes to healthcare delivery systems. King et al (1995) identified four reasons why families make a commitment to care; these were the perception that families were

obligated to care; that families are owners of their own difficulties; that families should protect vulnerable members and that those family units are self-reliant units.

The vital role that carers play in mental health settings was given new impetus by guidance published jointly by the Princess Royal Trust for Carers⁴ and the National Mental Health Development Unit. *The Triangle of Care: Best practice guide in acute mental health care* (2010) promotes an essential three way partnership between professionals, service users, their carers and families. The approach emphasises the need for better local strategic involvement of carers and families in the care, planning and treatment of people experiencing mental ill health and calls for better partnership working between service users, their carers and organisations in order to achieve the best possible outcomes. This report was in response to the perceived utilitarian relationship that exists between carers and mental health services in which the interests of service users and providers take precedence over those of carers (Rowe 2010).

There are advantages for mental health services in having a good working relationship with carers and these include;

- Sharing information and risk management practice (Gray et al 2008)
- Providing effective packages of care that include helping with recovery and medication concordance (Rapaport 2006)
- Providing effective and safe care (Slade et al 2007)

Challenges however exist within this relationship and Gray et al (2008) found that families were often discouraged from engaging with services and may be seen by professionals as ‘part of the problem’. Carers feel they are excluded and ignored by mental health services (Lyons et al 2009), patient confidentiality being one focal point, and yet are expected to cope without support (Pinfold et al 2007). Carers’ relationships with professionals in mental health have not always been benign as professionals may be influenced by the psychiatric models that sought to blame families for causing mental illness (Jones 2002; 159).

Patient confidentiality is an issue that requires understanding when engaging with families. Wynaden and Orb (2005) found confusion among health professionals as to

⁴ The name was changed to the Carers Trust and a second edition of the Triangle of Care was published in 2013.

what constitutes confidential information that could be freely shared with family members. Gray et al (2008) state that some professionals have used 'confidentiality' as a smokescreen to withhold information from carers and Pinfold et al (2007) identify issues of consent, professional roles and relationships as further barriers. An example might be that the service user withholds consent to the disclosure of information or they might not be asked to give their consent. Szmukler (1999) claimed that much could be achieved when health professionals and family members use an ethically sensitive approach to engagement. This ethically sensitive approach involves clearly establishing through informed consent from the person with the mental illness on what basis family involvement will proceed.

Health and social care literature over past decades has focused on a link between caring and the measurement of burden (Wynaden 2007). Caregiver burden has been defined as 'a psychological state that ensues from the combination of the physical work, emotional and social pressures and the economic restrictions that arise from taking care of patients' (Dillehay and Sandy 1990; 265). The key carer is seen as the person who provides most support to the family member who is ill. The burden of caring for a person with a diagnosis of schizophrenia is associated with reduced quality of life and with a significant impact on the health and functioning of the care giver. Added to this many family caregivers lived with a feeling of 'complicated grief' described by Jones (2002) in which the carer held ambivalent feelings towards their relative with severe mental illness; hostility in response to unpredictable behaviour and a sense of betrayal in that the person had not really gone away- they were visible, but they were never the person they once were.

Recent studies refer to the impact of care rather than burden of care (Roick et al 2006). Distress associated with caring can be reduced through a collaborative relationship with service providers (McCann and Baker 2001). However, caring can also be a source of satisfaction, and satisfaction has been positively correlated with improved access to services (Chin and Greenberg 2004).

Gutierrez-Maldonado et al (2005) found that married caregivers tended to have poorer functioning and health scores than parent-child relationships and being married was not a protective factor for perceived burden. The study however did not measure marital satisfaction. They suggest that the potential for greater positive social support, as a

function of marriage, was not being realised because of the impact of the diagnosis on the marital relationship. In the Gutierrez-Maldonado et al study, it was mothers who were typically responsible for most aspects of daily care such as overseeing pharmacological treatments, controlling drug and alcohol use and helping the patient to manage their free time.

Rowe (2012) reviewed literature about mental health professionals' expectations of carers and what family carers expect of themselves. Despite initiatives and legislation, that there has been only a slight improvement for family carers. Rowe recommends that mental health service providers involve family members in the provision of services and make it easier for carers to access these services. Caring for a relative with severe mental health problems is a distinct and unique experience. Family members place some obligations on themselves which include; involvement in their relative's care; information sharing and assisting with recovery. Carers had rights alongside the obligations and these rights were about respect and being acknowledged as a partner in care. Rowe suggests that for improvements in relationships and support to occur, it will necessitate a change in professional attitudes and practice and more awareness among carers of mental health issues.

Based on the literature findings about burden, the Burden questionnaire was used within this research study (see section 5.14.3). Caring can be a positive experience and one concept associated with positive caring experiences is resilience and this is discussed in the next section.

3.9 Carers and resilience

The concept of resilience is described by Marsh et al (1996; 4) as 'the ability to rebound from adversity and prevail over the circumstances of our lives based in part on our personal disposition, on the nature of the family and on the community of people who provide support'. Carers often show strength of character and courage (Wilkinson and McAndrew 2008) which are attributes they need to form meaningful dialogue with professionals (Pinfold et al 2007). Smith et al (2007) suggest that the concept of resilience is useful for providing a balance to the concept of family burden. Resilience helps us to understand why some carers cope more ably with living with psychosis than

others and that recognising the positive aspects of the caring role forms part of the carer's coping response.

Marsh et al (1996) propose that mental health service providers should design services that not only reduce family burden but also maximise and capitalise on a family's resilience. Examples of family resilience are dealing with adversity, coping with uncertainty and problem solving. Mohr et al (2000) found that collaboration with service providers, including some skills training and contact with other carers, was most helpful. Carers can be involved formally through involvement in treatment plans (McKenzie 2006) or less formally through communication with professionals.

3.10 Conclusion

In conclusion, the deinstitutionalisation process within mental health during the 1960's onwards led to a fundamental shift in the approach to mental health care. The concept of community care was invoked and has evolved ever since, as have the role of the mental health nurse and the use of depot medication. Community care resulted in more patients with a diagnosis of mental illness living with or near family members. This proximity has resulted in the role and contribution of carers being discussed within academic health and social care literature.

In the latter half of this period key government policies have promoted the concept of service user involvement within health services and in the management of personal health needs. This involvement aligns itself to a recovery philosophy where recovery is evidenced through the making of choices by the service user, participation in decisions and taking more control over their lives. Integral to making recovery achievable is the process that brings patients, family members and practitioners into a shared partnership and responsibility for the treatment enterprise. However, there are practitioners who view recovery as idealistic and service users who fear early discharge and loss of services.

Whilst choice is valued within recovery-orientated services, availability of choice occurs within the context that the patient has the capacity and enough information to make an informed choice. Choice may not always be welcomed by the patient as the literature suggests it may be a way of reducing budgets and may contribute to the loss of the collective patient fora which have contributed much to current service structure.

The policies which promote user involvement use a lexicon that implies involvement without spelling out how this may be evidenced; for example, patient led services, user involvement and stakeholder involvement. This ambiguity opens up possibilities for innovative solutions to be developed at a local level, solutions which include elements of uncertainty and risk. Service user and family involvement is pertinent to this study and as such, the findings will contribute to the literature about this issue.

Taking on the role of administering a depot IM injection requires the learning of new skills. In learning a new skill, it is likely some element of transfer will occur from previously learned skills. The frequency and distribution of practice sessions can affect the learning of motor skills and serial skills are best learnt with spaced out sessions as one prolonged session can induce boredom and fatigue. In the learning of a new series skill, beginners initially focus on each element separately. Later after considerable practice they are able to combine elements to form a unified sequence. Anxiety and fatigue can impact the performance of a skill and hence, judgement on competency should be assessed over a number of episodes. The environment in which the procedure takes place is relevant as the administrator, recipient of the injection and home environment has emotional associations.

In the administration of an intramuscular injection, a combination of skills, procedures and rules is relied upon to complete the intervention and the NMC has prescribed standards to work to. The learning of psychomotor skills, opportunities to practice and the assessment of competency in those skills are relevant to this study as supportive persons are learning a new skill though they have abilities and experiences to build on.

The role of family members and carers within mental health care has changed significantly since community care was established. UK policy requires health professionals to support carers but 'support' is not defined. Within the amended MHA (DH 2007a), cared for and caring are not defined though they are important in the role of the nearest relative. Caring, for some family members is a burden which has impacted on their own health whilst for others caring is a positive experience. Carer resilience contributes to positive experiences and outcomes. The literature about carers suggests that partnership working with mental health services is essential for improved outcomes for the patient though it is sometimes challenging. Whilst policies may refer to and promote engagement with carers, it is the clinician who determines how carers are

received at the point of contact. Contributing to the partnership working between carers and services is how and what information is shared with family members, thus making confidentiality an issue to be understood and managed by all parties. Partnership working is a broad term and leaves open the possibility of non-professional carers having diverse roles within this working and caring relationship.

Within and between mental health professionals there are variations in the beliefs and attitudes on the issue of depot medication. These beliefs revolve around depot medication being old fashioned, stigmatising and of questionable acceptability to patients and relatives. Depot injection was perceived to be only needed when health professionals thought patients were not adhering to oral medication and might be a way for mental health services to identify non-adherence. There is a dearth of studies exploring patient and carer views of depot injection. Some patients preferred depot injections because of convenience and their control over timing whilst other studies report the depot as being less acceptable to patients and their relatives. Studies have found that there was an aspect of stigma associated with having a depot injection but this may not come from the service user but from the health professional. What is unclear from the reviews is the role the relationship between the prescriber, administrator and the patient plays; how important and what amount of information about depot injections is necessary and required; the confidence and knowledge of the health professional and what other factors may be important. What is less uncertain is that the administering the depot injection is an integral part of the mental health nurse's role.

We wait to learn what personalisation and choice has in store for practitioners and service providers over the coming years. User involvement will continue to generate different views and ideas and new types of relationships between users, carers, service providers and practitioners and this is likely to require political and ethical sensitivities. Different voices are expressed in different ways and it is important to hear these voices and not mute differences to conform to some presumed or promoted structure. The results of such hearing can be uncomfortable but it is a source of unsettling the established norms and can bring about change. There is hope and evolution in the continued critical engagement with all parties who are able, receptive and wanting change. This change can be delivered within an empowering process and by innovative solutions. Empowerment as a concept, its theoretical basis and conditions for implementation will be discussed in the next chapter.

Chapter 4

Empowerment and Innovation

4.0 Introduction

The term empowerment entered the academic discourse in the 1960s in conjunction with the U.S. Civil Rights Movement (Bartunek and Spreitzer 2006; Manojlovich 2007). This chapter will offer a definition of empowerment and discuss empowerment values and its theoretical basis alongside its relationship to power. Three key theorists will be identified and their contribution to understanding empowerment discussed as well as the conditions for empowering people with enduring mental illness. How empowerment relates to nursing and the implications for mental health services will be explored. Empowering individuals or groups offers the possibility of developing practice and this chapter will discuss innovation in practice, its challenges and opportunities.

Within health, empowerment has been recognised as a core element of health promotion and disorder prevention in various international instruments such as the Ottawa Charter on Health Promotion (WHO 1986) and the Bangkok Charter of Health Promotion in a Globalised World (WHO 2005). In the United Kingdom, the fields of nursing, psychiatry and psychology have added the term empowerment to their code of ethics and individual practitioners are urged to empower within their practice (NMC 2007; SLAM/SWLSTG 2010; BPS 2013). The term has now been incorporated into models of practice with people with mental illness, including rehabilitation care and the recovery perspective. Within UK health and social care policies, the word 'empowerment' is used without giving it a definition or outlining how it might be evidenced. Warner (2000; p 39) described it as a buzzword that is used and abused by those at both ends of the political spectrum.

Within this chapter, empowerment will be analysed through a range of published work but in particular, the work of three key theorists will be relied upon; Zimmerman (2000), Handler (1996) and Linhorst (2006). Zimmerman's work is relevant in its understanding of and application to community empowerment, positive psychology and definitions. Handler developed his work through rehabilitation services and Linhorst has built on this work through its pragmatic application to everyday mental health practice. Linhorst's basic premise is that despite significant limitations, people with severe mental illness can

be empowered when certain conditions are met. Empowerment is important for three reasons: people with mental illness have a right to access opportunities to improve themselves; people with mental illness who are empowered have an improved quality of life and empowerment of people with mental illness benefits society.

Handler's (1996) position on empowerment is that it is a relational and dynamic process and is never permanent. Empowerment is not about clients controlling the agency they receive services from, but having a genuine voice in participating in decision-making, with both sides benefiting. Zimmerman (2000) agrees with Handler that empowerment is dynamic and argues that having control may not be necessary for empowerment to occur. Gaining experience in the decision-making process may be empowering even when the client is not making the actual decision. In this respect, empowerment can refer to a process as well as an outcome. Linhorst (2006), concerned that empowerment was nothing more than a buzzword, developed practical guidance on operationalising the philosophy of empowerment, the conditions under which it is likely to occur and a practical model for working with clients who have enduring mental illness. This makes Linhorst's work appropriate for this study.

4.1 Definition

A definition by Rappaport (1984; 2) sees 'empowerment as a process, the mechanism by which people, organisations, and communities gain mastery over their lives'. This definition suggests that empowerment is a process where 'gaining control' is a key concept, alongside efforts to gain access to resources, working with others, overcoming obstacles that inhibit the making of personal choices and an understanding of the socio-political environment. Empowerment is about increasing the capacity of individuals to become more in control over their lives. It is a means through which greater participation in decision making is facilitated, along with increased dignity and respect and a sense of belonging and contributing to a wider community. Implicit within this definition is being able to get others to accept your definition of the situation.

The World Health Organisation (WHO 2010) summarises empowerment as referring to the level of choice, influence and control service users exercise over all events in their lives and about their rights as citizens. For mental health services, empowerment can be

seen as referring to the level of choice, influence and control which service users can exercise over services provided. The WHO (2010) suggests that the key to empowerment is the removal of formal or informal barriers and the transformation of power relations between individuals, services and governments. However, in a European-wide review of empowerment implementation, the WHO (2009) reported that mental health service users and families were not involved in decision making processes about practice and policy as expected and this had not significantly changed over recent years.

In healthcare settings, empowerment ideology is gaining popularity as a means of enhancing patients' sense of control over their well-being (Nyatanga and Dann 2002). Empowerment represents both a process and an outcome involving the individual's or group's ability to pull from within themselves the power to influence or control significant events in their lives. Within current mental health service delivery in the UK, the recovery philosophy guides practice and a central tenet of the recovery philosophy is empowerment (Warner 2009) (see section 3.5).

4.2 Power

Power, which refers to the ability to exercise influence and motivate action toward achieving a particular goal, is a concept that is tightly intertwined with the concept of empowerment. Power structures in society as a whole and organisations in particular are maintained by individuals who occupy so-called powerful roles as well as by individuals who comply with existing constructions. Empowerment of individuals within these constructions requires the mobilisation of power. Therefore, while empowerment cannot exist without power, power can exist without empowerment (Ellefsen and Hamilton 2000).

Power is always present in organisations because it exists both formally and informally. Formal power is fixed and relative to an individual's hierarchical position within an organisation. Informal power is based on relationships and the influence one can exert or the action one can motivate by virtue of those relationships (Kanter, 1993; Laschinger et al 2006). This analysis of power is taken one step further by Casey et al (2010), describing power in three dimensions, where overt and covert power pertain to formal

and informal power, and institutional power pertains to the oppressive and hegemonic power that limits critical social empowerment.

Understanding the relationship of power to empowerment is essential, because in nursing, power is often viewed negatively (Gorman & Clark 1986) or seen as antithetical to caring. Nurses, themselves, are often responsible for reifying this construction by failing to express that their work is based on knowledge and skill, rather than personal virtue (Gordon 2006). Benner (1984) and Duffy (1992) suggests that caring, which is the essence of nursing, requires involvement, courage, and initiative on the part of the individual nurse to motivate change in care environments for the betterment of patients and families. As such, caring requires action, and this action is motivated by nurses' professional power (see sections 3.3, 4.2 and 4.4.4 for further discussion of power).

4.3 Empowerment values

Empowerment suggests a distinct approach for developing interventions and creating social change (Zimmerman 2000). An empowerment approach goes beyond ameliorating the negative aspects of a situation by searching for those that are positive. i.e. identifying strengths instead of cataloguing risk factors and searching for environmental influences instead of blaming victims. Within a health context, empowerment directs attention towards adaptation, competence and natural helping systems which Cowen (2000) postulates as characteristics of an empowering approach. These characteristics can be linked to the concept of resilience (see section 3.9).

Alongside the distinct approach to interventions, empowerment also calls for a distinct language. Rappaport (1985) states that an empowering orientated language can redefine our roles as professional helpers. He suggests that traditional language can unwittingly encourage dependency and maintain the idea that help is unidirectional. Professional language limits the discovery of indigenous resources within those seeking help. Language used within an empowering approach replaces words like 'client' and 'expert' with 'participant' and 'collaborator'.

An empowerment orientation suggests that participants have an active role in the change process. The evaluation of an empowering process includes participants in the planning and implementation process and also in the sharing of results (Zimmerman 2000). This

approach suggests that both quantitative and qualitative methods are necessary for evaluation (Lincoln and Guba 1986). Fetterman (1996) discusses an empowerment evaluation as a process that not only involves participants but aids them to develop skills in self-evaluation.

Starting from the 1980's onwards, nursing as a way of developing its professional autonomy, sought to liberate itself from the bio-medical model, a model it had become dependent on as a source of knowledge (McCoppin and Gardner 1994). This meant nursing adapted an approach of 'holistic individualism' with an emphasis on the individual patient's experience. With nursing's emphasis on individualism, the theme of patient empowerment has come to be recognised as an essential part of nursing practice (Ashton and Rodgers 2005). It has been suggested however, that nursing's understanding and subsequent adoption of empowerment largely rested on abstract theoretical concepts, which were adopted with only a basic understanding of their meaning (Chambers and Thompson, 2009). However, there is some consensus within nursing that it is a positive concept. Keiffer (1984) suggests that while empowerment is intuitively appealing for theory and practice, its applicability is limited because of conceptual ambiguity. This ambiguity, Adams (1990) argues, arises from the tradition of self-help in the welfare system and the idea that dependency is morally harmful to both the individual and society. Within nursing, Gilbert (1995) suggests the ambiguity related to empowerment is a failure to conceptualise power and its effects in relation to health. To understand the concept of empowerment we need to understand the concept of power (Bradbury –Jones et al, 2008) (see sections 3.3, 4.2 and 4.4.4 for discussion related to power).

4.4 Empowerment as a theory

A theory of empowerment includes both process and outcomes (Zimmerman 2000). The theory suggests that actions, activities or structures may be empowering and that the outcome of such processes results in a level of empowerment. However, both empowerment processes and outcomes vary in their outward form because no single standard can fully capture its meaning for all people in all contexts (Zimmerman, 1995). For example, the behaviours necessary for a 16 year old mother to become empowered are different from the behaviours for a client with mental health issues who wants to gain useful employment. Thus empowerment is context and population specific.

A distinction between empowering processes and outcomes is crucial in order to clearly define empowerment theory (Zimmerman 2000). Empowering processes are the ones in which attempts to gain control, obtain the necessary resources and an understanding of one's socio-political environment are key. The process is empowering if it helps people develop skills so that they can become independent problems solvers and decision makers. From an organisational perspective, outcomes might include organisational networks, effective resource acquisition and policy leverage. From a community perspective it could be access to resources, for example the Carers' group and Carers' centre and involvement in decision making fora. Each level of analysis is inherently connected with each other. Individual, organisational and community processes are interdependent and are both a cause and a consequence of each other. The three levels of analysis can be understood from differing theoretical perspectives, namely critical social theory, social psychological theory, organisational management theory and post structuralism. Broadly speaking these differing perspectives view empowerment respectively as stemming from emancipation, organisational factors or as a process of personal growth – all relate to this research study and are discussed in the following sections.

4.4.1 Critical social theory

Critical social theory is based on the premise that certain groups in society are in a subordinate position and the theory is associated with improvement in the conditions for these oppressed groups. Patients who have a mental illness are deemed to be an oppressed group. Much of critical social theory is based on the work of liberation pedagogy (Freire 2008). The controlling group has greater power and status than the oppressed group (Fletcher 2006). In critical social theory, power is extra-personal, which means that an increase in power for one person is compensated by someone else surrendering part of their power (Kuokkanen and Leino-Kilpi 2000). From this perspective, empowerment is equated with liberation and as such may involve a struggle as the group with power are not willing to hand over that power, responsibility or resources unless they see an advantage in doing so (Skelton 1994). Whilst critical social theory offers a means of understanding empowerment, power is not always repressive

and therefore critical social theory may be inadequate in capturing the complexity of empowerment (Bradbury-Jones et al 2008).

4.4.2 Social psychological theory

Empowerment can be viewed from an individual's perspective (Kuokkanen and Leino-Kilpi 2000) and in this it is seen as a process of personal growth and development. Zimmerman (2000) refers to this as psychological empowerment (PE). The individual's beliefs, values and perceptions are key factors. To be empowered from this perspective is to be psychologically enabled (Menon 2002). Psychological empowerment includes beliefs about one's competence, efforts to exert control and an understanding of the socio-political environment. Understanding one's social and political situation involves the ability to identify those with power, their resources, and their connections to the issue of concern and factors that influence their decision making. The different dimensions of PE include personality, cognitive (self-efficacy) and motivational aspects of perceived control and all relate to the participants in this research study. One way to develop these skills is through participation in relevant activities. The specific action taken to achieve goals is not as important as simply being involved and attempting to exert control (Zimmerman 2000). The challenge in promoting the individual viewpoint is that cultural and political influences may be overlooked, resulting in a naive analysis (Bradbury-Jones et al 2008).

4.4.3 Organisational and managerial theories

Organisational theory is concerned with the distribution of power in organisations and particularly how this occurs from the top down (Kuokkanen and Leino-Kilpi 2000). The difference between critical social theory and organisational theory is that organisational theory does not account for oppressed groups. Kanter (1993) argues that structural factors within organisations are more important for empowerment than individual qualities. Kanter proposed four conditions for empowerment: opportunity for advancement; access to information; access to support; and access to resources. Kanter's four conditions are relevant to this research study in that patient and carer require them in order to participate in the study and develop their potential within the study. The environment provides more

or less empowerment opportunities depending on how many of the four structures are present. Considering power within organisations contributes to an understanding of 'empowerment' but it is limited in that power is not solely distributed in a top-down manner (Bradbury-Jones et al 2008). Power also operates from the bottom up and laterally (Foucault 1995).

4.4.4 Poststructuralism

Poststructuralism is usually associated with the work of Michel Foucault (Bradbury-Jones et al 2008). Foucault's conceptualisation of power is that it is not fixed. Thus, health care professionals and patients have differing positions in the healthcare hierarchy by virtue of their status. Power, because it is not fixed, is exercised differently in different forms by each group depending on the context. For example, patients can exercise power by choosing not to attend appointments or allow community nurses access to their home. Thus, understanding empowerment of nurses or patients is not about liberation or a hierarchical distribution of power, it is about understanding the 'operations' through which nurses and patients are situated and how power is exercised variously in different contexts (Bradbury-Jones et al 2008).

Under the Foucauldian concept of 'disciplinary power', hierarchical observation and examination are two of the methods by which it is exercised. Disciplinary power and observation can be linked to the work of Foucault and Panopticism (Foucault 1995). The Panopticon is a type of institutional building designed by Jeremy Bentham in the late 18th century whose design is to allow a watchman to observe (-*opticon*) all (*pan-*) inmates of an institution without them being able to tell whether or not they are being watched. The Panopticon prison design was invoked by Michel Foucault in *Discipline and Punish* (1977) as metaphor for modern "disciplinary" societies and their pervasive inclination to observe and normalise. The Panopticon is an ideal architectural figure of modern disciplinary power, a kind of laboratory of power (Foucault 1977; 204). The Panopticon creates a consciousness of permanent visibility as a form of power, where no bars, chains, and heavy locks are necessary for domination any more. Foucault proposes that whilst panopticism relates to all hierarchical structures like the army, schools, hospitals and factories, it applies to non-institutional forms like the tachographs in heavy goods vehicles and the monitoring of drug addicts.

An example of how a panoptic concept may be applied to current health care is in patients being given responsibility for their own care. In the UK this is reflected in policies such as *The Expert Patient* (DH 2001c) and *Self Care -A real choice* (DH 2005c) which have underpinning philosophies of empowering patients to take control of their own lives. An important point linked to the enactment of these policies is that the 'self-managing' patient still has to report to the healthcare professional for guidance, advice, monitoring and resources. Thus the patient may take some responsibility for their care but the healthcare professional is always visible.

In disciplinary power, 'experts' are called upon to make normalising judgements and the so called caring professions maintain their surveillance of the 'population' as judges of normality (Gilbert 2001). Normalising judgements are inherent in the vast domain of gestures, attitudes, tasks, discourses, uses of time, and habits that are not addressed so much at what one does, but at who one is (Foucault 1977: 178) Foucault implies that people are not seen for what they really are but are slotted into a series of categories such as nurse, lunatic, pervert, madman, social incompetent, irresponsible, work shy or violent. These categories then dominate our thinking and thus our approach to their care. Once categorised, as say mentally ill, people have difficulty in escaping from the implications of the category to which they have been assigned.

For Foucault it is through discourse (through knowledge) that we are created. Consequently we are the sum of our experiences (the knowledge we encounter). According to Foucault, truth, morality, and meaning are created through discourse and every age has a dominant group of discursive elements that people live in unconsciously. Change may only happen when a new counter-discursive element begins to receive wide attention through the means of communication. Foucault divides knowledge into subjugated and popular aspects. Subjugated knowledge is knowledge that has no place or that which has been confined to the prison or clinic by dominant and established history of ideas. Popular knowledge, Foucault suggests, is a particular local knowledge which is incapable of unanimity (not taken as a view of all concerned) and also refers to disqualified knowledge of people low in the hierarchy such as health care users and nurses (Ryles 1999). Both subjugated and popular knowledge are elements of a historical knowledge of struggles. Bradbury-Jones et al (2008) suggest that an analysis of patients' knowledge reveals a paradox. Patients are encouraged to self-manage and be 'expert' in their own care (DH 2001c). Empowered patients will ask or should ask questions and

want to be actively involved in decision making processes related to their care. If they do so, instead of maximising their empowerment, they may well find themselves disempowered and labelled as ‘difficult’ (Nyatanga and Dann 2002). In effect their voice is silenced and their knowledge is disqualified.

In summary, the relationship between knowledge and power was addressed by Foucault (1988) and the main conclusion was that they were intertwined. Foucault states that knowledge is produced through regular and identifiable procedures and that these determine what can be said and by whom. Those in powerful positions are able to exert their version of ‘truth’ (Hui and Strickley 2007). The role of nursing in this context is to develop new forms of knowledge and new ways forward (Ryles 1999). It is incumbent on nurses to question the truths that hold sway within nursing and consider whose interests these best serve. The questioning of truths is pertinent to this study (see section 1.1) in that the patient was asking for the delivery of a medical intervention through a non-traditional delivery route.

4.5 The evidence base for empowerment

There is extensive evidence that a reduced sense of empowerment is associated with lower self-esteem, higher sense of stigma, poorer quality of life and a range of negative outcomes (Warner 2009). Disempowerment has emerged as a key risk factor in the aetiology of disease (Ryan et al 2012). Compatible with these findings is the literature on learned helplessness which suggests that absence of influence or control can lead to the onset of depression (Garber and Seligman 1980).

There is an evidence base to suggest that empowerment is ‘not just a set of values’ but leads to positive outcomes in care. These positive outcomes include increased emotional wellbeing, independence, motivation to participate and more effective coping strategies (Ryan and Deci 2000; Thompson and Spacapan 1991; Macleod and Nelson 2000). Evidence in this area comes from three approaches. First, the *shared decision making* model for medication management developed by Deegan & Drake (2006). Research shows that shared decision making in mental health has the potential to improve mental health care as it impacts on quality of life, autonomy, choice and health outcomes. Another approach is through the use of *Joint Crisis Plans* (JCP), sometimes known as

advance directives, to cover arrangements for admission to hospital which can reduce involuntary admissions and improve service users' sense of control of their mental health problems (Henderson et al 2004; 2009). Finally, the use of an educational approach (rather than a therapeutic approach) to *illness-management and recovery*, is designed to provide people with severe mental illness with the information and skills necessary to manage their illness effectively and work towards achieving personal recovery goals (Mueser et al 2002). The benefits for service users include an increased knowledge of illness, coping skills, personal goal identification and attainment.

Jormfeldt et al (2008) observed a direct link between levels of empowerment in people using mental health services and subjective ratings of health while Barrett et al (2010) found that mental health service user empowerment mediated the relationship between treatment and satisfaction with mental health services. Fingeld (2004) states that when discussing empowerment at an institutional level, funding agencies should be better appraised of the benefits of patient empowerment, particularly when related to treatment philosophies and choice. In this way, intervention strategies and outcome goals will ideally accommodate the client's strengths while simultaneously being responsive when setbacks occur. Health institutions are reminded to support front line health care providers through this process since any discussion about power relinquishing may be challenging and staff resistance may occur.

4.6 Empowerment –key defining precepts

Working within an empowerment philosophy requires an understanding and application of some key defining precepts. Table 4.1 contains key concepts related to the work of Linhorst (2006). The precepts discussed in the following section have been distilled from the literature and developed through personal supervision.

In aiming to achieve empowerment, a first step is to agree a *common agenda* between all parties involved. It is for the practitioner and the provider of services to recognise their agenda when engaging with others in the empowering process. Practitioners, patients and carers do not always know or are not always aware of their personal agendas and not knowing or being clear about agenda aims, is potentially a pitfall for empowerment (Van Regenmortel 2009). Crucially there should be no hidden agenda between participants.

In aiming for organisations to work within an empowering philosophy a process of *enlightenment* and awareness is required (Van Regenmortel 2009). This requires the establishment of enabling structures to be developed within the organisation, referred to as enabling *niches*. Enabling niches incorporate staff members and policies and include qualifications, supervision, training, reflective culture, democratic culture and participation of practitioners (Kieffer 1984).

Alongside an enabling niche culture, practitioners need a positive basic attitude to care which includes respect, participation and a focus on strengths. Practitioners aim for what is the *least intrusive intervention*, which is not a replacement of one form of control with another but is an agreed step towards the patient's goal (Van Regenmortel 2009). Working towards an agreed goal may necessitate the patient and carer taking on more responsibility and learning to manage this responsibility is not a linear process. Empowerment is always in relation with others and autonomy in relationships with others is important. This is why the word inter-dependency is used within empowering literature. This inter-dependency is the skill and knowledge to ask for help when required and is not a static construct.

Table 4.1 in the next page outlines Linhorst's (2006) basic concepts of empowerment.

Table 4.1 Basic concepts of empowerment for clients with mental illness (Linhorst 2006)

Empowerment involves holding power, control and influence - Holding final decision-making power is most empowering. However, empowerment exists on a continuum and it can occur in some instances through a sharing of power.

Resources are critical to empowerment- Obtaining resources helps individuals to gain increased control over their lives.

Empowerment can refer to a process - Any process that prepares people to participate more effectively in an activity that increases their power, control or influence can be considered empowering. For example, participating with staff to review a care plan can be an empowering process for clients.

Empowerment can refer to an outcome - Empowerment outcomes are the consequences or results of empowerment processes. The enactment of a revised policy that resulted from a client and staff group is an example of an empowerment process.

Short term and long term empowerment outcomes - Outcomes can be short term, such as completing an educational programme, or long term, such as obtaining a competitive job of one's choice.

Subjective and objective empowerment outcomes - Subjective outcomes are those that are self-perceived or attitudinal such as one's sense of control or self-esteem. Objective outcomes reflect actual power held and usually are reflected behaviourally.

Empowerment can refer to an ideology - Ideology refers to the values and beliefs that comprise empowerment.

Empowerment involves an interconnection between individuals and their environment- Empowerment is reflected in power over one's environment, but one is dependent on the environment for resources and opportunities that others control.

Empowerment is situational – Empowerment is specific to particular activities at a specific point in time. Individuals can be empowered in one activity but not another, and empowerment can increase or decrease as the context or circumstances change.

One cannot empower another - People must empower themselves. However, others play a critical role in providing the individual with supportive relationships, resources, decision-making opportunities, and other things many people need to empower themselves.

4.7 Conditions for empowerment

Can people with severe mental illness meaningfully participate in decision making and activities that allow them to take more control over their lives? If so, what are the limitations to this empowerment? The limitations to empowerment (Manning 1999) reported by people with mental illness include: poverty; social isolation; the effects of stigma held by the public at large and mental health professionals; the effects of psychiatric disability at some times and some areas; the unintended effects of institutionalisation, particularly dependency and compliance; the inequitable distribution of power and the lack of models to share power.

Handler (1996) argued that it is possible to empower vulnerable populations. For him, the question is not, if it is possible, but under what conditions empowerment is likely to occur. He wrote ‘the task is to discover the conditions that will facilitate the creation and nurturing of empowerment in discretionary dependent relationships’ (Handler 1996; 291). Handler (1996) found that empowerment of dependent persons is not the norm in human services, and when it does occur, it is never permanent. The relationships that form the basis of empowerment exist in a particular context and contexts are always changing. Because of changing contexts, empowered clients must continually struggle to preserve their status.

Linhorst (2006) outlines key conditions for empowering people with severe mental illness. The conditions are divided into those that are internal to the person with mental illness, such as the management of psychiatric symptoms, and psychological readiness and other conditions which apply to the person’s environment and include: trust and respect, reciprocal incentives, choice availability, participation skills, culture and access to resources. These conditions are discussed in more depth in the following sections and apply to whatever aspect of the empowering process is being worked with. The processes Linhorst discusses empowering people through include; treatment planning, employment, policy development, research, decision making and service provision. Empowerment through employment is discussed in more depth in this study (see section 4.7.7).

4.7.1 Managed psychiatric symptoms

There is evidence that some people are incapable of meaningful participation in decision-making and other activities, because of the symptoms of mental illness (Spaulding et al 2003). Handler (1990) argued that clients must be free of internal constraints (referring to psychiatric symptoms, skills and psychological readiness) to meaningfully participate in decision making.

These symptoms are particularly related to cognitive functioning capabilities and examples are a person's ability to concentrate; to process information; to screen out irrelevant information and to make logical constructive decisions (see sections 2.2-2.4). On top of these challenges for the client with symptoms related to mental illness is the possibility of co-existing disorders like personality disorders, depression, anxiety and substance misuse. Decision-making capacity is however, context specific (Handler 1990) and this is now recognised within the Mental Capacity Act (2005). Having a mental illness does not by itself negate people from participating in decision making or other activities. Handler's view is that most clients with long term mental health difficulties suffer from impaired areas of judgement at one time or another but the person who cannot exercise any judgement in any area at any time is rare (Handler 1990; 57). Because of the possibility of these fluctuating abilities, the participation capacity of people with mental illness is examined in the context of the specific decision in which they seek to engage (see chapter 2 and sections 5.13 -5.13.2 for study specific strategies).

4.7.2 Psychological readiness

The lack of psychological readiness to meaningfully participate in an activity that has the potential to empower inhibits empowerment. Handler (1990) noted that people who do not hold power can use various means to avoid the subjective feeling of powerlessness. This can be manifested as self-deprecation and apathy and these internalised states can prevent people from participating in empowering activities. The lack of confidence may stem from repeated failures associated with relapses, lack of necessary skills, inadequate environmental supports, poor planning and from setting goals inappropriate to an individual (Pratt et al 1999). Rapp (1998) suggests that feelings of powerlessness and fatigue in this client group distil from frustration and dependency as clients make efforts

to engage in behaviours that do not lead to the changes they are aiming for. Rapp suggests that the constant emotional energy that is expended in this process may serve to decrease the level of energy needed to sustain goal orientated efforts. Nelson et al (2001) described the lack of personal motivation as being associated with self-defeating thinking and a lack of self-esteem, as well as fear of failure, fear of making one's own decisions and simply fear.

4.7.3 Mutual trust and respect

Handler (1990) believed that mutual trust and respect between clients and care agencies are critical to empowerment. He states that:

‘in order for the workers to share responsibility with the clients, the workers must believe that the clients understand, agree, and are willing to cooperate; workers must respect the capabilities, autonomy and responsibility of the clients. The clients in turn, will not give this kind of response unless they have confidence in the workers’ competence and professionalism and believe that they share a common belief in the clients’ best interests (1990;136).

Handler (1990) indicated that trust as a condition for empowerment was a given and states that at the individual treatment level, relationships need to be based on a high degree of trust (See sections 2.9-2.9.3 for discussion about trust). Those in power demonstrate trust and respect when they genuinely listen to the preferences of people with mental illness and act on them whenever possible, show concern for them in the proceedings and give them accurate information about decision making processes. Fitsimons and Fuller (2002) wrote that at the organisational and policy level, participatory decision-making structures are most effective when they emphasise mutual respect.

4.7.4 Reciprocal concrete incentives

Handler (1990) states that the decision making process is boosted by client and staff having concrete incentives for meaningfully participating together in decision making. In order to engage, clients must believe they will get something concrete or material out of

the relationship that is worth the effort it takes to engage in the activity. Likewise staff must also believe they have something meaningful to gain from client involvement. Handler (1990; 152) wrote that reciprocal concrete incentives increase the client's value to the worker and thus change the power relationship. Thus the worker has a concrete professional stake in client empowerment. Staff are less likely to involve clients in decision making when staff have nothing to gain from that participation. Trust alone is not enough to sustain participation. Both parties, especially the party in power, need to receive something material in return. Examples might include a good Care Quality Commission report, a lowering of a patient's care needs or a discharge from the service, all of which will reward the practitioner and service in outcome measures.

Barnes and Bowl (2001) state that a recognition that both parties can benefit from participation is a much more effective starting point for increasing the meaningful participation of people with mental illness in activities. Organisations planning to emphasise an empowering approach to clients with mental illness must ask 'what are the professional rewards for fostering empowerment'? An example of this approach is that people with mental illness are more likely to meet their treatment goals when they meaningfully participate in treatment planning because they have a greater investment in the process (Bassman 1997).

4.7.5 Availability of choices

Handler (1990) and Linhorst (2006) heed the importance of having choices. The ability to choose among alternatives is at the heart of power and empowerment. They believe that choices considered wrong by others can still be empowering for powerless individuals. Handler and Linhorst add that for choices to be informed ones, clients must have information they can understand and utilise in the decision making process (see section 2.3 for MCA guidance on information and decision making). Having a range of choices, including the choice not to choose, and information about those choices is integral to empowerment of people with severe mental illness (Rapp 1998). Choice is also supported in the recovery perspective (Jacobson and Greenley 2001; see section 3.5). Gilson (1998) identifies the consequences of not offering meaningful choices; to offer scaled back options, limited opportunities or inadequate support is not choice, but a continuation of practices of domination and paternalism. Handler (1990) supports the

position that people with mental illness should be allowed to make the ‘wrong’ choice. The rationale for this is that people cannot improve their ability to make choices without going through the process of making poor choices and learning from them (see section 2.3 on MCA and unwise decisions). However, excessive respect for the abstract notion of choice can lead to the perpetuation of neglect or to an increase in the risk of neglect and other harms. Choice must be kept in context and other values must be weighed in the balance (Linhorst 2006)

Currently within the UK, choice is high on the government’s health policy agenda (see section 3.4). For example, *From Values to Action; The Chief Nursing Officer’s review of mental health nursing* (DH (2006a); *Independence, Choice and Risk –a guide to best practice in supported decision making* (DH 2007c); *The Choice Framework* (DH 2013b). However, as discussed in section 3.4, choice is not necessarily conducive to improving outcomes and this particularly relates to patients with chronic conditions where choice may damage continuity of care.

4.7.6 Participation culture, skills and resources

Handler (1990) emphasised that structures and processes for conversation must bring people together in such a way that clients are participants with something to offer rather than merely subjects. Bringing powerless people together with decision makers is not enough. The use of consensus models or participatory models is the most likely route to successful involvement. One such example is the involvement of clients in treatment planning (Anthony et al 2002; Rapp 1998). Other models are the advocacy model, user councils, elected representatives and medication management. The client would require or be enabled to possess the interpersonal and problem-solving skills required to meaningfully participate in treatment planning.

Even when preferences are not adopted, people with mental illness still experience a sense of fairness in the process if that process adhered to the elements of procedural justice (McKenna et al 2003). Regardless of the treatment planning structure, family members should be involved when they have a genuine, constructive interest in their relative and where the person with mental illness agrees to it (Davis 2002; Marshall and Solomon 2000).

Handler (1990) argues that powerless individuals cannot become empowered without obtaining resources. Given the nature of powerlessness, powerless people are unlikely to develop sufficient resources on their own. Handler (1990) identified social movement groups to offer support, information and a collective voice and Nelson et al (2001) identified the importance of natural supports such as family members or friends as well as peer support and self-help groups (see section 3.4 on service user groups and severe mental illness). Another type of resource is access to training and skills development with the view to engaging with decision making, employment or education. Some of these skills include verbal and nonverbal communication, leisure skills, education skills, problem solving skills and work skills (Spaulding et al 2003). Spaulding et al remind the reader that the inability to perform a skill does not by itself indicate abnormality. Rather, it means a person simply does not possess a particular skill or that something is preventing the use of the skill that a person possesses. The skill needed is context specific.

People with severe mental illness can learn skills (Anthony et al 2002). Improving psychiatric symptoms through medication or other means does not necessarily result in improved skills and functioning and participation in educational and rehabilitative activities is usually necessary. Part of learning a skill is practising it. Skill development relates to this research study in relation to the supportive person learning the skills on injection administration (see section 1.4).

Culture exists at various levels including professions and organisations and shapes the interactions with that system and may be defined as values, beliefs and norms that are shared by a particular social system (Glisson 2000). Handler (1996) was concerned with the aspect of professional norms within human service agencies and how professionals are not expected to violate their own professional norms. Consequently if these norms do not support shared decision making, professions are unlikely to do it. He states that for empowerment to occur there has to be a change in professional norms on the part of the power holders – they have to come to believe that the client is part of the solution to their professional task. The empowerment of staff is included in the discussion of culture, because staff are more likely to adopt values, beliefs and behaviours supportive of empowerment when themselves are empowered within organisations (Linhorst 2006). Engagement and staff time are integral parts of the organisational and personal culture.

Staff need time to engage and involve clients rather than making unilateral decisions about care (see section 4.6 on enabling niches).

4.7.7 Empowerment through employment

Employment status can affect an individual's sense of self-esteem and self-identification and is particularly pertinent to this study. A catalyst for the original service user question which led to this study was employment (see section 1.1) and employment was relevant to four of the case studies. The social importance of employment is articulated by Knisley et al (2003; 140) in that 'in our society we define ourselves as well as others by what we do - our work'. Work is an essential element of our participation and acceptance in our communities'. Provencher et al (2002) suggest that employment plays an important role in the recovery process of many people with mental illness by promoting a sense of self-empowerment and self-actualisation. These sentiments are supported by the policy *No Health without Mental Health* (DH 2011a) and the literature review *Social Inclusion and Mental Health* (Boardman et al 2010).

Waddell and Burton (2006), in a systematic review about employment and mental health, concluded that in general work is beneficial to health and well-being; lack of work is detrimental to health and well-being, leading to higher consultation rates with GPs than in the general population, increased prevalence of depression and anxiety and higher suicide rates. For people without work, re-employment leads to improvement in health and well-being, whereas continued unemployment leads to deterioration; for people who are sick or disabled, placement in work improves health and psychosocial status; the health status of people of all ages who move off welfare benefits improves. These benefits apply equally to people who have mental health problems, including those with severe mental health problems. Working is, for most patients, a positive clinical outcome and can be an intervention in its own right.

Waddell and Burton (2006) conclude that while there is no evidence that the work itself is harmful to the mental health of people with severe mental illness, the workplace can have negative connotations. The workplace can be associated with stress where choice in activity is limited and the work culture is one of bullying, harassment and stigmatising, particularly for people with a mental health condition. The key for mental health

practitioners is that clinical interventions should support patients into and to remain at work. The Equality Act (DCMS 2010) means that employers and service providers have to make reasonable adjustments to ensure that people with a disability are not disadvantaged substantially compared with non-disabled people. Reasonable adjustments are recommended so that people can remain in work. *Access to Work* is a valuable Department for Work and Pensions (DWP) scheme designed to financially assist employers with costs beyond that of reasonable adjustments, helping to produce a more efficient support system in the workplace. Some reasonable adjustments suggested by Perkins et al (2009) in *Realising Ambitions* that could support a person with mental illness stay in employment include arranging for someone who became very drowsy after her monthly medication to take a day off and make up the hours elsewhere or enabling a person to arrange their hours to permit them to attend a weekly therapy session. These adjustments imply that the patient is happy to share information about their mental distress with their employer and seem to put the entire onus on the patient and employer to adjust. There is no suggestion that mental health services should adjust their availability.

Henderson et al (2013) found that there were encouraging improvements in employers' awareness of common mental health problems and in their attitudes towards employing people with mental health problems between 2006 and 2010. However, three quarters of employers wished potential employees to disclose mental health problems prior to employment and this suggests some resistance to the equality legislation which makes it unlawful to ask candidates pre-employment health questions.

4.8 Applying the conditions for empowerment

The conditions for empowering people with severe mental illness have at least three applications (Linhorst 2006). One is to guide the development of new programmes or activities that have the potential to be empowering. Programmes need to have adequate resources devoted to training clients and staff, sufficient time to allow meaningful participation to occur and both staff and clients need concrete incentives to meaningfully participate together. A second application is to provide a structure for conducting process evaluations of programmes that claim to be empowering. Evaluation is based on exploring each of the seven conditions as discussed in sections 4.7.1 – 4.7.7. Examples of

the questions asked are; do the consumers have the required skills level to meaningfully participate and is the culture supportive of shared decision making? Evaluation processes used within this study were CPA review meetings, skill competency assessments, individual feedback and outcomes such as the maintenance of employment. The third application is to use the conditions for analysing how to better understand under what circumstances specific activities can be empowering and this study contributes to the literature on this issue.

Relating to conditions one and three above, developing a programme that has the potential to empower (this study) aligns itself to developing innovative practice and this will be discussed in the following sections.

4.9 Innovation

‘There is nothing more difficult to plan, more doubtful of success, nor more dangerous to manage than the creation of a new order of things... Whenever his enemies have the ability to attack the innovator, they do so with the passion of partisans, while the others defend him sluggishly, so that the innovator and his party alike are vulnerable’ (Niccolo Machiavelli, *The Prince*, 1513). This quote highlights some of the challenges an innovator faces and these challenges will be explored within this section. This section will give a definition of innovation and review its status within current health policy and service design. There is a currency of emphasis on innovation – innovation as a strategy to drive up quality of care, offer choice and in managing economic challenges. Frameworks for an innovation organisation and journey will be offered alongside implementation challenges and opportunities

Innovation is a complex term that encompasses a range of interventions; it can only be understood in relation to context (Williams et al 2012). Baregheh et al (2009; 1334) define innovation as a multi-stage process whereby an organisation transforms ideas into new or improved products, service or processes. Greenhalgh et al (2004:582) define innovation as ‘a novel set of behaviours, routines and ways of working that are directed at improving health outcomes, administrative efficiency, cost effectiveness or users’ experience and that are implemented by planned and co-ordinated action.’

The innovation development process often begins with the recognition of a problem or need which in turn stimulates research and development activity. This need or problem can come from any part of the organisation or the customers it serves. For health organisations, feedback from patients is one source, but this feedback has to be listened to and its relevance understood. An innovation can come from a chance discovery when health practitioners are problem solving one area and discover something else. This is referred to as serendipity and is the accidental discovery of a new idea (Rogers 2003). It should not be assumed that adoption of all innovations is desirable. Furthermore, the same innovation may be desirable for one adopter in one situation but undesirable for another potential adopter whose situation differs.

For the innovator, some questions require answering. For example; how do I interpret this request or problem? Where do I take this idea in order to make sense of it? How do I use it? What operational problems am I likely to encounter and how can I solve them? The innovation-decision process is the process through which an individual passes from first knowledge of an innovation to the formation of an attitude toward the innovation to the implementation and use. A model of change proposed by Prochaska et al (1992) aligns itself with the innovation-decision process. In Prochaska's model there are five stages. The first stage is the precontemplation stage - this is aligned with comprehension of messages and knowledge and skills for possible adoption of the innovation. The contemplation stage is aligned with persuasion – discussions about the innovation and the formation of a positive image of the innovation. Prochaska's third stage, the preparation stage, is aligned to decision making- the seeking of additional information about the innovation. The action stage is aligned to the use of the innovation and Prochaska's fifth stage, maintenance, is aligned to the integration of the innovation into one's routine.

The innovation process in health and social care is rarely linear, but it is helpful to think of its components as: discovery, adoption, diffusion and routinisation. This process is commonly considered to proceed at a relatively slow rate in many health-care systems across the world with either deficits or variation in service outcome as a result (Williams et al 2012).

4.10 Innovation and the NHS

There is global acknowledgement of the need to improve services for those experiencing mental illness, with learning disabilities or those who abuse substances (WHO 2010). The Picker Institute (www.pickereurope.org) is a not-for-profit organisation whose mission is to make patients' views count in healthcare. They have worked with over half a million patients since 1998 and formulated eight dimensions of care that reflect the patient's most important concerns (www.pickereurope.org). One of these key dimensions is respecting the patient's values, preferences and expressed needs.

Government policy in the UK outlines the importance of using resources efficiently, improving access to services and driving up quality (Darzi 2008). Challenges for the public sector, particularly financial, are reflected in the government asking for efficiencies to be created within their service provision while improving quality and access to services (DH 2010c). Payment schemes such as Commissioning for Quality and Innovation (CQUIN) (DH 2009c) strive to embed quality innovation in all dialogues between commissioners and providers and shift cultures to focus on continued quality improvement. Furthermore, in frontline services clinicians are being challenged by processes such as Quality, Innovation, Productivity and Prevention (QUIPP) (DH 2010e), emphasising the need for quality processes to be integrated into practice alongside standards set by professional bodies. This challenges service providers to break down the barriers imposed by age, gender, diagnostic criteria and geographic location, and requires a move away from traditional, medically orientated services toward services which support recovery and enable those experiencing mental ill-health to become included in their communities (DH 2011a). All these drivers are supportive of transforming health provision to be accessible, socially inclusive, efficient, and of a high quality.

Innovation continues to be actively promoted as outlined in the NHS's Operating Framework for 2012 – 2013 which asks the NHS to prioritise the adoption and spread of innovation and good practice. It sets out that commissioners and providers should have due regard to this report when developing local CQUIN schemes. The framework builds on *Innovation Health and Wealth*, a policy document which set guidance about quality measures and innovation (DH 2011b). The NHS Commissioning Board, through its legal duty to promote research and innovation, is expected to influence behaviour by setting the right expectations about innovative practice.

4.11 Implementation and diffusion of innovation

The evidence base on diffusion of innovation is growing but remains patchy and methodologically limited (Williams et al 2012). Implementation of an innovation occurs when an individual or decision making body puts an innovation to use. Until implementation occurs, the innovation process is strictly a mental exercise of thinking and deciding, whereas implementation involves an overt behavioural change as the new idea is put into practice. There is a difference between adopting a new idea and putting the innovation into practice, as problems as to how to use the innovation crop up at the implementation stage. Challenges to implementation are usually more complex when the adopter of an innovation is an organisation rather than an individual and include issues of professional power and gate-keeping (see section 3.3). Within an organisation, more people are involved in the decision making process and organisational structure which gives stability and continuity to others may resist the implementation of an innovation. Within the organisational culture, it is the informal psychological and social aspects of the organisation that influence how people think, what they see as important, how they behave and which ultimately determine the success of reforms (Cameron and Quinn 2003).

A summary of the essential factors for embedding innovation in the NHS is provided in table 4.2. (Words in bold type are those of the authors).

Table 4.2 Summary of essential factors for embedding innovation in the NHS (Williams et al 2012)

- Successful innovation requires inter-functional and inter-organisational co-ordination and **collaboration**
- No single implementation tool is likely to be sufficient to bring about sustained innovation
- No single approach will be successful in all settings. It is the **interaction** among the innovation, the intended audience and the context that determines the adoption rate
- Innovations need to be **adapted** as well as adopted into the local context
- A receptive climate for innovation will develop incrementally and over varying periods of **time**
- A multi-determinant and **multi-layer** approach is essential
- End users and other stakeholders should be engaged as **active** change agents rather than passive recipients of innovation
- Financial and other **incentives** can support adoption of new ideas and services
- **Campaigning** approaches which ‘market’ new ideas have been beneficial elsewhere
- Centralised approaches to spreading new ideas should not be discounted but local **buy-in** and adaptation are important

The characteristics of an innovative idea as perceived by the members of a social system determine its rate of adoption. Rogers (2003) identifies five attributes of innovations, namely: relative advantage; compatibility; complexity; trialability and observability. A role attached to innovation practice is that of a change agent. A change agent is more technically competent or attitudinally ready than his or her potential adopters. This difference frequently leads to ineffective communication. Whilst both parties will be technically competent, the application of the innovation, which is largely attitudinal, will mean that they are communicating on differing levels.

The spread of new knowledge into practice is a slow and unpredictable process (Nutley et al 2007). Much time and many resources have been put into trying to understand why individuals, teams and whole organizations do not embrace continuous change in a dynamic way, and why the introduction of new technologies, practices and processes are not part of a repertoire of behaviours, skills and attributes possessed by most workers.

This phenomenon is experienced in every healthcare system across the world (Woolf 2008) and international research agendas are being developed to improve the uptake of new knowledge into practice (Graham and Tetroe 2007). Innovation must also compete with the goals of health-care reform such as efficiency, equity and risk management. Strategies that focus solely on individual adopters are limited to the most simple of innovations, just as initiatives that focus primarily on the innovation itself have been consistently shown to be insufficient in driving improvement in practice (Williams 2011).

The process usually requires significant changes to the way things are being done. New methods mean new training, while care pathways invariably have to be overhauled, prompting disruptive re-training or organisational changes. Existing procedures have to be decommissioned, while budget 'silos' and tariffs often act as a disincentive to change. The current economic climate will impact on adopting innovation (Williams 2011). The question of leadership is important and is a focus of current NHS development. If the drive for innovation is to become embedded in the NHS, rather than treated as a mere add on, then managers must be exposed to and involved in it throughout their careers.

Nursing has a long history of exploring the factors that impede or enhance the uptake of new knowledge into practice (Estabrooks et al 2006). Trends within the discipline have shifted from a focus on the individual and their characteristics (education, awareness of research, skills and attributes) to appreciation of the impact of the wider environment. Social influence theory indicates that although the dissemination of information raises awareness and promotes a predisposition to change, there are many, often stronger, influences affecting the individual's response to such knowledge (Mittman et al 1992). For example, custom and habit, assumptions and beliefs of peers, particularly medical colleagues (who are deemed to have power), prevailing practices and social norms all exert strong influences on an individual.

4.12 Conclusion

In healthcare settings, empowerment ideology is gaining popularity as a means of enhancing patients' sense of control over their well-being. It represents both a process and outcome involving the individual or groups ability to pull from within themselves the power to influence or control significant events in their lives. Within current mental

health service delivery in the UK, the recovery model guides practice and a central tenet of the recovery model is empowerment. However, within the academic and policy literature there is concern that empowerment as a concept or philosophy is nothing more than rhetoric and its application to practice is complex.

The theory of empowerment can be explored through differing theoretical positions. These include critical social theory, social psychological theory, organisational and managerial theory and poststructuralism. Poststructuralism is associated with the work of Michael Foucault and the concept of disciplinary power through the panopticon. An example of how the panoptic concept may be applied to current health care is in patients being given responsibility for their own care through policies such as the '*The Expert Patient*' which has the underpinning philosophy of empowerment. An important point linked to the enactment of these policies is that the 'self-managing' patient still has to report to the healthcare professional for guidance, advice, monitoring and resources. The healthcare professional is always visible.

To understand the concept of empowerment we need to understand the concept of power as power is interwoven with empowerment. Understanding the relationship of power to empowerment is essential, because in nursing, the literature suggests power is often viewed negatively or seen as antithetical to caring. Empowerment and power are important concepts that need to be understood in the context of the patient, family, service and organisation. There is a need for mental health nursing to action the theoretical understandings of empowerment (Chambers and Thompson 2009) and this study will contribute to this process.

The literature suggests it is possible to empower vulnerable populations such as patients with severe mental illness. Relationships that form the basis of empowerment exist in a particular context and contexts are always changing and because of these changes, empowered clients must continually struggle to preserve their status. There is an evidence base to suggest that empowerment is 'not just a set of values' but it leads to positive outcomes in care. Alongside the distinct approach to interventions, empowerment also calls for empowering orientated language. Professionals can replace words like 'client' and 'expert' with 'participant' and 'collaborator'.

The literature on empowerment identifies key precepts that require understanding, such as common agenda setting, enabling niches and least intrusive interventions in order to

achieve empowerment. Key conditions are identified which promote the empowerment of people with severe mental illness. These conditions are divided into those that are internal to the person such as symptom management and psychological readiness and conditions which apply to the person's environment such as trust, reciprocal incentives, choice availability, participation skills and access to resources. Empowering patients through service provision may involve innovation.

Current government policy continues to outline the importance of using resources efficiently, improving access to services and improving quality and innovation. The innovation can come from feedback, problem solving or research and development. Innovation is currently promoted within the NHS. A degree of uncertainty and perceived risk is involved in the diffusion of innovation process and this uncertainty can be reduced by obtaining information. The culture of an organisation, professional gatekeeping and individual readiness will influence the acceptance or rejection, wholly or partially of an innovative idea. In any case, it can take a prolonged period of time for a new idea to be accepted into practice. Enabling carers to administer a depot injection is an innovative idea and its application to practice through an action research process will be discussed in following chapter.

Chapter 5

Methodology

5.0 Introduction

In this chapter I will discuss the context and setting where the study took place and the process of participant recruitment. The study gained ethical approval following a two year journey through LREC. This LREC journey is discussed at length as it raised important issues related to liability cover for the carer. The process of consent gaining is outlined alongside the rationale for using pluralistic paradigms within this study, including critical social theory, pragmatism and interpretivism. The chapter contains an in-depth analysis of action research and its application to practice. The methods used to collect the study data are identified, discussed and outlined.

5.1 Research setting

This study took place in a south London NHS mental health Trust which acted as sponsor for the purposes of research governance. The Trust provides mental health services for three London boroughs and the study involved two of the boroughs. As the chief investigator of the study, I have previously worked with the Trust and have knowledge of the organisation and some of the key managers and clinicians within the organisation.

The context within which the study recruited participants was one of service restructuring. Within the borough where all study participants were recruited, service reorganisation resulted in the amalgamation of three separate depot clinics into one central clinic base. Service restructuring was significant in that the service manager recommended the researcher try another borough within the Trust as the climate within this borough was more settled. This was not done. The restructured central mental health base accommodated five separate mental health teams that provided community mental health services throughout the Borough for clients who have long term mental health needs. Teams within the mental health base are called 'Recovery' teams, and the overall service philosophy is called 'a Recovery service' (see section 3.5).

During this period the total number of clients receiving a depot injection within the borough was 815 and the depot clinic where the researcher attended and recruited had 380 clients registered to attend. The remaining clients had their depot injection administered by the community nurse or were under the care of the assertive outreach team which administered their own depot injections. A sample survey completed through care co-ordinators and the depot clinic nurses, estimated that fifty percent of the clients attending this clinic had a supportive person. This information was based on the number of relatives, friends or professional carers who attended Care Programme Approach (CPA) meetings or supported the client on attendance at the depot clinic. Potentially, this suggested that approximately 190 patients were potential participants for the research study.

The depot clinic attended during the study was operational three days a week between 9.30am and 4.30pm. On a busy day, up to 50 patients would attend the depot clinic. This worked out that each patient had approximately eight minutes per appointment. The clients were not offered individual appointment times; they received a number on arrival at the clinic from the receptionist and the depot was administered in numerical order. All nurses who worked within the building and who had care co-ordination roles were rostered to administer the depot injection – this worked out that each nurse did one depot clinic every two weeks.

The researcher attended this newly created central depot clinic, following ethical approval of the study, on 12 occasions following negotiated permission from the service manager. Negotiation to attend specific depot clinic days was done through the senior nurse who had responsibility for clinic management and the depot administration nurse on the day. An office adjoining the depot clinic was made available to be a base for the researcher.

5.2 Research paradigms

A precise definition of a paradigm is somewhat obscure as the philosopher Thomas Kuhn who introduced the term used it no fewer than 21 different ways. The original use of the term by Thomas Kuhn (1970) defined a paradigm as a set of generalisations, beliefs and values of a community of specialists. Kuhn argued that it is difficult to think outside a

paradigm - they represent world views that encompass ontological, epistemological and methodological assumptions and these will be discussed in relation to this study. A term used by Creswell and Plano Clark (2011) to describe these assumptions is worldview and this, they suggest, is used synonymously with paradigm. Paradigms are human constructions distinguished by differences in beliefs and values and as such, cannot be proved or disproved (Guba and Lincoln 2005; Moccia 1988).

Within these sets of beliefs, values and practices, differing ontological, epistemological and methodological approaches are distinguished. Denzin and Lincoln (1994) state that ontology questions what the real world is and what can be known about it. Epistemology questions the relationship between the knower and what can be known, and methodology questions how researchers can go about finding out what they believe can be known. Thus the researcher's ontology directs the epistemology and subsequently the methodology and the paradigm provide a lens through which to view or accomplish an investigation.

There are many research paradigms, methodologies and strategies available to the nurse researcher (Welford et al 2011). Different paradigms can inform different aspects of clinical practice research depending on and often guided by the state of knowledge about a particular area of care (Weaver and Olson 2006).

Crotty (1998) categorises a paradigm according to its theoretical perspective, its ontology, its epistemology, its methodology and its methods.

- The theoretical perspective or philosophical stance lies behind the methodology in research questions and can include critical theory, pragmatism and interpretivism
- Ontology challenges the researcher to consider what they believe in. My belief in relation to the study is that the world is practical, influenced by humans and situationally responsive
- Epistemology is concerned with the theory of knowledge embedded in the theoretical perspective. It informs the research and can include objectivism, subjectivism and pragmatism
- Methodology is the strategy or plan of action that links method to outcomes and governs the choice of methods. Methods are the techniques and procedures used

to gain data and could include under an action research methodology both qualitative and quantitative approaches such as interviews, questionnaires, observations, triangulation, reflection and intervention.

Adherence to one paradigm within a research study is a commonly held belief. Fawcett et al (2001), however, advocate multiple modes of inquiry to meet nursing knowledge needs. Proponents of the use of several paradigms within a research study argue that knowledge from one perspective can complement knowledge developed from other perspectives within the study (Leddy 2000). Within the academic debate around paradigms, Leddy recommends capturing the processes and products from multiple paradigms in order to meet the demands of nursing knowledge. This knowledge could and will be a combination of scientific, professional and personal knowledge, relationship with the patient and clinical experience, all of which will contribute to ethical decision making. Meleis (1997) argues that in a discipline like nursing working with human beings, it is not realistic to expect that any one theory could explain, describe, predict or change any number of the discipline's phenomena.

An example within this study could be the patient and supportive person asking for knowledge about the benefits of the prescribed medication. As the principal researcher, I could use scientific knowledge to respond to this question. If however, the question was about how the patient feels if his mother gives him his injection, then I would have to use knowledge of the family and knowledge of my limitations about this knowledge in order to ethically respond.

5.3 Research paradigms and this study

The origin of this study was a mental health service user request. It was a practical question about the possibility of a person, other than a mental health nurse, administering a depot injection. Theoretically, enabling a person, who is not deemed to be in a position of power, to gain knowledge and skills would involve action. The process of this action, praxis, is an opportunity to develop knowledge and theory and additionally, the individuals involved in the process will develop their own interpretation of the process and their own view of any outcomes. For example, the health professionals

could be dominated by the concept of risk whilst the patient may be led by wanting choice within the depot administration process. With this in mind, a multi-paradigmatic approach was taken within this study. The paradigms used to underpin the study were critical social theory, pragmatism and interpretivism.

5.3.1 Critical social theory

Critical social theory is inspired by the writings of Marx, Habermas and Freire and includes emancipatory movements (Weaver and Olson 2006). Critical social theory is oriented toward critiquing and changing society as a whole, in contrast to a traditional theory like hermeneutics which is oriented only to understanding or explaining it. A critical social theory perspective assumes that truth exists as ‘taken for granted’ realities shaped by social, political, cultural, gender and economic factors that over time are considered ‘real’ (Ford-Gilboe et al 1995). The theory is concerned with countering oppression (which may be part of this ‘taken for granted realities’) and redistributing power and resources (Maguire 1987; Lutz et al 1997). Within a critical social theory paradigm, research becomes a means for taking action and a theory for explaining how things could be (Maguire 1987). Process and not the product is emphasised and there is a desired focus on praxis or the combination of reflection and action to effect transformation (Mill et al 2001). Mill et al suggest that theory and action are closely linked – research goes beyond description towards action to change inequalities. The research process itself is characterised by continual redefinition of problems and by cooperative interaction between researchers and those whose environment is being researched. The emphasis within critical social theory on practice and process to develop theory makes it relevant to this study.

Critical social theory has been criticised for focusing on collective rather than individual issues. The theory asks individuals to engage with, and change pre-existing social orders that they individually had no part in creating and of which they may not be aware of the significance (Weaver and Olson 2006). This criticism may apply to this research study in that patients and supportive persons are asked to individualise the experience of applying a complex medical intervention without being fully aware of the professional, legal, ethical and risk frameworks about intramuscular injection giving (see section 4.4.1).

5.3.2 Pragmatism

Pragmatism comes from the Greek word for action and is about determining the value of an idea by its outcome in practice. Weaver and Olson (2006) suggest that pragmatism calls for a theory to be designed and tested in practice and its main aim is for knowledge to arise out of actions, situations and consequences. Murphy (1990) explains that in pragmatism there may be academic definitions and explanations of a concept but how it is understood and applied in everyday practice is what is important. ‘What works’ is of interest to practitioners and researchers who espouse a pragmatic philosophy (Creswell 2003) and makes it a relevant research paradigm for this study.

Ontologically, pragmatists have regard for the reality of and influence of experience in action. Johnson and Onwuegbuzie (2004) state that epistemologically, pragmatists reject traditional dualism, in that they reject the concepts, for example, of pure objectivism or subjectivism. They prefer a more commonsense philosophical dualism approach which acknowledges that interactions between subject and object are integral to the solving of problems.

Pragmatism allows the researcher freedom in their choice of methodological approaches (Patton 2002). Methodological choices are based on their appropriateness for answering the research question and multiple methods can be used. This can mean a mixture of qualitative and quantitative methods. Applying a pragmatic approach to nursing can move nursing beyond the boundaries and restrictions of a single paradigm towards theory construction that is tailored to fit particular situations (Weaver and Olson 2006).

A criticism of pragmatism is that it fails to answer the question, for whom is a pragmatic solution useful? (Mertens 2003). Is the solution for the patient, the family or mental health services? Each will interpret the solution differently. On the other hand, Johnson and Onwuegbuzie (2004) suggest that pragmatists view theories instrumentally in that theories are true and become true to different degrees and to different people based on how they work. In Johnson and Onwuegbuzie’s definition, workability is based on the criteria of predictability and applicability.

5.3.3 Interpretivism

An interpretive paradigm emphasises understanding the ‘meaning’ individuals place on their actions (Weaver and Olson 2006). Phenomena are studied through the eyes of the

people in their lived situations and interpretivism assumes multiple shared realities. Ontologically, interpretivism is about truth being viewed from multiple perspectives that are holistic, local and specific (Forde-Gilboe et al 1995). Epistemologically, there are discussions about how to develop an objective science from subjective experience (Denzin and Lincoln 1994) and one way of overcoming this paradox is by denying the opposition of subjectivity and objectivity. Both subjectivity and objectivity can co-exist (Denzin and Lincoln 1994).

Theory generation from an interpretivist perspective is inductive and methodologically case studies and phenomenology are options for use. Interpretive paradigms can employ multiple methods such as interviews and observations and can combine qualitative and quantitative approaches. Interpretive paradigms recognise that the participant is an expert and there is no single ultimate interpretation of reality (Morse and Field 1995). Theory generated through the interpretative paradigm has enabled nurses to develop insights into unique individual responses within clinical situations that could improve the care of those involved (Van der Zalm and Bergum 2000). Developing insights into clinical situations makes interpretivism appropriate for this study.

However, the interpretive paradigm has limitations in that it has tended to ignore the influences of biological factors and social structures on individuals' actions (Weaver and Olson 2006). Additionally, Weaver and Olson suggest that studying phenomena through the eyes of people and achieving multiple realities, limits the construction of theory.

5.3.4 Summary

Within this research study a number of approaches have been used. From a theoretical perspective, the question about empowerment lends itself to a critical social theory paradigm as a link to emancipation and social change is relevant. Mental health service users are deemed to be a group in need of a louder voice and the hearing of their views and the actioning of their viewpoint underpins the current study. Praxis is at the core of critical social theory and this relates to this study as it does to the paradigms of pragmatism (what works) and interpretivism (insights into unique clinical situations). Taking a view that enabling a supportive person to administer a depot injection is a choice-related action, this action encourages the sharing of power and knowledge with

the health professional. The nurse, as the administrator of the injection, may have to modify their traditional role and as such, nursing theory will develop. There will be differing and individualised solutions to the practical problems faced by families and practitioners and this is respected within pragmatist and interpretive paradigms.

This research study was designed to implement a service user request in clinical practice and the methodology used for this implementation was action research which is discussed in detail in the next section. An overview of the study methodology and methods is presented in figure 5.1. in the next page.

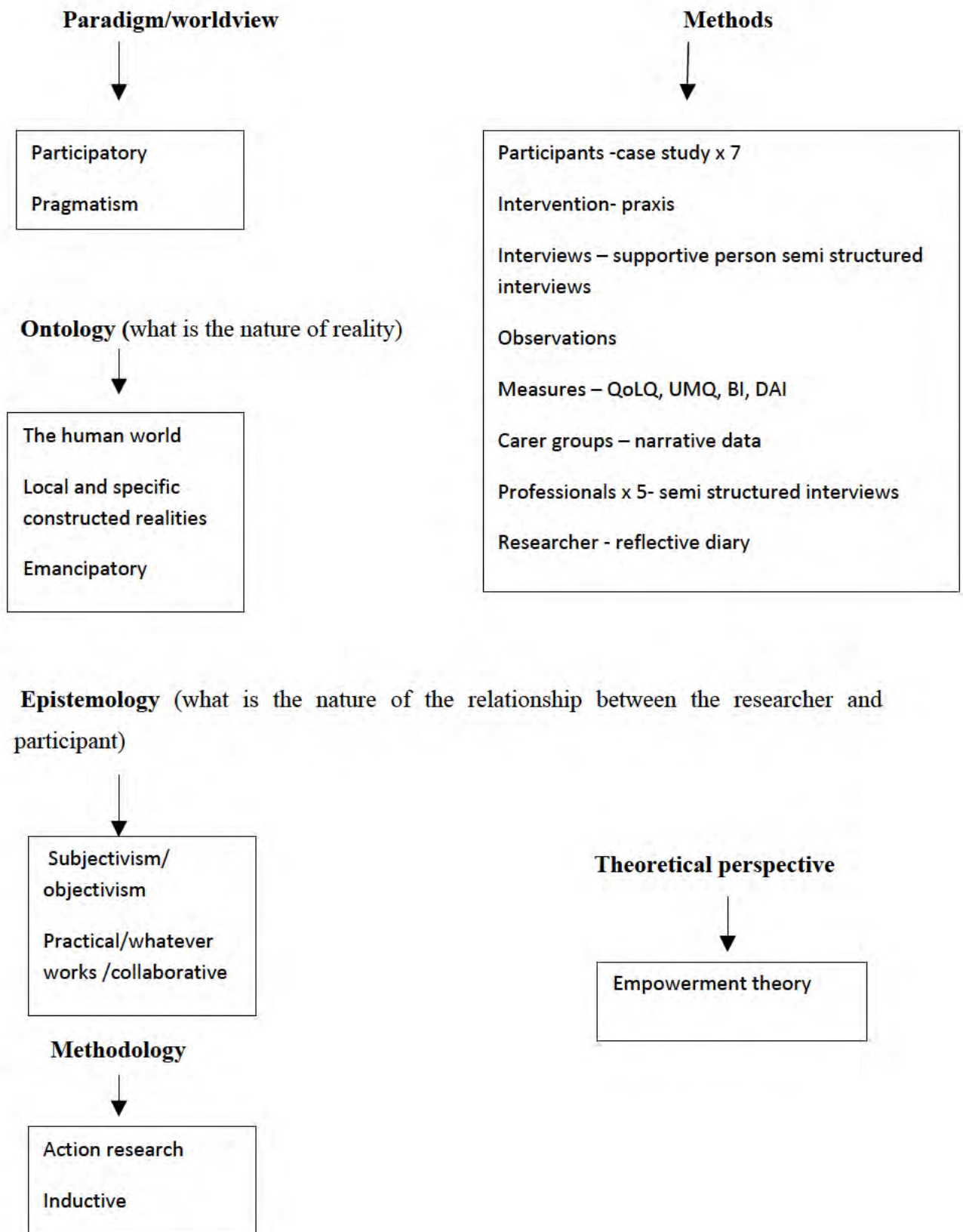


Figure 5.1 –Overview of study methodology and methods used in this study

5.4 Action research

The development of action research is largely attributed to its originator, Lewin (1946), who recruited research participants from areas he was investigating to help identify problems in, and develop strategies for, improvement within the participants' own social contexts. From these beginnings, the basic premises of social research evolved and the orientation of action research is largely attributed to a set of propositions developed by Lewin. These propositions are that research should be focused on social practices that are susceptible to improvement and those responsible for practice should be involved in research (Lewin 1946).

A variety of approaches to action research have emerged since the original work of Lewin during the 1940s and it is suggested that this is one of the reasons why action research as a method and philosophy may not lend itself easily to definition (Holter and Schwartz-Barcott 1993). Since the 1940s various disciplines have adopted the basic ideas used by Lewin and action research has evolved into a method reflecting different epistemologies, ideologies and methodologies. Action research has since become a generic term used to describe a variety of research approaches whose principle aim is to improve a practical situation (Carr and Kemmis 1986; Webb 1999; Hart and Bond 1995; Waterman et al 2001; Stringer 2007). In this respect, the term action research is said to describe more fittingly a particular orientation and purpose to inquiry rather than a research methodology (Reason and Bradbury 2006). Reason and Bradbury (2006: xxii) propose that action research consists of a 'family of approaches' that have different orientations, yet reflect the characteristics which seek to 'involve, empower and improve' aspects of participants' social world.

5.4.1 Characteristics of action research

A number of authors have attempted to identify the characteristics that illuminate the uniqueness of action research and distinguish it from other methodologies. Carr and Kemmis (1986: 164) specify the underlying principles of action research which probably best reflect the ideology of Lewin's (1946) original work. These include:

1. Participatory character

2. Democratic impulse

3. Simultaneous contribution to social science (knowledge) and social change (practice).

Carr and Kemmis (1986: 165) suggest that contemporary proponents of action research are critical of both the assumptions and applications that underpin these principles. However, they continue to be cited in the stated characteristics of action research methodology. Action research as a methodology has evolved, yet continues to reflect strongly the original fundamental principles. Although the terminology and nuances may be altered, the fundamental principles remain. For example, this is evident on closer examination of the characteristics proposed by Reason and Bradbury (2006: xxii), who affirm that action research should involve (participatory), empower (democratic impulse) and improve (contribution to knowledge and practice). Lewin's (1952) influence is also clearly evident in the way action research is described in health related literature. For example, Holter and Schwartz-Barcott (1993: 299) identify four distinguishing characteristics of action research, namely: (1) search for solutions to practical problems; (2) collaboration between researcher and participants; (3) implementation of changes in practice; and (4) development of theory. Hart and Bond (1995: 40) produced a useful typology of seven criteria framed within four broad traditions of action research, which they suggest retain the distinct identity of action research. In summary, these also reflect collaboration and involvement, a practice focus and intervention.

Drawing on action research literature, four key characteristics have been identified.

5.4.2 Participatory nature

Lewin (1946) emphasised the importance of involving participants throughout the research process and identified this as an essential attribute. His emphasis led to the evolution of one of the most recognised characteristics of action research; that it is participative in nature and is underpinned by collaboration between the researcher and practitioner. Participation as a characteristic of action research can take a number of forms and it is helpful to consider these from three perspectives.

First, participation describes a research partnership or a form of inquiry that is a collaborative endeavour between researchers and participants. Whyte et al (1991)

maintain that this involvement is the defining feature of action research. In their definition of action research, Waterman et al (2001: 11) describe a 'group activity founded on a partnership between action researchers and participants'.

The extent of collaboration between researcher and participant can be highly variable. Indeed, variations in participants' level of involvement have been criticised as some studies claiming to use action research methods have failed to demonstrate true collaborative intent. Some authors advocate that when collaboration is evident throughout all the stages of the research, there is more opportunity to obtain practical solutions to problems identified for investigation (Holter and Schwartz-Barcott 1993; Waterman et al 2001). This includes participant involvement in problem diagnosis, development and implementation of action plans and subsequent evaluation of these processes.

In their typology of action research, Hart and Bond (1995: 41) indicate that the degree of participation often reflects the broad approaches of action research and acknowledge that this can vary through different stages of an inquiry. Jenks (1999) and Waterman et al (2001) contend that the levels of collaboration often vary between studies, from those that encourage participation in particular stages of the inquiry, to those that are fully collaborative during all aspects of the project. Collaboration can therefore range from informing a review and diagnosis of a particular problem to identification of solutions, testing and evaluation of that solution in practice.

A second perspective reflects group activity rather than individual effort, and is often a hallmark of action research. Koch and Kralik (2006: 38) describe the purpose and outcome of group activity. They view collaboration as a means of networking for a common cause, where common ground is discovered with others to whom the research aim is important. In this way, they suggest, shared interests are advanced through a process of dialogue and co-operation.

Third, action research is collaborative in that participants locate their inquiry in their social world and in doing so may involve others in aspects of the research. Carr and Kemmis (1986: 165) suggest that as action research progresses, there is an expectation that a widening circle of those affected by practice would be involved in the research process. In respect of nursing practice, this perspective of participation reflects the reality

of patient care as a collaborative endeavour participated in by a range of health care practitioners.

5.4.3 Investigation into social practices

Whenever possible, action research involves participants developing their own knowledge and practice that reflect the social and political values of their own social world (Kemmis 1993). In this way, the epistemological basis of action research may differ from other forms of research, in that knowledge and practice is generated from the perspectives of different participants in the research process. This includes the researcher but also practitioners, service users and family members who (as individuals) have access to local knowledge, have insight into the workplace and have access to the history, structures, processes and cultures of where they work (Holter and Schwartz-Barcott 1993; Jenks 1999). Elden and Levin (1991: 131) contend that this unique knowledge into a particular situation by those who spend time in it provides an insight that cannot be obtained by outsiders. Kemmis (1993: 182) describe this as access to practical theories, which in turn results in informed action or praxis. Hammersley (1993: 217) emphasises the value of participants' firsthand experience and the information and understanding they bring to a situation. Significantly, he also observes that participants are in an ideal situation to test theoretical ideas in a way an observer never could and to provide particular insight into the evaluation phase.

The contention is that only the practitioner or those directly involved can have access to the perspectives and commitments that inform particular actions. In this regard, action research encourages individuals to investigate their practice and the context in which practice occurs, to formulate accounts of their situations and devise appropriate plans (informed action) which reflect their practice situation.

By involving community mental health staff, service users and carers at the outset of my research, it was essential that I acquired their insight and views of medication administration. I recognise that the context of practice is an integral part of this process and therefore participants were encouraged to examine the impact that context had on their own practices. In doing so, they provided a particular perspective of practice that could not be attained solely by a practice outsider. The positions reviewed in this section

all conclude that participants who investigate their own practice are then more likely (than those who do not) to identify and implement appropriate interventions to change practice.

5.4.4 Contribution to practice change

A further characteristic of action research is the commitment to the improvement of practice (Kemmis 1993; Hammersley 1993). In other words, action research attempts to identify and implement solutions to solve problems or improve practice as an actual part of the research process. In their definition of action research, Waterman et al (2001: 11) refer to a 'change intervention aimed at improvement and involvement'. Reason (1994) describes this as one of the basic aims of action research, whereby a specific group of people are helped both to identify and to influence change in an aspect of their working or social world. This is one way in which action research can differ from other forms of social research. Participants are encouraged to search for solutions to problems and then apply these within their own practice setting.

This intervention is reflected in Lewin's (1952) original reflective spiral of planning, acting, observing and reflecting and continues to form the basis of action research inquiry. For example, Holter and Schwartz-Barcott (1993) include implementation of changes in practice in their action cycle, whilst Hart and Bond (1995) refer to a change intervention. Waterman et al (2001) describe contribution to practice change as 'action', a term that will be used in the description of the research phases in this study.

The involvement of participants in both investigation and alteration of their practice has a number of consequences. First, there is an underlying belief that if participants implement change it is more likely to be relevant and sustained. This is based on Lewin's premise that the interaction between the participants and the social system leads to solutions for practical problems and changed practice (Holter and Schwartz-Barcott 1993). Kemmis (1993) maintains that praxis can only be researched by the participants themselves. It is therefore logical to suggest that solutions and interventions are more relevant and sustaining if generated by participants.

Secondly, in direct contrast to other research approaches, action research normally includes the implementation of solutions as a part of the research process. There is

therefore no delay between study completion and the implementation of solutions to problems identified. The research process itself includes action or implementation of change and importantly, subsequent evaluation of that action. In this way action research can produce a different type of knowledge from that produced by other research methods, knowledge that is arguably more useful in practice because it has emerged from practice.

With reference to the use of research knowledge in health care settings, Sharp et al (2005: 2) contends that 'good practice evidence is failing to become good practice as the enduring problem of the implementation of evidence into practice persists'. The response to this dilemma is reflected in renewed focus on the concepts of knowledge transfer, knowledge and research utilisation and implementation. Greenhalgh et al (2004) refer to the process of bringing new ideas, practices or technologies into consistent and appropriate use in clinical settings. The potential for action research to act as a vehicle for knowledge transfer is well recognised. For example, a scoping study exploring the potential use of action research and applied research to support evidence-based practice in the National Health Service Scotland (NHSS), supported action research as a positive response to the current challenges of moving research into practice (Sharp 2005). In a review of 48 studies, action research was perceived as a way of effecting change (Waterman et al 2001). Furthermore, Waterman et al (2001: 22) suggest that one reason action research was selected as a method in the studies reviewed was an attempt to bridge the research-practice gap.

Thirdly, action research has an empowering benefit. As participants become involved in identifying their own issues and problems and take action to address these concerns, they enhance this sense of empowerment (Elden and Levin 1991; Lindsey 1999). Furthermore, Elliot (1991) contends that expertise developed during this engagement enhances the participants' ability to discriminate and make judgments. These qualities are reflected in Waterman et al's (2001:26) observation that empowerment occurs through personal development and engagement in aspects of the research process.

5.4.5 Development of theory

In a review of fifty-two action research studies Waterman et al (2001: 40) identify that the less visible outcomes of studies are related to their failure to produce knowledge or contribute to existing theory. Although outcomes from the inquiries or from different stages of inquiries were often apparent, Waterman et al (2001) found that the explanations that supported changes or outcomes were not. It emerges in the literature that one of the major criticisms directed at action research is that it does not effectively contribute to theory generation. Dick (2004) notes the dearth of action research literature for theory building. However, in response many authors concur that development of theory is not the main purpose of action research. Reason and Bradbury (2006: 2) suggest that the primary purpose is to produce practical knowledge that is useful to people in their everyday lives. Building on this, Waterman et al (2001: 16) contend that action research places emphasis on practice or behaviour, with research being the tool to bring about and support change. Therefore, they argue that research should not be judged purely by research outcomes or theory development. Responding to these dilemmas, Herr and Anderson (2005: 5) describe the goals of action research as a double burden. They suggest that it is concerned with both action (improvement of practice/ social change) and research (creating valid knowledge about practice).

There are essentially two strands of theory production described within an action research framework; the construction of local theory for testing (Argyris and Schön 1991) and the eventual contribution of theory produced to existing theories (Reason and Bradbury 2006). The term local theory perhaps best reflects the notion that knowledge produced through action research inquiry is contextually bound. In other words, the theory that arises from an action research study is influenced by the social situation in which it is created. For example, the social situation in my study refers to the staff, service users and carers who participated in my study and the contexts within where they live and work. Whilst there is a danger that a small-scale localised study can have its impact overstated, action research does not attempt to generalise solutions to problems that may apply to similar settings, as interventions are designed for a particular context.

As action research is context specific and situational, its purpose is not to produce general assumptions. However, it is still possible that the theory can contribute to existing theories by generation of additional knowledge for use by others. Whyte et al

(1991) argue that there is potential for action research to make this theoretical contribution by placing ideas in the context of pre-existing literature. For example, knowledge gained can add to existing knowledge from previous empirical studies (Jenks 1999), contribute to theory on organisational culture (Whyte et al 1991), provide knowledge about settings where change is being implemented and can add value to the discipline or topic being investigated.

A process of reflection is used to make the theory explicit, that is, practitioners reflect on their practice as the project progresses (Argyris and Schön 1991). Theory can then be generated or refined and its general application explored through the cycles of the action research process. Jenks (1999: 254) describes a process whereby practitioners discover the factors that facilitate or inhibit their practice. Thus, insight allows participants to reflect and importantly these insights become local theory. As research progresses, the participants test the local theory by developing interventions that place the theory in action. They evaluate the intervention and as a result refine the theory (Jenks 1999). A continuous cycle of planning, acting, evaluating and theorising may persist until the desired level of action is achieved.

Knowledge that may be advanced through this process of reflection and research includes practical and propositional knowledge (Heron 1981; Waterman et al 2001). Practical knowledge relates directly to the problems and solutions in a particular setting and is best understood by Reason's (1988: 4) description of 'knowledge of how to' apply a skill or demonstrate practice competence. Propositional knowledge explores the context of action and, for example, encourages the researcher to ask questions about what is happening, and the reasons behind actions (Waterman et al 2001). Thus, theory generated through action research produces knowledge that forms an extended epistemology that informs about practice change and helps to develop theories to explain phenomena.

5.5 Approaches to action research

Reference to a 'family of approaches' (Reason and Bradbury 2006: xxii) helps to illustrate the notion of a common purpose to action research inquiry but also signifies the diversity of approaches and assumptions which underpin the different orientations. In this section, I examine three different approaches to action research; empirical-analytical,

collaborative and critical action research. However, in doing so I also acknowledge that there are inherent difficulties when attempting to distinguish between the different approaches. I suggest that this is made more difficult by the different positions that exist in the literature, in relation to the associated philosophical traditions.

Furthermore, I do not attempt to ‘over categorise’ action research inquiry, as in doing so the connections that exist between the different orientations are lost. In this respect the three approaches reviewed in this section do not describe a prescriptive approach to action inquiry, rather they help to identify the underpinning epistemological and methodological issues that characterise the three different approaches described here.

The empirical-analytic approach, which is concerned with testing effectiveness of an intervention, is guided by a technical or instrumental approach to inquiry. Interpretative research serves a practical interest that is guided by informed action in practice. Critical research has an emancipatory interest, said to empower and free people from social constraints.

5.5.1 Empirical-analytic action research

The breadth of action research inquiry can be demonstrated along a continuum that starts from a positivist, scientific method of inquiry into social change and moves towards a qualitative focused methodology. The positivist end of the continuum perhaps best reflects Lewin’s early work and his scientific approach to solving social problems. There is broad consensus as to what constitutes this approach to action research, as descriptions tend to reflect a positivist tradition. For example, in their typology of action research Holter and Schwartz-Barcott (1993: 301) describe action research at the positivist end of the action research continuum as ‘technical collaborative’. Whitelaw et al (2003) refer to a technical scientific and positivist orientated approach, while Hart and Bond (1995: 38) describe this type of action research as ‘experimental’.

The aims of empirical action research reflect these positivist descriptions in that they include the testing of particular interventions based on pre-specified frameworks and therefore draw on traditional scientific methods (Holter and Schwartz-Barcott 1993; Whitelaw et al 2003). Empirical research therefore largely describes an approach with an experimental predisposition, one that can be used to test theory or used to identify causal

relationships. This method of inquiry can be seen in research approaches that test the effectiveness of particular interventions on selected outcomes. In this respect, Kemmis (2006: 95) is critical of technical research that suggests success is measured when the goals of a project to test an intervention have been attained. He contends that this is an inherently narrow perspective that fails to take account of the situation in which practice is being carried out.

A further constraint when considering empirical action research as a method of inquiry, concerns the involvement of nurses as participants. Robottom and Colquhoun (1993: 50) assert that participant involvement is one of the main distinctive features of any action research inquiry but describe research at this end of the continuum as being carried out 'on other people', as opposed to with, or for, participants. In empirical research the role of researcher and participant are quite distinctive, with the researcher maintaining main influence and control. Although participants' expertise is acknowledged, their role and influence in the research may be limited. For example, Whitelaw et al (2003) suggest that participants' contribution may be confined to the provision of feedback about a particular intervention. Empirical-analytic action research is an appropriate method of choice when participant involvement is required to test or evaluate an intervention. However, this approach would not on its own suit my research aims that emphasise three of the action research characteristics reviewed earlier. These are participation and collaboration, practice context and commitment to improvement of practice. In this respect, an empirical-analytic approach to my inquiry would limit the scope of research.

5.5.2 Collaborative research

Moving towards the middle of the action research continuum, a more collaborative orientation between researcher and participants emerges, with Robottom and Colquhoun (1993: 50) suggesting that collaborative research is done 'with other people'. Reflecting the collaborative nature of this form of action research, Holter and Schwartz-Barcott (1993: 301) describe a 'mutual collaborative' approach to inquiry. Similarly, Whitelaw et al (2003) also convey this collaborative intention, identifying the 'mutually collaborative and interpretive' orientations that form the basis of this type of action research.

Kemmis (2006: 95) recognises that this approach to action research has aspirations to change practice, whilst encouraging participants to consider the influence of the practice context on them and their aspirations. This approach brings participants and researcher together to identify common problems, seek and try out possible solutions and monitor the progress of these solutions. One approach to collaborative inquiry described by Reason (1994: 326) as co-operative inquiry reflects these stages. He proposes that co-operative inquiry takes place within a cyclic phase of action and reflection. Participants, as co-researchers, identify a practice situation that can be influenced or changed, implement the chosen intervention, reflect on progress and modify intervention in light of experience (Reason 1994).

In relation to my study, the aims of the research question are addressed mostly through the collaborative approach to action research. Importantly, collaborative inquiry focuses on participation and collaboration, practice context and commitment to improvement of practice. However, in relation to participation, Reason (1994) suggests that this approach suits a group of people who view themselves as relatively empowered and who wish to explore and develop their practice together. In this respect, participants in my research are service users and carers who may be considered as holding disempowered positions and are therefore in a difficult position to influence change. In this respect critical action research would be more pertinent.

5.5.3 Critical action research

Critical action research reflects the work of Freire (1970) that emerged from work carried out with people experiencing oppressive social conditions in the third world and disenfranchised groups in Latin America. Essentially, Freire's approach to action research was aimed at helping oppressed groups to identify problems and subsequently take action to improve their conditions. Participant empowerment is a key aim of this approach. Holter and Schwartz-Barcott (1993:39) consider this an enhancement approach that assists practitioners in 'identifying and making explicit fundamental problems by raising collective consciousness'. Kemmis (2006: 95) describes how critical action research aims at improving outcomes and the self-understandings of participants but is also transformative, in that it aims to reconstruct the practitioners' practice setting. Participatory action research (PAR) is one of the most recognised forms of critical action

research, although this too has different forms, reflecting different intellectual traditions. Drawing on a number of these traditions, Reason (1994: 328) describes three aims of PAR. These include: the production of knowledge and action directly useful to a group of people; the empowerment of participants through construction and application of knowledge through a process of consciousness raising and a commitment to action.

The approaches used to meet these aims are similar to those identified by Reason (1994) for co-operative inquiry, in that participants engage in cyclic activities to explore and improve aspects of their practice or their own role within practice. The process of reflection is fundamental to both approaches. Despite these similarities, differences emerge between the two on closer examination of their respective aims. For example, critical action research is concerned with transformation of practice; co-operative inquiry focuses on the practical possibility of changing (enhancing) practice. Critical social research historically evolved from working with oppressed groups in society and thus begins with the premise that participants are fundamentally disempowered within their social context. In contrast, co-operative inquiry begins with the understanding that participants are empowered individuals who are in a position to influence practice.

With reference to my study, there are aspects of critical action research that fully reflect the aims and questions of my study. Specifically, I would suggest that the emphasis on oppressed groups is a concise reflection of the reality of service users and carers in medicines management. However, critical social theory has been criticised for focusing on collective rather than individual issues and in this study the participants are individual patient and carer dyads (Weaver and Olson 2006; see section 4.4.1). There was no collaboration between the research dyads. Furthermore, the emphasis on practice transformation provides realistic expectations of what study participation can achieve.

Like the other approaches described, critical action research is underpinned by the same characteristics that form a common thread connecting all types of action inquiry. Each one emphasises a different approach to inquiry, yet they all share certain characteristics that distinguish action research from some other modes of inquiry. Despite some differences in ideologies and purpose, all three approaches emphasise the systematic testing of theory in practice contexts. All three approaches support the notion that people can be self-reflective about their world and take action within it. A principal outcome of all three approaches is a change in the experience of those involved in the inquiry.

Through engagement both in action and the research process, participants are potentially empowered to influence their circumstances. At the outset of the study, one of my main challenges could have been to locate my inquiry in one of the three broad orientations to action research described in this section. However, my decision not to do so reflects the belief that each approach contains the common attributes, previously identified, which provide a framework for my inquiry. If I had chosen to use one model of inquiry exclusively, there was a risk that the study would have been guided by ideological perspectives that would not have entirely reflected the circumstances of participants or requirements of my study.

5.6 Methodological limitations of action research

In this section I address some of the limitations of action research, with a particular focus on issues of validity and bias. Validity in research is usually posed in terms of what constitutes a credible claim to the truth and therefore provides a useful means to examine particular issues related to the quality of the research. Bradbury and Reason (2006: 343) debate the need to have standards of validity, or criteria that may not be congruent with the concerns of action research, yet concur that dialogue about validity helps to highlight important questions about research choices. Herr and Anderson (2005: 54) developed an extended version of five validity criteria which they suggest reflect the common goals of action research. Although they too assert that validity criteria for action research are tentative and in a state of flux, their criteria provide a valuable, if somewhat overlapping benchmark from which to evaluate the validity of research. The following sections examine each of the five criteria and I consider the implications of each of these for my study.

5.6.1 Process validity

Process validity broadly refers to the method employed with the research. When considering action research, Herr and Anderson (2005: 55) propose that reflective cycles should be apparent in the research methodology. Closely linked with process validity in action research are related issues of rigour. Rigour in action research has been subject of considerable debate from which different perspectives have emerged. In particular,

tensions are reported in the literature between the need to demonstrate scientific rigour at the expense of practical relevance, or practical relevance at the cost of scientific rigour. This tension is clearly described by Argyris and Schön (1991: 85) who suggest that if social scientists 'favour the rigour of science', they risk becoming irrelevant to the practitioner's demand for usable (practical) knowledge. Alternatively, if they favour action research they risk falling short of prevailing research standards for rigour. Argyris and Schön (1991: 85) challenge the researcher to achieve standards of rigour without compromising research relevance.

Kemmis (1993: 185) suggests that rigour derives from logical, coherent interpretations of the reflective spiral, thus advocating that rigour is embedded in method as participants engage in cycles of observing, reflecting, planning and acting. Bradbury and Reason (2006: 344) agree that as the cycles of action and reflection develop, this fosters development of both understanding and of practice. It is in this way that the strength of action research emerges from the movement between elements in the cycle; the subsequent questioning of each creates a process of validation.

In section 5.9, figure 5.2 and figure 6.1, I present an interpretation of action research cycles used in this study. The cycles consist of four phases of inquiry; problem identification, planning, action and evaluation. The principles of action research inquiry embedded in this cycle were selected to advance understanding of practice, which includes both practical and propositional knowledge about third party risk in the process through LREC (see sections 5.11.1 – 5.11.4) and the recording of home administered depot injection (figure 6.1). Rigour is demonstrated through the involvement of participants in each of these phases and in the methods used to collect data. Waterman et al (2001: 47) suggest that one response to criticisms of rigour is the inclusion of multiple perspectives or methods, which incorporates triangulation, or the use of several kinds of data. Finally, feedback to study informants as a study progresses is also identified as a way of data checking and ensuring participants' perspectives and experiences are represented clearly (Waterman et al 2001).

5.6.2 Democratic validity

Herr and Anderson (2005: 55) describe democratic validity as the extent to which research is carried out with all the parties involved in the investigation. They pose two provoking questions in relation to participation, asking how deep and how wide participation really is. Participation and collaboration were previously identified in this chapter as characteristics of action research methodology. Although there is recognition that differences exist in the level and nature of participation, there is consensus that the ongoing exchange between researcher and study participants in the diagnosis and evaluation of problems and in data gathering process and review of findings, is pivotal to the approach (Whyte et al 1991; DePoy and Gitlin 1994; Waterman et al 2001). As participants act as co-researchers throughout the process this helps to add validity and helps to verify outcomes.

Herr and Anderson (2005: 55) also refer to Cunningham's (1983) perspective of local validity in which problems and relevant solutions emerge from specific contexts. Waterman et al (2001: 35) describe this as a real world focus that acknowledges the context in which research takes place. However, a frequently cited criticism of action research is that by emphasising local problems there is an inability to generalise findings to wider contexts (Waterman et al 2001). Denzin and Lincoln (1994: 100) refer to this as external validity, described as the extent to which findings can be generalised to similar settings to the one in which the study occurred. Referring to a participative worldview, Bradbury and Reason (2006: 344) also draw attention to the need to ensure issues raised by the research are addressed at both local and macro levels, suggesting that researchers pay attention to the implications of research findings within the wider context (see sections 4.9-4.11 on innovation). In chapter six I have made associations between the literature and my data and findings, to show how they connect with a wider knowledge base.

In response to the challenge of generalising findings from action research, and the criticism of research transferability, Koch and Kralik (2006: 139) advise the researcher to describe the context and participants. They suggest a judgment of transferability can then be made of the actions, or the application of theoretical propositions, arising from the research. In agreement, Bradbury and Reason (2006: 347) propose that a study can be

used by inquirers with similar concerns as well as helping to clarify their own circumstances.

5.6.3 Catalytic validity

Catalytic validity refers to the transformative potential of action research, specifically the education of both researcher and participant (Herr and Anderson 2005: 55). In effect, this describes the process by which those involved deepen their understanding of theory and context and can be encouraged to change it. I would suggest that this is best described by Carr and Kemmis (1986: 148) as 'commitment to action'. However, they caution participants against action that undermines a project, suggesting that common commitment to prudent action results in more desirable outcomes. In this respect, engagement in praxis, described as wise and prudent action (Carr and Kemmis 1986: 190), provides a more explicable and understandable measure of validity than does the term catalytic validity.

5.6.4 Outcome validity

One criticism of action research is that projects stop following problem diagnosis or implementation (Watkins 1991; Waterman et al 2001), yet there is agreement that the practical outcome of research is important (Reason and Bradbury 2006). Herr and Anderson (2005: 54) describe outcome validity as resolution to the problem that led to the study and the extent to which action orientated outcomes were achieved. While achievement of outcomes provides a clear benchmark for measuring outcome validity, Reason and Bradbury (2006: 34) offer a more extended epistemology of outcome in action research. They propose that outcomes should be explored reflexively; a process that not only assesses the outcome of action but also examines the impact and value of outcomes. For example, value may take account of the utility of participant learning (Reason and Bradbury 2006), whilst impact refers to the lasting effect of the action or outcome (Waterman et al 2001).

5.6.5 Dialogic and process validity

Herr and Anderson (2005: 55) describe dialogic and process validity as the generation and dissemination of new knowledge. As previously identified in this chapter, there is a dearth of both practical and propositional knowledge emerging from action research studies (Waterman et al 2001; Dick 2004). Arguably, through production and dissemination of this thesis, the debates about the practical and theoretical issues described can be extended. However, I acknowledge that limitations with dialogic and process validity persist if wider dissemination is not achieved.

5.7 Addressing bias in action research

All research is biased (Fox et al 2007) and bias is likely to be more pronounced when a practitioner is conducting research in his or her own workplace. Issues of bias in action research have been the subject of some debate in the literature. There is consensus in the belief that action research is inherently a biased methodology and that this can occur from a number of perspectives. For instance, Carr and Kemmis (1986: 192) suggest that bias can arise if researchers analyse their own practice. Waterman et al (2001:34) contend that lack of researcher independence or separation contributes to bias. It is also important to note that bias is not a particular problem related to action research but can arise with any of the methods used in qualitative methodology. In response to these concerns, Herr and Anderson (2005: 60) recommend that biases be examined and procedures put in place so they do not have a distorting effect on outcomes. With reference to my research, bias is considered by examining it from the three perspectives; methods, researcher and participant bias (see sections 5.8.1 and 5.13).

While participants' insights are crucial to the development of action research, conflicts can arise because of this participation. For example, Hammersley (1993: 218) suggests that people may be misguided about their own intentions and motives during the research. In this regard, issues of vested interest by participants may be a threat to bias and validity, as participants use aspects of research involvement for purposes other than that for which the research was intended. I would suggest that this might be one of the more difficult aspects of bias to overcome, not least because participant intentions may not always be visible to the researcher. One way in which this can be offset is to consider

processes for recruiting participants, and through participant engagement and reflection throughout the research cycle. A further problem related to participant bias is identified by Waterman (1998) who suggests that understanding of a phenomenon requires viewing within a wider context, which may be difficult for those involved.

It is therefore important to recognise the potential for bias when reporting findings. Considering a related issue, Carr and Kemmis (1986) also question whether practitioners can understand their practice in an undistorted and unbiased way as their perception may be clouded by other conditions. However, Kemmis (1993) offers his own perspective of this problem and actually questions whether value-free and objective social science is possible. As the researcher within this study, personal bias was acknowledged and challenged through supervision, the reflective log and the insider/outsider debate (see sections 5.5 -5.8.1). Methods will be discussed in section 5.12 and key factors related to bias and methods are addressed through triangulation, inclusion of stakeholder groups and fora (CPA reviews) and prolonged engagement which Stringer (2007) suggest are checks and balances to the data collection bias.

By considering issues of validity and bias in action research, I have indicated safeguards which have been taken to minimise some of the effects which have the potential for affecting the legitimacy of my study.

5.8 Insider/outsider action research

Insider research refers to when researchers conduct research with populations of which they are also members (Kanuha 2000) so that the researcher shares an identity, language, and experiential base with the study participants (Asselin 2003). This insider role frequently allows researchers more rapid and more complete acceptance by their participants. Therefore, participants are typically more open with researchers so that there may be a greater depth to the data gathered.

The insider/outsider debate in AR is important as it appears researchers are more likely to be successful in generating change if they are 'inside' the setting – that is already established in the setting rather than joining from outside (Waterman et al 2001). However there appear to be as many arguments for outsider research as against, with the

same issues able to be raised in support of outsider research, as against it. (Serrant-Green 2002; 38).

For each of the ways that being an insider researcher enhances the depth and breadth of understanding a population that may not be accessible to a non-insider scientist, questions about objectivity, reflexivity, and authenticity of a research project are raised because perhaps one knows too much or is too close to the project and may be too similar to those being studied (Kanuha 2000; 444).

Presenting the insider/outsider debate in a dualistic manner is overly simplistic (Corbin and Buckle 2009). It is restrictive to lock into a notion that emphasizes either/or, one or the other, you are in or you are out. Rather, a dialectical approach allows the preservation of the complexity of similarities and differences. There is a status of being a 'previous insider', a role which gradually wanes as the people worked with move on.

When my study commenced I was an insider within the mental health organisation that delivered patient care. My role as team manager gave me a position of influence within the organisation and in care delivery. Directly it gave me access to the 60 patients who were in receipt of a depot injection within the community team and as such were potential participants for the study. I had access to practitioners who had direct care responsibilities and as such were influential in facilitating me access to participants. Before gaining ethical approval I had become an outsider as I had joined the local university. I did have insider links to the organisation in that I had a role as link lecturer and attending Trust nursing meetings and conferences. Throughout the study I had a nominated clinical supervisor from within the Trust, part of whose role was facilitating access. More directly, I worked with the lead nurse for the depot clinic and she disseminated information about the study and spoke directly to patients and families.

Though being an outsider getting inside was made easier by being known. I had insider knowledge of people, personalities and organisational policies – I had relationships with the research and development department of the mental health trust and as suggested by Hart and Bond (1995) and Coghlan and Brannick (2010) this insider knowledge was useful as the project progressed.

5.9 Bracketing

Within qualitative research literature there are authors who urge researchers to increase 'objectivity' by taking into account (bracketing) previous experience, personal bias and feelings in understanding their influence on the research (Morse and Field 1985; Heron & Reason 2006). Within action research, research findings feed directly back in the environment from which they are generated within collaborative and participatory processes, and personal responses to the social setting can be drawn upon as a rich source of data and an avenue for learning about the context (Cassell 1978; Lipson 1984). The challenge for the researcher is to hold in abeyance the classification he or she imposes on perceptions with a view to being more open to primary and imaginative meanings offered by participants. So in this research the challenge for me was to set aside preconceptions from my work as a mental health nurse. The situation was more complex than in much research, however, since I was also necessarily drawing on my identity and skills as a mental health nurse. The study participants required my knowledge of practice to give them confidence and the Trust required that legal, ethical and moral processes would be followed.

Within this study, when participants sought feedback on aspects of their actions, e.g. the injection administration process or the storage of medication, my response was based on a combination of nursing knowledge, safety, risk and policy. My response was procedural within what I knew to be safe. When participants asked for feedback on their expectations of services or whether they should inform their children of parental mental illness, then whilst I aimed for an independent questioner approach, it was not always easy to avoid a counselling role because of my previous experiences and role. A reflective diary is one way to develop the skills of bracketing (Wall et al 2004) and reflective practice may be viewed as a specific dimension of action research (Coghlan & Brannick 2010). Examples of how I used reflective practice to alert me to my values and assumptions are given on page 194.

5.9 Phases of inquiry

This section will review the four phases of action inquiry used in my study. Each phase is identified as a component and depicts a sequential progression of events that move from

one phase of the inquiry to the next. However, in reality all phases are interconnected and form part of a reflective, iterative process where there is movement back and forth between the phases (see figures 5.2 and 6.1).

The distinguishing characteristic, which underpins an approach to action research inquiry, can be seen in its reflective approach. This is based on the notion of a cyclic process of reflection that involves a number of phases. While some differences exist in the precise interpretation of this cycle, the basic premise continues to reflect Lewin's ideals of research and action. For example, Stringer (2006) describes the processes of action research as looking, thinking and acting. Kemmis (1993: 178) identifies planning, acting, observing and reflecting. For the purposes of this study, it is helpful to refer to the cycle provided by Waterman et al (2001: 11):

1. Problem identification (fact finding)
2. Planning
3. Action (change)
4. Evaluation

Essentially this cycle identified by Waterman et al (2001) describes a process where research participants engage in activities that include identification of specific problems, planning and development of strategies to address the problems, implementation of actions and finally evaluation of the consequences (see figures 5.2 and 6.1). Whilst the steps outlined suggest a logical, almost linear process of events, in reality movement between phases is more iterative as participants move back and forth between stages in the cycle. Many descriptions of an action research cycle include reflection as a discrete phase (Kemmis 1993; Jenks 1999). The decision not to do so in this study, reflects the belief that reflection is a central component of the whole action research cycle (see figures 5.2 and 6.1) and that each phase in itself involves critical movement between reflection and action.

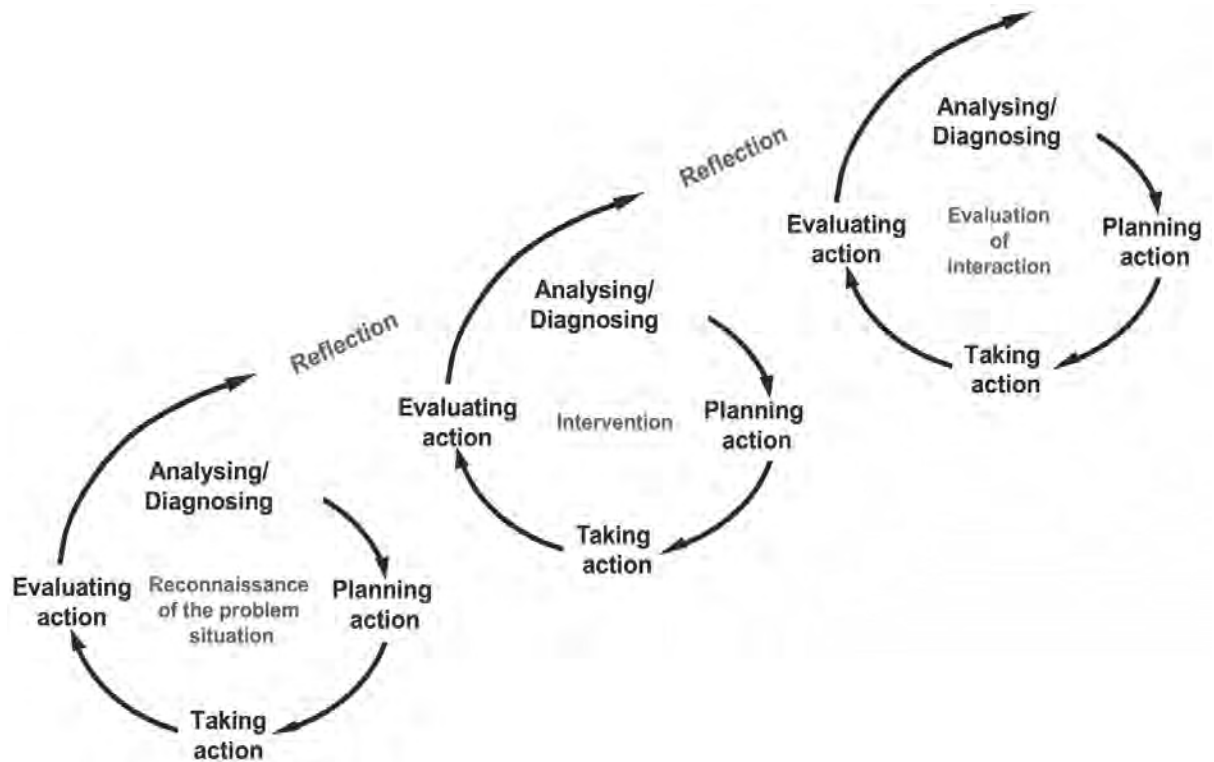


Figure 5.2 The action research cycle

Source: Adapted from Coghlan and Brannick (2001) p 19: Cardno and Piggot-Irvine (1996), p 19

5.9.1 Problem identification

Problem identification describes the first phase of this inquiry, where the goal was to gain an overall impression of the issues involved when carers are enabled to administer depot medication by injection. Essentially, this was an exploratory phase, which Waterman et al (2001) describe as a period of fact finding. In action research, this phase is normally associated with a detailed review and analysis of a situation leading to identification of problems and subsequent areas for development. The problem identification in this study was a question posed by a client who was on a regular prescribed depot injection and who had achieved employment. Rycroft-Malone (2006: 106) supports this initial review of practice, suggesting that ‘there needs to be questioning in order to realise there might be dissonance between current practice and what best practice (client centred care) ought to be’.

Study participants are central to the exploratory process and their initial review of issues located within their social context is normally regarded as the first step in the research. While this is fundamental to action research inquiry, problem identification can also be informed by other sources, for example, a literature review.

Although the review helped to establish an initial baseline for the research, most importantly the first phase of the inquiry was informed by the experience of the mental health service users themselves. Data generated through clinic observations and interviews with participants contributed to the research process on a number of levels. Through participation, insight into the practitioners, carers, service users and organisation was achieved. This process resonates with Kemmis' (1993) notion of praxis, whereby participants engaged in a form of self-reflective inquiry which took account of their understanding of depot administration and the situations where the practice was carried out and by whom. Jenks (1999: 258) emphasises the value of participants' practical input at this stage of the research to establish that the resulting interpretations accurately represent the reality of the situation.

It is also important to highlight a further function of this phase in relation to the collaborative nature of action research inquiry. Hart and Bond (1995: 194) suggest that meetings in the early stages of the research provide an opportunity for negotiation around the detail of the inquiry. In this respect, this first phase also provided an opportunity for clarifying roles and expectations about the purpose of the study. This phase also helped to establish relationships and gave a collaborative perspective to the inquiry. An example of problem identification related to this study is the outcome from the initial LREC application where liability and carer cover were identified as a potential problem (see sections 5.11-5.11.4).

5.9.2 Planning

Although identified for the purposes of explanation as a discrete stage, in reality and consistent with methodology, this phase overlapped with the previous phase where exploration of depot administration was bound up in the same activity. One of the challenges of providing a coherent account of action research is to include the dynamic and iterative processes that participants engage in, which do not always follow the linear

and logical pathway implied here. This is pertinent when considering the planning phase. Actions or intentions to change practice, expressed at the outset of the study, in reality became part of a cyclic process that was adjusted throughout the duration of the research, in response to a range of conditions that influenced any planned change. For example, while participants identified potential actions in the early stages of the study, this was not the only time they engaged in planning activities.

5.9.3 Action

The action phase of an action research inquiry is essentially a period of activity described as intervention phases (Meyer 2006: 282). In terms of logical progression, this phase follows planning and illustrates the interventions in which nurses have engaged. However, like the planning phase, this is a deceptively simple description of events. The action phase is also cyclic as participants engage in a cycle of planning, intervention, reflecting, re-planning and so on. Significantly, reflection is an important component of this phase. When engaging in reflection, participants think about the way the new action has affected them and has impacted on their practice. Adjustments to action may be reviewed at this stage in response to the outcome of the interventions. If the action has been successful, this may also act as a spur to continue with the intervention or to modify it.

The action elements of this study can be considered from a number of perspectives and reflect both individual and collective action. The administration of an intramuscular injection, which was important for development of carers' competence, formed an essential part of this as did the process of clarifying liability cover for carers (see section 5.11.- 5.11.4).

With a focus on research findings and current evidence, participants were encouraged to evaluate the relevance and application of these to their practice.

5.9.4 Evaluation

Evaluation occurs at several identified points throughout the selected actions or at their conclusion. This phase reviewed how interventions had developed, were refined and

implemented since the initial planning phase. In essence, this phase considered the extent to which individuals or groups were successful in implementing change. Furthermore, the evaluation phase also took account of new or previously unplanned actions that had arisen. In order to establish a meaningful evaluation, Jenks (1999: 261) advises that this phase includes reflection on what has been achieved and factors which have facilitated or hindered this achievement. I maintain that this is a significant element of evaluation in my study, as understanding of the conditions that facilitated or hindered carers' involvement in the administration of depot medication, along with strategies used to reduce the impact of barriers to this process, is important.

In my study, a further aspect of evaluation considered the merit of service users', carers' and mental health professionals' involvement in action research inquiry and evaluated their feelings about being involved in the study and the contribution this made, if any, to their practice and professional development.

5.9.5 Closure

Closure of action research is not a discrete phase identified in the literature. However, I suggest that it is a phase of the research that merits consideration. Hart and Bond (1995: 197) refer to closure as ending the study and a process of moving on. However, the very nature of action research with its cyclic phases and continuing potential for action may result in interventions being continued beyond the timeframe of the study. Waterman et al (2001: 39) caution against research that discourages the establishment of an end-point, yet a dilemma can arise when considering the lasting impact of an action research study.

Waterman et al (2001: 39) suggest that studies that have a lasting effect or influence can be categorised as having impact. I contend this may be difficult to determine by a set time on study completion. Nevertheless, I agree that while there may be no definitive end to the way mental health services will collaborate with carers and service users, there was a need to identify a point of participant withdrawal from the study. Martin (2006: 174) also reminds us that the researcher must let go at some point and allow participants to take responsibility for their actions and learning.

5.10 Conclusion to action research

This chapter section so far has discussed the origins and characteristics of action research. AR is participatory in nature, investigates social practices and contributes to practice change. All of these points are salient to this research study as it involves practitioners, carers, patients, local and national organisations in an investigation related to mental health clinical practice. The approaches to AR include collaborative working and critical action research. Critical action research relates to this study as the participants are an oppressed group with a request to transform current mental health practice through their involvement. There are methodological limitations to AR about validity and bias. These are potential generic issues within AR methodology and I will strive to illustrate how they were addressed in this study. The phases of AR are structurally distinct but in reality iterative. Closure within this study originated from the practitioners, families and researcher and will be illustrated in the following sections as will the specific research methods used within the study to collect the data.

5.11 Ethical approval

Since effective healthcare should be based upon research and practice evidence, the Mental Health Trust's Research & Development department sponsored the study application to a Local NHS Research Ethics Committee (LREC).

National and international ethics legislation, guidelines and codes of practice such as the Helsinki Declaration (World Medical Association, 2007; item 1) underpin and structure research practice with human participants. The World Medical Association developed the Declaration of Helsinki as a 'statement of ethical principles to provide guidance to [researchers] and other participants in medical research involving human subjects'. Importantly, considerations 'related to the well-being of the human subject should take precedence over the interests of science and society', and all research involving humans must promote autonomy, beneficence, non-maleficence and justice (Beauchamp and Childress (1989).

Within the NHS, Research Ethics Committees (RECs) are responsible for ensuring all research projects comply with ethical frameworks such as the Helsinki Declaration. Since seeking their opinion and review is mandatory for all NHS-based research, they have a

secondary function in forcing researchers to think clearly and in detail about the ethical dimensions of their research. Researchers can, understandably, be more focused on the practical, logistical and procedural aspects of the study (Toffoli and Rudge 2006) and so the LRECs perform a valuable function.

General discussion with the LREC was unfavourable given that a possible scenario had not been considered within the application. The scenario was as follows:

Nurse A, supportive person B and user C have been recruited to the research project

Nurse A teaches supportive person B to give user C a depot injection

What would happen if carer B has an 'off day' and makes an error or injures client C, and this arose not from a skills or knowledge deficit but rather accidentally or by chance?

The question raised by the LREC was whether user C would be covered by existing NHS liability cover. A satisfactory answer was not available so the LREC outcome was that this would need to be clarified before any favourable opinion could be offered. Clarifying this query led to a two year journey involving the local NHS Trust, the Trust's legal department, the Royal College of Nursing's legal department, the Nursing and Midwifery Council (NMC), the National Health Service Litigation Authority (NHSLA), research supervisors and others.

5.11.1 Clarifying indemnity and liability

Being unable to satisfy the LREC was a major disappointment and setback to the researcher. However, the researcher's perception of the ethics committee's judgement was that it was one of supportive encouragement. The desire to seek clarification was further nurtured by the researcher's knowledge of practice in other health care disciplines where relatives are routinely engaged in the delivery of medications by injections e.g. in child care (Evans 1994), rheumatology care (Arthur et al 1999), palliative care (Lee and Headland 2003) and endocrinology treatment (Bevan et al 2007). Following discussion with practitioners within these groups, it became increasingly clear that the question of liability had not been answered or indeed actively considered. It was implicit that the liability cover of the NHS nurse delivering care and the initial training in injection administration would be extended to the user and carer (supportive person).

The local NHS Trust supported an application to have the issue of medication and liability reviewed by its legal advisers. From a legal perspective, the administration of Prescription Only Medicines (POM), which include all medicines administered parenterally including by depot injection, is governed by the Medicines Act (1968) and secondary legislation under that Act. It is unlawful for any person to administer (other than to him or herself) any POM drug unless he or she is an appropriate practitioner or a person acting in accordance with the directions of an appropriate practitioner. Providing the carer (supportive person) acts in accordance with the directions of an appropriate practitioner (the prescriber) he/she may lawfully administer the medication. In this case it is clear that whilst the carer (supportive person) is legally allowed to administer the depot injection if in accordance with the directions of an appropriate practitioner, it remained unclear whether he/she had liability cover in the event of an 'off day' as described above, and indeed how the concept of acting 'in accordance with the directions of an appropriate practitioner' is operationally defined in practice. For example, does 'acting in accordance' mean contemporaneously in the presence of the practitioner or can the carer act independently following a course of instruction?

From a professional point of view, the Nursing and Midwifery Council (NMC) supports the administration of medication by carers whenever it is appropriate (NMC 2007). The NMC states that if one delegates this responsibility to another person, the delegating nurse must ensure that the carer is competent to carry out the task. This will require the education, training and assessment of the carer and on-going support as and when required. The delegating nurse should periodically assess the competency of the person to whom the task has been delegated. Again, the issue of liability cover appears to remain unconsidered and unanswered.

5.11.2 NHS indemnity: general principles

Indemnity in the NHS is managed through The National Health Service Litigation Authority (NHSLA). It is a special Health Authority and part of the National Health Service; it is not an insurance company. The NHSLA was set up in 1995 to indemnify English NHS bodies against claims for clinical negligence following the disbanding of

Regional Health Authorities. Up to 1995, Crown immunity gave hospitals some protection against claims whilst Regional Health Authorities covered other liabilities. Following reorganisation, RHA's became regional offices of the Department of Health. Individual hospitals were now responsible for liability cover and were not large enough to pay for expensive liability cover and the NHSLA was set up so that hospitals could pool resources. The sole function of the NHSLA in 1995 was to administer the 'Clinical Negligence Scheme for Trusts' (CNST). In general, the CNST covers healthcare professionals involved in NHS-based and approved research such as this project, but does not extend this cover to carers (supportive persons) providing care in the context of the research project.

In 1999, the responsibilities of the NHSLA were expanded to include non-clinical claims under the 'Liabilities to Third Parties Scheme' (LTPS). Most NHS Trusts and Primary Care Trusts (PCT's)⁵ are members of the CNST but some have opted to register their liability in the open insurance market. As a practitioner and researcher it is important to know which type of indemnity applies and to be clear what the liability scheme provides cover for.

The majority of queries referred to the NHSLA (98% -99%) are answered by on-site case managers (NHSLA 2004). However, if the query referred to the NHSLA is more involved or contentious (such queries are generally called high value cases), the case is referred to the Technical Claims Unit (TCU). This unit is commonly referred to as 'the good and learned' (NHSLA 2004a). The TCU team is made up of legal, medical and insurance experts. If a decision cannot be made by this group, the head of this department can then refer the case to the Department of Health. The complexities of the query raised regarding this project were such that it was referred to the TCU.

5.11.3 NHS indemnity: cover for carers

As previously discussed, no cover exists for the carer (supportive person) under the Clinical Negligence Scheme for Trusts (CNST) scheme as the NHS CNST indemnity guidelines refer specifically to care provided by 'members of Healthcare Professions employed by NHS bodies' (NHSLA 2004 b). 'Healthcare Professions' is defined in

⁵ As of April 1st 2013 PCT's have been replaced by Clinical Commissioning Groups.

paragraph 4.2 to include doctors, dentists, nurses, midwives, health visitors, hospital pharmacy practitioners, registered ophthalmic or registered dispensing opticians working in a hospital setting, members of professions supplementary to medicine and dentistry, ambulance personnel, laboratory staff and relevant technicians. A carer (supportive person) in the community would not qualify as a healthcare professional.

An initial response from the NHSLA was that carers were not covered and, as such, the research project would not receive ethical approval, indemnity being a prerequisite (see appendix 3). This was a hugely significant statement with ramifications beyond the immediate research project since it was implicitly stating that carers involved in the administration of medication by injection, and the recipients of this medication, were not covered in the event of an injury. The response spurred more dialogue between the NHSLA and the researcher, and this was assisted by the submission of particular caring scenarios which illustrated points about carers, medication and the recipients of that medication. These scenarios were based on the published literature and information leaflets (see section 2.1). The use of case scenarios was important as the key decision makers in the TCU were from a variety of backgrounds e.g. legal and insurance experts with an emphasis upon abstract risk management rather than everyday concrete clinical practicalities. The assumption of the researcher that the TCU staff knew the inner workings of community care within a mental health setting was an error. Following further deliberation and reflection, it also became clear to all involved parties that the focus on identifying liability cover for the carers within the CNST scheme for the purpose of the research project itself was erroneous and that the LTPS instead needed to be considered.

5.11.4 Carer indemnity – liability to third parties scheme (LTPS)

Consideration was therefore given to the indemnity of carers under the LTPS (Liability to Third Parties Scheme). Under Schedule 3 of this scheme (Public and Products Liability Claim), Item 2 provides “indemnity to other persons” and item 2.1(a) provides indemnity to ‘any relevant person’ (NHSLA 2004b) (see appendix 4 and see appendix 4A for Trust’s legal advice correspondence). The Scheme states that a member, a person employed or engaged by that member shall be taken to include ‘an authorised voluntary worker’ (NHSLA 2004b).

The considered view of the NHSLA was that an agreed carer within the community would fall within the definition of an ‘authorised voluntary worker’ and therefore indemnity would be provided in the LTPS scheme in respect of their legal liability in the event of accidental personal injury which may arise in connection with the relevant function and which occurred during the membership year. Individual trusts must register to belong to the indemnity schemes so it is important for a researcher to check that his/her employing trust is not only a CNST member, but also a current member of the LTPS scheme.

As both a researcher and practitioner it was hugely important to pursue the issue of liability cover for carers within the context of this research project and also within clinical practice in general. However, delays in obtaining ethical approval due to whatever reasons can have serious implications for the progress of any research study given tight logistical and funding timescales. It was very tempting to abandon the entire project but given the time invested and also the previously unconsidered clinical implications, it was felt that indemnity clarification was imperative. Also, it was considered inevitable that other clinicians working in a similar area would eventually encounter the same issues and, additionally, given that public money is involved, it made sense to continue.

Prolonged interaction with an NHS Research Ethics Committee may shorten the time available for data collection, analysis and dissemination. In addition, delay in starting a study means potential participants are lost to recruitment. In the researcher’s experience, the degree of research-mindedness generated within the clinical team has decreased due to the perceived complexity of getting NHS-based research approved and initiated, whilst the culture of risk and litigation within wider society and the NHS itself has increased. Study fatigue can set in for self and others. Interested and supportive managers and key clinical staff may move on during the sometimes long process of approval, resulting in the necessity to renegotiate access to the research sample, access that had been built up through negotiation and the formation of relationships. In this particular project, once a decision had been received from the NHS Litigation Authority, the application process itself to LREC had evolved and changed to an on-line application system. A new application therefore had to be formulated and submitted, necessitating more delay.

When embarking on this research project, a project born out of clinical practice and user need, it was frustrating and challenging to commit much time and resources to a process with a very uncertain outcome. It also illustrated a point about encouraging nurse researchers to follow due process with the NHS ethical approval system. It must be emphasised that NHS RECs do not place unnecessary barriers before research but instead exist to ensure only high-quality research is undertaken within the NHS; research where legal and indemnity responsibilities and provisions are clearly outlined.

The process of learning throughout the research application process itself must also be acknowledged and disseminated, as must the support and encouragement of a Trust research and development team. Personally, the experience has heightened the respect and value placed on NHS REC members and also illustrates the importance of sustainability and completion. A prerequisite for the researcher, therefore, is to have a mindset of time, patience and endurance. The potential for researchers to avoid NHS research - recasting it as clinical audit or potentially circumventing due process altogether- is understandable, but entirely unacceptable.

5.12 Methods

This section will discuss the key sources of data used in the study. The recruitment and suitability of participants will be outlined alongside the study consent process. The baseline assessment tools identified in the LREC application are briefly described with rationale for their use.

5.12.1 Staff interviews

The study completed semi-structured recorded interviews with five members of staff from the mental health teams. Two of these were medical staff who prescribed depot injections and were responsible clinicians for participants who had expressed an interest in the project, two were nurses who had many years of experience of administering depot injections and one was a service manager (nurse background) with responsibility for borough wide mental health services. An invitation to undertake an interview with the GP was unsuccessful. The data were transcribed and analysed by thematic analysis. The

semi-structured schedule was developed through the discussions at two group meetings, from patients and supportive person feedback and from the literature. It was submitted with the ethical application. (A copy of the semi-structured interview schedule is in appendix 5).

5.12.2 Carer groups

Within the mental health trust, staff had been identified, known as carer support workers, who play a key role in working with carers of patients with mental health needs. In liaison with the carer support workers, three carer groups were attended where information about the research project was presented and discussed. The number of carers who attended these meetings varied between six and 12 per meeting with a predominance of older female carers. These meetings were facilitated by a member of staff from mental health services. One group was co-facilitated by a staff member from Rethink, the mental health charity. Data from these meetings were contemporarily recorded and analysed. Further data arose from the carer groups following my departure and these were emailed to me by the family support worker.

5.12.3 Individual staff

Individual discussions took place with thirty members of staff from mental health services and observational notes were recorded by the researcher. There were ad hoc meetings while I waited in the staff room, staff who were administering the depot injection at the depot clinic, staff who attended study days and who inquired about the project and collectively to a wider audience at a Trust nursing conference and clinical governance meeting with multi-agency staff attendance. All of these discussions and feedback were counted as peer feedback. External to the seven case studies I worked with, I gained feedback from supportive persons and patients whilst waiting in depot clinic and during the drop in sessions I held at mental health centres for anyone to discuss the project. Telephone discussions took place with patients and supportive persons as my contact details were on the research study leaflet and disseminated by staff from mental health centres.

5.12.4 Reflective diary

The researcher maintained a reflective log throughout the study.

5.13 Recruitment of study participants

Following ethical approval, active publicity for the study and recruitment of participants commenced in 2006. The first patient and carer dyad were accepted onto the study in 2007 and collection of study data was completed in 2012. All community mental health teams within two of the study boroughs were written to informing them of the research project. Study information leaflets were enclosed alongside a request for me to attend a team meeting. Six team meetings were attended by me for periods varying between 20 and 40 minutes each. The purpose of these meetings was to inform team members of the research project, to engage them as collaborators to the study and to access participant recruitment. The study was additionally promoted through attendance at Trust nursing conferences and targeted senior managers, in addition to attending depot clinics.

No participants could be recruited to the study unless the practitioner collaborators within the mental health teams engaged with the process of recruitment. Opportunities were created within these meetings to challenge the status quo and as such were educative. Information gained from one meeting was used as a topic for discussion at the next. An example of this action research cycle in action was that in the first team meeting, only doctors and nurses were invited on the basis that they were the key practitioners involved in medication management. A social worker queried why they were not invited as they were care co-ordinating a number of clients who may be interested and they, as care co-ordinators were happy to share information about the project.

5.13.1 Referral and assessment of participant's suitability

For this study, it was not possible to involve any research participants other than those with mental illness who are prescribed depot medication. Referrals to the study came through care co-ordinators or expressions of interest from a patient or a supportive person who had heard about the study. Recruitment to the study was slow and challenging and

fewer numbers of participants were recruited than expected. Once an expression of interest was received, a discussion took place with the care co-ordinator or with the senior nurse who co-ordinated the depot clinic. They initiated contact with the patient and family member, made introductions and negotiated further access, either at the patient's home or at the depot clinic. If the patient and supportive person expressed an interest in continuing, then the researcher attended an out-patient or care programme approach meeting (CPA). When all parties agreed to proceed, study consent forms were signed. The consent forms were the standard Trust consent forms for research participation. A two week period was the required period between the review discussions and the signing of consent forms. This was to allow time for reflection, reconsideration and clarification questions if necessary.

Inclusion criteria for the study included the patient having a stable mental state, having family support and being willing to take part. Ascertaining family support was through patient and co-ordinator knowledge or the attendance at CPA reviews of family members. The study was open to patients newly prescribed a depot injection as well as patients with long-standing depot prescriptions. The presence of learning disability was an exclusion criterion.

5.13.2 Consent related to this study

Patients who attended the depot clinic were approached by the researcher following permission by the depot clinic nurse. Information leaflets (see appendix 2) were given to patients, with the offer of supportive discussions, and in total thirty patients were seen through this approach.

Relating consent seeking and capacity to this research study (see chapter 2), participants who expressed an interest in the study underwent tiers of screening. The screening process involved time, family members and health professionals. Patients had been screened by the health professional known to them prior to meeting me. After information about the study was shared with the potential participant, a minimum period of two weeks was a REC requirement before follow up contact or decision making discussion could be held. An interest by the patient at this stage would then be discussed at a Care Programme meeting (CPA). This meeting involved the patient, medical and

family members. One participant was prescribed a depot by her GP who contributed actively to the discussions about consent. A number of patients recommended by the health professional were not invited to join the study because of a combination of capacity and ethical concerns (see case study 5) (see appendix 12 for consent form used with participants).

5.14 Baseline assessment process – use of measuring tools

In preparation for the LREC application, key issues were identified through peers, literature and clinical practice (see section 2.1). Such issues were the participant's quality of life, carer burden, medication knowledge and attitudes and relationship change as a result of the role development. A validated tool was sought to measure these identified concepts. Further details are given for each measure used within the study.

In facilitating the application to the NHS REC contact was made with local and national fora and professional bodies. Locally, the project was presented at the clinical audit forum and clinical governance forum for professional and clinical guidance. These fora were multi-professional – inclusive of medical, pharmacy, nursing, occupational therapy, psychologist, social work and management.

The use of psychiatric measures in research involving clinical practice can be complicated – there are a number of measures available and the key is to match the research question with the participants, the information that could be obtained, the cost of acquiring it and the supervision required during the use of the questionnaires. The measures used within this study were chosen for all of the above reasons following research and professional supervision. The Trust's clinical governance framework supplied and supported the selected measures and cultural factors which might influence the selection were considered.

In order to establish a base line so that any potential changes in the knowledge of medication, attitude, quality of life and relationship changes that might occur as a result of the role could be evaluated, a number of validated tools were used. These validated tools are discussed in the following sections and include; the Quality of Life questionnaire (Lancashire QoL) (Oliver, 1992); Understanding of Medication Questionnaire (McPherson, 1996); Drug Attitude Inventory (DAI) (Hogan et al, 1983).

These tools were completed by both the patient and the supportive person in two case studies both initially and following a period of unsupervised depot administration. The questionnaires were completed by case study 4 initially only as they had to withdraw from the study due to medication side effects. (see section 6.3 for questionnaire data relating to individual case studies). However, the data were not analysed as there was too little information to draw any conclusions.

The Understanding of Medication Questionnaire (UMQ) was modified through consultation with the published author. The rationale for this was to omit a number of questions in the original questionnaire that were related to extra pyramidal side effects (EPSE).

5.14.1 Lancashire Quality of Life Questionnaire (Oliver et al 1997) (see appendix 6)

The Lancashire Quality of Life questionnaire (LQoLQ) is a structured interview for measuring the health and welfare of people with mental health needs. It combines 'objective' factual material related to several of a client's life domains together with a client's self-assessment and a professional assessment based on observation. The interview takes about thirty minutes and is recorded on the interview sheet.

Quality of life has become an important outcome measure in many disorders, including mental health, and there are a number of measures. This particular profile was used in this study following review of the literature, the research question, discussions with supervisors and the clinical governance team. The profile covered such domains as family, work, mental health and physical health, and was completed by both patient and supportive person. The purpose of using the profile within this study was to capture whether or not the elements of home administration and choice would lead to a change in both the patient's and supportive person's quality of life as measured by the LQoLQ.

This profile was completed with both the patient and the supportive person in case studies 2 and 3 before the study and after unsupervised administration. The outcome scores from these completed questionnaires were analysed manually by the researcher.

5.14.2 Drug Attitude Inventory (DAI) (Hogan and Awad 1983) (see appendix 7)

The purpose of the DAI is to gain some understanding of how patients view the use of psychiatric medications and the nature of their experiences on these drugs. The DAI consists of 30 questions related to the patient's current feelings about medication. It is designed as a self report instrument but support can be given if the patient asks or needs it. The DAI assesses the patient's subjective response to medication and encapsulates themes about medication impact and attitude and beliefs about medication. A scoring scale accompanies the DAI with 15 items that are deemed to have a true response and 15 items that are deemed to be false. A correct positive score gets 1 with an incorrect score awarded minus 1. The final score is the sum of the total of plusses and minuses. (see appendix seven).

The questionnaire has good internal consistency and high test/retest reliability has been demonstrated over short term use. Permission from the authors is not required on clinical research projects.

Within this study, this questionnaire was completed by the patient and supportive person in case studies 2 and 3. The score was analysed manually by the researcher and discussed with the patient and supportive person.

5.14.3 Burden Interview (BI) (Zanit and Zanit 1990) (see appendix 8)

The BI was designed to assess the subjective burden of caring for an elderly or disabled person on the basis of a composite of several aspects of the caregiver's reactions to his or her experience. The BI is a self-administered questionnaire with 22 questions related to the impact of the patient's needs on the caregiver. Responses are scored on a Likert scale 0-4. Studies have identified a mean score when this measure has been utilised in the care of patients with dementia and it is for dementia that the measure has been validated. The authors however state that the measure can be used in other caring scenarios and with a wide range of caregivers. The BI is sensitive to change over time so it can be used to assess the outcome of an intervention.

The rationale for using this measure in my study was to highlight the concept of burden as peers and voluntary groups had identified burden as a possible outcome for the person

administering the depot injection. This measure was completed by the supportive person in case studies 2 and 3.

5.14.4 Understanding of Medication Questionnaire (UQM) (McPherson 1996) (see appendix 9)

The original Understanding of Medication questionnaire (UMQ) was designed by McPherson and measures knowledge of antipsychotic treatment. Fourteen stem questions relate to factual knowledge, treatment practice, and treatment rationale, effects of stopping medication, side effects, precautions, tardive dyskinesia and risk/benefit analysis. The 14 stem questions had a possible score of between 0 and 35. The questionnaire includes an assessment as to whether or not the completer requires prompting to elicit a response (score 0-11) and an 'error' response score (score 0-7), for example, when the completer says they are on Piportil medication instead of Depixol.

With the agreement of the author (McPherson), the original UMQ was modified to better suit my study in that this study related to intramuscular injection medication only. Two questions were omitted from the original UMQ in the modified version. Those two questions, Q9 and Q10 had 6 stem questions between them. Q9 related to tardive dyskinesia. Whilst recognising that tardive dyskinesia is a serious side effect of antipsychotic medication, particularly the older typical antipsychotic medications, the study was anticipating clients who are prescribed both typical and atypical antipsychotic medication. Q7 in the modified version asked about the side effects of the medication the client was taking. Q10 from the original UMQ was omitted as it related to the risk benefit analysis of side effects of the medication, which again were covered under Q 6 and Q7.

The modified version has 8 stem questions. The total score from the stem questions range from 0-23, prompt scores range from 0-4 and error scores range from 0-5.

The UMQ was completed with case studies 2 and 3, with the patient and supportive person, both as a base line assessment and on completion of unsupervised administration of depot medication. The rationale for using the UMQ within this study was to provide baseline knowledge about antipsychotic medication, implement the project, which entails an educative component and then measure change in knowledge scores.

5.14.5 Relationship changes – semi-structured relationship interview (see appendix 10)

In the preliminary discussions with staff and patients in preparation of the study a concern expressed by all parties was about the potential for a change in the relationship between the patient and the supportive person who was administering the depot injection. From the feedback given a list of behaviours and attitudes were formulated into a semi-structured interview schedule and this was submitted with the application for ethical approval. The key areas covered in the semi-structured interview schedule were around whether knowledge and skills gained as a consequence of taking on the role of administration had influenced attitudes towards each other; time spent together; behavioural changes towards each other; feelings of control and power and emotional aspects of administration to a person who was a member of the family. This interview was completed with both patient and supportive person in case studies 2 and 3. The potential for relationship change was discussed with other participants and potential participants as an information sharing and consent seeking process.

5.14.6 Mental health professionals – semi-structured interview schedule (see appendix 5)

Following ethical approval of the study, it became clear that more formal interviews with mental health professionals would be necessary in the pursuit of data. This required an amendment submission to the ethics committee which was approved in June 2007. Key headings and sub-headings covered in the semi-structured interview schedule evolved from two meetings of mental health professionals, supervision and service user consultation. The mental health professionals meetings were convened opportunistically as part of structured meetings which took place within local services and at the university. Service user consultation took place when I attended depot clinics and the service user group who contribute to lecturing at the university. Broad headings covered within the semi-structured interview were: staff attitudes towards having a supportive person rather than a nurse administer the depot injection; how to assess the suitability of potential participants; trust; concordance; professional territory and relationship impacts.

5.15 Case study

Within this study, seven case studies were utilised as the structure through which the intervention was initiated, observed and analysed. The intention behind the method is to make theoretical rather than empirical generalisations (Yin 2003). The selection of each case is therefore crucial and should be based on an explicit and defensible rationale: For this study convenience sampling was used (Denscombe 2003) (see section 5.13). This raises questions about the participants that are willing to subject themselves to the intense scrutiny that case study methods demand. Within this study, participants were a mixture of service- led referrals with discharge as the desired outcome, and service- user led participants, who expressed dissatisfaction with current service delivery and were seeking an alternative to fit in with their employment and holiday aspirations.

Case study methods may be empowering for participants because they value their experiences and reveal how their work contributes to service development within organizations (Payne et al 2007). They can therefore be both affirming and challenging, as they may expose both conflicts and tensions.

The limitations of case study methods mainly focus on the representativeness of ‘cases’ and how they are selected, and mean that claims for generalisability are largely restricted to similar organizations and locations. However, the purpose of this method is not to be representative of the wider population or world but to represent the unique case (Stake 1998; Denscombe 2003) and in some instances to develop a typology of services (Rolls and Payne 2003a). Another possible limitation is the ‘Hawthorne effect’. The intensive engagement of the research team with one case means that such close scrutiny may change behaviour away from normal patterns and lead participants to present a ‘good face’ to the researchers.

An overview of the seven case studies, questionnaires completed and how data was analysed is presented in figure 5.3 on the next page.

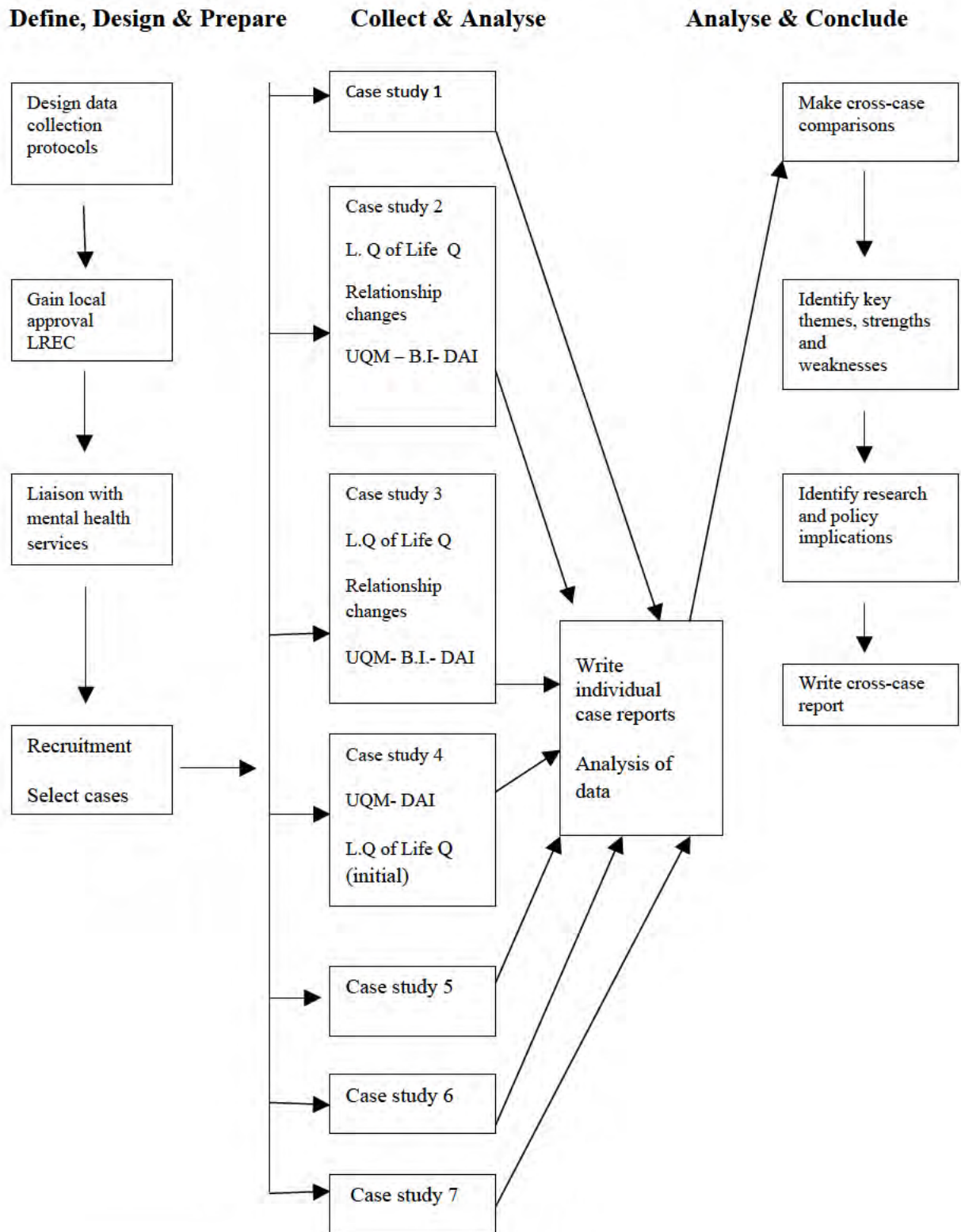


Figure 5.3 An overview of the data from the seven case studies

5.16 Training package

One of the study aims was to develop a training package that would assist any supportive person and patient taking on the role of administering an intramuscular depot injection in the future. From the beginning of this study, a checklist of important issues was developed and evolved through participant feedback and evaluation (see appendix 11 for complete training package). This training package evolved through an action research cycle (see section 6.2 for individualised case study session content) and includes headings under rationale, background information, communication, care planning, knowledge and skills, health and safety, support structures and children. Integral to the training package is confidentiality, disclosure and partnership working. Future developments would be to design teaching and training modules on each of the headings stated so interested persons could undertake modular training.

Participants within this study commented on published literature related to intramuscular injection giving and its usefulness to them in supporting their learning. Participants differed on what they found informative and understandable so future users could ascertain literature that is current and informative for them. One key reference on IM injection giving, the Royal Marsden Manual of Clinical Nursing procedures, was found to be useful and consequently is identified in the training package. A summary of the training package was given to participants on completion of the research study.

5.17 Conclusion

In this chapter I have discussed the context and setting where the study took place and the process of participant recruitment. The participants were recruited from two London boroughs and within a climate of service reorganisation.

Within this study I used a combination of philosophical assumptions such as critical social theory, pragmatism and interpretivism. All research has philosophical assumptions that guide inquiry and these operate at a broad abstract level. Critical social theory is based on the premise that certain groups in society are in a subordinated position and is relevant to this study as mental health service users are perceived to be a subordinated group. Pragmatism calls for a theory to be designed and tested in practice and its main aim is for knowledge to arise out of actions, situations and consequences; an

interpretative paradigm emphasises understanding the ‘meaning’ individuals place on their actions. Within academic research it is acceptable to use multiple paradigms in order to meet the demands and complexity of nursing and client-centred knowledge. This study was designed to gain a deeper understanding of an aspect of clinical practice and an action research approach was used.

Action research is understood to be a variety of research approaches whose principal aim is to improve a practical situation where a problem solving approach is used within recursive action cycles. Action research consists of a ‘family of approaches’ that have different orientations, yet reflect the characteristics which seek to ‘involve, empower and improve’ aspects of participants’ social world. This study used a combination of empirical-analytic, collaborative and critical action research approaches (see sections 5.5.1-5.5.3).

The study gained ethical approval following a two year journey through LREC. This LREC journey is discussed at length within the chapter as it raised important issues related to liability cover within NHS insurance schemes for carers. The value of the ethical process was recognised and worked with to solve the liability issue. The query was referred to the Technical Claims Unit (TCU) (see section 5.11-5.11.4). The initial response from the TCU was disappointing but more importantly hugely significant as many carers are involved in care delivery within the NHS. This illustrated how practice evolves through a practice development process rather than solely an ethical one. The process of problem solving this issue was in itself empowering for the researcher and sponsoring Trust.

The sources of data generated within this study include: data from depot clinic observations; narrative data from professionals, patients and carers; semi structured interviews with health professionals; data from carer group meetings, case studies and a reflective diary. Validated research tools such as the Quality of Life Questionnaire, Burden Interview, Drugs Attitude Inventory and Understanding Medication Questionnaire were planned to be completed within the study though insufficient data was captured. Case studies were utilised as the structure through which the intervention was initiated, observed and analysed.

In the next chapter the focus is on thematic analysis, a précis of the seven case studies and the study findings.

Chapter 6

Findings

6.0 Introduction

Within this chapter the study findings and the process by which the study data were analysed will be discussed. The chapter will outline how the codes and themes were developed using the Braun and Clarke approach to thematic analysis. A précis of the seven case studies (five of which involved the administration of depot injection) will be outlined. The data from the differing study items were analysed individually and presented as cross theme findings. Data extracts are identified by their source in support of an audit trail of evidence. The aims of the research study are restated and links are made to the research aims throughout the findings chapter. Themes associated with the research aims such as risk, the development of knowledge and skills, relationship impact and the views of practitioners (inclusive of the role of the mental health nurse) will be discussed. Other themes evolved out of the study data related to the research aims whose importance to the study became evident because of their numerical presence and dominance in project discussions such as trust, stigma, concealment and disclosure, and these are also discussed. Published literature related to themes as discussed in the thesis will be linked to the study findings.

The aims of the research study were:

- to explore the elements of risk management involved in enabling carers (supportive persons) to give depot injections
- to develop a training package that may be useful for others to use should such a request be made
- to establish whether enabling supportive persons to give depot injections would have an effect on the relationship between the user (recipient of the medication) and the supportive person (giver of medication)
- to ascertain the views, concerns and attitudes of medical staff (prescribers) and mental health nurses (administrators of depot injections) about enabling carers/relatives (supportive persons) to give depot intramuscular injection medication.

6.1 Analysis of data

6.1.1 Thematic analysis (TA)

The data corpus generated within this study was analysed using thematic analysis or TA as it will now be referred to. Throughout this section the published work of Braun and Clarke (2006; 2012) on thematic analysis will be the key reference. TA will be defined and important considerations required of the researcher such as style of analysis and epistemological approach will be discussed. The development of thematic analytic skills, the difference between inductive and deductive analysis and the process by which the data were analysed will be outlined.

6.1.2 Definition and process of TA

Thematic analysis (TA) is a method for systematically identifying, organising and offering insight into patterns of meaning (themes) across a dataset (Braun and Clarke 2006). TA is becoming widely recognised as a unique and valuable method in its own right (Joffe 2012) alongside other established approaches like grounded theory, narrative analysis and discourse analysis. Engaging with TA provides the qualitative researcher with a foundation in the basic skills of qualitative data analysis.

The focus of TA is not about identifying unique and idiosyncratic meanings and experiences found only in a single data item, though they are important and relevant to the study – it is about identifying what is common to the way a topic is talked or written about and making sense of these commonalities. Meanings and experiences identified within the data corpus which are common are not necessarily in and of themselves meaningful and important (Braun and Clarke 2012). The patterns identified by the researcher need to be important in relation to the topic being explored and the research question. Within this research study, important topics include: mental health; role change; criteria for accepting who could take on the role; the teaching of skills; change in practice; liability; risk and uncertainty. The views and experiences of participants in this study are important; namely those of the patient, supportive person, mental health professional, service provider and researcher. Unique and idiosyncratic experiences within this study were noted, linked to individual case studies and extracts used when contributing to a discussion. An example within this study was the smoking of cannabis

by one of the participants and this became relevant during an educational session (see section 6.7.8).

In using TA a number of decisions need to be identified and considered by the researcher and made explicit. Such decisions relate to defining a theme and the approach to analysis. The approach to analysis relates to whether a complete data analysis or one particular aspect of the data is analysed, whether an inductive or theoretical thematic analysis is required, whether a semantic or latent focused analysis is aimed for (see section 6.1.4) and the epistemological position of the researcher. Within the semantic approach to TA, themes are identified within the surface meanings of the data. This is about what the participant has said and what has been written. In contrast, thematic analysis at the latent or interpretative level goes beyond the semantic content of the data. All of these important decisions relating to this study are clarified in the following paragraphs and sections.

Themes or patterns within data can be identified in two primary ways within TA, namely in an inductive or bottom up way (Frith and Gleeson 2004) or in a theoretical or deductive or top down way (Boyatzis 1998). An inductive approach means that the codes and themes identified derive from the content of the data themselves. Inductive analysis is a process of coding the data without trying to fit it into a pre-existing coding frame or the researcher's analytic preconceptions. In this approach, there may be little relation to the questions asked by the researcher within an interview process. In contrast, coding in the deductive approach is driven by the researcher's theoretical or analytic interest in the area. The researcher brings to the data a series of concepts, ideas or topics that are then used to code and interpret the data. Braun and Clarke (2012) suggest that the coding and analysis of data will often use a combination of both inductive and deductive approaches. It is not easy to be purely inductive as researchers are always bringing something to the data when they analyse it. Conversely, they rarely ignore the data when they code for a particular theoretical construct.

Another decision the researcher needs to consider when working with TA is the epistemological paradigm as this guides what can be said about the data (Braun and Clarke 2006). Semantic analysis links to the realist/essentialist paradigm where motivations, experiences and meaning are theorised in a straightforward way because of an assumed unidirectional relationship between meaning, language and experience (see

chapter five on methodology and section 6.1.4 on semantic analysis). Realism is a doctrine that suggests certain objects and theories in science are real and essentialism is the view that for any specific entity, for example a concept or group of people, there are a set of attributes which are necessary to its identity and function (Jones-Devitt and Smith 2007). Within this study, the diagnoses of psychosis and schizophrenia were taken as real with attributes that define the diagnoses such as symptoms of illness which were important within the study. These symptoms were treated by medication and this was not questioned within the study. In summary, this study analysed the entire data set identifying themes primarily inductively at a semantic level of analysis within a realist/essentialist epistemological paradigm.

A theme captures something important about the data in relation to the research question and represents a meaning within the data set. Braun and Clarke (2006) suggest that researcher judgement is necessary to determine what a theme is and the number of instances of a theme within the data does not, in itself, make the theme more crucial. The data analysis within this study is a rich description of the entire data set and not a detailed account of one particular aspect of the study. Giving a rich description of the entire data is particularly useful when investigating an under-researched area and working with participants whose views on the topic are not known (Braun and Clarke 2006). This is particularly relevant to this study as it was an investigation into an area with no published literature and accounts for evolving themes from the data that were not explicitly stated in the research question. Examples include trust, stigma, disclosure and concealment.

The reason TA was used in this study is because it is flexible and accessible and offers a way into data analysis that teaches the mechanics of coding and analysing qualitative data systematically. TA as a method of data analysis contributes to making the results of qualitative research more available to a wider audience and has potential for use within action research projects (Fine et al 2002). TA, rather than being an approach to conducting qualitative research, is an approach to data analysis and Braun and Clarke (2006; 2012) suggest a six phase recursive process;

- Familiarise yourself with the data and identify items of potential interest
- Generate initial codes
- Search for themes
- Review potential themes

- Define and name themes
- Produce a report

The data corpus for this study includes participant case studies, practitioner interviews, carer meetings, observational field notes, reflective diary and measurement tools. Practitioner interviews were audio-recorded and transcribed by the researcher. Each individual piece of data collected will be referred as a data item. Data from case studies were analysed individually. These case studies were uniquely different in that the participant's experience of mental illness, their rationale for becoming a participant and the relationship between patient and supportive person were different. The amount of education and support was also different. For example, two of the supportive persons were registered health professionals at one stage and consequently had skills of injection giving. Cross comparison was then completed between the case studies where common themes were identified (see figure 5.3). Data from the health professional interviews were analysed and cross comparison completed as were data from the carer groups and observational data (see appendix 13 for summary of practitioner codes and themes).

In the theme development, all data sets were recognised with itemised data extracts given as both audit trails and as evidence of their unique position within one of the data bodies. A data extract refers to an individual coded chunk of data which has been extracted from the data item. Where common themes emerged between all the sources of data, then data from all sources were used in the discussion of this theme; for example, when discussing trust, all types of data are used and recognised to enrich the discussions. Unique contributions offered by the supportive person or patient or professional are recognised and an audit trail provided.

There are a number of computer-assisted qualitative data analysis software programmes available e.g. NVivo. Whilst there are pros and cons to the use of computer programmes, computer-assisted software was not used in the analysis of data within this study. The rationale for this was one of personal preference. Personal competency and knowledge of the computer programmes when the study commenced would have necessitated training and with the size of the data set, the investment of time would be disproportionate to the benefits.

6.1.3 Generating and managing codes

Codes within TA identify a feature of the data which is interesting to the analyst and refer to the most basic segment or element of the raw data or information that can be assessed in a meaningful way regarding the phenomenon (Braun and Clarke 2006). A code is a pithy label that captures what is interesting about the data (See table 6.1 for examples within this study). Within this study, coding was completed on the transcripts, within a margin on the transcribed page and the relevant data highlighted. The data was tagged so that the source could be identified by the researcher (See example on pages 159 and 170).

Overall, within this study there was a preference for the inductive based approach as the orientation was to prioritise participant or data based meaning. In the data analysis process two peer review structures were utilised – one a service user academic and one a lay person with a background in education who independently reviewed anonymised case study data to check for theme correlation. Discussions with study participants took place throughout the study period.

Learning the mechanics of coding and analysing the data within the TA framework were aided by attending a series of research seminars on data analysis and two one day workshops on TA facilitated by Braun and Clarke (2006 and 2012) where samples of the data were identified, discussed, coded and themes developed. The work was peer reviewed.

The study findings are discussed in section 6.3. The itemised data extracts given as examples to link themes to participants' data are generally short – 1 to 3 lines. The rationale for this is based on a number of reasons; working within a realist/essentialist paradigm (see section 6.1.2), the newness of the topic, participants' understanding of the process at that period in time, the home context in which the teaching and administration of the injection took place, time limitations within the home and the researcher importing previous role and knowledge experiences into the process which may have inhibited some opportunities to explore participant statements further.

6.1.4 Theme identification and development

Searching for themes is an active process. Braun and Clarke (2006; 2012) suggest that if a code is big or important, then it can be a theme. Examples within this study where codes were deemed important and developed into themes were trust, stigma, disclosure and concealment.

One specific approach to theme development from initial coding with TA is that of counting the prevalence of a code within the data corpus. Braun and Clarke (2012) suggest that counting is not the most important criterion for determining themes, researcher judgement and study aims are also important. Counting was used when more concrete practice was undertaken (see appendix 13 for summary of practitioner codes). For example, within this study, participants not wanting to speak of their mental health diagnosis within the home or inform their employer of the diagnosis were counted under a concealment theme. Researcher judgement is necessary to determine what a theme is and this judgement can be corroborated through peer review and with participants. Another aspect of theme development is the level at which the theme is identified within the data, namely at a semantic or explicit level or at a latent or interpretative level (Boyatzis 1998) (see section 6.1.2)

Within this study, I primarily focused on the semantic or explicit level of the data for theme development. An example is provided from case study 2;

R states he could not inform his work manager due to stigma. It is a macho environment. They would laugh/joke about being 'mental', negative language 'nutter' wind up. It would be easier to quit and claim benefits.

Codes identified from this piece of data are stigma management, fear, choice making and concealment. If a latent and interpretative TA approach was taken with this data, the theory of self-esteem may be relevant but was not used in this study. Fear as a code is not developed as a theme as it is inherent in the discussion about stigma and concealment (see sections 2.6 - 2.6.3 and 2.7 - 2.8.1 respectively). The study originated from a choice related request and choice is discussed under personalisation and recovery (see sections 3.4 and 3.5 respectively).

Further examples of theme and code development are given in table 6.1 related to disclosure and concealment.

Table 6.1 Theme developments from case study 2- examples of data categorised under themes; disclosure and concealment

Disclosure

Since the family crisis⁶ last Christmas other people outside the family now know about R and schizophrenia- R's mum, my mum, two friends, cousins that R was brought up with. This is a huge change (**RW⁷ page 12 verbatim data**)

R⁸ told his mum early on this year. R's mum used to use the word 'schizo' around the house to refer to the dog. R's mum used to ask, what is wrong with you R- schizophrenia? But you are 'normal' she always replied. R's mum expects everyone with a mental illness to have a banner around his/her neck with 'mental' on it. (**RW verbatim page 12, dated 3/12**)

R informed the two eldest children of his illness and need for injection. Discussed the smoking of cannabis and how this contributed to his illness. R reports feeling good about informing his children. Used booklets to support (**page 24, 2/10- summarised data**)

Concealment

RW reports the rationale she gave to the children for my visits is that I am teaching how to give an injection as part of her job. (page 9, 26/7- summarised data)

I could not inform my work manager due to stigma. It is a macho environment. They would laugh/joke about being 'mental', negative language 'nutter' wind up. (**page 1, 19/7 verbatim**)

Before we get the injection ready can you pull the window curtains (**RW verbatim page 12, 4/09**)

No dosage or name of medication on card (**Researcher's notes page 12, 4/09**)

FD20⁹- schizophrenia, psychosis on letter received from health centre- what do they mean? (**R's query about a letter from mental health team with diagnostic code, page 20, 29/3/11 verbatim**)

Children might see the calendar? (putting reminders when depot is due) (**page 12, 5/4 summarised notes**)

I do need to have more knowledge about the whole thing. Medically, before you came along it was his secret. I did know he was having an injection monthly. I only know what he tells me and I read the handout the doctor gave us (**RW verbatim page 30, 6/12**)

⁶ Crisis described by supportive person following awareness of cannabis smoking.

⁷ RW is participant's wife.

⁸ Participant in receipt of depot injection.

⁹ FD20 is a code taken from the ICD 10 and used in letters to note patient's diagnosis.

6.2 Case studies

Case study 1

O is a client who lives in a South London Borough with her husband and son. O has a diagnosis of schizophrenia and has been in receipt of a depot injection three weekly for 14 years. The onset of the illness occurred after the birth of her only son 14 years ago. She attends the local depot clinic for her injection which is held within her GP surgery building. They are both in the 40s and have lived in the area for many years. Mr O works full time as an engineer. Mrs O works part time as an office cleaner. They had no previous experience of administering intramuscular injections and O did not have a care co-ordinator from local mental health services.

O heard about the research project from a CPN through her attendance at the GP surgery for her depot injection. Her interest in having an alternative option to the GP clinic was the gaining of part time employment nine months previously, and the fact that she usually worked on the set morning of the clinic, which was a Wednesday. In December 2006, shortly after the study received ethical approval from LREC, a brief introductory session took place with O. Two months elapsed from initial discussion with O to a more exploratory information-giving session. Within this time gap, O had discussed the project with her GP, who was very supportive, and her husband. At the initial meeting, it was agreed that O would make contact with me by telephone if she felt interested in pursuing the project.

Shortly after this meeting, the family members signed the consent form and agreed to take part in the project up to the administration of one depot injection under supervision. Alongside the project, the family were planning to relocate near O's sister, who lived outside the Borough.

O and her husband had four training sessions, of one hour duration on a weekly basis before supervised depot administration was undertaken. The training sessions were a combination of skills and education and were based on the Royal Marsden's Clinical Nursing textbook (Dougherty and Lister 2006) guidance on the administration of intramuscular injections. A video on IM injection giving was watched and discussed as part of session 2. The video was borrowed from the fertility clinic of a local hospital that uses the video to teach partners IM injection skills.

O and her husband did not wish to complete the questionnaires outlined within the project, for example, on quality of life, burden and medication knowledge. They felt they did not have time and relocated away from London in the summer of 2007.

The overall time frame the participants were with the study was 17 weeks from introduction to depot administration. From the client picking up the research information leaflet to making contact with the researcher was two months. Two meetings were held over the next month to discuss the project and agree consent. This was followed by four teaching sessions of one hour each followed by supervised depot administration (see appendix 16a for summary of timeframe, contacts and content).

Case study 2

R is married, lives with his wife and four children and for the past 15 years has a diagnosis of schizophrenia. He acquired full time employment three years before this research study commenced and wanted an option to receive his depot injection at a place and time that would be convenient for him. Since gaining employment, R did not have a care co-ordinator from the mental health services and attended outpatient appointments with the psychiatrist. Within this case study, R's wife is his supportive person and the administrator of his depot injection.

I met R for the first time when he attended the depot clinic for his monthly injection in May 2008. R had heard about the research project from B (depot clinic co-ordinator). He had given R an information leaflet on the project, and had gained R's consent for me to contact him to discuss further details. R and his wife completed the Quality of Life questionnaire (Lancashire QoL) (Oliver, 1992), Understanding of Medication Questionnaire (McPherson, 1996); Drug Attitude Inventory (DAI) Hogan et al, 1983) and a semi-structured relationship interview. His wife completed the burden questionnaire.

The process by which R moved from beginner to unsupervised IM injection giving was: three practice and educational sessions on intramuscular administration and depot preparation with the support of a manikin borrowed from the researcher's university skills laboratory; two supervised depot administrations with educational support, feedback and evaluation; one practice session; two supervised depot injection administrations followed by two practice sessions. The medication (single dose) and

equipment for the supervised administrations were collected by the researcher and delivered to the home. The sessions were held weekly, of about one hour duration, at the family home during the daytime, evening or weekend depending on family availability and occurred over a period of five months (see section 6.5 for knowledge and skills development). R, the recipient of the depot injection attended one of these sessions. During this period of time, if the depot was not being administered under supervision, R attended the depot clinic for his medication.

The Royal Marsden Manual (Dougherty and Lister 2008) guidance on the administration of intramuscular injections was the procedural guide used and medication specific information was acquired from the Trust's pharmacist. Diagrams of the upper outer quadrant were acquired from the internet and additional reading material (Hunter 2008) was given as homework. Hunter's article was identified by another research dyad as being readable and understandable to the lay person. R was able to assist his wife in site selection through his experience of having IM injections over the years.

Once unsupervised depot administration commenced in May 2009, two sessions on relapse prevention took place with both husband and wife using the work of Barker et al (unpublished) on early warning signs. Refresher sessions took place on both injection techniques and early warning signs as and when the participants requested and if competency issues were observed by the researcher. Medication access by the patient went from a single dose to three doses being collected by the patient from the local mental health centre. A plan for accessing health services for equipment and disposal of used equipment evolved in consultation with the mental health team. Voluntary groups who offer support and education to parents on how to teach children about mental illness were important for this dyad.

R and his wife completed six supervised depot administrations before completing depot administration unsupervised. Detailed review followed each three depot administrations. Following this period, a reassessment of competency took place after every six depot administrations. The competency framework was based on the Royal Marsden's textbook IM technique procedure and supported by guidance from the practice document used by nursing students at the researcher's university.

The data from the questionnaires completed by R and his wife were not fully analysed since there were too few responses to provide even indicative findings. However, overall,

from the questionnaire data R reported a lower quality of life in 2011 than in 2008 and this he suggests is down to lack of finance and employment contentment. He accepted full time employment from the position he was in at the time, a patient with mental health issues with work as his goal. In 2011, R reported that work was no longer his goal, but employment in an area of interest and with the potential to earn more money. His wife reported through the burden questionnaire moderate stress in finding time to administer the depot injection within a busy home life and through the UMQ, considerable knowledge gain about her husband's mental illness and the medication he was taking.

In 2011, R spoke at a Recovery conference about the study and how it enabled him to develop knowledge and confidence about working and managing his illness and about having choice in when to have his injection.

R's wife continues to administer his depot injection and acquires the medication and equipment from the GP. The couple state that confidence in their GP significantly changed for the better following a mental health crisis through which they felt well supported. R has been discharged from mental health service care at their request and is GP managed. In July 2013 he gained new employment, with the potential to earn more money, through his own efforts and this process and experience has significantly improved his self-esteem (see appendix 16b for summary of timeframe, contacts and content).

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Case study 3

D is a gentleman with a diagnosis of schizophrenia for 18 years and had been made aware of the research study by the depot clinic co-ordinator who had given him a research information leaflet three weeks previously during his last attendance. D expressed an interest in having his mother administer his injection. His mother had in the past worked as a health professional and within this role had administered intramuscular injections, though not viscous depot injections. They live independently about one mile apart. Within this case study, D's mother is the supportive person who administers the depot injection and first contact was made in November 2007.

D had a care co-ordinator who was a community mental health nurse. He was supportive of the research study and held a meeting with D and his mother without my presence to

discuss the research project. The research study was discussed and agreed at a CPA meeting in January 2008. During February 2008 D's mother undertook one educational session about medication based on the Trust's information leaflet on D's prescribed medication and one IM practice assessment session. Following this, the supportive person undertook two supervised depot administration sessions before unsupervised administration took place. Relapse prevention education was discussed within CPA reviews and undertaken by the care co-ordinator. D and his mother additionally contributed to the study by reviewing published literature on intramuscular injections, made comments about content readability and relatedness which were developed within an action research cycle with other participants (see section 6.5).

D and his mother completed the Quality of Life questionnaire (Lancashire QoL) (Oliver, 1992), Understanding of Medication Questionnaire (McPherson, 1996) and Drug Attitude Inventory (DAI) (Hogan et al, 1983) at the study entry in 2008 and again in 2011. They also completed the semi-structured relationship interview.

A significant difference in the UMQ completed by D in 2011 is that he wrote in the word 'schizophrenia' himself. In 2007 he wrote 'no name'. Throughout this case study, D or D's mother did not use the word or diagnosis of schizophrenia at home or at CPA reviews.

D's mother continues to administer D's injection and they have an allocated care co-ordinator from the mental health services (see appendix 16c for summary of timeframe, contacts and content).

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Case study 4

A is in a professional carer partnership, an arrangement that had been in place for six years. The carer is a lay person with whom A spends most of her time. This client has a diagnosis of psychosis and a care co-ordinator who was a CPN. A utilised a combined approach to receiving her depot injection. She attended the local mental health centre depot clinic mostly but periodically would request a home administered depot injection by the CPN. Client A received information about the research project from her care co-ordinator and first contact was in April 2007. Client A's primary reason for considering the research project was to facilitate a holiday abroad which she and the carer were

planning with a longer term view of more frequent holidays and for longer periods. A was prescribed a depot medication which necessitated two weekly administrations, which they felt restricted their holiday period.

An analysis of meetings completed during this case study shows that overall 12 individual appointments/contacts were completed. Of these six appointments were with the client and her carer at their home. The remaining six appointments/contacts involved meetings and liaison with the responsible mental health team, nurse advisor and Trust pharmacist. Separate meetings with the nurse advisor and Trust pharmacist were to discuss the management of Risperadol medication, which A was prescribed. This is a newer type of medication which is dispensed with its own needle and syringe.

The client and her professional carer completed the initial Quality of Life questionnaire (Lancashire QoL) (Oliver, 1992), Understanding of Medication Questionnaire (McPherson, 1996) and Drug Attitude Inventory (DAI) (Hogan et al, 1983). During my time with both client and carer I was concerned about significant side effects from the medication. In consultation with the client and carer I initiated a CPA review meeting in October 2007 following which the intramuscular injection was stopped by the responsible team. A message on my voice mail a few days later from the client's responsible clinician apologising for having to change the medication from IM to oral, acknowledged the appropriateness of my reporting the observed side effects, was supportive of the research study aims and overall enhanced our collaborative working relationship. I had no further meetings with the client and carer, and hence, no follow up questionnaires were completed (see appendix 16d for summary of timeframe, contacts and content).

Case study 5

This client H lived on her own as her husband had died three years previously and her grown up children lived many miles away. She had worked for many years but had taken retirement since having a minor stroke two years previously. H was in receipt of a depot injection three weekly for many years, usually at the depot clinic, for the treatment of a psychotic illness. She did not have a care co-ordinator from the mental health team. For this case study, two meetings were held; one with the responsible mental health team and

one with the patient and a community mental health nurse from the local team in December 2008.

H had a partner who visited and stayed with her for a few days every two weeks. During the meeting with H it transpired that the partner had alcohol misuse issues and spent time with H when money was scarce. From the meeting with H, my assessment was that she hoped by having the injection from the partner, he would spend more time with her. Following the stroke, H used a walking stick to support her. The mobility impact of the stroke made it more challenging to get on the bus to attend the depot clinic. This mobility challenge was behind her request for home administration of her depot. For H, home administration referred to the depot clinic CPN administering the depot injection at her home.

Ethically, I felt H was vulnerable and her rationale for wanting the partner involved in depot administration potentially could compromise her dignity and emotional wellbeing. H was hoping to involve her partner in the administration of her depot injection and this would result in him spending more time with her. I did not progress the research with H and have reflected on this. A joint discussion between H and her partner would have been helpful to clarify how he felt about the project and this would have been more in line with empowering philosophy (see chapter 4) where the process as well as the outcome is important (see appendix 16e for summary of timeframe, contacts and content).

Case study 6

This husband and wife team (L) requested more information about this research study following information from her care co-ordinator in December 2007. L is a client with a diagnosis of schizophrenia and her husband was the supportive person in this case study. L is prescribed, for the past eleven years, a regular depot injection as part of a treatment plan. L and her husband have been married for thirty years; their children live away from home but visit the family home with their grandchildren. L and her husband have pets, a cat and a dog which are very much included within the home. L took retirement from full time employment. The key rationale for L's interest in the project was her concerns about current service reliability and in particular, meeting regular faces within the mental health team. 'If the project is not for us at this moment, we can learn and assist others to benefit

from this project' (quote from L). They assisted the research study by a two hour in-depth discussion which was assisted by the presence of the simulation buttocks (manikin) and injection equipment.

This husband and wife team agreed the project 'was a novel idea' for them. They required more information about the project and their concerns and for this reason engaged in a role play session so they could develop a deeper understanding of the project. Issues raised within the meetings led L and her husband not to engage in the project at this time. Their view was that it would have been ideal when L was in full time employment and when accessing the depot clinic was not easy within clinic opening hours (see appendix 16f for summary of timeframe, contacts and content).

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Case study 7

This husband (M) and wife team took up the home administration of depot medication before this study received ethical clearance. The husband has a diagnosis of schizophrenia; his wife was a practising registered nurse and is the supportive person in this case study. The family have three children. They commenced home administration in full consultation with the patient's psychiatrist and care co-ordinator primarily for employment purposes. The mental health team felt that because M's wife was a registered adult nurse and the participants engaged with the mental health team, they were allowed to administer the depot injection. M is considered by the mental health team as an educated patient.

When M first raised home administration by his wife, the CPN and psychiatrist at the time requested his wife administer two depot injections under supervision from the CPN in order to assess the requisite knowledge and skills. These two sessions involved education with leaflets provided by the Trust pharmacist about the prescribed medication and side effects. The patient's CPN was active in supporting the patient's choice and when ethical approval was gained, M and his wife together with the allocated CPN contributed to the study data. An initial in-depth interview took place in the family home with husband, wife and children present. This was followed by six monthly contacts.

This family were committed to the project and problem solved at every stage when challenges arose. M had two admissions to hospital during the period his wife

administered his injection. One of these hospital admissions was under a section of the mental health act. M and his wife developed confidence in collaborative working with local services, joint care planning, and medication supply and support structures which worked for them. Whilst M accepted his depot injection willingly on most occasions, there were episodes when he would initially refuse to have the injection. Following an admission to hospital, a key feature of the care plan was a strategy to manage M's reluctance or refusal to accept the depot injection from his wife. The agreed plan was that his wife would ask on two further occasions over the proceeding seven days and if M continued to refuse his injection, the process of administration was returned to the CPN. Later, as the care plan evolved, an additional strategy was built in on the occasions M refused his injection and this was seeking the support of their religious minister, whom they both trusted, and who would ask M on one occasion to have his injection. Detailed patient relapse indicators were identified in the care plan, the actions to take if observed and this plan evolved over time.

M's employment schedule was the catalyst for exploring the option to have his wife administer the depot and he discussed it with the mental health team at one of his out-patient appointments. Lack of access to mental health services, who were willing to administer the depot on an evening or weekend, was the reason the question came up in the first instance between the husband and wife.

No assessment questionnaires were completed. M has now retired from full time employment and has reverted back to receiving his depot injection at the local depot clinic. His experience and knowledge gained is promoted through his membership of local service user groups and he is a vocal contributor to Trust community meetings (see appendix 16g for summary of timeframe, contacts and content).

6.3 Findings

The study findings are discussed in the next section. The findings relate to the research aims in relationship to risk, developing a training package (knowledge and skills development), relationship impact and practitioner's views and concerns. In addition, other themes evolved through the data as being relevant namely, trust, stigma, disclosure and concealment. Stigma, disclosure and concealment are discussed under one heading.

Discussions are presented under main theme headings and related sub headings, some of which include; home care, employment, therapy and service provision. Consequently there may be some brief overlap between the themes as the context of the theme is restated. The discussion includes data extracts with links to literature and other relevant sections of the thesis.

6.4 Risk

As discussed in sections 2.2 – 2.7, risk is associated with the administration of an intramuscular injection irrespective of who administers it and understanding risk within this study is one of the research aims (see section 1.1). There are risks attached to the preparation, selection and administration process, the avoidance of key anatomical features and to the disposal of used equipment. Risk is attached to the medication itself and there are risks attached to adopting novel ideas. Within the findings section, risk will be discussed in the context of mental illness, innovation, home, relationships, service provision and depot recording processes.

6.4.1 Risk and mental illness

The nature of mental illness, and the potential for participants to relapse, was perceived by practitioners as an important aspect of risk and risk management. The potential changing nature of a patient's profile means that assessment of mental state is an ongoing and evolving process (see section 2.2-2.3). Risk factors change over time – for example, substance misuse, changes in mental state, changes in and awareness of insight levels and support structures. The concerns here were about the carer and family having a knowledge base to interpret changes in the patient's behaviour and mood and to attach these changes to an overarching framework of the patient's potential relapse signature (see section 2.7; sections 2.14-2.15 on disclosure) (see appendix 11 for training package (knowledge and skills requirements). Additionally, if the patient and carer were not aware of significant behavioural and mood changes in the patient and this significance was brought to light during a home visit by the CPN, a third party, this could undermine the confidence and relationship between the patient and carer. Psychosis as an illness is identified as a potential third party illness (Gamble and Brennan 2006) in that, unlike

having a cold, it is not the person themselves, at least initially, who readily recognises and becomes aware of the significance of changes in behaviour and mood (See appendix 11 – Training Package a check list of knowledge, skills, support and communication states that have evolved throughout the project and developed through an action research cycle).

There was concern by mental health practitioners that the carer would and could be open to persuasion or possible coercion by the patient not to report changes in patient presentation to the mental health team, or become sensitive to change and report frequently (observational data).

Patient role within the nurse patient relationship, the nurse's skills (medication management) come first, then they build a relationship with the client based on that role (we (nurses) are not required to know the patient intimately). Opposite of what the carer might experience which is emotional relationship first, then medication management (GM101-/4- interview data).

Practitioners felt there was a risk that the patient and carer could collude together in the keeping of information to themselves and exclude the CPN from the sharing of information. There is the potential for mental health services to respond to these observed colluding events with a firm and controlling approach rather than taking the opportunity to problem solve between the services and the family. The family could be working within a concealment model (see sections 2.7 -2.8.1 on concealment and this chapter).

Within the potential for patient relapse, practitioners had concerns that the carer could become the focus of the patient's mental illness, particularly as they were the person who was administering the depot medication. Concerns identified by practitioners were about the carer becoming the focal point of the patient's thoughts, in particular, the patient getting paranoid about the carer.

No problem with others doing it – (giving the depot) but these are mentally ill (GTTN – note data).

Would he become paranoid towards me as his carer (ECG/2- data from carers group).

The carer would become the focal point of the patient's strange thoughts if unwell (BN101- interview data).

In summarising the previous two sections, the data identifies concerns related to relapse and mental illness. Practitioners' concerns relate to possible collusion between the patient and supportive person in concealing information from mental health services and both practitioner and carer concern that the supportive person may become the focal point of the patient's relapse. Relapse may not be recognised by the patient themselves and in the absence of third party observations (CPN), the data highlights the importance of the supportive person being enabled to learn patient relapse indicators and seek appropriate support, which highlights the importance of disclosure in this study.

6.4.2 Innovation and risk

As discussed in sections 4.9-4.11 an innovation is an idea or practice that is perceived as new by an individual or group. The newness of an idea means that some degree of uncertainty is involved and this uncertainty implies a lack of predictability, of structure and information. The lack of information impacts on the uncertainty in a situation where choice exists among a set of alternatives. The level and depth of information may not yet be available to satisfy some aspects of the uncertainty. Newness of an innovation may be expressed in terms of knowledge, persuasion or a decision to adopt. The knowledge aspect is gained when an individual learns of the innovation's existence and gains some understanding of its functioning. Persuasion takes place when an individual forms a favourable or unfavourable attitude towards the innovation and this involves seeking innovation evaluation information in order to reduce uncertainty about the innovation's expected consequences. Involving carers or supportive persons in the administration of a depot injection is perceived as a new idea within the mental health arena.

The origins of the innovative idea will influence the decision to adopt or not. This innovation resulted from a service user request for choice as to where her depot medication could be received. Within the mental health services therefore, there was uncertainty about the innovation.

There is uncertainty around the potential of the project –who would you discuss it with? This is not a change that has come from the Department of Health – nor is it a directive from the Trust (GM101/1- interview data).

There is a risk in hearing and acting on service user led requests - the risk of destabilising the status quo, the service delivery model, relationships between patients and practitioners and the system by which monitoring takes place. There is a risk in offering choice as choice involves options and flexibility and within a mass delivery-orientated service model, this can create some uncertainty and possible fragmentation. Yet choice and involving patients and families are very much part of the recovery philosophy - a philosophy mental health services have based their delivery of services around. Translating aspects of the recovery philosophy into practice - the aspects of choice and responsibility taking, involved risk-taking to the organisation, to the practitioners and to the families.

This change has not come from the Department of Health - nor as a directive, so what level of nurse could work consultatively with the bureaucratic nature of our service in the fulfilment of this project (GM101 –interview data).

The service is usually offering rather than involving- this is a change of mind set and not easy for the practitioner (BN101/1- interview data).

Transfer of responsibility- how are service users seen within the hierarchy – suggest seen as low status – how risky is the transfer of responsibility (GTTN-notes from clinic observations).

From the study participants' point of view (both patients and health professionals), some saw the novel idea as a threat and more information would be required before adoption could be considered. Other potential participants saw the novel idea as an opportunity to move on from where they currently were, whilst for others, who had achieved stability within current services, even if the service was malfunctioning, the status quo gave them a semblance of routine and safety.

It is a novel idea - we have now established a routine that we are not keen on breaking. The current service is not a stable process- it is a porous system- there are separate systems, GP and mental health service. I would require confidence in the current system before aiming to give a depot injection (Case study 6- note data).

A lack of confidence in the current system made this participant less likely to seek an alternative. He had concerns about the number of differing practitioners and systems

(home treatment, crisis team, duty team) that he encountered when his wife had urgent care needs. His wife had retired from employment so having an alternative to the depot clinic was not an imperative. This was a reflection of his lack of confidence that if he opted for an alternative to the current system, the current system would help in the manner he would expect if something went wrong with the new system.

When a carer administers the depot injection, they share a role with the mental health nurse. The role of administration is traditionally a hallmark of the mental health nurse. As a consequence, there is the risk that the routine of the organisation and of the nurse will be destabilised. The role of the community nurse is destabilised in that it becomes uncertain, within the context of a family member administering the depot injection, what role the CPN will play. Linking the role of home administration of the depot to the absence of a role for the mental health nurse has potential risks. For example, when a patient comes to the depot clinic for his depot injection and the nurse says 'he is my responsibility' or 'no, he is not as he has his depot injection at home'. Taking a dichotomous stance, based on the role of depot administration, is of concern. For example, when the patient from case study three came to the depot clinic to collect a supply of depot medication for home administration, the depot nurse's initial response was not to give any medication. The suggested solution was a prescription from the patient's GP. When the patient offered a rationale as to why a prescription from the GP could not be acquired at short notice, ten ampoules of medication were given to the patient by the nurse. Ten ampoules of depot medication is enough medication to last the patient thirty weeks, which is a long time and a lot of medication to have within the home. The guidance given at the time, which had been discussed at the patient's CPA review, was three ampoules of medication maximum at any one time.

I got 10 ampoules of medication from the depot clinic when they initially said they could not give any. When ascertained I was having my depot at home (Case study 3- note data).

There is a risk that the importance of the depot administration, given high status by nurses as an indicator of their role, is equated with a change in the patient's needs when someone other than a nurse administers the depot. A risk is attached if significance is given to the administration of the depot injection by a family member as a behaviour or

indicator which warrants service reduction by mental health services, rather than an opportunity for engagement and enactment of the recovery philosophy.

Depot administration is often seen as a strong part of community nurse's role (BN/101/6).

There is a risk that the individual needs of the patient are not understood as viewed through the lens of 'home administrator' by the mental health nurse. An inherent risk within this approach would be that the 'role of home administration' is what dominates the interaction and not the individual needs of the patient. The role of home administration of depot medication has been enacted because there is a mental illness with a prescribed medical intervention, and choice was requested by the patient as to who should administer the medical treatment. The CPN should keep their focus on the patient and their individual needs and not just be an administrator of a depot injection. The role of the CPN was alluded to within three of the research case studies. The participants in these case studies had developed competency with supportive person administration. Through evidencing this competency, mental health service's decided to withdraw or modify the allocated care co-ordinator role. Two care co-ordinators were crisis point contact only whilst the third allocated care co-ordinator was withdrawn from the client's care. In Care Programme Approach language, the patient was changed from level three to level two and this had implications for the patient (see section 6.4.5).

Having a CPN is a validation of how ill I am and nothing else- nothing to do with having a depot injection at home (Case study 3 – note data).

In summary, the data suggests that service developments create both opportunity and fear within providers and receivers of services. Depot administration is a key role for the mental health nurse and sharing the role with a lay person created uncertainty in relation to role responsibilities. This dissonance is a potential risk issue. The lens through which a patient is viewed in terms of their depot injection, i.e. nurse or supportive person administration, contributes to decision-making about service provision and level of support. The data suggests there are challenges for the practitioner in working collaboratively and this has implications for recovery orientated services.

6.4.3 Risk and the home as a base for medical treatment

Where responsibility was passed to the supportive person for depot administration, they had been the person who had made themselves available to the researcher in order to develop the prerequisite skills and knowledge. With four of the case studies, the patient who required the depot injection was not available, due to employment or choice, to attend all the training sessions. The supportive person was now in the position of having a role in supporting, motivating, sharing, clarifying, monitoring and discussing with the patient the taking of ownership and responsibility with the organisation and management of the depot injection. This potentially could lead to conflict within the relationship and stress for the supportive person and patient.

I am his wife – I see him as normal. He has always been the same to me. Because I see him as my husband and not as a patient I find it difficult to tell him or to keep reminding him what might need doing (Case study 2 – note data).

Enabling a supportive person to take on the role of depot administration may have an impact on the role of the patient in responsibility-taking for such tasks as contacting their GP for a prescription or remembering the injection due date. There is a risk involved if the supportive person judges the patient's potential for responsibility-taking by their maintenance of full time employment (see section 2.2-2.3). If the patient is employed, then they must be able to take a lead and take the responsibility to keep the schedule of depot administration in order. The risk is in viewing behaviours such as employment as a guide to make an overall judgment about competency and responsibility-taking (see chapter 2 for further discussion on competency). Within that framework, the impact of a psychotic illness and potential vulnerabilities to stress may be underestimated. Enabling the patient to recognise and take on additional responsibilities and control needs to be incorporated within the teaching programme of the project.

Where the patient is viewed as being equal within the home relationship and not 'being cared for' there is the potential that no clear leader emerges within the relationship about the administration and management of the depot injection. This was an issue identified by two of the research case studies. Where this happens there is a potential risk that the partners drift into non-decision-making and the depot administration becomes irregular and ad hoc. Where there is clear vision, clear ownership of responsibilities and clear

expectations, and then the depot is more likely to be administered within schedule expectations. The recipient of the depot injection in one case study stated she had concerns that if her relationship with her supportive person drifted into irregular administration, she could get known as a ‘non complier’ (patient’s words) and this label worried her greatly. She feared getting known as a ‘non complier’ by their neighbours, and felt the neighbours would get to know about the medication issue; they just would. One example of how the neighbours would find out would be through visits from mental health practitioners.

We drifted into a ‘non decision’ the longer we left it the lower down the agenda it went (Case study 3 note data).

There is a risk of non-compliance – people with mental illness get stereotyped by the public and you could get known as a ‘non complier’ (Case study 1 note data).

In engaging with the role of administering the depot injection, a transfer of knowledge and information took place between mental health services and patient and supportive person. There was a risk that this new knowledge could destabilize a family by a role change for one member and information change for all. Disclosure (see section 2.8 -2.8.1 and this chapter) was an important concept within this process as it was an individualised judgement as to what knowledge supportive persons and the patient had previously shared. One important aspect of knowledge related to possible blood borne infections which the patient had not disclosed to their supportive person and were significant in the event of, and management of a needle stick injury. This sensitive information was discussed individually between the patient and responsible clinician or at CPA meetings.

Knowledge may lead to me questioning or analysing my partner’s diagnosis. You might analyze the behaviour of others? Relationships could be impacted on as a consequence (Case study 6/2 note data).

It occurred to me over the past week that if my husband learns how to administer my depot injection, it would give some power and control over me and may want to give an injection when not due. This has not occurred to him. We will discuss it further when the time was right (Case study 1 session 3).

Additionally the giving of an injection to a family member and the resulting pain of the injection (Field 1981) could create stress for the supportive person and impact on

relationships. Practitioner data suggested that the pain on injection giving and the supportive person's interpretation of the patients response may lead to the supportive person disobeying the training. The word disobeying used by the practitioner implied power but this was not followed up by the researcher. The issue of pain was discussed during the educational sessions and was identified in the educational literature used within the study (see section 6.5). Pain could also be an issue for the supportive person in the event of a needle stick injury.

Needle stick injury was discussed with the Trust's infection control nurse who explored the possibility of retractable needles for the study. However, retractable needles were not available at the time but are now more accessible and will contribute to the management of risk for future adopters of the innovation. The provision of syringes with retractable needles (safety engineered protection mechanism) is now mandatory following the implementation by May 2013 of EU directive (2010/32EU) and the evidence suggests the risk of needle stick injuries will be significantly reduced.

Feeling guilty for hurting – I have never enjoyed doing it – putting a needle in him. He is my husband and I love him (Case study 3 data).

Feelings, pain and symptom response may lead to disobeying the training (GP/19/1- interview)

The administration the depot injection within a busy family home, whilst offering choice and flexibility to the patient, has to fit in with the competing demands of the family home, inclusive of children. If the depot injection is not seen as relevant and important, and not planned for, then it will fit into all the other demands of the home and as a consequence, administration can be irregular.

This is the time you have negotiated with me to administer the depot injection. The family members are multitasking and the administration of the depot has to fit into the overall schema of the home (Case study 2- note data).

I see my husband as normal – so the administration of the injection should not be such a complicated process. Child comes into the kitchen from having a bath, RW upstairs getting the other children ready for bed – will you do some ironing for tomorrow. We will do the thing later (Case study 2).

There is a risk inherent in this data of minimising the importance of the skills and knowledge required to administer a medical intervention. One supportive person (a registered nurse) expressed an opinion following three years of administration that the

injection itself was about 20% of the overall project. On reflection the injection may have been deemed 20% because of her prior confidence in IM injection administration which promoted discussions of other aspects of supportive person administration such as relapse symptom understanding, care plan development and crucially getting the GP and mental health services to respond to their support needs.

The injection giving itself is perhaps 20% of the overall project the dominance of the procedure (skills) to the detriment of knowledge in support of the illness, medication and procedure (Case study 7, the supportive person is a registered nurse).

There is also a risk that by home administration by the supportive person, the patient becomes unfamiliar and deskilled at attending the depot clinic and at any future time, if handing back the administration, the lack of ease of access back to a depot clinic could be distressing for the patient. The patient would be unfamiliar with the routine and may not have knowledge of the staff. The supportive person, by administering the depot injection, is protecting the patient from the distress of visiting the depot clinic, whilst, conversely, reducing the patient's social contacts with a resulting potential increase in isolation.

The storage of equipment related to the administration of the depot injection was a risk factor raised by both participants and practitioners. Home is a space that is generally ordered for the provision of the three key elements of privacy, security and identity (Twigg 2006). Illness can impose a radical re-ordering on the home, in particular by the storage of equipment linked to the person's illness. The look, feel and smell of the room are disturbed. For example, the home takes on the role for storage of medication, equipment, labour, and an identity change for both partners. The home becomes a venue where medical treatment is administered. Any place where medical treatment is administered necessitates its inhabitants to have the knowledge and skills to manage this medical intervention.

The home was also identified as a place where wider family members visit, where pets are kept, where children roam and guests are looked after. This open house philosophy carried with it some risks; risks that the medical equipment could be discovered. This discovery could lead to questions about its use and necessity and potentially harm the unsuspecting. Discovery of the equipment could also lead to changes in relationships as

mental illness has the potential to carry stigma and fear (Corrigan 2005; Pandya et al 2011) (see sections 2.6 – 2.6.3 and 6.5).

How to store the drug – my grandchildren visit my home. What about the cat and dog- are they safe? (Case study 6- note data).

Safety and storage would be an issue for me- particularly keeping equipment away from my nephews and nieces and anybody else who has no business to know about it (BHC/4- data from carer's forum).

Privacy is one of the key elements linked to home space. Conversely, a lack of privacy can be one of the most disliked features of institutional care settings. For example, the depot clinic at one of the larger mental health centres was viewed as not offering privacy.

No private waiting room- open corridor you see people shaking and blank looking- I would not want my family member going there (GTTN- clinic observational note data).

However, home administration is not a panacea for this institutional lack of privacy. Home administration may only tip the balance of power towards the patient in a limited way. In private settings, there is vulnerability and risk of abuse. Care settings that are hidden from view have been sites of neglect and abuse as have been evidenced in the recent past (Twigg, 2006).

The other person (carer) taking control (GP19/2- interview data).

The risk of the carer becoming dominant and dominating (BN101/2- interview data).

In summary, the home as a place of privacy, security and identity is altered when medical equipment, required for the care of one of its residents, is stored within the home. The equipment needs to be stored safely and to do this, knowledge and skills are required of its inhabitants. Study participants and carers identified that safety was an important factor for their children, visiting nephews, nieces and pets. Home administration may offer privacy for the patient but there is concern that within private settings the patient and carer are vulnerable and potentially at risk of abuse. Summarising this paragraph highlights change within the home as a result of taking on a new role. The possibility that

this change impacted on the patient participant relationship with their supportive person is discussed in the next section.

6.4.4 Relationship impact and risk

One of the stated aims of the research project was to establish whether enabling supportive persons to give depot injections would have an effect on the relationship they have with the recipient of the injection (see appendix ten). Five of the case studies used language that could imply potential impacts on relationships; two case studies completed the relationship change questionnaire.

The study did not appear to have significantly influenced relationships in a negative way. Responsibility-taking and responsibility-giving are issues that came through in all the case studies with ‘power over’ and ‘control’ being mentioned once. Burden was not identified as a particular issue within the study, generally participants being unaware of it as a concept. Burden is subjective term which could mean many things. The impact of caring is a more relevant term.

I would say he relies on me more – whereas before I did not have anything to do with the injection at all, now it has turned completely around, all down to me type of thing. Referred to a discussion last Saturday when he asked me when his injection is next due? I say, what are you asking me for? You should know. It seems all the responsibility lies with me. And that is the thing I am trying to get him to do – he has to take more responsibility. ‘You tell me when it is due and I will do it’. He is more than capable of remembering when the injection is due. It is not my responsibility to remember (RW supportive person, case study 2- note data).

I would be more dependent on my husband if he gave me my injection– he checks my medication every night as it stands. If I started to become unwell- it would be a lot of responsibility on my husband. Responsibility is an important issue. (Case study 6).

There appears to be a healthy respect for the adult receiving the injection and that if everything was normal, the patient would not be in the position of having to receive treatment. The injection-giving did not appear to take on significance within the relationship but seemed to fit into already established patterns of behaviour. A

philosophy shared by supportive persons was that patient wishes should be considered and discussed with them. If challenges arose, they should be discussed with a health professional.

I always take the wishes of the family member into consideration. In fact, carers should always take the wishes of the client into consideration. Discuss issues with them and refer to the medical team before taking a decision (Supportive person case study 3).

Four of the case studies within the project incorporated husband and wife partnerships. In two of these, the husband was in receipt of the injection –in the other two, the wife was the recipient. It was important for these couples that the titles husband and wife were used and not the title of carer. Within the research study literature and assessment tools used, the word carer is frequently used. Use of the word carer within the home may disclose an aspect of personal life to others members of the home about one member being in need of care. The use of husband and wife titles creates an image that everything is normal, and an indicator that relationships are what are important within the home and a label which might indicate an illness role, is not required.

Use husband and wife titles – I am not a carer (Case study 6).

I am his wife; I am not his carer (Case study 2).

Within the case studies, whilst there was a healthy respect for adulthood and responsibility taking, the parameters to this were uncertain (boundary ambiguity). This uncertainty was about how much the supportive person should be doing within the role of depot administration, and within these parameters there was the possibility of being intrusive (see section 4.6 for a discussion of linking the least intrusive intervention to empowerment philosophy). Once the key psychomotor skills of IM injection had been developed and competently delivered over a period of time, (three years for three of the case studies) by the supportive person, clearer expectations of responsibility taking and sharing emerged. The perception that the supportive person was offering choice to the depot recipient was important, even having choice associated with being dependent.

I am happy I am able to do it as it takes a lot of pressure off him. It makes his life easier which was the whole point of the project. It is something I have learned to

do. I have never really sat back and thought about it (RW supportive person case study 2).

I feel lucky as a Mum in that we have always had a balanced family working relationship like – so I don't think the question of control has ever been there – as a mother I have always let my children go – you know what I mean, so as an adult, he is an adult, so there is liaison without any issues. He is dependent by choice. I am thinking of other things besides the jab (Supportive person, case study 3).

There was a confidence in the recipient of the depot injection in all case studies that the supportive person would deliver the injection as expected. This discussion about responsibility was contained within the role of injection administration – responsibility within the wider context, for example, crisis management and linking with mental health services remained a topic for on-going development and clarification. Relationships overall within these case studies showed a determined hopefulness rather than blind care giving.

In case study 7, a husband and wife dyad who were seen by the practitioners as an 'educated couple', there was real energy to understand each other and problem solve in the working of supportive person depot administration. Both partners worked full time and had young children. The participants discussed the parent's illness with their children and the rationale for the injection giving. This case study resulted in a care plan that epitomised role clarity, relapse recognition, access to services strategies and a problem solving approach that enabled the detail to evolve as the study progressed. This care plan development was an example of an action research cycle.

6.4.5 Service provision and risk

Data from observations and corridor conversations identified that one potential benefit of the study from mental health services' viewpoint would be a reduction in provision or discharge from the mental health services. The reductions in service provision could lead to withdrawing the care co-ordinator and a reduction in CPA status which was attractive within the context of service reorganisation with a focus on targets. However, this change in service was not what all the patients and supportive persons wanted. A contribution to

the decision-making about service reduction was the significance attached to the administration of the depot injection (see section 6.4.5). Unless a wider picture was seen of the patient and their needs, the service reduction presented a potential risk. The anticipated service benefit was clear in the language used in referrals made to the study by practitioners such as ‘the service is required to make a 10% reduction in case load numbers and we want to discharge this patient from our service’. I referred to these referrals as ‘needs led referrals’ as opposed to ‘client led referrals’ and illustrated the influence of service reorganisation and understanding the context within which the study took place (see section 5.1). These referrals indirectly said that if the nurse is not administering the depot injection, the patient must be ready for a change in service provision. A reduction in CPA status could have financial implications for the patient as their level of benefit could change and discharge from the service resulted in case study 2 being charged for the prescription they received from their GP for their depot medication.

The organisation is getting away from caring. It is all facts and figures (GTTN 07/07).

This is not a happy climate to work in. There is a lack of communication and inexperienced managers whose only interest is targets (GTTN -CPN 02/11).

What if the client had a relapse, who would monitor? how would the carer manage? (ECG/1- data following carer meeting).

For three case studies this change in service provision became a concern. The mental health team viewed home administration of depot injection as a behaviour that warranted a reduction in service provision. This was not what the dyads expected. Concerns expressed by the case study participants were fear of isolation and being without a support structure from service providers should an untoward incident occur.

Is there a risk of overdosing and abuse? Who would be around to help me? (BHC/4- note data following carer meeting).

This loss of service support was different to the negotiated and planned changes in service provision negotiated by two of the case studies. The research dyads, instead of care co-ordinator support, were offered support through out-patient appointments. In case study seven when the dyad became confident in other aspects of the depot administration, the appointments moved from four monthly to a yearly appointment with the psychiatrist.

In case study two, out-patient appointments were offered three monthly. Out-patient clinics were generally administered by junior medical staff on a rotational training programme. Family members were ambivalent about the value of such appointments with staff that rotated every six months. They perceived the meetings as boring and of little value to them. The interaction at the appointment, they felt, was based on the patient's diagnosis in that the doctor kept looking at the computer, reading a history and asking questions that they themselves could have asked. For example, how are you? What medication are you taking? What is your sleep pattern like? Nobody asked to see the home record of administration card as evidence of supportive person administration and involvement.

We have no confidence in the current service. If you were to give an injection I would want the service to be supportive with continuity. At present this continuity does not exist (Case study 6).

I wish they would ask to see the medication record –our role in research and our interest in mental health would have been validated. It made us feel like, why should we bother? (Case study 2).

No one asks to see the medication record. They do not seem interested in it (Case study 3).

There is a risk attached to the perceived lack of value of these appointments and the change from having a care co-coordinator. The inexperienced doctor asking the same repetitive questions, changed every six months. The message perceived by the family was one of little importance. The depth and level of discussion and hence assessment was repetitive and not progressive. Family members felt progression was inhibited by the doctor not following and understanding the journey of home administration and what approach may be necessary in order to pick up and validate any changes. There was the need to risk-assess and risk-manage within the context of the research project. There was no longer a third party (mental health nurse) involved in the administration of the depot injection or in care co-ordination. This out-patient appointment was the third party interaction. It was an opportunity to get feedback on the participant's progress with the project, alongside routine assessment and monitoring requirements that the out-patient appointment necessitated, but this opportunity was not taken. This may illustrate how nursing and medicine view roles and responsibilities, with particular reference to the depot administration. Any change in role administration leaves a potential gap in process

and information gathering which necessitates a role change for another aspect of the service i.e. the out-patient appointment. This may take some awareness building and time, and would be a recommendation for future practice.

6.4.6 Administration of depot recording and risk

Within local mental health services, there is a written policy on the management of the depot clinic, which includes guidance as what actions are to be taken if a patient does not attend for his or her depot injection, for example, to send a reminder letter to the patient's home address, a phone call or a home visit by the community mental health nurse. Adopting the administration of a depot injection by a carer led to changes in the mental health's team monitoring of the injection administration process. The practitioner relied on feedback from the study participants for the depot administration record. This loss of control by practitioners created unknowns and uncertainties for them. Consequently, this necessitated other changes in the practitioner's approach; for example, collaborative working relationships, trust and reporting strategies had to be developed. Developing a uniform reporting system became an action research cycle in identifying and implementing possible collaborative solutions. One specific example of this in practice was the integration of the participant's home record of depot administration chart into the Trust's information system (see figure 6.1). The participant scanned the record chart at home and emailed it to the mental health centre where it was attached to the patient's clinical file. Another example was the patient phoning the depot clinic and informing the clinic nurse of the date he or she had their depot injection.

It is a new concept for clients and carers and for us to hand over- I am not a controlling person but I do like to know what is happening – it is a form of control (BN101/8- interview data).

Role change from being an enforcer to 'not be in the position of controlling him' – is this the practitioner letting go on the basis of knowledge being demonstrated (GP/19/5- interview data).

The perceived shift in control and the consequential tension emanating from the change is cognate with the discussion about tensions as articulated by the *Commission for Social Care Inspectorate (CSCI)* (2006). The Commission suggested that where policies and

philosophies are promoted which encourage the taking of responsibility by patients, the giving of choice and the taking of risks, there are likely to be tensions with health professionals. The tension was within the context that overall, health professionals retained statutory responsibility to patients and to the wider society. Tensions are to be expected when individuals want to self-manage and risk take, thus conflicting with the practitioner's perceived duty of care.

In reference to the CSCI's suggestions about choice and responsibility taking, there is a risk that practitioners will equate their suggestions to all LTC's such as asthma, diabetes and arthritis without understanding how the concept of 'insight' relates to, and complicates mental illness (See section 2.2-2.4 on Insight and Capacity).

Mental illness is different to other LTC's – insight as a concept (GP19/4-interview data).

Insight as a concept is associated with mental illness but as discussed in section 2.2 it is relevant to all medical conditions. Understanding additional challenges posed by mental illness contributes to the management of risk. There is much that mental health, in the delivery of choice and responsibility-taking can learn from the management of other LTC's and this includes the gaining of knowledge and skills required for self or family management. This is discussed in the next section.

6.5 Knowledge and skills

The NMC (2007) require nurses who administer IM injections to undertake safe and accountable practice and similar expectations are required of any person taking on that role (see section 3.7). One of the research aims was to develop a training package for potential future use and within this aim, understanding the process, equipment, literature and learning styles of participants in gaining of the prerequisite knowledge and skills is relevant to the study (see section 6.1). In teaching of supportive persons the knowledge and skills to administer intramuscular depot injections, a number of teaching styles and approaches were used, namely demonstration, practice, observation, feedback, homework, literature, video on IM injection administration and discussion. The teaching aids used to develop the injection skills included; injection pads, foam ball, orange and manikin.

An area identified by four lay supportive persons as problematic was the identification of the upper outer quadrant of the buttock injection site. Diagrams of injection sites were given to participants and feedback on their usefulness was used within the study through an action research cycle. In case study one, a page on the administration of medication and an anatomical drawing of the upper outer quadrant was used. This article, Hahn (1990) was written for health professionals. Feedback from case study one found the diagram difficult to interpret and confusing as a guide. Following this feedback, the article by Hunter (2008) was used. Participants found that both articles advise using imaginary lines to divide the buttocks without saying the genesis of the dividing line. Another strategy for identifying the upper outer quadrant, an imaginary line between the iliac spine and greater trochanter with a vertical line coming off the midpoint was more understandable with the aid of diagrams. Case studies one, two and seven, husband and wife dyads, reported this guidance gave them clarity as they were able to practice identifying this site outside of the injection process. Recipient knowledge and expertise in receiving injections was an additional process used by participants to aid identification of the upper outer quadrant.

The supportive person in case study three critiqued an article by Hunter (2008), *Intramuscular injection technique*, and wrote comments on how and where this article could be written for the lay administrator of injections. On page 36 of the Hunter article there are diagrams illustrating injection sites. Comments entered by the supportive person on these diagrams changed dorsogluteal site to buttocks and mid deltoid site to the upper arm muscle. Overall the black and white print version was found to be unclear and not useful as a guide whilst the colour version was clearer and more useful as a guide to support the administration of an IM injection (see appendix 14 for example).

Preparation guidance for the giving of an IM injection taken from the Royal Marsden Manual was given to each participant. Feedback on the guidance suggested it was helpful and made more sense once confidence had been gained in administering the depot injection. Feedback on all the literature highlighted the importance of having educational material designed for or chosen by the participants and not assuming that material designed for another group, i.e. nurses, automatically transfers or is understood by lay persons.

The homework you gave was complex and potentially off putting. Without the practice, reading this handout would have been frightening and off putting. For me, the diagram confused me as to identification of the upper outer quadrant (Supportive person, case study 1, session 3).

All case studies reported that information and education related to medication and IM injection giving made more sense once one depot injection had been administered within the study. The expressed rationale for this was that the concentration and focus they had on the giving of the first injection was dominant.

I feel much less anxious after administration ,better now that I have done one (RW case study 2 16/11 page 5 following first supervised injection administration).

Case study one reported that the foam ball used in the injection practice, best replicated the resistance encountered when administering the injection through the skin and muscle. Other participants found the manikin and injection pads realistic and useful.

An issue raised by all participants, including those who were or had worked as health professionals, was the giving of a viscous oily based medication. This issue was worked with using an action research cycle and the recommended outcome was to start with drawing up water in the syringe, and move on to drawing up vegetable oil to get a feel for the pressure needed with differing substances before administering the medication itself. Supportive persons were able to experience and practice opening a medication vial and drawing up medication following discussions about accessing samples with the trust pharmacist.

Opening the vial and aspirating the water was relatively easy. Aspirating the depixol medication was more difficult. I found that I aspirated too much air into the syringe as the medication being viscous, was difficult to draw up (Supportive person case study 1 –session 3, worked as an engineer).

the depot medication as a substance is thick and viscous, that is something I need to be aware of (Supportive person case study 3 who had previously worked as a health professional and administered intramuscular injections within that role, 30/11 page 2).

Co-ordinating all aspects of the injection technique was identified in the data as a challenge that required extra practice sessions and required a focused mind. This relates to the work of Schmidt and Wrisberg (2008) as discussed in section 3.7. There are many cognitive and psychomotor skills involved in the administration of an IM injection and the novice learner has to develop the sequence and deliver the performance. In the learning of serial skills, beginners initially focus on each element separately and concentrate on the order the elements of the skill are delivered in. Later after considerable practice, participants were able to combine elements to form a unified sequence and this was evidenced during the study period. Practice sessions were required between observed injection administration episodes in order to hone skills following feedback on performance.

What I found difficult was co-ordinating my fingers to hold the syringe, do the Z track, support the syringe, withdraw the plunger and talk to others at the same time (Supportive person case study 1 on practicing injection administration session 2).

I think co-ordination during the administration of the injection requires ongoing development. How to hold the needle safely whilst supporting the skin and withdrawing the injection (RW supportive person case study 2 following third supervised injection administration and six practice sessions 11/1/09).

In developing the Z track technique, an orange with cling film over it was used to replicate moving skin sideways. Patient specific administration positions were identified following literature guidance. Some patients preferred standing up when receiving the injection and being distracted during preparation and administration. Distraction topics included family issues, current affairs, singing and sports. Case study three evolved into lying down during injection administration although they felt this was more time consuming and potentially more noticeable by their children as they had to use the bedroom.

An issue that caused surprise to lay supportive persons in the administration of depot injections was the size of the green needle used and the amount of the needle that entered the muscle for injection administration.

Explicit in the data about supportive persons developing the knowledge and skills to administer the depot injection was the concept of trust and findings related to trust are discussed in the next sections.

6.6 Trust

Data from case studies, practitioner interviews, clinic observations and carer groups raised the concept of trust, mistrust and trusting within mental health care many times. Trust was the focus of one of the questions asked in the semi structured interview with mental health practitioners the eliciting question being ‘Would you have any concerns about trusting a carer/relative to give the injection as prescribed? If yes, what may be your concerns? How could these concerns be reduced?’ (see appendix 5). Within the practitioner interview data, trust and trusting were identified 23 times (see appendix 13). Trust, trusting and mistrust were key characteristics which influenced practitioner referrals to this research project, practitioner and patient relationships, dyad relations and patients’ views of mental health service provision. Trust was a concept that was used by both medical and nursing practitioners as a measure by which potential patients and carers would be considered suitable for inclusion in the research study. In other words, trust and trusting were being used as judgement tools. The data will be analysed from the multidisciplinary team and participant points of view and within a macro level as a link to society’s view of the mentally ill and the provision of services. The research did not differentiate between the implied meanings given to trust as espoused by the differing participants within this research.

One of the attributes of trust is a dependence on another individual to have a need met (Hupcey, 2001; see sections 2.9-2.9.2). Within this research the patient’s need for a depot injection did not change. It continued to be a need. What changed was the process by which the injection was received by the patient – through a different person. What also changed was the patient’s view that choice about when, where and who administered the depot injection was an option. In achieving this change, the patient needed to trust a person other than the nurse and the nurse needed to trust the patient and supportive person. All sides needed to trust the service provision, its structures and receptivity to role change. Practitioners needed trust in their professional bodies and in their guidance about delegating roles to another person. The findings are discussed in relationship to

behaviours, psychosis and LTC's, organisational changes and the assessment of competency.

6.6.1 Trust forming and mistrusting behaviours

The concept of trust utilised by individual practitioners was very influential in the decision-making process about referral to this research study. Trust was both a subjective mixture of behaviours and perceived relationships of trust with the patient. The behaviours noted which were interpreted by practitioners as indicators that the patient and carer could be trusted were: carers attending CPA meetings; carers and patients attending appointments together and patients and carers initiating contact with mental health services if circumstances changed.

Practitioners identified some behaviours by patients or carers which contributed to a 'non trusting' relationship. These behaviours related to being chased up for any reason by a member of the mental health team; having had letters written to remind them to attend appointments; any episode where information came to the notice of the practitioner from a third party about some relevant health issue and how many issues with medication compliance came up over the years. No limitation was placed by the practitioner on the timeframe over which a judgement was made; it could go on for a long time. An additional factor, and potentially open to subjective opinion was the non-trusting of a carer if a 'crisis' was dragged out. What was interpreted as a crisis was subjective and as such would require discussion to distil the components of that judgement.

Alongside these behaviours, practitioners and participants expressed a view that they had 'trusting relationships' with others. They knew this because they 'felt trusted' and conversely trusted in return. This often appeared personal and was interpreted personally.

Not trusted if you have a history of being 'chased up' 'a decision not to trust if letters had to be written to the patient many times (BN101/3 interview data).

Not trusted if the carer has a history of dragging out 'the crisis' (GP19/5¹⁰ interview data).

¹⁰ GP19 is the code used to identify a medical practitioner and 5 is the page number on the transcribed data

Contact with services initiated by client and carer as evidence to trust building (BN101/4 interview data).

Potential to develop trust with behaviours like attending appointments and carers attending. What happens between carers and me is key compliance behaviour, (GP19/5 interview data).

I can trust my patient and they see that they can trust me (GP19/5 interview data).

Within the practitioner - patient relationship, there was selectivity on the practitioner's side as to which aspect of the patient's behaviour was focused on in making a judgment about 'trust' and 'trusting'. The patient and carer were trusted to store and monitor the taking of oral medication, manage finances, fulfil employment responsibilities and arrange appointments to manage physical health needs. However, the non-trusting behaviours (see extracts above) appeared to carry more weight and dominated the decision making process. Also, there was no discussion about what the practitioner might do in order to enhance or encourage the patient or carer in meeting and understanding these 'trusting' behaviours. On reflection I could have explored trust forming behaviours with practitioners further.

Within each mental health centre, a small number of patients were given their depot injection at home by the community nurse. These patients were not study participants. Despite knowing the patient for many years, practitioners perceived they were at best tolerated within this relationship and worked with, as long as they followed and complied with, what they called the 'patients test'. The practitioner felt they were never trusted, just tolerated. An example of the 'patients test' is given in the following extract;

Each time I do a home visit to administer a depot injection to patient X and family Y I am required to show my identification card, I am required to show the needle, syringe, and medication before I prepare the injection. Following preparation, the patient requests to see the syringe and the one or two millimetre level of medication. Post administration, the patient and or carer asks to see the syringe to check if the medication has been administered. Knowledge around the process of injection administration and medication management were required if the practitioner was to pass the test. The patient and carer could and would ask questions around the medication and key anatomical sites. The medication questions are about how does the medication work? What does it do? How long does it stay in the body for? (BN101/5 interview data).

The demand for evidence and knowledge by the patient and the carer was interpreted differently by different practitioners. Some felt that the questioning about medication and injection administration was healthy and recovery orientated (see section 3.5) and therefore welcomed. Other practitioners reported feeling challenged by the questioning and linked the behaviour to the patient's mental state. Practitioners reported feeling uneasy at being the ones answering the questions as they expected to be the ones asking the questions. For either side, being in the spotlight was not easy.

Practitioner not being trusted after 'many years' – the evidence and behaviours required to maintain the status quo (BN101/3 interview data).

Practitioner needing confidence that they will be included and acknowledged as a knowledgeable person (GP19/4 interview data).

Within home settings in particular, practitioners reported feeling uneasy about asking many questions themselves to the patient or the carer as they were not sure how this would be interpreted. Their concern was that such behaviour implied lack of trust. Because of this uncertainty, the patient's care, referred to by the practitioners as the 'status quo', stayed static and in the practitioner's opinion that was the desired goal for now. The practitioners felt at arm's length to the care and were intuitively judging whether the carer and the patient had a 'trusting relationship' with them.

The carer may feel I was not trusting them if I asked too many questions when I was visited their home (BN101/ interview data).

A level of trust has already been established because the person (carer/family member) is known to the client (GM101/1¹¹ interview data).

Within the research process itself, as the researcher there were times when my trust in the participants was questioned. When working with case study 2, there was a period of time when I was not confident that the depot injection was being given as per prescription plan. My concern was based on the limited contact I was receiving from the participants and this was exacerbated, in my eyes, by how little focus was being given to the administration of the depot injection when I visited the home. The specific behaviour in this instance was an absence of communication - for example, the lack of a text to confirm or disconfirm the administration. When I initiated contact, the reply I received

¹¹ GM101 is code used to identify a service manager and 1 is the page number on the transcribed data

was 'we did it last night'. This to me was evidence that the administration was five days late.

On a home visit following this episode, I asked to see the record of administration card on which the carer recorded the date and site used during administration, because I did not trust that this family were administering the depot injection as per plan. The card was found after some difficulty, a difficulty I put down to the family not knowing where it was. My conclusion from this was the card was not being used. Perhaps I demonstrated that I was building on mistrust and not trust. When the card was seen, there was no dosage or name of medication on the card. This further added to my mistrust since I interpreted this as a sign of lack of attention by the carer.

There were tensions in me related to my background as a community psychiatric nurse and my current role as researcher. On this occasion, due to the lateness of the family contact and the lateness of giving this month's depot, I felt like taking control, I felt urged to go and organise them, I felt urged to go and speak in a stern voice and tell them off. Is this my tension between my background as a community psychiatric nurse and my research role? Was it that the service had trusted me with this research and with his family and I was fearful in some way that the project would be discontinued?

My reflection following this visit was that it was a mistake to have asked for the card at that particular visit – I was checking up because I did not trust. This gave me cause for anxiety in that I was fearful of the outcome. I questioned whether this was real action research and was consequently uncertain. 'Will the time come when I will not initiate contact to see what happens? Is it me trying to control rather than living with 'choice'? Is this about the family reducing social contact with others and if so, who would be chasing by now from the mental health services?' Additionally, there was also the absence of clear aims against which the family's performance might be judged. **(Researchers reflective log related to case study 2).**

Placing this experience within the wider context of home care for this family, I later ascertained that the card was stored in a secure position to avoid it being found by their children, who were not aware of their parent's need for injection at this time. The absence of a medication name on the home record card and its secure location were therefore concealment and protective strategies (see sections 2.7- 2.8).

My professional expectations were that the recording on a medication administration card should include name, medication, dosage, date, site of administration and the signature of

the depot administrator. I transposed these expectations into the family home environment. Yet when there is only one medication and only one person to receive it, what is a reasonable record for the family to keep? The home record card would be viewed at the next CPA meeting so other mental health professionals would judge and maybe even question the validity of the home record card. This potential scenario would reignite the discussion about trust and mistrusting behaviours. It highlighted for me a dissonance between mental health clinic and family expectations.

A further example of home and clinic divergent expectations related to cannabis smoking. This example illustrated the participant not altering behaviours because of my presence or was unaware of the information's potential impact or meaning. This participant awareness could relate to capacity and insight (chapter 2) or relate to knowledge, coping styles and information. There was a dissonance between what I observed and what was reported in review meetings. The patients and supportive person's world was being interpreted by me through my cultural and professional viewpoint. Ethically, by stating my point of view, in the CPA or review meeting, unless agreed prior to the meeting, the potential impact this would have on relationships and the study. One potential impact was a change in trusting relationships, participants withdrawing from the study and a loss in and between organisational relationships with the participants, an action I would not have desired. This relates to Van Regenmortal's (2009) work that within empowering philosophy, identifying common and differing agenda's between participants is relevant (see section 4.6) and to bias in AR when participants may use research involvement for reasons other than which was intended (see sections 5.7-5.8). It was important for me to recognise my personal agenda and not have a hidden agenda. I was clear in my discussions and in consent seeking that if I observed or heard something that caused concern, I would discuss with the participants and seek clarification.

Following discussion with the family and clarification of expectations, it opened up an action research cycle which revisited the recording of data which is reasonable for a home record and acceptable as evidence by the mental health team. The outcome for this family was the date, site and signature as a minimum data entry. When I link the concept of trust-forming behaviours, e.g. the family doing what I expect, and I as a researcher placing judgement on this behaviour, the work of Sellman (2007) is relevant (see sections 2.9 – 2.9.3). Sellman suggests that an assumption that trust is something that occurs

between equally competent adults, cannot explain trust in nursing because of the unequal power relationship between patients and healthcare professionals. To be in receipt of nursing is to have a need and be outside the terrain of everyday routine. In that context, we negotiate trust from the perspective of the patient role and enter into a trusting relationship between those who are vulnerable and those who, if they choose to, exploit that vulnerability. Perhaps I was still in the nurse role and whilst I was still a nurse I was working within a research role and within an action research study which implies some degree of uncertainty. Sellman (2007) additionally suggests that the everyday meanings of trust take account of circumstances and understanding the meaning of trust is contextually bound. Trust in this context was within a family home and I was measuring it by professional expectations.

6.6.2 Trust, psychosis and long-term conditions

During the research recruitment phase, mental health practitioners identified that within the mental health centre, seven patients who had a diagnosis of schizophrenia and in receipt of a depot injection by nurses, had insulin dependent diabetes. These seven patients were not participants in the research study. The practitioners reflected on how the patients were deemed competent and trusted to administer their own insulin injection, whilst at the same time the person was not being trusted to manage their psychosis. The diabetic services, through its practitioners, trusted these patients to administer their insulin whilst mental health practitioners had elements of mistrust towards the same person in that they were being treated with a depot injection administered by a nurse. In this instance, one aspect of the client i.e. one diagnosis, diabetes, with implied self-management as a treatment modality, was trusted whilst another aspect i.e. the diagnosis of psychosis was not trusted. There are significant differences between the self-administration of a medicine and third party administration with the potential risk of an adverse incident (see sections 2.5 – 2.6 and sections 5.11.3 - 5.11.4). As a researcher, it would have been beneficial to have explored with both the diabetic service and mental health service why and how the same individual patient can be viewed differently but this was not undertaken within this study. The paradox resonates with Skidmore's (1994) argument that the person with a 'psychosis', albeit under control, is never really trusted to dispense his/her own medication (see section 2.9.3).

I have clients who are on depot medication that I administer, who are also on insulin and they give the insulin themselves. Why do I trust with one drug and not another? (GM101/2 interview data).

Why do people with mental illnesses not have the opportunity to have home injections? I know people with diabetes – how come they can inject themselves? We are not trusted (underlined to emphasise the tone of voice used by the patient). The giving of injections is a job for the boys/staff at mental health centres (Case study 2 participant).

There are of course, differences between the administration of insulin, which is self-administered by subcutaneous injection and the depot injection which is by intramuscular injection. In Canada (Mound et al 1990) and New York State in the United States patients are assessed and taught to self-administer intramuscular injections (personal communication and observation data). In Canada self-administration of depot injection is promoted because the thigh muscle is seen as suitable and is accessible. In New York State, the buttock is the preferred site for administration and the patient is provided with a mirror to facilitate self-administration.

Subcutaneous injections are easier to self-administer and, legally, less challenging as there is no third party involvement and the patient is taking responsibility for self. Involving other persons, third parties in the administration of medication is legally more challenging with the possibility of third party injury (see sections 5.11.3 – 5.11.4). Also, the management of diabetes through the self-administration of insulin has a longer history of success. The self-administration of insulin started in the mid 1920's and had its share of criticism to begin with (Tattersall 1995). Teaching and learning the skills of administering insulin are delivered through the diabetic service which has a philosophy and history of this approach and expectations that self-administration is achievable. In exceptional circumstances only, will someone else administer the insulin.

We trust them with oral medication – why is injection different? (BN101/6 interview data).

The value system of the service provider and practitioner are important and relevant within a care delivery system (Woodbridge and Fulford 2004). When a value system is based on mistrust, for example, mistrusting the patient as a consequence of the diagnosis

of psychosis rather than taking an individualised approach to understanding the patient, questions do need to be asked about the genesis of diagnostic mistrustfulness and its impact on the client group. If the diagnosis of psychosis has implied connotations for the practitioner, then perhaps, problem solving with individual patients on the basis of inherent mistrust because of the diagnosis is difficult. In other words, if mistrust has been institutionalised by the service provider and the practitioner, then problem solving on that foundation is difficult and problematic and interferes with person-centred care. Whatever the patient puts in place may not matter because it will not make logical sense to the practitioner or service provider who is working on a platform of mistrust. It is the mistrust that dominates and this mistrust makes problem solving more challenging.

6.6.3 Developing trust within organisational changes

Within current local mental health services there are frequent organisational changes such as: team amalgamations, staff rotation and team base changes resulting in patients being transferred to and between teams. Consequently, the patient is meeting practitioners who are unfamiliar with their care needs, often through single meetings. The clients and carers within the study felt destabilised and disappointed by these frequent changes and felt it was difficult to build up trust in a series of ‘one off’ meetings. They reported losing confidence that longer term care planning was achievable within this structure. The participants felt that practitioners relied on the medical diagnosis as the lead topic within the interview, and because the parties were unfamiliar with each other, the practitioner spent most of the time reading the computer screen to ascertain history at the clinic. The patient and carer felt that the personal strengths of the patient were not being acknowledged and utilised.

RW¹² reports it is difficult when you see a different psychiatrist every time you attend the clinic. They ask the same questions – questions that I (his wife) could ask. They (psychiatrists) do not know R – all they have is on the screen in front of them. All they see is the diagnosis ‘schizophrenia’ and then they ask the usual questions (Case study 2- notes recorded following out-patient appointment).

‘In the current climate, it is about people being discharged from hospital without notice, change of personnel every time you have an appointment – how little

¹² Wife of R who is in receipt of depot medication

relationships are valued – change of psychiatrist and GP (GCG/2- carer from G team, page 2 notes from carer meeting).

For three dyad participants within the study, who had by now three years experience of administering the depot injection, reliance on the diagnosis as the lead topic was frustrating to them. They had moved on in their confidence, competence and knowledge of medication administration and felt they would have benefitted from a practitioner who was moving along with them with more focused discussions about the management of long-term conditions, employment or home life. Building trust is more challenging for the patient and carer as ‘one off meetings’ rely more on behaviour, the behaviour of the past, rather than continuity and relationship-building, for the practitioner to gauge trust. It also makes it more difficult to move to a more collaborative and trusting relationship, where expertise and knowledge could be demonstrated and understood on both sides. It is likely that the pattern of one- off meetings encourages maintenance of the conventional hierarchical mechanisms within the patient- practitioner relationship and may ultimately contribute to maintaining the sickness model. The practitioner’s reliance on the computer screen and diagnosis as a structure of appointment management, results in the appointment meeting being more like a base-line assessment rather than longer term management review and discussions which are relevant to all long-term conditions (LTC).

6.6.4 Trust and the assessment of competence

This study was about supportive persons taking on the role of administering a medical intervention through intramuscular injection. The role of depot administration is traditionally done by a nurse so transferring the role to a lay person necessitated a degree of trust (see sections 1.3 and 2.9 - 2.9.3 respectively). The literature on trust and collaborative working is analytically useful here. One model (Newell and Swan, 2000) espouses the triad of companion trust, competence trust and commitment trust. The frequent changes resulting from the service and personnel change make the nurturing of any form of trust, to a significant extent, difficult. Companion trust is based on judgements of goodwill or personal friendships and continuing reciprocal exchange (Newell and Swan, 2000). Companion trust is harder to develop given the social,

temporal and bonding opportunities currently offered within service provision. There is almost the absence of opportunities for practitioners, patients and carers to meet with a view to developing friendships and the enablement of reciprocal exchanges. When the contact between professionals, patients and carers is the formally structured CPA review and outpatient appointment, these meetings being months apart, it limits the opportunity for companion trust to develop. Conversely, from a practitioner's point of view, they have known some patients for many years and expect that companion trust would have developed. This development may be expected to reduce the amount of behaviours that require evidencing when the practitioner visits to administer a depot injection instead of the evidence required to maintain the status quo (see section 6.6.1).

Practitioner not being trusted after 'many years' – the evidence and behaviours required to maintain the status quo (BN101/3 interview data).

Competence trust is based on perceptions of the other's competence to carry out the tasks that need to be performed. This is derived from either witnessing this competence first hand or from contextual cues such as 'the reputation of the institution' that the person works for or the status of the professional group to which they belong (Newell and Swan, 2000). This is problematic when the rationale for collaborating with the service users and carers is traditionally their diagnosis and needs. Developing competence trust would mean changing from a diagnosis or lay person status, to include evidencing competency in the psychomotor skills of intramuscular injection giving, a skill traditionally done by a professional group. Judging competency is not easy when the task being judged is novel and untested and the group taking on the role are a non-professional group. This lay group do not have a track record of demonstrating the psychomotor skill of injection giving. It might explain why nurses who were patients or carers themselves, were discussed as being potential participants for the research project. Two of the research project dyads had supportive persons who had worked or were working as nurse or midwife. An additional referral related to a nurse who was the recipient of the injection. Perhaps mental health practitioners were thinking about nurses as a professional group and expected them to care and comply. Nurses as supportive persons require less input in the teaching of the psychomotor skills.

It is important for the injection giver to be competent and for me to have confidence in the person who is administering my depot injection (Case study 7 participant feedback note data).

I asked questions around major anatomical features- the sciatic nerve and artery and RW knew how to identify the greater trochanter. Very impressed with knowledge and told her so. RW reported she had read some material I had given her. (Case study 2- note taking following observed depot administration and competency assessment by researcher).

Medical staff, as well as seeing carers and patients who were or had been in professional roles before being diagnosed with an illness, as potential research participants, also talked about the ‘educated’ patient who may be suitable for the research project (interview data and clinic notes). The educated patient is discussed in the literature on health literacy which is defined as the ability to access, understand, appraise and apply health information (Nielsen-Bohlman et al 2004) (see section 2.2-2.4). Health literacy can be developed through education with an emphasis on the skills and abilities of individuals and their participation in decision making about health. The development of skills, abilities and participation relates health literacy to empowerment (Jochelson 2009; Wills 2009) (see chapter 4). Perhaps the practitioner is aiming for some connection with the patient and supportive person other than a diagnosis to frame their judgement of potential suitability for the research project. This was a novel and innovative project so the practitioner had no other benchmark to measure by. It could be that the ‘educated’ and the ‘professional roles’ had enabled more friendship trust to be built up over a period of time.

Role change from being an enforcer to ‘not be in the position of trying to control him’ – the practitioner letting go on the basis of knowledge being demonstrated – all within the context of recovery (GP/19 interview data).

Commitment trust is based on contractual commitments between the parties, which can act as a control-based mechanism that will continue to support the collaborative partnership if the other two forms of trust are lacking. Newell and Swan (2000) view this definition as being in alignment with the definition of trust given by Das and Teng (2001; 6) as ‘expectations held by one party that another will behave reliably and predictably’ (see section 2.9.2). My interpretation of this definition is that this trust is one-way and it is difficult to see where the collaborative partnership aspect of commitment trust is

evidenced. The expectation of mental health services is that the patient will behave in a certain way, for example, attend appointments and take medication. The patient's experience is that they in return are expected to behave without a commitment from the provider that facets of personal recovery will be validated (See section 3.5). The patient's and carer's expertise (health literacy) and the patient's employment are not being recognised as indicators of change within a personal recovery framework. This contrasts with the principles of recovery (Shepherd et al 2008) who espouse the view that recovery represents a move away from pathology, illness and symptoms to health, strengths and wellness. The patient may feel they have progressed in their own personal journey but that is not being recognised by the service provider.

Reflecting on my role as the researcher, the recognition of personal progress was equally challenging. Letting family members take control and administer the first intramuscular injection without direct supervision was anxiety provoking. The supervised injection administrations and the standards of knowledge, skills and attitudes observed over the previous months suggested it was right to move on to unsupervised administration by the family member. This was done in collaboration with the family member and the plan agreed with the mental health team. Newell and Swan's (2000) model of companion, competence and commitment trust is relevant. The participants had shown commitment, had developed competency and as the researcher, to some degree, I had become their companion. I was a consistent and regular person throughout their journey.

Discussed with Mum and D my anxieties around letting go and not phoning. Both smiled. Mum retorted that those who give will have to let go of something. It is about trust (Case study 3- interview data- researchers' note).

The concept of watchful care became more relevant to me at this juncture. I was not there to control but to recognise change and to be available at a distance to deliver watchful supportive care. This was achieved in this study through mobile phone contact.

Within this research study, risk management was aided by developing competencies and understanding trust. As the study progressed, the importance of stigma and the concepts of concealment and disclosure became relevant and findings related to these themes are discussed in the next sections. The themes are discussed in relationship to; depot clinic

attendance, employment, home administration, therapy, storage of equipment, home record charts, family member role change, children and crisis.

6.7 Stigma, concealment and disclosure

By attending the community mental health centre depot injection clinic, the patient is disclosing to others that he or she has a mental health problem and is in receipt of treatment (see sections 2.7 – 2.8.1). The depot clinic corridor in which the patient waits is an open corridor; other patients who are not in receipt of medication by injection treatment, may also be waiting. The patients who are waiting can present and visually demonstrate aspects of ill health or treatment side effects. Patients can be observed sitting in isolation, talking to themselves, looking distressed and showing the side effects of the treatment. Patients can be seen with hand or foot tremors or movements of the jaw and also patients who have changed appearance in that they have gained weight over a relatively short period of time. The patient is seeing evidence around them of distress through observing other patients. This experience relates to the work of Pachonkis (2007) in which for patients who are in the presence of similar others, the presence of stigma-related cues within the environment can make their concealed stigma salient.

‘if you go to the depot clinic on a Wednesday or depot day, you see people shaking legs and dribbling, looking blank. There are no tea or coffee facilities. There is no private waiting room – it is an open corridor. I would not want a family member there. It is no wonder they are shocked (CPN-GTTN).

‘D states he is getting more sensitive to bad news. I do not like going to the depot clinic because of the things I see – for example, the sick people. Not nice things to see’ (Case study 3).

Some people may not want to attend the depot clinic – there is stigma attached to this attendance (Case study 6).

However, discussion with three patients in the recruitment process, who did not become part of the study, identified that the community mental health centre building itself was felt to be supportive. The patients felt reassured by the structure of the depot clinic, the presence of others of similar experiences and the opportunity to talk to the depot clinic nurse.

I like to come to the clinic on Thursday as I get to meet people I know and talk to the staff. The nurse always asks how I am (GTTN 9/11).

Home visiting by the researcher, to participant homes who had young children, and who were not aware of their parent's mental illness, raised issues for the participants about disclosure. Three case studies within the research study had young children. One case study involved the children during my visits without concern. However, two of the participant dyads clearly expressed that home visiting by the researcher should be when the children were at school as neither family had informed their children about the parent's mental illness. The parents in the two dyads did not trust themselves or society that their children would not suffer if they and or their peers knew they had a parent with mental illness. As time progressed, parent employment schedules meant my visits to the home would vary and hence the children were at home some of the time. The children being at home and my visits being welcomed was disclosure whilst the rationale given by the parents for my visit concealed the true reason. Within this context, home visits prompted questions by the children as to the nature of my business.

An example of parental response to the six and twelve year old in case study two was the mother saying she needed to learn the skills of injection giving for her employment.

The 12 year old is asking, are you getting divorced? Are you fostering? (Case study 2 notes following home visit).

The question not established for these two families was whether researcher visits led to the children feeling unsettled and not trusting the rationale of the visits as stated by their parents.

6.7.1 Employment and the patient's dilemma

Achieving employment is a challenge for people diagnosed with a serious mental illness (see section 4.7.7). When employment is achieved, for some entirely through their own volition, for others with the support of an employment support worker, there is a dilemma for the patient as to what level and to whom they disclose illness concerns. For four of the case studies within the research project, once employment had been achieved,

challenges arose about access to mental health services to receive prescribed treatments. The patients, willing and recognising the need for these treatments, were seeking access to mental health services that could facilitate the provision of these treatments outside of the patients' working schedule (see section 2.2 related to insight). When the required mental health service provision was available only between Monday to Friday 9am to 5pm, and this was the time the patient was in employment, the patient was left with a dilemma.

The patient, in order to gain access to the service during employed hours, may have to disclose their mental illness to their employer and thus experience the potential consequences of this disclosure. The disclosure could be verbal to their manager or work colleagues, or the patient may non-verbally disclose through behavioural changes to their daily routine, for example, having to leave work early on a set day of the week or missing lunch or creating a story that their children were ill. One study participant, disclosed, non-verbally to his employer through drowsiness and being less effective in his employment on the Friday following receipt of his depot injection. This drowsiness was noted by his employer and resulted in discussions about his ability to do his job. The feeling of drowsiness was related to the depot medication which was administered during the week and had a peak absorption time of forty eight hours. The discussion and findings within this section about patients having to create stories to access treatment rather than disclose to others align to the work of Corrigan and Kleinlein (2005) in which individuals with a concealable stigma, such as a mental illness, are confronted with the dilemma of disclosure. Disclosure has the potential to result in loss of employment, social isolation and abandonment by friends or neighbours.

For another patient accessing treatment meant taking twelve days of his annual leave to attend for his monthly depot injection. His concern was that his employer would ask the reason for requesting a Wednesday off on the first week of every month. He had to conceal the reason for this regular and consistent pattern of behaviour. This led to stories being made up about family illness and he had to be on alert and pick up when fellow employees asked him about this. There was purposeful deception going on. The patient felt he was letting his employer down sometimes when the latter asked if he could take Thursday off instead. Getting known as 'the Wednesday off' man was a pattern he was aware of. On the other hand, taking twelve days out of eighteen days annual leave entitlement to attend the depot clinic, which worked as a concealing strategy within this

employment, meant that his family had the benefit of only six days annual leave for the family holiday.

Having to inform the manager why he needed these days off work, which he did not want to and did not tell him the whole truth (Case study 2 supportive person).

If I had to claim benefits, it would mean loss of work, loss of independence and a possible change in our relationship (Case study 2).

This is the third letter I have received from mental health services inquiring as to my non-attendance at my Tuesday appointments. I write back and tell them I am working full time and can they see me in the evening or week-end. I cannot tell my employer that I am receiving treatment for mental illness (GTTN/09 client who gained temporary employment, was offered full time employment and was in receipt of depot medication. Client was not a participant in the study).

The origins of this research study initiated from a patient, who had gained employment and was losing two hours paid employment through depot clinic attendance and sought an alternative. The options explored with her GP practice only partially met the patient requirements. Achieving employment is a significant achievement for a person with a diagnosis of psychosis and is an important goal in recovery-orientated mental health service delivery (see section 3.5). Yet by gaining employment and with the clinic hours as they are, the patient is placed in the invidious position of having to disclose to the employer either that they are in receipt of on-going treatment or not giving full information to the employer. In other words, either concealing or disclosing levels of information. Both options could have personal and financial implications for the patient.

6.7.2 Home administration; culture, relationships and concealment

For four case study participants, employment was the expressed rationale for their interest in home administration. However, expressed agendas can have hidden agendas attached. In linking this to empowerment philosophy, it is accepted that differing or hidden agendas can exist between the parties involved, although there should be a common agenda between all parties (see section 4.6) and that participants may use research involvement for reasons other than the intended research purpose (see section

6.8). Within this study, the potential hidden agendas at the beginning were about exiting mental health services and avoiding mental health centres.

I am a sensitive person. When I visit the mental health team base, I see other clients and worry and feel what they are going through. This bothers me a lot when I come home (Case study 3, 4/11- recipient of depot injection).

We were discharged from mental health services at today's CPA meeting. This is what we hoped for all along (Case study 2- supportive person).

Having the partner involved in the administration of the depot injection could be a way of coping with mental illness. It was possibly a way of avoiding contact with mental health services or avoidance of a depot clinic where there is visual evidence of distress. Having a GP involved in the prescribing of medication, on the surface can be seen as a progressive and positive move, a step away from involvement with mental health services. GP's are generally seen as not having an expertise in any given medical domain so they accessible for any health reason. Attendance at a GP surgery for a prescription for depot medication and equipment may be a less stigmatising process than seeing a psychiatrist for a prescription or attending a mental health centre. Attending a GP surgery is also consistent with the policy of moving more of the care of LTC's to primary care (see section 3.4 related to LTC's and choice).

Understanding the patient's role within the family home and the cultural significance attached to that role is an aspect of the patient's life that plays a part in whether supportive person administration of a depot injection is feasible. One potential referral to the study was a client who was male and from an Asian background. The research study was discussed with him by the depot clinic co-ordinator but the client stated that his status as head of the home and the association of mental illness with stigma meant he could not consider being a participant. Engaging with the study would have necessitated disclosing details of and the receipt of a medical intervention for his mental illness to a family member and he could not countenance this.

I am responding to a complaint from a patient about not offering a home visit to administer the depot injection. The patient did not like to attend the depot clinic. Having discussed with the patient, at his home, his concerns were one of being male, being the head of the household and being of Asian origin. Stigma around mental illness is a big issue in the Asian community. I did discuss the research

project with him as he has family members living with him, but the patient stated that as he is head of his household, he could not consider discussing his mental illness with a family member (Depot clinic nurse, GTTN).

In preparation for the supportive person administration of the depot injection, the study worked on reminder strategies by which the due date for the depot medication would be remembered. For some of the patients within the study, employment gained had been a factor in engaging with the research study. The achievement of employment, the distraction of this, the onus of self-responsibility and the break from clinic routine meant that strategies necessitated discussing and developing within the home so that administration dates would be adhered to. The objective was to avoid non-administration because the patient or supportive person forgot the date.

Identifying and remembering depot injection dates meant using calendars or diaries or in-house language codes. This led to discussions about the potential for information relating to the medical intervention to be seen by other family members or outsiders when the patient did not want to disclose it. Examples of reminder codes were a tick on the calendar date or a code in the supportive person's diary which would be difficult to decode without intimate knowledge of the patient. This code could be an abbreviated pet name from childhood or the patient's full name in initials only. Another example was an expression more commonly used in reference to the female monthly cycle 'time of the month' and this was used when the patient was male. This language development was new and based on increased sensitivity of the supportive person towards the patient.

This entry in the diary is a safe one- in the event of the diary being lost; no one would link the OVB to an injection or actually understand the meaning of OVB (Case study 3).

I remember because I am used to it- I do not remember because of how I am feeling. I have no extra symptoms to suggest the medication is due. For me, the medication makes no difference. I got used to three weekly as I have attended the H clinic for years. I have continued having the injection on the same day (Friday) that I used to have it when I attended the depot clinic (Case study 2 - recipient of injection).

I put a tick on the calendar (Case study 3).

I am likely to say 'are you all right? More frequently on or about the time of the injection is due (Case study2 supportive person).

Last week I noticed R's mood was different- he was impatient, less tolerant and quiet. I joked with him 'is it the time of the month?' Knew I had to do R's thing. (Case study 2 supportive person).

Clearly for some of the participants within the study, using the word schizophrenia or hearing it used within the context of their family member was difficult. For one participant couple, it took four years for the wife to say 'I have finally said it' meaning she had said the word schizophrenia out loud but not in the presence of her husband. For another study participant, the word schizophrenia was not to be mentioned within the home. This participant would inform other family members that he had depression but the most common agreed diagnostic title was one of a headache. There was fear and shame attached to the use of the word schizophrenia and for one family, whose eldest son had a diagnosis of schizophrenia, the fact that the eldest son was not able to follow in his father's footsteps was of huge significance.

The word/diagnosis 'schizophrenia' is not to be mentioned in the house. Why? Fear, disappointment, shame and concern. The agreed code is headache or depression to some members of my family (Case study 2 observer notes).

My husband is not keen for D to have his injection long term- I think the concept of needing the injection long term is difficult for him. He would prefer D to attend a church for a blessing or some sort of healing. For a father, it is having his eldest son/heir, to have a degree and take over the business from him and where we come from this is very important (Case study 2 supportive people).

In summary, taking on the role of depot administration requires adjustments to the patient and supportive person's communication within the home if concealing the mental illness is a factor. This involves developing reminder codes to assist remembering depot due dates. The language used by the dyads within the home to conceal or discuss mental illness is important to know.

6.7.3 Stigma and talking therapy

Within CPA review meetings, a referral to counselling services was discussed with two patient participants within the study. The referral discussion was about the view that personal therapy would enable the patient to be more alert to his own distress symptoms

and gain a better understanding. These two patients did not wish to engage in counselling (CBT therapy). On exploring their reluctance to engage in talking therapy, both felt it was a difficult to talk to a therapist about how they felt and it was a stigma to have counselling.

Fearful of discussing with a counsellor his issues – it is a stigma to have therapy (Case study 2).

In summarising, there are potential opportunities for concealment at both a personal and interpersonal level within the management of a mental illness. How individuals disclose levels of knowledge and to whom, influences their own psychological wellbeing, their family and mental health service relationships.

6.7.4 Equipment; storage, delivery and concealment

Participants within the research study devised a language when discussing mental illness or the medication related to the treatment of that mental illness, which concealed the mental illness from other family members and visitors.

In the early stages of the project, discussions took place between the participants and the researcher about the mode of contact and the times most suited to the participants to contact them. In relation to telephone contact, the time best suited to the participants was when the children were at school and outside of employment time. Lunch time contact was frequent as participants felt they had the privacy and space to talk to me and use a mobile phone. For contact by texting, the time did not matter.

When medical equipment, for example the needles, syringes or medication, were being delivered to the home or had been collected by the participants, a bag that promoted well known stores or a chocolate box brand was preferred.

We exchange bags, Marks and Spencer's bag. Joked about the 'drug exchange' programme (Case study 3).

D suggested leaving one copy of the research information leaflet at his flat and one at his mum's house. Things get lost here. The equipment will go to mums house (Case study 3).

Use a plastic bag and an empty Ferrero Rocher box to transport medication and equipment (Case study 3).

In discussions about the home administration of a depot injection, the storage of equipment linked to the administration of the depot injection was identified as an area of concern. Where would the needles, syringes, clinical waste box and medication be stored within the home that would make it safe and non-visible to others? The concerns identified were related to the safety of such equipment for others, particularly children and visitors, and fear about what would be disclosed if such equipment was found within the home.

The common factor linking storage sites within the home was one of height, for example on top of kitchen cupboards, or on top of the bedroom wardrobe. The bedroom wardrobe had two layers of protection. One was the height of the wardrobe such that a climbing resource like a ladder or chair was required to access it. The second was the bedroom was seen as less accessible by other family members and by visitors. The third tier of protection was the locking of the bedroom – this was not evident in the homes where children were always present but was in homes where children visited.

Where would the equipment be stored? Equipment given to Mum to be stored at her house, I am concerned that somebody might see the equipment in my flat. Things get lost in my house (Case study 3).

The bedroom is kept locked when I leave the house – we have a ‘drop in type home’. D has a key as well as me. Locking the bedroom is not new- I have always locked my bedroom as we operate a type of ‘open house’ (Case study 3).

The storage of equipment would be an issue for me- particularly keeping the equipment away from my nephews and nieces and anybody else who has no business to know about it (BHC/4).

The equipment is stored on the wardrobe in the bedroom. I would need a chair and a handle to reach. In fact, I am a short person that sometimes I cannot reach it, so I depend on R to get it (Case study 2).

Whilst the locking of the bedroom concealed the equipment, it posed a dilemma for the patient and the supportive person as they would require a rationale for the bedroom being locked and how this behaviour would be interpreted by others. As an aid to transporting

the medication and equipment from mental health centre to home, the Ferrero Rocher box was seen as a useful strategy. As an item for storage within the home, it had its drawbacks. Such a labelled box was attractive to children. The patient and family member involved in the administration of the injection had to stay alert to family visits and to people staying overnight and evolve other possible secure places.

The data from the study indicated that families did have concerns about the storage of medical equipment within their home. While it is important from a risk management and safety point of view to understand these concerns, it is an aspect of home administration that the patient and family had control over. Fears about disclosure to a wider section of society and their potential responses and the likelihood that it could occur, would be minimised by having clear structures about storage and information sharing within the home.

6.7.5 Home record charts and concealment

When the study initially started, the patient's prescription chart was collected with the medication from the mental health centre and brought to the home. Once the medication was administered and the prescription chart was signed, it would be returned to the community mental health centre. The heading on the prescription chart was of concern as it clearly stated 'depot anti-psychotic medication'. This was perceived as a problem as other family members might see it and ask questions (see figure 6.1 of action research cycle related to this topic).

The heading on the prescription chart is depot anti-psychotic medication. I have a problem with this heading- if and when extended family members were about and saw the chart. I would like a less obvious title (Case study 3 –supportive person).

As the research project progressed, discussions with the Trust pharmacist identified that the patient's prescription chart was Trust property and as such, should remain within the mental health centre. Utilising a problem solving approach and action research cycle (see section 5.9 and figure 6.1), it was agreed that a home administration card could be developed for the participants to keep a record of depot administered at home. This home record card would be family property and as such could have a title or heading that was

agreeable to the family. Following discussion with the families and the mental health team, the heading on the cover of the home administration record chart was ‘Medication home administration record’. In essence, the title could apply to any medication being taken in the home and was not an immediate discloser of anti-psychotic medication.

Figure 6.1 illustrates the action research cycle in developing the home record chart (see appendix 15).

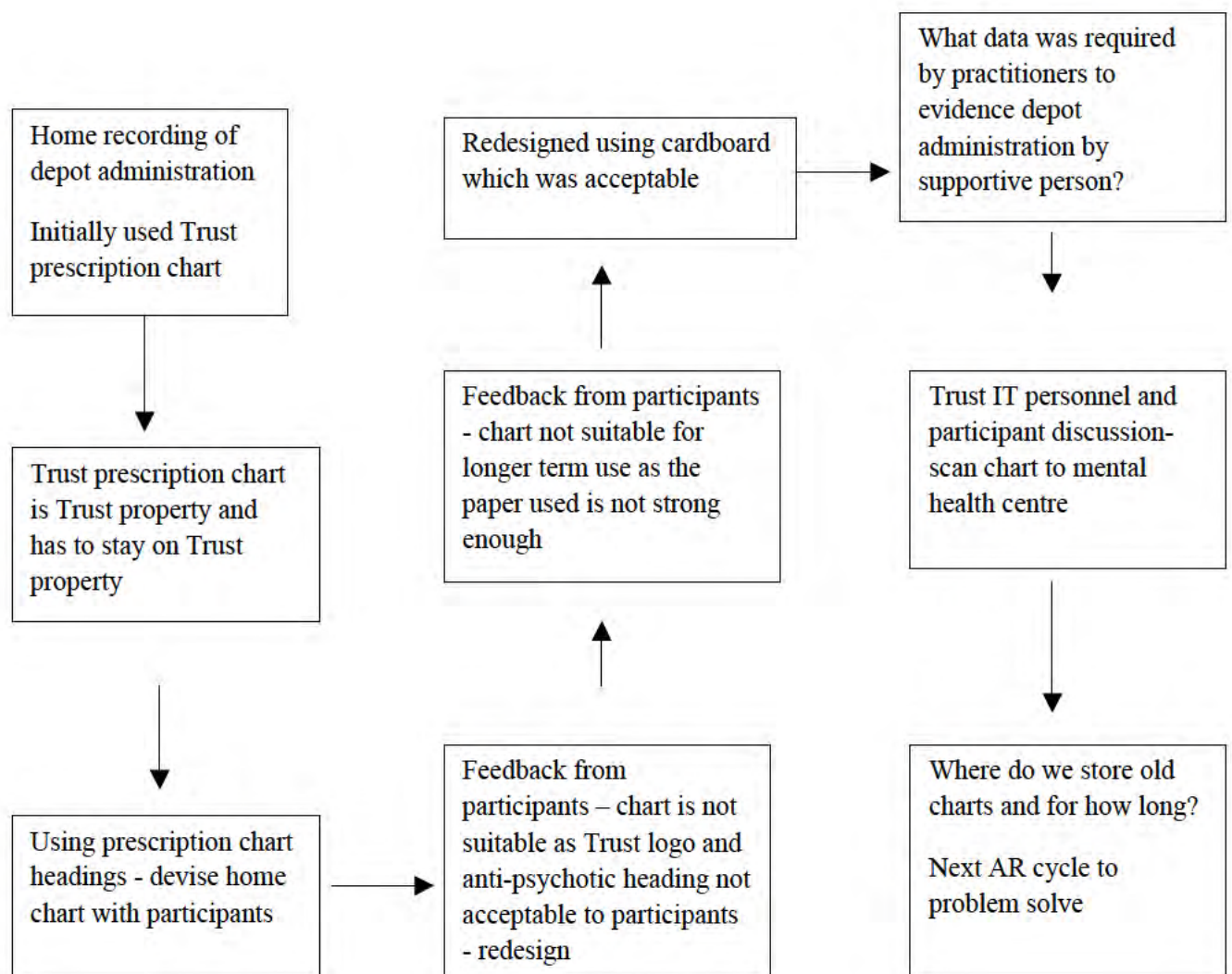


Figure 6.1 The action research cycle in the development of a home record chart

The study did not explore with patients or family members how any oral medication which was prescribed for mental health treatment was stored and managed within the home. Oral medication also had the potential to disclose information about medical treatment if seen by other family members. The question would be if the oral medication was stored within the same safety parameters assigned to the injection equipment, high up and requiring reminders, then maybe this storage contributed to patients forgetting to take their prescribed oral medication. The storage of oral medication prescribed for the treatment of a mental illness is an issue that may give rise to concealment and disclosure issues within the home for the patient. Mental health staff could be more alert to this issue and discuss it with the patient when the medication is first prescribed. This is a recommendation for future practice.

6.7.6 Role change of supportive family member and consequential disclosure

The family member taking on the role of administering the depot medication was required to gain knowledge of mental illness alongside the skills of administering an injection. A rationale for the knowledge of mental illness was that a link could be made to the depot treatment being offered. Additionally, home administration meant that third party interactions and observations, e.g. not seeing staff at the depot clinic, necessitated the development of a knowledge base by both the patient and the family member to recognise distress signs. This necessitated disclosing information about the illness itself and to a degree how the illness affected the patient. There was a role change from being a supportive person or carer to a person who administers the medication, both within a family structure.

The patient role within the nurse patient relationship, the nurse's skills (medication management) come first, then you build on the relationship with the patient. We, nurses, are not required to know the patient intimately before we administer the depot injection. This is not what the carer might experience. They would need to know about mental illness (GM101/4).

I do need to have more knowledge about the whole thing. Medically, before you came along it was his secret. I did know he was having an injection monthly. I only know what he tells me and I read the handout the doctor gave us (Case study 3 supportive person).

The gaining of knowledge about mental illness as part of the research project led to some concerns from the supportive person that this knowledge might impact on their relationship with the patient and the supportive person might indirectly gain more knowledge about the patient's illness. This knowledge might lead to questioning and analysing the patient's diagnosis and behaviour or even to the analysis of other people's behaviour. One participant felt it would give the supportive person power over her.

It occurred to me over the past week that if my husband learns how to administer my depot injection, it would give some power and control over me and may want to give an injection when not due. This has not occurred to him. We will discuss it further when the time was right (Case study 1 session 3).

I told the doctor I thought R was lazy. I feel guilty, now that I am aware of negative symptoms. Lack of energy could be a negative symptom (Case study 2 supportive person).

Relationships may be impacted on as a consequence (Case study 1).

I would not want to give my husband an injection- I would rather have the relationship as it is now (BHC/4).

One way of interpreting this fear and uncertainty about knowledge gain, would be to suggest that family members who are seen as supportive to the patient, have in fact limited knowledge of the mental illness and the impact of the illness on the patient. This would also suggest that there are degrees of concealment within long-standing relationships where the routine of attending for an appointment, or attending for a depot injection, is known about but little is known about the rationale for the appointment.

One wife who had been married for thirty years stated that parts of her body and person were private and she would be embarrassed if her husband gave her an injection.

I have known my husband a long time- I would be embarrassed if he gave me my injection (Case study 6).

It is not possible to know the level of information-sharing about long-term conditions that occurs in any marriage. Embarrassment is understandable in that the injection would be given in her bottom and as Lawler (1991) argues, there are taken-for-granted ground rules as to which parts of the body is it socially permissible to touch and see within

healthcare. The boundaries that any married couple accept about touch and visibility are personal to them and contextual. Lawler suggests that non-sexual touch is integral and fundamental to nursing, and the nurse will ordinarily negotiate permission to see and touch before the giving of an injection. In the administration of the depot injection by the husband at home, there would be overlap and confusion between healthcare touch and visibility boundaries and husband and wife touch and visibility boundaries. This was not explored within the study.

The husband in the case study six had never been invited by his wife to accompany her or enter the mental health centre even though for many years he had taken his wife in the car to the centre. He would wait in the car. By inviting the husband to stay outside, it is possible an aspect of his wife's life and care was being concealed from him. Within the context of the couple's current living arrangements, her perceived embarrassment if her husband gave her an injection and his expressed fear that knowledge of his wife's mental illness may make him question his wife's diagnosis, would suggest that there were aspects of mental illness that had not been discussed or disclosed between them.

In gaining knowledge about the illness and medication may lead me to question or analyse L's diagnosis. I might analyse the behaviour of others? Relationships may be impacted as a consequence (Case study 6).

My husband does a lot for me – without him I would not manage. He takes me to the clinic, he sits/waits outside the building as it is claustrophobic inside- there is such a small waiting area (Case study 6).

The patient in another husband and wife dyad, (case study 1) who embarked on the research study, did not wish to attend all the knowledge and skills information sessions. She stated that she did not want to 'know everything' about her illness or the injection process. This patient stated that, when she was a child, her father used to have periodic absences from the family home. Her father's absence was never discussed. The patient, who is now in her forties, assumed he had a mental illness and his absences from home were related to hospital admissions for treatment.

I do not want to attend all the sessions as I do not want to know it all (Case study1).

The study data suggests that as the time progressed the knowledge gained by the supportive person was used to support and be more responsive to the patient's distress.

I have more knowledge about his illness and medication. I did not know a lot about it before. It was not something we spoke about. We did not speak about it within the relationship. There is not more discussion now but it is more open. It is not hidden away. This refers to discussions with family members and with me (wife). He used to never really talk about it to me. He used to go for his appointments and that was it. I knew his appointments were for a depot (Case study 2).

In discussions within the carer groups, there was optimism that having a role in the administration of medication might contribute to a positive change in the relationship between husband and wife.

6.7.7 Consequences of children becoming aware

Case studies one, two, and seven within the research study had young children themselves and had not informed the children of the parent's mental illness. Case study six, whilst they had young grand-children visiting the house now, they had not discussed parental mental illness with their own children. Case study seven had informed and involved their children in discussions about parental mental illness. One parent who had a mental illness and who attended the depot clinic for her injection offered a rationale to her child for having to leave the home. 'I have a dental appointment'; 'I have shopping to do'. The boy of 14 years used to say to his mum that she was seeing the dentist very often.

The parents had concerns about the children finding the injection equipment within the home and then asking why it was there (see section 6.4.3). The parents had concern about the physical safety of the children and this particularly related to needles. They had to consider on one hand, the concealing of the injection equipment from their children, what to do if this equipment was discovered within the home by the children and on the other

hand what and how to inform their children about their parent's mental illness. The parents also had to consider if they informed their children, what the consequences for the children and themselves might be. The parents had real concerns that by disclosing to the children or the children finding out about their parent's mental illness, the children would become targets of abuse and bullying by their peers. The parents could control or influence what language and behaviours went on within the home in relationship to mental illness but could not control what went on outside the home with the children's peers. A potential consequence of the children becoming aware was that they may inadvertently let class mates know.

The parents were discovering that engaging with this research project, for the purpose of having choice about depot administration, elevated other issues about mental illness to the fore.

R fears informing the children as they may well be stigmatised by other children e.g. living with a madman (Case study 2).

I am concerned that if my son learnt about my illness, he might become a target of ridicule at school because of the associated 'stigma' with mental illness (Case study 6).

R informed the two eldest children of his illness and need for injection. Discussed the smoking of cannabis and how this contributed to his illness. R reports feeling good about informing his children (Case study 2).

The family of case study seven whose children were incorporated within the discussions about their parent's mental illness did not express any such concerns. It could be that by disclosing the parental mental illness to their children, the children's fear and mystique about the illness was reduced. The power of the secret would be reduced and as such the need to share their secret with other children would be reduced. Any concerns the children had about the illness could be discussed with their parents who in turn would offer the children support and protection from peer innuendo.

The data from the study identified that families did have concerns around the storage of equipment like needles, syringes, medication and prescription charts within their homes. While it is important from a risk and safety point of view to understand these concerns, it also seems to be an aspect of home administration that the patient and family could

control within the home. Relating to the other fears the family may have about how society's response if their mental illness was disclosed is out of their control, so the focus on indoor concealment might be a way of dealing with the uncertainty of what happens outside.

6.7.8 Disclosure through crisis

Two families experienced what they described as a crisis which necessitated them seeking support from a wider family network during the course of the research study. In seeking this support, disclosures took place about mental illness. In case study two, the crisis related to a discussion between the supportive person and the patient about the smoking of cannabis, which up to now, was occasionally tolerated. The supportive person, with a young family and patient in employment, wanted the smoking to cease. The resultant discussions led to the participants disclosing to a number of relatives, their mothers, and two selected and close friends about the diagnosis of schizophrenia. Reflecting on this disclosure, the research participants felt it did not change their relationships with their mothers. It did however change the relationship with one friend who had rarely made contact since the disclosure.

Since last Christmas (family crisis) other people outside the family know- R's mum, my mum, two friends, cousins that R was brought up with. This is a huge change (Case study 2 researcher's emphasis).

The patient in case study three, whilst on holiday abroad with his brother, had to seek his support to access medical facilities for his depot injection. The brother as far as the patient was concerned did not know of his mental illness. The outcome in seeking his brother's support was a change of relationship and the research participants felt this was the result of the brother whom the patient was visiting, discovering that the medication he was taking was for a mental illness. The supportive person surmised that the brother whom the patient was visiting found out more about the type of medication and was concerned for his young children. Since this event, the brother had not instigated an invitation to stay in his house which was a significant change in behaviour.

One brother of D is not so keen – an example – when D was in the USA some years ago, and he required his injection, his brother facilitated him attending a medical centre locally for his injection. This brother is now more reluctant to have D for a visit – he seems more distant (Case study 3).

Theoretically, planning for a crisis is more challenging if aspects of the mental illness presentation are being concealed. Family members who are involved in the administration of the depot injection medication having knowledge about mental illness would be a prerequisite for the whole project. Knowing and understanding detailed aspects of one's personal illness signs and symptoms in the event of a relapse would potentially be a threat as a level of information which may not be known to the family would need to be disclosed. This important point is a reason why disclosure as a concept is developed within this study. For one study participant, a threshold of distress had to be reached before disclosure was offered to their supportive person; reaching this threshold also meant that disclosure would and could be made to other family members as the patient's level of fear and awareness was altered.

RW reports her husband is someone who keeps his thoughts to himself until there is some sort of crisis and then he releases his feelings and concerns (Case study 2).

Thus the releasing of significant information may occur after the patient had reached a certain threshold of distress; this required an understanding and recognition from family members of the importance of a crisis in enabling disclosure and the post-disclosure support required by participants. Identifying supportive contacts and structures, not just the 9 to 5 mental health structures, was an important aspect of care planning and relevant to including in the training package for future users of the innovation.

6.8 The nurse and depot injections: role change and delegation

The study data suggest that the administration of the depot injection within mental health is a role strongly associated with the mental health nurse (see section 1.3). This data came from interviewing practitioners of medicine, management and nursing. Developing the expertise of administration had taken some time (years) and this expertise helps to define the nurse as an individual and as a member within the community mental health

team. The data highlighted that change to the current role of the nurse as administrator of the depot injection could take a number of directions and have a number of consequences, for example, loss of the role, a role change or a contribution to the development of recovery orientated services. What would remain within this change is the role of the nurse as care co-ordinator.

Injection giving and its definition of nursing (GP19/5).

We have always assumed that practitioners are best placed to administer depot injection (GM101/1).

Depot administration often seen as a strong part of the community nurses role (BN101/6).

Within the research data, loss was identified as an issue for the nurse. This loss was attached to the role of the nurse and the association of the role with the administration of the depot injection as well as to change that would occur due to the role change.

Emotional cost of letting go of the role, this would cause some anxiety (GP19/5).

Taken years to train – personal definition of expertise and why and how to let go. I think I would be fearful of being left out (BN101/3).

Linked to the feeling of loss, was the loss of expertise and its implied status. There was an emotional cost to letting go of the role. Part of this loss was associated with the investment in years to develop the skills and knowledge about medication management and develop the expertise about the administration of the depot injection. A link was made to professional territory. Another aspect of the change was the nurse losing control over the administration process and concerns that the patient and carer may collude to hide information from them. Adding to the loss was the fear of failure. If the patient and the role of depot administration came back to the nurse, it would be seen by the nurse as a failure. It was not clear from the data on whose side the failure might be.

It is a new concept for clients and carers and for us to hand over- I am not a controlling person but I do like to know what is happening – it is a form of control (BN101/8).

The other person taking control (GP/19/4).

The role change that may occur as a consequence of enabling the supportive person to administer the depot injection was related to decisions taken within the nurse's role as care co-ordinator. This role was about organising, conducting review meetings and offering education. An important function of being care co-ordinator was to make a decision about the suitability of the patient and supportive person for the research project.

In the event of the nurse deeming a patient not suitable for supportive person depot administration, interventions could be initiated to remedy the concerns.

A role to reject a participant from the project due to subjective values of 'good relationship' and 'any negativity' , another role of the care co-ordinator would be to direct the carer on 'what to do and how to do it (BN101/4 -interview data).

One decision may be to refer 'for couple therapy as a prerequisite to being accepted', correct 'family dynamics' before joining the project (GP19 interview data).

The nurse would have a role in observing the supportive person in the administration of the depot injection, giving feedback and assessing the knowledge behind the administration process. The nurse would then be required to make a judgement around their competency to take on and continue with the role. Without clear structures and measuring tools, this decision to agree to the continuation by the supportive person would involve subjective decision making. The skills of the nurse would require self-awareness and assertiveness within the decision making process. Whatever the outcome of the observation, there are challenges for the nurse to work in partnership with that supportive person and patient in the nurse's role as care co-ordinator. The supportive person attending the CPA meeting would now be in different role, and have different information which the services need, from the depot administration experience. This information and concerns would need to be heard and recorded and the nurse would have to include third party evidence into the patient's clinical notes.

The data suggests that by delegating the depot administration role to another person, the nurse would move into a more consultative role and this would be in alignment with the medical role of consultant.

Alignment with medical staff- a more consultative role (GM101/9).

The psychiatrist who prescribes the depot injection delegates the role of administration to the nurse, who in turn delegates to a supportive person. Potentially there would be a change in the relationship between prescriber and the nurse as a result of third party depot administration.

6.8.1 Service provision

Patients reported feeling upset by the frequent change in medical personnel whom they met at clinical review or outpatient appointments. Their expressed frustrations were that it was not possible to build relationships with the health service practitioners when there were new faces on every visit (see section 6.4.5). There is little time to develop these relationships; the focus of the appointment time is the regurgitation of the patient's diagnosis journey and the consequent risk management approach to questions.

it is difficult when you see a different psychiatrist every time you attend the clinic. They ask the same questions – questions that I could ask. They (psychiatrists) do not know R – all they have is on the screen in front of them. All they see is the diagnosis 'schizophrenia' and then they ask the usual questions .No one has ever asked to see the home administration record chart (Case study 2- supportive person).

Within these one off appointment meetings, it is possible to conceal information and the newness of the relationship, potentially inhibits the disclosure of more personal information.

Following outpatient appointments at the mental health centre, a summary of the meeting is sent home to the patient by letter. Most participants within the study were alert to these letters, knew they were from the health service and would put them discreetly to one side so they could be opened when alone. As the research project developed, the letter would state that the patient was having his depot injection by a family member and the relationship of the depot administrator would be stated i.e. by his mother, by his wife. Two case studies saw this reference in the letter as being really important as the same letter went to the GP and the next time they wanted equipment, participants would make reference to the letter from the psychiatrist.

The language used within the letters by the psychiatrist was of note. This particularly related to the use of diagnostic codes, for example, codes from the International Classification of Diseases (ICD10). The use of diagnostic codes could be seen as a strategy for concealing a fuller description of the diagnosis and concealing information from the family. Two of the participants stated that such letters were condescending in the language they used and were binned as soon as possible. The letters were glanced at rather than read in detail.

FD20- schizophrenia, psychosis on letter- what do they mean (Case study 3).

Overall, participants found that frequent changes to medical personnel who managed the out-patient appointments led to relationship building challenges and frustrations with the repetitive focus on the patient's history. The absence of interest by the doctor in seeing evidence of supportive person depot administration was disappointing. The letter sent to the home and GP following the out-patient appointment used diagnostic codes to identify the patient's illness and these letters were not read in detail by the participants. However, when the letter made reference to supportive person administration, this was supportive of the study participant gaining equipment from the GP.

6.9 Summary and Conclusion

The aims of this research study related to understanding risk, developing a training package, understanding relationship change and ascertaining practitioner views and concerns when supportive persons are enabled to administer depot injections. In the analysis of the data, other themes evolved which became important to the study, namely trust, stigma, concealment and disclosure. The data corpus were generated from five practitioner interviews, which were recorded and transcribed, seven case studies, (five of whom involved depot administration) three carer meetings, the researcher's reflective log and hours of observations in and about depot clinics. The data were analysed using thematic analysis and the findings chapter is a description of the entire data set. The data were analysed inductively at a semantic level and within a realist/essentialist epistemological paradigm. Realism is a doctrine that considers that certain objects and

theories in science are real and within this study, this applied to the diagnosis of schizophrenia and to the medication used in the treatment of the illness.

One of the research aims was gaining an understanding of risk issues related to this project, a project which involved third party involvement in the delivery of a medical intervention. Risk is associated with the administration of intramuscular injections whoever administers them. Risk was identified within the data relating to mental illness and the potential changing nature of a patient's mental state. Concern was expressed about the supportive person having the knowledge and confidence to recognise change in the patient's mental state and relate this to the practitioner. It was possible the supportive person would be open to persuasion or even coerced into silence and would keep any change in patient behaviour from the services. The points raised above are all related to the research aims as they identify the concerns of practitioners.

The data identifies that the newness of an innovation is related to degrees of uncertainty and predictability and hence related to risk. The origins of the innovation had an influence on adoption with practitioners in the context of delivering recovery orientated services, but the innovation had not come from within the hierarchical structure. The current service ethos of target attainment and financial efficiency made considering the service user request challenging. The offering of choice within a mass producing service was a challenge as the clients who had gained employment discovered and offering choice and responsibility-taking involved elements of risk taking to the organisation, families and practitioners. The study findings highlighted the challenge in delivering flexible and accessible services within the recovery philosophy.

Taking on the role of depot administration may have both a positive and negative impact on relationships and stress levels. The negative impact related to the pain associated with injection administration, potential power and privacy boundaries. Positive impacts related to supporting a family member and contributing to giving them an element of choice. Establishing boundaries about role and responsibilities within the relationship took time to develop and evolved throughout the life span of the study. The findings illustrated that problem solving is a critical skill as it enables care plans to evolve, be individualised and establish clear parameters for all involved in such a project.

Initially the dominance of injection-giving skills and knowledge was evident, but as the confidence and competence of the participants evolved, supporting structures such as

relapse symptom management, supply of equipment and liaison with services came to the fore. The data identified the complexity of literature written for health professionals and used by lay persons on a medical intervention and the challenge to maintain IM administration skills when the skill is used infrequently. Service responsiveness through appointment flexibility was identified by the participants as important though frustrating to establish and unpredictable as it was practitioner dependent rather than being organisationally embedded. Some participants aimed for mental health service input reduction so flexible appointment support was important. The data identified that offering routine out-patient appointments with junior medical staff was frustrating and repetitive, rather than progressive and respectful of the depot administration role through discussions about and seeking evidence from the home record. The absence of a demand by the doctor to see evidence of depot administration was disappointing to the participants. This reduction in support had financial consequences in that benefits were reviewed and payment was required for GP prescriptions. Other study participants had a reduction of service support which left them feeling vulnerable to managing uncertainties within their own or family member illness.

The development of knowledge and skills was labour and time intensive at the beginning, although this also included questionnaire completion. If the study was fully implemented an economic evaluation of the implementation costs would be necessary. This period included liaison with mental health services and recruitment. Home visiting to develop relationships, the skills and observations during the evening and weekends required flexibility and would need consideration for future adoption. The study was an action research study so it was relevant and important to go with whatever the participant requested so a deeper understanding of the home as a context could be established.

Study participants found engaging with the study raised issues about the storage of medical equipment within the home and the function of the home was affected. These concerns related to the delivery and storage of equipment which had the potential to disclose a mental illness to others and a risk to visiting family members. Disclosure and concealment also potentially apply to oral medication, so discussions with families about storage and access within the home should be considered as this may contribute to concordance rates. Depot administration had to fit in with the demands of a family home and home care necessitated the development of language to conceal mental illness from

others. Stigma management was of concern to the participants, their children and their employment.

Trust was highlighted in this study, including through trust in and between the patient, supportive person, mental health services and on the potential impact of the diagnosis of psychosis. Trust was a measure that influenced the delivery of care, was influential in practitioner's decision to delegate the role of depot administration and was both a mixture of behaviours and a perceived relationship status. Whilst the patient can exhibit trusting behaviours continuously like attending appointments and taking oral medication, non-trusting behaviours are powerful in their impact. A value system based on mistrust, on whatever side, can have an impact on care. Health literacy was relevant in the practitioners' consideration of potential research participants.

The status of the depot administration role is linked to the role of the nurse within the community mental health team and with professional identity. Delegating the role to another person was associated with emotional loss for the nurse and some anxiety about letting go of the role. Delegating the role involved the nurse in decision making processes about the suitability of the participants; teaching and assessing the participants in the administration process; on-going monitoring and support needs, which may involve a loss of services for the patient and support structure for the supportive person. By delegating one aspect of the nurse's role, the administration of the depot injection necessitated developing the knowledge and skills of the patients and supportive person. By enhancing the knowledge and skills and by letting go of the administration process, the nurse would then have to collaborate with a supportive person and to a patient in a different way. The relationship changed from a 'doing intervention' to an enabling and sharing intervention and this required new skills, and trust for the nurse to function. Potentially, there would be a change in the relationship between the nurse and the family and between nurse and psychiatrist as a core function of the nurse would be fulfilled by a third party. This change would involve trust, risk management and a change in the power relationship. Potentially both nurse and doctor could assume the other has responsibility to seek and check for evidence of depot administration and potentially the depot administration could fall through the gap. Theoretically, the role change by the nurse could be seen within an emancipatory stance within clinical decision-making as identified by the NMC (2010) and theoretically linked to the enactment of the recovery philosophy which is espoused by the NMC as well as national and local policy.

These themes arose within the context of gaining more knowledge about an innovation and within organisational and personnel change. Issues related to the key themes will be discussed in the next chapter under a wider lens.

Chapter 7

Discussion and Conclusion

7.0 Introduction

This chapter will restate the original research questions and place the issues raised in a wider context. The issues that are particularly addressed are about action research (AR) and its appropriateness for this study and the implementation of empowering philosophy with its implications for service delivery. Recommendations for practice, policy and research will be made.

The study data were derived over six years of implementation of the study. Data originated from five semi-structured interviews with prescribers and administrators of depot injections, seven case studies, three carer meetings, 30 hours of clinic observations, peer feedback opportunities, CPA and outpatient meetings and researcher reflection.

In this discussion, it is relevant to revisit the research questions (see section 1.1), and consider whether these questions were addressed and whether the methods and methodology used were appropriate for such a study. The questions asked are very focused on clinical practice. Theoretical underpinning is through empowerment philosophy (see chapter 4) and this theoretical framework will be used to underpin this discussion.

The questions stated in the LREC application (see appendix two) were:

to explore the elements of risk management involved in enabling carers (supportive persons) to give depot injections

to develop a training package that may be useful for others to use should such a request be made

to establish whether enabling supportive persons to give depot injections would have an effect on the relationship between the user (recipient of the medication) and the supportive person (giver of medication)

to ascertain the views, concerns and attitudes of medical staff (prescribers) and mental health nurses (administrators of depot injections) about enabling carers/relatives (supportive persons) to give depot intramuscular injection medication.

7.1 Research aims

The discussion and conclusion chapter will be presented under subheadings as identified in the aims in the research study.

to explore the elements of risk management involved in enabling carers (supportive persons) to give depot injections

Risk permeates all aspects of the study, including mental illness, third party involvement, the injection process, support structures, potential collusion between the supportive person and patient, home as a base for medical treatment, monitoring and letting go of the role.

The literature review in chapter 2 established that risk is an emotive concept, and its premise of negativity within mental health may obstruct rational debate about it within the caring context. The literature identified that the concepts of insight and capacity are central to mental health care and informed consent seeking. Permeating insight and capacity debates is an assumption about the impact of a diagnosis of schizophrenia on the patient's decision-making capabilities. The literature in chapter 2 established that the ability of the patient with a diagnosis of schizophrenia and psychosis to give informed consent is primarily one for the clinician who is engaged with the patient to judge. Whilst there is legal and professional guidance to support and inform the clinician in making a judgement related to consent seeking, this is not mental health specific and is likely to be influenced by the practitioner's values. However, isolating issues of insight and capacity as unique to mental health is erroneous as the literature suggests that they are relevant to all medical conditions. The origins of this study and the service response, together with recruitment difficulties to the study, would suggest that insight and diagnosis are very powerful in practitioner decision-making.

Integral to making values-based decisions, as discussed in chapter 2 is the issue of trust and mistrust. The literature discussed in chapter 3 relating to depot injection and practitioner perception states that it is a last resort treatment because of compliance issues and is associated with stigma by health professionals. This shows the importance of values-based practice within mental health (Woodbridge and Fulford 2004). Further understanding how values impact on and influence choice and responsibility-giving within mental health would be useful.

The literature review in chapter 2 suggested that there is a dearth of evidence about patients' own experiences of being risk managers. Data within this study suggest they were managing elements of risk e.g. managing stigma; working with services in seeking to receive the prescribed medical interventions; administering their own insulin; concerned that services might be withdrawn; and not enamoured with frequent changes in clinicians because of the impact on continuity of care. The process of enabling a supportive person and patient, through assessments, teaching, feedback, home visiting and time will develop a deeper knowledge and understanding of the person and perhaps contribute to reducing risk. Undertaking this process will involve disclosure; this was identified within this study as being a significant issue, but it enables a more inclusive risk assessment and consequently assists in the management of risk (Hupcey et al 2001).

The literature in chapter 2 suggests that carers are rarely taught risk management strategies, but had copied strategies from mental health professionals. Data from the study identified carer concerns about some aspects of risk, but equally showed that carers were able to develop detailed strategies within the individualised care plans to manage and recognise thresholds of distress. This study adds to the literature related to individualised care planning and the unique indicators of relapse as well as unique approaches to managing differences. It contributes to the literature on the development of shared care planning or protocols and how this process supported the carer in managing risk; for example, the home medication records (see section 6.7.5 and figure 6.1). Integral to shared care and the management of risk is understanding how other themes evolved within the study which contribute to working and the making judgements in mental health, namely trust, disclosure, concealment and stigma management.

Third party involvement related to liability and legal aspects was a concern established during the ethical clearance of this study. In gaining LREC approval, the study clarified the legal and liability framework that gives a structure to safeguarding carer involvement. Third party medication administration was identified within the study related to other medical specialisms, for example third party administration takes place within insulin therapy and arthritis care with supportive person administration of subcutaneous injections. This study also found evidence of family members or supportive persons administering medication by intramuscular injection in renal, infertility and multiple sclerosis care. What this study established through the LREC process was these developments may not have been through ethical procedures as the initial response from

the Department of Health to carer involvement in this study was that the carer would not be covered under liability frameworks. This is an important contribution to care delivery in that it is a concern of the practitioner and family member to have confidence in the legal and liability framework.

In summary, the literature review established that knowledge, skills and experiences derived from other long-term conditions within health care relate to understanding how supportive persons can have a role in administering a medical intervention in mental health. The literature establishes that insight relates to all medical conditions, third party involvement in a medical intervention occurs, intramuscular injections are learnt and administered by lay persons and that patients with a diagnosis of psychosis can self-manage an illness. The discussion for the mental health practitioner is what the similarities and differences are and what we can learn from these that could inform the discussion on risk and not isolate mental health. Key differences that the study identifies are about fluctuating insight and capacity, a values system of mistrust and perceptions of dangers of the diagnosis of psychosis and the absence of a history of trusting third party administration. This study develops the literature related to risk and the support structures deemed necessary to support the family and patient in taking on an administration role. Within this study, related concepts like trust, disclosure and concealment were identified as being important by practitioners and dyads. These concepts need acknowledging and working with in order to contribute to management of risk.

Chapter 3 identified that government policies about personalised budgets, the expert patient and devolved budgets suggest a transfer of risk away from the provider of services towards the patient and family, and that tensions exist between the enactment of these policies' philosophies (aligned with recovery philosophy) and a risk-averse approach. It is relevant to note that the Department of Health risk framework (DH 2007b) relates to three areas of risk; namely violence, self-harm and self-neglect – not to choice giving.

This study highlights the paradox of promoting choice and a recovery philosophy whilst managing practitioner, organisational and societal risk. Risk permeates all aspects of the study but the study suggests that if a problem-solving approach is taken, then it is achievable for a group of patients with a diagnosis of psychosis to have their depot injection administered by a third party.

to develop a training package that may be useful for others to use should such a request be made

There is literature and expertise on the teaching of skills and skills development (Benner 2001) and knowledge acquisition about injection administration. It would be reasonable to suggest that most if not all persons have skills and knowledge about medication management within the home, whether this is the management of an analgesic, antibiotic or hay fever medication. Recognising participants' existing knowledge about medication management can be a foundation on which to build IM injection technique. The teaching of key anatomical sites related to IM injection administration was facilitated by the use of manikins where key structures can be illustrated and where skin texture and resistance on administration can realistically be demonstrated. With the advent of the retractable needle and with newer depot medications being licensed for administration in the arm, the possibilities for lay person IM administration increase. An approach to risk reduction would be a strategy for the teaching and maintenance of IM injection skills when an activity is undertaken three weekly. The nurse, once the skills of injection administration are learnt, will be using these skills more frequently. A recall session every six months would provide an opportunity to refresh, assess and support the families in the administration of IM injection giving, alongside medication specific information; the extension of the expert patient could be the expert family.

The study established that expertise can be developed if the structures and processes are in place for as long as is required. With practice and expertise on both sides, the structures and processes can change. The study also established that, initially, supportive persons focused on the skills of injection administration. However, as competencies were gained, other important components of the supportive person administration role came to the fore, such as relapse awareness, accessing services and equipment, and maintaining skills and knowledge, all of which required developing. Integral to responsibility giving and sharing in a planned way is the gaining of greater understanding of the patient's and supportive person's needs and concerns. This greater understanding is likely to contribute to a reduction in risk, and through the process, expertise can be developed.

This action research study had organisational, practical, and academic outcomes and the sponsoring mental health Trust has been involved and informed of the study progress throughout. This was achieved at a clinical level through CPA and out-patient attendance

with participants, and at a managerial level through meetings with a recovery services manager who has been a constant and involved presence as well as a clinical supervisor throughout the study period. The sponsoring Trust requested that key structures and issues developed from the study be packaged as a manual. This manual will be based on the training package (see appendix 11) developed with the participants over the study period. The manualisation of the study outcomes will assist any patient and supportive person who may wish to administer their depot injection and clinical staff so they may facilitate choice within a body of knowledge. The journey for any future practitioner and service user will not be so cloudy due to the knowledge gained from this study. Legally and professionally there is a platform to start with and this will meet the second study aim. Additionally as the researcher, I feel obliged to promote through collaboration and marketing the maximum impact of the research on practice.

The study found that initial teaching and development of the skills and knowledge is time consuming at first, but over time demands reduce (Chapter 6). In managing risk within the initial process, active coordination by a committed, confident and flexible practitioner would minimise potential adverse events. The study also highlighted that disclosure, concealment, power, hidden agendas, and relationship impact are not readily identifiable by a patient and supportive person at the beginning so the practitioner would need to assess awareness and monitoring of these as the role develops.

Overall, in developing dyad competencies and minimising risk, consideration could be given to a modular approach to training for all patients and supportive persons who want to consider this depot administration option. Modules could include; understanding mental illness, anatomy and physiology, medication, skills development and maintenance, crisis management and service access. These modules could be given credits and packaged as part of the empowering and recovery philosophy. Recovery approaches like the WRAP and person-centred care are individually focused so a shift away from the individual to be more inclusive of family and employment would promote more sustainable services and recognise the family role within recovery. The literature in chapter 3 identified the family as key partners within recovery philosophy: partnership working with carers is essential to improved patient outcomes.

Considering the packaging of modular training, a suggestion would be each Trust to have five dyads involved in a similar project and coordinated by a named competent,

experienced and receptive practitioner e.g. a community matron who would build up expertise and confidence to develop further. This is particularly pertinent to a more rural setting where an economic argument could be put forward to the CPN's travelling long distances to administer depot injections. By working with a supportive person and client, even to administer every third injection would have financial benefits to it as well as the dyad choice element. Additionally, telephone support could be offered during the administration process.

to establish whether enabling supportive persons to give depot injections would have an effect on the relationship between the user (recipient of the medication) and the supportive person (giver of medication)

The potential impact on a relationship resulting from the supportive person taking on the role of depot administration is the third research aim. The literature in chapter 3 suggests that caring for a family member with schizophrenia can vary between being a commitment, to acceptance, to positive reward, to burden. Taking on a medical intervention alongside this could have the potential to impact on the relationship. Relationship impact was discussed in section 6.4.4. Study data overall highlighted positive relationships, with issues about power, demand and responsibility-taking requiring acknowledgement and discussion. Participant numbers who completed the evaluation on relationship change were small so it would be necessary to undertake a larger study to ascertain this.

to ascertain the views, concerns and attitudes of medical staff (prescribers) and mental health nurses (administrators of depot injections) about enabling carers/relatives (supportive persons) to give depot intramuscular injection medication.

Data related to this research outcome is integrated in research outcomes one and three. There is a significant contribution to the risk discussion based on practitioner concerns. Data distilled from medical prescribers of depot medication (two semi-structured interviews and clinic, CPA and meeting data) suggest that the depot prescribers do not have a generalised problem with the supportive person administering the depot. They identify some patients where this would not be feasible and some where it should be happening. The question is about the prescriber's connection with the depot administration process and the obligation of the nurse within this role. The nurse has responsibility for the administration process and has developed expert knowledge.

Handing over the role of administration of the depot to a supportive person could distance the relationship between the doctor and nurse, and this is significant given that medication is the dominant intervention discussed in review and appointment meetings in mental health. Medication is the lynchpin for discussions between doctor and nurse; roles are understood within prescribing and administration processes.

7.2 Action research and this study

The next section considers the study aims, and whether AR was an appropriate methodology to implement the study and answer the questions in an ethical and risk appropriate way.

A strength of AR is that it accepts the diverse perspectives of different stakeholders, the theory they each hold to explain why and how events occur as they do, and aims to find ways of incorporating each view into mutually acceptable ways of understanding events. This understanding enables resolution or a better understanding of the problem being investigated (see sections 5.3.2 and 5.3.3 on pragmatic and interpretive paradigms used within this study). These differing perspectives become subjects of interaction and negotiation as people creatively explore ways of conceiving the situation in ways that assist them in resolving a problem. Stakeholders in this study included; the Trust, NHS Insurance, families, patients, carers, mental health practitioners, managers and voluntary agencies.

There are essentially two strands of theory production described within an action research framework; the construction of local theory for testing (Argyris and Schön 1991) and the eventual contribution of theory produced to existing theories (Reason and Bradbury 2006). The term local theory perhaps best reflects the notion that knowledge produced through action research inquiry is contextually bound. For example, the social situation in my study refers to the staff, service users and carers who participated in the study and the contexts within where they live and work. More specific theory from within the study relates to individual responses to stigma management and individual experiences of engaging with the study such as the risk of disclosure by individuals with a hidden stigma. Within this study, participants developed local and contextual strategies for managing stigma within the home and work environments. The participant's potential

stigma or their awareness of its impact and significance is not recognised and recorded within the participant's care plan so theoretically, it is hidden from the practitioners as well. The medical aspects of the mental illness such as concordance and relapse prevention dominate the social aspects of the illness which are issues for the patient. Theoretically, there are power issues potentially built upon the view of practitioners that the important issues are what they discuss and not what the patient feels. The contribution to existing theory from this study could include a model for problem-solving ethical and liability factors in health research and the consequences of implementing empowerment theory for both participants and service providers.

The issue of informed consent is blurred within AR and consequently in this study. Participation in AR made it difficult to guarantee absolute confidentiality and anonymity because other staff within the mental health teams knew who was participating in the study. Neither researcher nor participant knew where the AR journey would take us therefore we could not fully know what we were consenting to at the outset. AR is an unfolding emergent process which evolves through cycles of action and reflection so it is not feasible to map out in detail all eventualities. This means that in AR continual renegotiation of consent between research and participants is required as the project develops (Meyer 2006). This occurred both implicitly and formally, within this study, as evidenced in attendance at meetings, home visits, and discussions with participants GP's, care co-ordinators and at Care Programme reviews. There were negotiated periods within meetings where I would absent myself so the participant, supportive person and practitioners could discuss study-related factors in my absence.

Whilst AR cycles unfold, it is possible to adhere to ethical principles as an action researcher. Boser (2006) suggests attention to externally developed guidelines that apply to those participating in and affected by the research; integrating these ethical principles at every stage and being transparent to the organisation and community. Within this study, academic, peer, clinical supervisors and participants offered fora through which ethical processes were articulated and challenged.

AR methodology, with its problem-solving cycles, participation and reflection is an appropriate methodology to use when gaining greater understanding about an aspect of clinical practice. Also AR is different from other research approaches in that it includes implementation of solutions as part of the research process. There is no delay between

study completion and implementation of solutions though this has its potential disadvantage in that the implementation may be seen as the researcher's role, and the study is usually small scale with no commitment that the implementation solution will be maintained. With this uncertainty in mind, an ethical question relates to whether participants are better off at the end than they were at the beginning of the study. This question links to evaluation within AR (see section 5.9.4). The changing organisational structure and personnel change (see section 6.6.3) may leave participants without emotional ongoing support to validate and hear their experience as practitioner awareness and connectivity with the study wanes. Hence as the researcher of the study, my obligation is to collaborate with the Trust and promote the research outcomes. The challenges identified here reflect innovation theory in that there are differences between adopting a new idea and putting the innovation into practice (Williams et al 2012). Some of the difficulties that arise relate to professional power and gate-keeping roles.

Within the study, participants allowed the researcher to get close. I was a visitor to their homes and to their world and in doing so they intentionally or unintentionally disclosed personal information that may not have been disclosed in a clinical setting. Examples from this study relate to what and how participants and family members disclosed in CPA or outpatient meetings in the presence of the researcher and where this information did not or only partially matched what had been observed in the participant's home.

The study agenda changed from the teaching of injection skills to a staying well agenda over a longer period of time for the participants who were in the study over a year. Propositional knowledge at this stage of the study necessitated looking ahead and relating study outcomes to managing potential relapse and to staying well interventions. As a researcher I had knowledge and competencies about psychosocial interventions and recognised their value and importance. If and when the patient and supportive person developed self-management injection competencies, staying well would be within the recovery and empowering frameworks. This example illustrates why AR was an appropriate methodology for this study – understanding the participant's views and seeing and recognising changes in dyad expertise leading on to developments in other areas of expertise.

Getting closer to participants through the study, by home visiting and working together to achieve the common goal of developing knowledge and skills about injection giving,

raised the issue of knowledge deficits. Local theory would suggest there are gaps in the knowledge related to the patient's and family's understanding of mental illness. The concealing of information is possible from both the service and family (see sections 2.7-2.8 and 6.7) and an assumption that patients and services know each other fundamentally impacts on risk management (see section 2.5) and the development of trusting relationships (see section 2.9.1).

Research, by its nature, will always ascertain greater knowledge and awareness of need than services can provide, cope with or understand. This gap contributes to the alienation of the practitioner from understanding and utilising the research process and data. This is particularly relevant to AR and to this study as it was local, small scale and undertaken by an insider, who became an outsider (see section 5.8). Research findings have many challenges to implementation in practice and this may in some way result from organisations' and practitioners' world views being influenced by national standards such as NICE guidelines so local developments are not prioritised.

7.3 Empowerment

Empowerment philosophy is underpinned by active involvement of the patient in their care, the offering of meaningful choices and the goal of employment. Whilst achieving employment may lead to improved self-esteem and self-worth (see section 4.7.7), it may increase the risk of stigma for the patient and lead to other challenges for the patient and family.

The literature discussed in chapter 4 suggested that philosophies like empowerment and recovery within mental health are gaining popularity, although within academic and policy literature there is concern that they are nothing more than rhetoric. These philosophies depend on understanding key concepts like patient involvement, partnership working and person-centred care. There is a national expectation that the philosophy of recovery and empowerment will be implemented in practice without a critical debate as to how and why. Published literature is growing fast on different methods of involvement, with little attention given so far, to the role which patients themselves wish to play, nor the conceptual meanings behind involvement or participation (Thompson, 2007). The practitioner has a problem in that the concepts are not defined and are left to

local and practitioner interpretation. Bradshaw (2008) suggests that as far as service user involvement is concerned, the task for policy makers and managers is to move from aspiration to reality. This study adds to the literature on the role the patient plays in seeking empowering choices and involvement, by initiating a request about a service delivery which is not currently provided. In this study this was done as an individual and not within a service user forum so the potential to be heard by the organisation or individual practitioner was limited. This is illustrated by the original request taking 12 months to hear, and being initially viewed as a possible relapse indicator. This also illustrates the potential to see mental illness as all-encompassing by practitioners, which will influence the outcome of the request.

Nevertheless, employment for the participants in this study has been a great success. For patients with mental illness gaining and maintaining employment is a challenge. The challenge for mental health practice and practitioners is acknowledging this and making adjustments to their services to meet employment needs and choice (See section 4.7.7 on reasonable adjustments expected of employer and patient). This adjustment is required within an organisational culture where payment by results, risk measurement and management and the promotion of choice and the expert patient agenda are competing within recovery and empowering philosophies.

Delivering employment support structures within mental health services requires a planned step down approach to support and to responsibility sharing. This process can be linked to recovery and empowering philosophies. Recovery orientated practice promotes the identification of patient goals (not professional goals); a belief in the person's strengths in the pursuit of these goals; the encouragement of self management and the importance of goals in taking a person out of the sick role (Shepherd 2007). Integral to working within these approaches is accepting that the future is uncertain and setbacks will happen. Stepping down is at the behest of the organisation as they have the power, but there is the potential for a crisis to occur due to the absence of a structure. The study findings suggest that for some participants, being stepped down was frightening and isolating, for others it was taken as an opportunity to learn, whilst others may use it as an opportunity to get discharged from mental health services (see section 6.4.5).

The study data identified one employed patient, who has acquired a label of non-attendee at appointments, though she values and seeks services offered. This label arose through

services offering appointments during her employment hours only. There is now the possibility for this patient that having a label of non-attendance will impact on her future status in view of the data about mistrust and how this influences practitioner decision-making (see section 6.3.1). This study highlights the importance of trust as a concept and the absence of discussion between patients, families and mental health services about how trust may be developed and the significance of any lapse in expectations. The study also highlights how the absence of a history and competency record is a challenge for services in the sharing of the administration of a medical intervention. For example, there were no lay persons with a history of administering depot medication. In comparison, diabetic services have a history of working with and trusting patients to administer their insulin. The study data would suggest there are opportunities for mental health services to learn from the management of other LTC's.

The two dyads that were offered discharge from services experienced frustration, when wanting to get primary and secondary services to understand their position and respond accordingly. Routinely, a yearly appointment was offered to the patient. Both of these service access and supports worked because the individual practitioners were knowledgeable of the family's needs, understood the significance and supported their endeavour by being responsive. This took time to develop and on reflection unless the patient and supportive person were assertive, committed problems solvers and had access to the research support structure, developing this process of access with services may not have evolved as it did. For one of the case studies, this support and access structure evolved and reached a status of being supportive without the family having to be repetitive and insistent in their communication with the services. Challenges arose when the community nurse and psychiatrist moved from their position and the team administrator (who had not changed) became a link person until the replacement practitioners understood and responded. This example links to the work of Handler (1990) who states that those relationships that form the basis of empowerment exist in a particular context and contexts are always changing. Because of changing contexts, empowered clients must continually struggle to preserve their status. Zimmerman (2000) suggests that theoretically, there are three levels to empowerment theory, namely societal level, organisational level and personal level, with a preponderance of research on the personal or psychological level. Zimmerman suggests that this preponderance leads to an erroneous conclusion that empowerment is solely an individual-level construct. The

examples in this study suggest that patients experienced personal empowerment but without organisational or societal change they may be more vulnerable to a changing context. The promotion of personal recovery goals that move the patient away from the sick role, aligned with personal empowerment approaches, could be a lonely journey unless supportive structures are available and responsive. Handler (1990) suggests that the party with power need to receive something material in return for patient involvement and empowerment and this could relate to the reduction in service provision for some participants in this study.

The mental health staff in this example could be identified as an enabling niche which is relevant to empowering philosophy (see section 4.7). Enabling niches include staff, qualifications, supervision, and a democratic culture with a participatory ethos. Handler (1990) argues that it is possible to empower vulnerable populations; the question is under what conditions empowerment is likely to occur. The organisation and selected personnel within the organisation who nurtured and supervised the development of this study could be classed as an enabling niche. In my view, participant homes were enabling niches in that patient potential was recognised, problems solved and skills developed. However contexts change and as evidenced, when key personnel move, the niche can dissolve as it appears to be practitioner specific rather than being held within organisational structures. Zimmerman (2000) suggests that organisations can be empowering even if policy change is not achieved because they provide settings in which individuals can attempt to take control over an aspect of their lives.

Empowerment and power are important concepts that need to be understood in the context of the patient, family, service and organisation. There is a need for mental health nursing to put into action the theoretical understandings of empowerment (Chambers and Thompson 2009) and this study will contribute to this process. This study has the potential to act as an illustration for nurses on how to process a service user request within an empowering framework. Disaggregating the components of empowerment related to this study, discussing how empowerment could be delivered and evidenced and taking on responsibility for this process were nursing issues. Many of the power holders in this study for example, service users and families, the Trust, the legal, medical, insurance and professional body all demonstrated that they can and will work to problem solve in the delivery of an innovation.

This study highlights that empowerment is a concept discussed within the nursing literature and within this discussion there appears to be a predominance of definitions and challenges in understanding empowerment, and a dearth of discussion on the application and consequences of empowering patients. For example, within this study, the consequences included the stigma faced within employment, personal consequences of concealing stigma, intrusion within the family home by both equipment and skills development, getting a non-attender label and potential changes in service provision. This study highlights that understanding expectations of empowerment, from whatever side, is important and needs to be managed. Individual participants may develop a sense of empowerment even if wrong decisions are made, because they develop a greater understanding of decision making processes and work to make their concerns known.

The author hopes that the discussions and findings from this study will act as a spur to further research, policy and practice developments and has outlined possible implications in the following sections.

7.4 Recommendations for policy research and practice

The essential factors for embedding innovation within the NHS are outlined in table 4.2. Although this study has used action research, in order for the findings to be adopted more widely, the MRC (2008) guidelines on complex interventions, based on more 'orthodox' health research approaches, have been drawn upon. These state that the process from development to implementation of a medical intervention may take differing forms and whilst the process implementation can be viewed through the stages of piloting, development, implementation and evaluation, often the process will not follow a linear or even a cyclical sequence. It is important to begin thinking about implementation and asking the question 'would it be possible to use this intervention, and if so, by whom?' For example, will this intervention be useful to national or local policy makers, practitioners, patients or Trusts? With these questions in mind, what kind of information have we got and what further information is required in order to establish viability and implement the changes indicated by the new evidence? The findings of this study addressed uncertainties associated with the intervention but further development is needed, particularly in relationship to acceptability to mental health services, families, patients, economic considerations and the management of risk. In order to achieve this,

the policy climate must be supportive, in particular the current emphasis on service user empowerment.

7.4.1 Future Policy

Linhorst (2006) proposes that two of the processes through which patients are empowered are policy development and service provision (see section 4.7). Bradshaw (2008) suggests that as far as service user involvement is concerned, the task for policy makers and managers is to move from aspiration to reality (see section 3.2). Implicit in this approach is that local organisations are pressured to implement user involvement but have local discretion as to how this is evidenced. Recommendations from this thesis are therefore aimed at both a national and local level policy development.

Kemshall (2002) identified that a more responsive public service is not only more exposed to risk but subject to greater scrutiny through audit and naming and shaming mechanisms. This fear has the potential to inhibit local implementation of creative service provision. Kemshall suggests that by advocating reasonable risk-taking, there is the potential to be open to creative solutions that can be used to empower service users through service provision and involvement.

- At a national level, policies should give practical examples of how user involvement, choice and empowerment are enacted within a more responsive public service. This has to include a national discussion on risk and how risk is defined.
- At a local level, mental health Trusts should develop local policy with patient, supportive person and practitioner participation relating to the administration of a depot injection by a supportive person. This policy would support practitioners in that they will have a structure to guide them (see section 6.4.2) on innovation and risk, and through audit and evaluation, the policy can evolve and develop. The policy should clarify the role and purpose of the out-patient appointment in monitoring and supporting the patient and supportive person in view of the practitioner being the sole reviewer of the patients care (see section 6.4.5). The

development of a policy would mitigate the impact of key personnel changing (see case study 7) on the supportive person and patient.

- Local policy should develop a Nurse, Patient and Supportive Person Competency Framework and protocol which will include the issues identified in the training package (appendix 11), i.e. criteria for competence, evidence CPA reviews require (see section 6.7.5) and the support structures available to potential users of the innovation (examples of competency frameworks can be taken from other health disciplines). In working with this protocol and competency framework, risk can be understood within a framework that all participants engage with a narrow range of information/educational material, within one environment (home) and within a stable context. The supportive person is learning the skills to administer the depot injection to one person only.

7.4.2 Future research

In section 5.1 of this thesis, a sample survey estimated that fifty percent of clients (out of 380), had a supportive person. This figure suggests that there is a potential pool of participants who may be interested in carer administration.

- A recommendation for future research would be to carry out a survey of supportive persons and patients to ascertain the potential interest, and under what conditions they would undertake the administration of depot medication. Participants invited to take part in the survey should be provided with an overview of what is involved, based on the findings of this small study so that participants have a framework on which to base their interest.

Due to the innovative nature of this study and government policy promoting the efficient use of resources and improving access to services (see section 4.10), an economic evaluation of the intervention is essential. This may be particularly relevant in rural communities where long distances are covered by nurses in the delivery of depot injections.

- A recommendation for future research would be that one community mental health team in each Borough should work with up to three supportive persons

using the current training package. Through this process, the knowledge and skills of practitioners in teaching and collaborating with supportive persons/patients would be enhanced. Practitioners would be required to document contact and sessions they engage with so that an economic evaluation of viability could be developed.

- Input required at the beginning of the project to gain the prerequisite knowledge and skills would be more intense (see sections 6.5 and 6.9) with lower levels of input required over time. Patients can be in receipt of a depot injection for many years and this difference in input needs to be born in mind within the economic evaluation.

One of the stated aims of the study was to establish whether enabling a supportive person to administer a depot injection would impact on their relationship with the recipient of the injection. The literature in chapter 3 suggests that caring for a family member with schizophrenia can vary between being a commitment, a positive experience to being a burden. The data from this small study (see section 6.4.4) identified positive relationships, with issues about power and responsibility-taking requiring acknowledgement and discussion.

- Participant numbers were small in this study so a recommendation for future research would be a larger scale study where relationship impact is evaluated.
- In view of the time taken to clarify liability for this study, (see section 5.11) a recommendation for future research is that there should be a more streamlined process where this can be ascertained more speedily.

7.4.3 Dissemination of findings and future practice

The uptake of the thesis findings will be affected by how acceptable the study findings are to practitioners, managers and service providers and the promotion of acceptability to the differing stakeholders will be integral to dissemination. The MRC (2008) recommend a mixture of interactive rather than didactic educational meetings, feedback and reminders to disseminate research findings.

- A short article will be written for the sponsoring Trust's in-house journal outlining potential practice application.

- A series of short presentations to key staff groups aimed at generating awareness and discussion on study findings. Fundamental to these discussions will be practitioners airing acceptability issues, which will include their views on risk and trust related to this innovation (see sections 6.4 – 6.4.6).
- The intervention will be manualised. The pamphlet will outline key aspects of the study as pertaining to practice application in order to assist practitioners who are interested and responding to similar service user requests.

This thesis is based on an original and innovative topic and as argued in sections 4.9 – 4.11, innovation in healthcare implies some degree of uncertainty and predictability. The findings on innovation and risk (see section 6.4.2) suggest service innovation creates opportunity and fear for both providers and receivers of services.

- A recommendation for future practice would be to offer ‘drop in’ skills and information sessions provided locally where practitioners demonstrate intramuscular injection administration using manikins, so that interested families and practitioners can gain insight and awareness into the process. Supportive persons already administering depot medication can maintain skills by attending these sessions. This opportunity would facilitate discussions related to informed consent and capacity (see section 2.3) and give patients and supportive persons an opportunity to assess risk (see section 2.5.2). Attendance at these information sessions would be a prerequisite for potential participants.
- The number of teaching and observed sessions required in achieving competency by individual supportive persons and patients would be determined by the nurse teaching the skills. In sections 6.2 and 6.5, of the thesis, knowledge and skills required by the participants were discussed and evaluations of the case studies suggest a minimum number of sessions. A recommendation is that 10 sessions over a period of six months be taken as a baseline, including four for the teaching of skills and knowledge, four for supervised injection administration and two for additional practice and support. Further support needs and monitoring would be negotiated and group skills training could be considered. If so, it is recommended

that at least two individual sessions precede it so that participants can discuss confidentially issues.

- A designated nurse should be nominated within each mental health team to oversee training and monitor standards. It is imperative that mental health teams have an alert structure so that supportive persons/patients queries can be responded to quickly.

In section 6.7.7 of the thesis, the equipment and medication necessary to administer a depot injection were identified by participants as potential evidence that could disclose to others the presence of a mental illness within the home. Disclosure is related to stigma (see sections 2.6-2.6.3) and concealment (6.7.4) which were identified within the study. Oral medication also has the potential to disclose the presence of an illness and if similar storage management strategies are assigned to oral medication as injection equipment, i.e. locked bedroom or on top of the wardrobe, then these storage strategies could contribute to reduced medication concordance rates.

- A recommendation for future practice is for mental health practitioners to be more alert to this issue and to discuss concerns with the patient and family members when oral medication is prescribed.

In conclusion, current government policy promotes a more responsive public service within financial restraints and innovative practice has the potential to respond to public and patient needs and acceptability. This innovation through judicious policy, research and practice has the potential to offer a creative solution that can empower service users through service provision and involvement.

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Bexley & Greenwich Local Research Ethics Committee

Ranken House
Queen Elizabeth Hospital
Stadium Road
Woolwich
SE18 4QH

Telephone: 0208 836 6740

Facsimile: 0208 836 4862

2 September 2005

Mr John J Crowley
Senior Lecturer
University of Greenwich
School of Health and Social Care
Mansion Site
Bexley Road,
London SE9 2PQ

APPENDIX 1

Dear Mr Crowley

Full title of study: An investigation into the feasibility of enabling carers/relatives of clients with enduring mental illness to give prescribed intra-muscular depot injections.

REC reference number: 05/Q0707/48

The Research Ethics Committee reviewed the above application at the meeting held on 26 August 2005. Thank you for attending to discuss the study.

Ethical opinion

The following points were discussed:

- Consent Form - both carer and patient would be consented on both taking part and interviews being recorded.
- Exclusion of people with learning disabilities - the researcher has no experience of working with this group of people, so this was acceptable.
- Length of questionnaire - the researcher will help with the completion of the form as and when required, but felt the content was necessary.
- Researcher will seek advice on the ability to consent if this is felt necessary.
- The committee advised that the data should be kept for 5 years from the completion of the study.
- If the carer gave an injection and there was an adverse reaction such as fainting, would the carer know what to do? The first two injections would be given in the Health Centre and advice would be given on how to deal with this type of situation should it occur.
- The relationship between the carer and patient was also discussed, in regard to the modesty of the patient.

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the research sites listed on the attached form.

You are being invited to take part in this research study. Before you decide whether to take part, it is important you understand why the research is being done and what it will involve. Please take some time to read the following information carefully and discuss it with others if you wish. Please ask if there is anything that is not clear or if you would like more information.

1. What is the purpose of this study?

In mental health care, patients are prescribed medication by their doctor that has to be given by injection every two to four weeks. This is often referred to as a depot injection.

Traditionally, nurses give these depot injections either at a clinic or at your home. Recently, a user of mental health services living in Greenwich and prescribed such medication asked if her husband could give her the depot injection, instead of the community psychiatric nurse. She felt it would give her more choice in when to have the medication and would also save the time she spent attending the clinic every three weeks. Within mental health care, a relative giving a depot injection is not normally considered, so little information was available to help this family with their request. However, after some training and practice, the patient's husband was able to develop the necessary skills to give his partner her injection.

The purpose of this study is to find out more about the concerns that may arise when relatives or carers (supportive persons) are enabled to give depot injections.

18. Who has reviewed the study?

The study has been reviewed and approved by:

- ◆ Greenwich Research Ethics Committee
- ◆ A professor of nursing at Greenwich University
- ◆ A senior lecturer in mental health work at South Bank University.

19. Who can I contact for further information?

You can contact the researcher, John Crowley, on 020 8855 8886.

If you do decide to take part in this study, you will be given a copy of this information leaflet and a signed consent form to keep. Thank you for taking the time to read this information leaflet.

16. What will happen to the results of this research study?

The information gained from this study will be shared with local service user and carer groups and community mental health teams who may wish to use to develop and improve local community mental health services.

The results of the study will be used by Oxleas NHS Trust in the development of guidelines and a training information package to help other carers/relatives who want to develop the skills to give a depot injection. The researcher would aim to share the information with other interested groups through conference presentations and also through publication.

17. Who is organising and funding the research?

Oxleas NHS Trust has paid the University of Greenwich so that the researcher is officially registered as a research student in health research. The university will supervise the researcher during this research study. The researcher may apply for other funding resources during the course of the study and will be happy to share this information with you if requested.

2. What sort of questions will I be asked?

Examples of the types of questions the study would aim to explore with your help include:

- ◆ How can a supportive person best learn the skills to give a depot injection safely?
- ◆ How can the community mental health team acknowledge and resolve any difficulties that may arise between you and your supportive person on the issue of medication?
- ◆ Where would you get your medication?
- ◆ How can the local community mental health team support you?
- ◆ How can your doctor monitor your illness and medication?
- ◆ How can we develop an agreement and understanding with the doctor who prescribes your medication and the local community mental health team so that everyone knows what to do and who to contact if difficulties arise?

Additionally, the study would also like to explore and understand any changes that may arise in your relationship with the person who is giving you your depot injection.

3. Why have I been asked to take part in this research?

The researcher in this study, who is an experienced mental health nurse, has asked local community mental health teams to nominate users of their service who:

- ◆ Are prescribed medication by a doctor to treat a mental illness and this medication is given by depot injection, usually by a community psychiatric nurse.
- ◆ Are supported by a person who may be interested in understanding the illness and may also be interested in developing the confidence and skills to give the depot injection.

The doctor who prescribes your medication and the nurse who gives your depot injection are aware that I have approached you to take part in this study and they will continue to support you.

4. Do I have to take part in this research?

No. It is up to you to decide whether or not to take part. If you do decide to take part, you will be given this information leaflet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive.

14. What if something goes wrong?

The researcher's main aim is to minimise potential harm. The researcher will work with you and your supportive person in supervising the depot injection process until all parties agree they feel comfortable and confident to do it without the researcher being present. You will have the contact details of the researcher and the local community mental health team if difficulties arise. A copy of Oxleas complaints procedure will be made available upon request. Individuals that take part in this research project are covered under Oxleas NHS Trust indemnity insurance.

15. Will my taking part in this study be kept confidential?

The researcher in this study works for Oxleas NHS Trust and as such is bound by trust guidelines on confidentiality. Members of the local community mental health team who are involved in your care will know of your participation in the study and your GP will be informed. The researcher and the supervisors will focus on the progress of the study and not on your illness or personal details.

11. What are the possible benefits of taking part?

The possible benefits to this study include:

- ◆ You are likely to learn more about your illness and gain confidence in sharing this with the carer or relative who is willing to learn the skills to give your depot injection;
- ◆ You may find you will have more choice in when and where you can have your injection;
- ◆ You will be helping to develop new knowledge.

12. What if new information becomes available?

Two experienced supervisors from local universities, who are experienced in mental health and research, supervise the researcher. If new information becomes available during the study, the implications of this will be discussed with the supervisors, you and your local community mental health team. Adjustments to the study will be made accordingly.

13. What happens when the research study stops?

When the study stops you will have a choice of options. If you and your supportive person feel confident that the necessary skills have been learnt to give your injection safely, you, your supportive person and the researcher will negotiate with the local community mental health team to see how best to support you.

5. What will happen to me if I take part?

The researcher in this study will talk to and seek the views of the people in the local community mental health team who know you best. In particular, the doctor who prescribes your medication and another member of the community mental health team that you know will be asked for their views and agreement on how this study may be of assistance to you and your supportive person. Your GP will be informed of the study.

Any concerns raised will be discussed with you in partnership with the local community mental health team. You may discuss your concerns with your local community mental health team without the researcher being present if you desire. Working together is important, as the local community mental health team will continue to be responsible for your treatment and care. They will be the first point of contact if you have any questions or concerns.

If you do agree to help with this study, you and your supportive person will be asked to sign a consent form. The researcher will arrange further meetings at a place and time of your convenience to complete four assessment questionnaires. These questionnaires are about your understanding of your illness, medication and how your supportive person views your needs. They will help the researcher develop an awareness of your needs.

6. What do I have to do if I want to take part?

Take some time to read this information leaflet. The researcher will make contact with you within two weeks of today and arrange a time and place at your convenience to discuss the next stage.

7. What is the drug or procedure that is being tested?

The community mental health team is aiming to learn and understand what benefits and what concerns may arise if your relative or carer gave your injection instead of the community psychiatric nurse.

8. What are the alternatives for diagnosis or treatment?

The researcher is not able to offer a change to your diagnosis. Only your doctor and the local community mental health team can do that. The alternative to how you receive your injection is to continue as before, e.g. your injection will continue to be given by the community psychiatric nurse.

9. What are the side effects of any treatment received when taking part?

The treatment in this study is the treatment you are currently prescribed by your doctor. If you have concerns about the potential side effects of this treatment, the researcher will be happy to discuss them with you, your doctor and the local community mental health team. The researcher is not able to prescribe any new treatment.

10. What are the possible disadvantages and risks of taking part?

All activities have potential disadvantages and risks. The researcher, who is an experienced mental health nurse, will endeavour to minimise any disadvantages and risks to you that may possibly arise during this study:

- ◆ Any injection received, no matter who gives it, has the potential to cause pain and, very rarely, may cause nerve damage. The study will minimise these concerns by closely supervised practice.
- ◆ When you are working closely with other people, particularly if these people are talking about your health, tension and embarrassment may occur.

If concerns do arise during the study that undue distress is being caused to you or your carer/relative, discussions will take place between yourselves, the local community mental health team and the researcher. The options would be to have a break in the study or perhaps asking the community psychiatric nurse to give the injection as before.

15th October 2004

Your Ref: -
Our Ref: Trust General Enquiry/Oxleas/MS

Mr John Crowley
St Nicholas Mental Health Centre
79b Tewson Road
Plumstead
London
SE18 1PB

- SCHOOL OF HEALTH & SOCIAL CARE
AVERY HILL CAMPUS.
UNIVERSITY OF GREENWICH.
BEXLEY ROAD
SE9 2PQ.

Dear John

Re: Depot Injection – Indemnity Enquiry

I refer to your correspondence concerning this matter and to our numerous telephone conversations.

May I firstly please take the opportunity of raising this query.

The whole issue of care within the community and the potential liability of the carer, should an injury arise to the patient as a result of the carer's negligence, has certainly been given a great deal of thought within the Authority.

As previously advised no cover exists under the CNST Scheme as the NHS CNST Indemnity Guidelines refer specifically to care provided by "members of Healthcare Professions employed by NHS bodies". The carer in the community would not qualify as a Healthcare Professional.

Consideration was then given to the indemnity that we provide under the LTPS (Liability to Third Parties Scheme). Under Schedule 3 – Public and Products Liability Claim the wording is extended to include:

"2.1 – Indemnity to other persons
2.1(a) - Any relevant person"

"relevant person" means in respect of a member, a person employed or engaged by that member shall be taken to include:-

- (i) Authorised voluntary worker

It is considered that an agreed carer within the community would fall within the definition of an authorised voluntary worker and therefore indemnity would be provided in the LTPS scheme in respect of their legal liability in the event of accidental personal injury which may arise in connection with the relevant function and which occurred during the membership year and on or after the membership date and within the territorial limits, the public and product liability claim will be legal liability for compensation, costs and expenses.

I have checked our records and confirm that Oxleas NHST joined the LTPS on 1st April 1999 and Greenwich PCT joined LTPS on 1st April 2001 and both memberships are current.

I attach a copy of the relevant pages of the wording and would refer you specifically to the highlighted areas.

I hope that this answers the queries raised by you and satisfies the requirements of Bexley and Greenwich Local Research Ethics Committee.

Would you please note that I have arranged for a copy of this letter to be sent to Bexley & Greenwich LREC and also to Caroline Hall at Oxleas NHS Trust.

If you have any queries concerning the above please do not hesitate to contact me.

Yours sincerely

Mark Smitheram
Case Manager

Direct Line: 020 7430 8819
Fax Number: 020 7405 4307

Encs

Cc: Mr Karim Hussain - Chair, Bexley & Greenwich LREC Healthcare Library,
Education Block, Queen Elizabeth Hospital NHS Trust, Stadium Road, Woolwich,
London, SE18 4QH

Your Ref: REC/144/OCT/03

Cc: Ms Caroline Hall - Legal Administrator, Oxleas NHS Trust, Pinewood House,
Pinewood Place, Dartford, Kent, DA2 7WG

in these Rules and a reference to a numbered regulation is a reference to a regulation which bears that number in the Regulations.

Clause headings and the index are for ease of reference only and are not to affect the interpretation of these Rules.

Words denoting the singular include the plural and vice-versa.

3. Coverage of the Scheme

Subject to the terms of the Regulations (as amended or varied from time to time), the liabilities to which the Scheme applies are any liabilities to which a member is subject in respect of loss, damage or injury which

- (a) arises out of the carrying out of any Relevant Function of that Member;
- (b) is a qualifying liability; and
- (c) is not a qualifying liability for the purposes of the National Health Service (Clinical Negligence Scheme) Regulations 1996 (as amended) the National Health Service (Existing Liabilities Scheme) Regulations 1996 (as amended) or a qualifying expense for the purposes of the National Health Service (Property Expenses Scheme) Regulations 1999.

would not be as if being carried out by a health care professional

"Qualifying Liability" means, in respect of a member, a liability which falls within the definition thereof at Regulation 4 (2), and which is either an Employers' Liability Claim, a Public and Products Liability Claim, a Directors' and Officers' Liability Claim, a Professional Indemnity Claim or a Personal Accident Claim, save where in each case a General Exception applies.

4. Membership of the Scheme

4.1 Eligibility for Membership

A body is eligible to participate in the Scheme if it is a body of the kind described in Regulation 3. The Administrator shall, having regard to the information provided by the Applicant, and to such other factors regarded by the Administrator as material, determine whether or not an Applicant should be admitted as a Member.

4.2 Application Forms

The Administrator shall have the power to prescribe a form or forms of application to be delivered to the Administrator by Applicants and to require certain information on the Applicant's activity profile in accordance with Regulation 6(4). All Applications shall be made in accordance with Regulation 6(3).

4.3 Date of Commencement of Membership

Membership shall commence in accordance with the provisions of Regulations 6(1), 6(2) and 6(6).

4.4 Period of Membership

A Member may only terminate its participation in the Scheme in accordance with the provisions of Regulations 7(1).

5. Provision of Information

5.1 General

Members will be required to provide (at their own expense) such information to the Administrator and/or the Scheme Managers on their activities as may be determined from time to time by the Administrator which information shall include, without limitation, the information referred to in these Rules and in Regulations 6(4) and 10. Members acknowledge and agree that any and all

SCHEDULE 3 – PUBLIC AND PRODUCTS LIABILITY CLAIM

Qualifying Liability :

1. Definition

In the event of accidental

1.1. Personal Injury or

1.2. loss of or damage to Property or

1.3. obstruction, trespass, nuisance or interference with any right of way, air, light, water or other easement or loss of amenities

which arise in connection with the Relevant Function and which occur during the Membership Year and on or after the Membership Date and within the Territorial Limits, the Public and Products Liability Claim will be legal liability for Compensation, Costs and Expenses.

2. Extensions to Schedule 3

For the purposes of these Rules, a Public and Products Liability Claim will (provided that in respect of sub paragraphs 2.2 to 2.15 inclusive the circumstances arise in connection with the Relevant Function and that the event giving rise to legal liability occurs during the Membership Year and on or after the Membership Date and within the Territorial Limits) include:

2.1 Indemnity to Other Persons

If the Member so requests the Scheme will indemnify:

- (a) any Relevant Person;
- (b) any Relevant Person's personal representative in respect of legal liability incurred;
- (c) any principal for whom the Member is carrying out a contract for the performance of work but only to the extent required by the contract conditions and is considered reasonable in the view of the Administrator;
- (d) the owners of plant hired in by the Member but only to the extent required by the hiring conditions and provided always that the terms upon which the Member hires the plant are no more onerous than the standard form of contract of the Contractors' Plant Association (CPA) or Hire Association of Europe;
- (e) the officers, committees and members of organisations established in order to provide canteen or sports and social facilities or educational or welfare services primarily for the benefit of any Relevant Person;
- (f) persons providing first aid, ambulance, first or security services primarily in connection with the Premises;

against legal liability in respect of which the Member would have been entitled to indemnity under this Schedule 3 if the claim had been made against the Member.

2.2 Legal Expenses arising from Health and Safety Legislation

- (a) In the event of any act or omission or alleged act or omission leading to criminal proceedings brought in respect of the Health and Safety at Work etc Act 1974 or the Health and Safety at Work (Northern Ireland) Order 1978 or similar safety legislation of Great Britain, Northern Ireland, the Isle of Man or the Channel Islands

or

the title National Health Service Litigation Authority, to administer the Scheme and shall include where appropriate the Board and any committee or sub-committee of the Board and the officers of NHSLA;

"*Personal Accident Claim*" means a claim arising from liability detailed at Schedule 6 hereto;

"*Personal Injury*" means Bodily Injury and wrongful arrest, detention, imprisonment and malicious prosecution;

"*Persons*" includes companies, statutory bodies, partnerships, firms, individuals, government departments and other administrative organisations and any other body of persons, whether incorporated or unincorporated;

"*Pollution Liability Claim*" means a claim of the kind described at sub paragraph 3.9 of Schedule 3 hereto;

"*Premises*" means all premises owned, occupied or used by the Member in the United Kingdom;

"*Products Supplied*" means goods including labels and containers and packaging

(a) on which work has been completed by or on behalf of the Member at the Member's normal place of business or that of the party who carried out the work on the behalf of the Member; or

(b) which has been handled, stored, sold, supplied, transported or financed by the Member and which at the time of the event giving rise to a Claim are not under the custody or control of the Member or any Relevant Person;

"*Professional Indemnity Claim*" means a claim arising from a liability of a type detailed at Schedule 5 hereto;

"*Property*" means material property;

"*Public and Products Liability Claim*" means a claim arising from a liability of a type detailed at Schedule 3 hereto;

"*Qualifying Liability*" means a liability of the kind described in Rule 3;

"*Regulations*" mean the National Health Service (Liabilities to Third Parties Scheme) Regulations 1999 (S.I 1999 No. 873);

"*Relevant Function*" means the function of providing services in England for the purposes of the National Health Service Act 1977 or by virtue of section 7 of the Health and Medicines Act 1988 or under paragraph 14 or 15 of Schedule 2 to the National Health Service and Community Care Act 1990;

"*Relevant Person*" means, in respect of a Member, a person employed or engaged by that Member, and shall be taken to include:

- (a) a person under a contract of service or apprenticeship with the Member
- (b) a labour master or person supplied by a labour master
- (c) a person employed by labour only sub-contractors
- (d) a person hired to or borrowed by the Member including volunteer drivers in connection with community bus schemes
- (e) person being a prospective driver whilst driving
- (f) person undertaking study or work experience
- (g) person supplied under any youth training or similar government scheme while working for the Member in connection with the Relevant Function
- (h) director or trustee
- (i) authorised voluntary worker
- (j) committee members or review panel members

adverse accident panels.

The person dealing with this matter is:
Duncan Gordon-Smith
Direct dial 020 8780 4704
Direct fax 020 8780 4728
Email dgordon-smith@capsticks.co.uk

Capsticks

Ms Caroline Hall
Head of Legal Services
Oxleas NHS Trust
Pinewood House
Bexley Hospital
Old Bexley Lane
Bexley Kent
DA5 2BF

Your ref: APPENDIX 4A

Our ref: C

27th Nov

Dear Caroline

Depot Injections – indemnity query

I refer to your e-mail of the 10th November 2003. I have undertaken this work under the supervision of Peter Marquand, a partner in the clinical law department. I have set out a brief summary of the background as I understand it, followed by my comments below.

Background

John Crowley, a registered mental health nurse, has drafted a research proposal that aims to look at the possibility of carers administering depot injections of anti-psychotic drugs to patients at the Trust. The research aims to explore the elements of risk management involved in enabling carers or relatives to give depot injections and to develop the Trust guidelines and a training package for use by other carers or relatives and health professionals.

Under the research proposal, carers will be supervised until a degree of confidence and competence is attained at all stages during the injection technique. The first two unsupervised injections will be given at the local mental health clinic which will give an opportunity to iron out any unforeseen difficulties. The next two unsupervised injections may be undertaken at the recipient's home if they choose to do so. Thereafter the researchers will co-ordinate the prescribing and supply of medication and equipment to the subjects and monitoring arrangements.

The ethics committee reviewed the research proposal and wanted clarification on whether the carers involved in the research project would be covered by the NHS indemnity.

Advice

General Comments

Although you have not asked me to comment on the proposed study in broad terms, I note that the question which prompted its drafting was, "What stops my husband from giving me my depot injection?" From a legal perspective, the administration of prescription only medicines (which include all medicines administered parenterally including by depot injection) is governed by the Medicines Act 1968 and secondary legislation under that Act. Under the Act, it is unlawful for any person to administer (otherwise than to himself) any prescription only drug unless he is an appropriate practitioner or a person acting in accordance with the directions of an appropriate practitioner. Providing the carers involved in the project are acting in accordance with the directions of an appropriate practitioner (e.g. the prescriber) they may lawfully administer the depot injection.

I assume the Trust has satisfied itself that a responsible body of professional opinion would be supportive of such a study having regard particularly to the safety implications arising out of it. Intramuscular injections are not without risk (e.g. nerve damage caused by the needle) and if the study is fundamentally flawed in terms of the assessment of the risk it carries, then it is conceivable that the Trust and possibly the ethics committee could be held liable for endorsing it.

Indemnity –negligence of the carer

The purpose of the NHS indemnity (with financial cover from the Clinical Negligence Scheme for Trusts (CNST)) is to ensure that should a person, to whom an NHS body owes a duty of care, come to harm as a result of a negligent act or omission of someone employed or engaged by that NHS body in carrying out their treatment, there will be funds in place to cover any compensation that is payable as a result. In general, the CNST will cover healthcare professionals involved in a clinical trial such as that proposed here.

The case of the carers in this case is slightly different because they are not professionals but are part of the trial arranged by the Trust. They might be classed as 'engaged' individuals and therefore be covered for the purposes of the project. However, this is an unusual situation and I suggest that an approach is made to the National Health Service Litigation Authority (NHSLA) which administers the CNST, requesting confirmation that carers would be covered as part of the project. Please let me know if you require any assistance in drafting such a letter.

Indemnity –harm accruing to the carer

It is also conceivable that a carer might suffer harm during the administration of a depot injection, for instance a needle stick injury. Any damage in these circumstances would not have been as a result of treatment provided to him or her by the Trust and therefore the CNST is not appropriate. The NHSLA runs another scheme called the Liability to Third Parties Scheme (LTPS) which may provide cover in these circumstances but once again I suggest that an approach is made to the NHSLA requesting confirmation that carers would be covered as part of the project.

I trust this is of assistance but should you have any further questions or require clarification on any point please do not hesitate to contact me.

Yours sincerely

Duncan Gordon-Smith

Research – Teaching carers/supportive persons to give depot injections

Interview prompts to elicit staff attitudes and concerns

Attitudes

- Could you please tell me how you feel/opinion about supportive persons being enabled to give depot medication injection in mental health?
- Can you think of any potential benefits by the supportive person giving the depot injection?
- Can you think of any potential disadvantages by the supportive person giving the depot injection?
- When discussing ‘enabling supportive persons to give injections, a frequent comments is ‘clients with diabetes do their own or relatives injection’ – do you see similarities with this? What are the differences?

Suitability

- How might you as a practitioner assess a supportive person/client relationship to see if they were candidates to be considered for taking on this role?
- Within your current case load, so you have client/supportive relationships that you would consider as being:
 - Potential participants for this role?
 - Definite participants
 - Not suitable?
- From where you are at today, what criteria would you use to make these distinctions?
- Any cultural/religious beliefs that should be considered if a supportive person was enabled to give depot injection?

Relationships

- Can you foresee any effects/changes on relationships?
 - Relationships between client and supportive person?
 - Your relationship with client and supportive person?

Concordance

- Can you think of any potential effects upon medication concordance?

Professional territory

- What do you think the impact would be on the professional role of the nurse if a supportive person was enabled to give depot injection?
- If so, what potential difficulties may this pose?
- Do you personally see it (if you are a nurse) as a hard thing to give away this role?
- What would you perceive the role of the nurse to be if not directly giving injections?

Trust

- Would you have any concerns about trusting a carer/supportive person to give injection as prescribed?
If yes, why may you have concerns?
How could these concerns be reduced?
- Would you be able to identify any 'key indicators' that would need to be present to enable you to say whether this 'trust' was present or not?

Remarks

- Since commencing this interview have your views changed on the project?
If yes, can you say in what way?
- Is there anything else I have not covered or that you would like to tell me?
- Are there any questions you would like to ask?

Thank you for your time and for sharing your experience with me.

APPENDIX 1

LANCASHIRE QUALITY OF LIFE PROFILE:

Introduction and Instructions

INTRODUCTION

The Lancashire Quality of Life Profile is a structured interview for measuring the health and welfare of mental health clients. Since its development began three years ago influences such as the recent White Paper on community care and the Lancashire Mental Health Strategy 'New Futures' have made it important that suitable means of monitoring the progress of mental health cases resident in the community be devised and that these become part of our departmental operational procedures. The Lancashire Quality of Life Profile is our attempt to begin this process.

Our profile builds upon recent American and British questionnaires developed for research on clients with similar life predicaments. In addition we have both developed our own material and incorporated questions from sources not so far used in this sort of research. We have piloted the questionnaire here in Lancashire on several occasions and it is now ready for employment within the agency.

The Lancashire Quality of Life Profile gives a fairly comprehensive, if brief, profile or outline of an individual client's current level of psychosocial functioning. It combines 'objective', factual material related to several of a client's life areas or domains with 'subjective' material drawn from the client's self-assessments. Also included is a professional quality of life assessment based on observation and prior knowledge of the case.

The interview seeks to strike a balance between the structure required to produce reliable results and the flexibility necessary to produce an interview atmosphere where additional material of a clarifying nature can be safely sought and received. Continuous pruning of the questions has reduced the interview to the minimum length necessary to produce a useful client profile.

INSTRUCTIONS

General instructions

1. Each questionnaire should, wherever possible, be completed in a single interviewing session. Previous experience leads us to believe that about one hour is generally sufficient time. Only one questionnaire is to be completed for each client. If, for some reason, an interview requires more than one session to complete, the same form should be used, continuing on from where the previous session stopped.
2. Interviews are best conducted in a quiet place with sufficient privacy to allow the client to feel that he/she can speak freely without being overheard. As the interview requires the attention of both the worker and the client, an environment free of unnecessary or frequent interruptions is also highly desirable.
3. In each interview information is gathered in the following order:

Initial information

- Section 1: Client's personal details
- Section 2: Client's general well-being
- Section 3: Work/Education

Section 4: Leisure/Participation
 Section 5: Religion
 Section 6: Finances
 Section 7: Living situation
 Section 8: Legal and safety
 Section 9: Family relations
 Section 10: Social relations
 Section 11: Health
 Section 12: Self-concept
 Section 13: Client's general well-being
 Final remarks
 Interviewer comments

4. All answers for the interview must be made in the spaces available. Along the right-hand side of each page is a vertical margin containing data column codes. This area is for data processing only and should not be written in.

5. Please, complete all questions.

Specific instructions

1. NAME or IDENTIFIER. Affix the client's name or other personal identifier such as an identification number. This is necessary to ensure that the same client has not been interviewed twice and that, should the client be contacted again at a later date, that information can be accurately updated.

2. ADDRESS. Complete in cases where the client has recently changed address or is planning to do so in the near future. If client is 'homeless', indicate with NFA (No Fixed Abode).

3. DATE OF INTERVIEW. In the unlikely event that the interview should take place on two different dates, include only the first date.

4. INTERVIEWER'S NAME. Please state your name on EACH interview.

5. STARTING TIME. Be sure to note the time at which the interview actually begins. This is compared with the FINISHING TIME at the end of the interview to give a measure of the length of the interview.

6. BEFORE beginning the interview it is necessary to introduce yourself, tell the client exactly what the purpose of the interview is and to gain his/her consent. Following is a model introduction which we have tried previously and which works well.

'Thank you for allowing me to speak with you. My name is Mr/Mrs/Miss/Ms _____ and I work for the Lancashire Social Services Department.'
 (You can display Lancashire Social Services identification at this point, if required.)

'I am visiting you because we are interested in finding out all about the things which go to make up your everyday life and how you feel about them. We want to get a fairly complete picture of the quality of your life at present so that we have a better idea of how to develop our services in the future.'

'To do this, I will need to ask you questions about many different areas of living. I expect that I shall take about an hour of your time.'

'Before we begin, I would like to say that anything which you will say to me will be held in confidence. Normally this would mean that only I and my superiors in the Social Services Department would have access to it and no information will be

passed on to others without your knowledge and consent. I hope that this will help you to feel that you can speak openly and honestly with me. Also, you may find some of the questions difficult or too personal to discuss. In either instance, please do not hesitate to say so. You may decline to answer any questions which you like and may also stop the interview at any time. I will certainly understand.'

7. CLIENT DECLINES INTERVIEW. In instances where the client declines to be interviewed, please indicate so on the interview form also stating the reason if one has been given. Also include here clients who have not been interviewed for other reasons: e.g. they were acutely ill at the time and/or you judged that it would not be in their best interest, etc. In all instances please give a clear explanation for not proceeding.

SECTION 1: CLIENT'S PERSONAL DETAILS.

- 1.1 Insert current age to nearest year.
- 1.2 Indicate sex with a 'tick' or 'X'.
- 1.3 Insert correct letter for ethnic group.
- 1.4 Insert age for cessation of formal education to nearest year.

Where a client was unwilling or unable to answer such a question, or where the question was, for some reason, not applicable to the client, please insert only DK for 'did not know' into the appropriate space.

SECTION 2: GENERAL WELL-BEING.

Give the client the Life Satisfaction Scale (LSS). They should keep it for use throughout the interview. It helps the client to give verbal expression to a range of satisfactions from LOW (i.e. 'Couldn't be worse') to HIGH (i.e. 'Couldn't be better') and contains a variety of expressions between these extremes (DISPLEASED MOSTLY DISSATISFIED, MIXED FEELINGS, MOSTLY SATISFIED* and PLEASED). It is numbered correspondingly from 1 (low) to 7 (high). Please record ONLY THE NUMBER corresponding to the words chosen by the client.

The use of the Life Satisfaction Scale may be explained to the client as follows.

'Please look at this' (show the client the Life Satisfaction Scale).

'This is a chart which will help you to describe how you feel. We will be using it throughout the interview to help you with questions about many areas of your life. All you have to do is to point to the part of the chart which best describes how you feel when you are asked. As you can see, it covers all of the feelings from when you are most satisfied with something or approve of it most strongly to when you are least satisfied or most strongly disapprove.'

'For example, if I asked you if you liked fish and chips you might say "couldn't be better" if you really liked them a lot. This would show the strongest possible satisfaction or approval. On the other hand, if you hated fish and chips you might point to "couldn't be worse". This would show the strongest dissatisfaction. If you felt about equally satisfied and dissatisfied with fish and chips you would point to the middle of the chart and "mixed". This would tell me that you were uncertain or of mixed feelings. As you can see, there is room for many shades of opinion in either direction.'

- 2.1 Enter LSS score.

SECTION 3: WORK/EDUCATION.

- 3.1 Circle client's answer. Here, as elsewhere, only one answer should be recorded.

per question. For example:

YES - the client 'agreed' with the statement.
NO - the client 'disagreed' with the statement.
DK - the client 'did not know' or would/could not answer.

3.2 Where employed, please list occupation.

3.3 Indicate number.

3.4 Indicate amount.

3.5-3.7 Enter LSS score. NB Clients who are currently employed will be asked 3.5 and 3.6. Clients NOT CURRENTLY employed will be asked only 3.7. ALL clients should be asked one or the other.

SECTION 4: LEISURE/PARTICIPATION.

4.1-4.5 In some instances where a series of such question are asked, the scoring has been simplified to 1 = YES, 2 = NO and 3 = DK (do not know, was unwilling to answer, question not applicable). In these instances, however, the same rules apply with ONLY ONE answer being CIRCLED per question.

4.6-4.8 Enter LSS score.

SECTION 5: RELIGION.

5.1 Enter appropriate letter.

5.2 Enter appropriate number.

5.3-5.4 Enter LSS score.

SECTION 6: FINANCES.

6.1 Enter total income before deductions or payment of expenses.

6.2 List benefits.

6.3 Circle client's response.

6.4 Enter amount required.

6.5 Circle client's response.

6.6-6.7 Enter LSS score.

SECTION 7: LIVING CIRCUMSTANCES.

7.1 Enter appropriate letter.

7.2 Enter number of years and months.

7.3 Enter number.

7.4-7.5 Circle client's response.

7.6-7.12 Enter LSS score.

SECTION 8: LEGAL AND SAFETY.

8.1-8.2 Circle client's response.

8.3-8.4 Enter LSS score.

SECTION 9: FAMILY RELATIONS.

9.1 Enter appropriate letter.

9.2 Enter number.

9.3 Enter appropriate letter.

9.4 Circle client's response.

9.5-9.7 Enter LSS score.

SECTION 10: SOCIAL RELATIONS.

10.1-10.4 Circle client's response.

10.5-10.6 Enter LSS score.

SECTION 11: HEALTH.

- 11.1-11.5 Circle client's response.
- 11.6 Enter number of years.
- 11.7 Circle client's response.
- 11.8-11.10 Enter LSS score.
- 11.11-11.20 Circle client's response.

SECTION 12: SELF-CONCEPT.

- 12.1-12.10 Circle client's response.

SECTION 13: GENERAL WELL BEING.

- 13.1 Enter LSS score.
- 13.2 Cantrill's Ladder is a measure of global well-being scored by the client him/herself directly on the questionnaire. Have the client look at the ladder and make one mark, preferably an 'X', at the point on the ladder which best expresses his/her current level of life satisfaction. The mark need not rest on any rung but may lie anywhere on the ladder. The mark must lie WITHIN the ladder, however, and not next to it.
- 13.3 Enter appropriate letter.
- 13.4.1-13.4.3 List only one item per line.

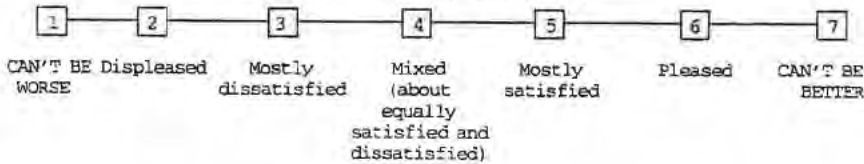
SECTION 14: FINAL REMARKS.

- 14.1 Circle client's response.

SECTION 15: INTERVIEWER COMMENTS.

- 15.1 Enter number of minutes.
- 15.2 Enter appropriate letter.
- 15.3 Mark with a 'X' for Quality of Life Uniscale.

LIFE SATISFACTION SCALE (LSS)



LANCASHIRE QUALITY OF LIFE PROFILE

FOR OFFICE
USE ONLY

CARD 1

NAME OR IDENTIFICATION NUMBER _____	_____ 1-5
ADDRESS (optional): _____ _____	
DATE OF INTERVIEW: _____	_____ 6-11
INTERVIEWER'S NAME: _____	_____ 12-14
If the client DECLINES to be interviewed, please state the reason(s) and STOP HERE: _____ _____	_____ 15
STARTING TIME: _____	
SECTION 1: CLIENT'S PERSONAL DETAILS.	
1.1 The client's age is: _____ years	_____ 16-18
1.2 The client is _____ male _____ female	_____ 19
1.3 The client's ethnic group is: _____	_____ 20
a. White b. Black-Caribbean c. Black-African d. Black-Other e. Indian f. Pakistani g. Bangladeshi h. Chinese i. Other	
1.4 At what age did the client leave full-time education? _____ years	_____ 21-22
SECTION 2: GENERAL WELL-BEING.	
2.1 Can you tell me how you feel about your life as a whole today? (LSS) _____	_____ 23
SECTION 3: WORK/EDUCATION.	
3.1 Do you have a job? _____ YES / NO / DK	_____ 24
3.2 (If YES) What is your occupation? _____	_____ 25-26
3.3 How many hours per week do you work? _____ hrs.	_____ 27-29
3.4 How much money are you paid weekly (gross)? _____	_____ 30-32
How satisfied are you with:(LSS)	
3.5 your job? (or sheltered employment; occupational or industrial therapy; studies) _____	_____ 33
3.6 the amount of money that you make? _____	_____ 34
3.7 being unemployed or retired? (if appropriate) _____	_____ 35

SECTION 4: LEISURE/PARTICIPATION.

In the past fortnight, have you: Y N DK
 4.1 been out to play or watch a sport? 1 2 3
 4.2 been out shopping? 1 2 3
 4.3 been for a ride in a bus, car or train
 other than for transport to and from work? 1 2 3
 4.4 watched television or listened to radio? 1 2 3
 4.5 In the past year, have there been times
 when you would have liked to have had more
 leisure activity but were unable? 1 2 3

How satisfied are you with: (LSS)

4.6 the amount of pleasure you get from
 things you do at home? _____
 4.7 the amount of pleasure you get from
 things you do outside your home? _____
 4.8 the pleasure you get from radio or tv.? _____

SECTION 5: RELIGION.

5.1 What is your religion now? _____
 a. Protestant d. Muslim
 b. Roman Catholic e. Hindu g. None
 c. Jewish f. Other

5.2 How often have you attended religious
 services in the past month? _____

How satisfied are you with: (LSS)

5.3 your religious faith and its teachings? _____
 5.4 the frequency which you attend services? _____

SECTION 6: FINANCES.

6.1 What is your total weekly income? _____
 6.2 Which, if any, state benefits do you receive? _____

6.3 In the past year, have you been
 turned down for any state benefits for
 which you have applied? YES / NO / DK
 6.4 About how much more money per week do you
 need to be able to live as you would wish? _____
 6.5 During the past year, have you ever lacked the
 money to enjoy everyday life? YES / NO / DK

How satisfied are you with: (LSS)

6.6 how well-off you are financially? _____
 6.7 the amount of money you have to spend
 on enjoyment? _____

FOR OFFICE
 USE ONLY

_____ 36
 _____ 37
 _____ 38
 _____ 39
 _____ 40
 _____ 41
 _____ 42
 _____ 43
 _____ 44
 _____ 45-46
 _____ 47
 _____ 48
 _____ 49-51
 _____ 52-53
 _____ 54
 _____ 55-57
 _____ 58
 _____ 59
 _____ 61

SECTION 7: LIVING SITUATION.

7.1 The client's current residence is: _____

- | | |
|----------------------|-----------------------------------|
| a. Hostel | f. Private house (owner occupied) |
| b. Boarding-out | g. Private house (rental) |
| c. Group home | h. Flat |
| d. Hospital ward | i. Other |
| e. Sheltered housing | j. None |

7.2 How long have you lived here? _____ yrs. _____ mos.

7.3 How many other people live here? _____

7.4 Do your family live here too? YES / NO / DK _____

7.5 In the past year have there been times when you wanted to move or improve your living conditions but were unable to do so? YES / NO / DK _____

How satisfied are you with: (LSS)

- | | | | |
|---|-------|-------|----|
| 7.6 the living arrangements here? | _____ | _____ | 10 |
| 7.7 the amount of independence you have here? | _____ | _____ | 11 |
| 7.8 the amount of influence you have here? | _____ | _____ | 12 |
| 7.9 living with the people who you do? | _____ | _____ | 13 |
| 7.10 the amount of privacy that you have here? | _____ | _____ | 14 |
| 7.11 the prospect of living here for a long time? | _____ | _____ | 15 |
| 7.12 the prospect of returning to live in hospital? (if applicable) | _____ | _____ | 16 |

SECTION 8: LEGAL AND SAFETY.

8.1 In the past year have you been: Y N DK

a. accused of a crime? 1 2 3 _____ 17

b. assaulted, beaten, molested or otherwise a victim of violence? 1 2 3 _____ 18

8.2 In the past year have there been any times when you would have liked police or legal help but were unable to get it? 1 2 3 _____ 19

How satisfied are you with: (LSS)

- | | | | |
|---------------------------------------|-------|-------|----|
| 8.3 your general personal safety? | _____ | _____ | 20 |
| 8.4 the safety of this neighbourhood? | _____ | _____ | 21 |

SECTION 9: FAMILY RELATIONS.

9.1 What is your current marital status? _____

- | | |
|------------|--------------|
| a. Married | d. Divorced |
| b. Single | e. Separated |
| c. Widowed | f. Other |

9.2 How many children do you have? _____ 22-24

FOR OFFICE
USE ONLY

CARD 2

1-2

3-5

6-7

8

9

10

11

12

13

14

15

16

17

18

19

20

21

22

23-24

9.3 How often do you have contact with a relative?	_____	FOR OFFICE USE ONLY	
a. daily	d. annually		
b. weekly	e. less than annually		
c. monthly	f. not appropriate/DK		25
9.4 In the past year have there been any times when you would have liked to have participated in family activities but were unable? YES / NO / DK			26
How satisfied are you with: (LSS)			
9.5 your family in general?	_____		27
9.6 the amount of contact you have with your relatives?	_____		28
9.7 your marriage? (if applicable)	_____		29
SECTION 10: SOCIAL RELATIONS.			
People differ in how much friendship they need:			
		Y N DK	
10.1 Would you say that you are the sort of person who can manage without friends?	1 2 3		30
10.2 Do you have anyone who you would call a "close friend" (i.e. who knows you very well)?	1 2 3		31
10.3 Do you have a friend to whom you could turn for help if you needed it?	1 2 3		32
10.4 In the past week, have you visited with a friend?	1 2 3		33
How satisfied are you with: (LSS)			
10.5 the way that you get on with other people?	_____		34
10.6 the number of friends you have?	_____		35
SECTION 11: HEALTH.			
		Y N DK	
During the past year have you:			
11.1 seen a doctor for a physical illness?	1 2 3		36
11.2 seen a doctor for your nerves?	1 2 3		37
11.3 been in hospital for your nerves?	1 2 3		38
11.4 Do you take medication for your nerves?	1 2 3		39
11.5 Do you have any physical handicap which effects your mobility?	1 2 3		40
11.6 How old were you when you were first admitted to a psychiatric hospital/ward? (if appropriate)	_____ yrs.		41-42
11.7 In the past year have there been times when you wanted help from a doctor or other professional for your health but were unable to get it?	_____	YES / NO / DK	43

How satisfied are you with:(LSS)

			FOR OFFICE USE ONLY
11.8 your general state of health?	_____		44
11.9 how often you see a doctor?	_____		45
11.10 your nervous well-being?	_____		46

During the past month, did you ever feel:

		Y	N	DK	
11.11 pleased about having accomplished something?		1	2	3	47
11.12 that things were going your way?		1	2	3	48
11.13 proud because some one complimented you on something you had done?		1	2	3	49
11.14 particularly excited or interested in something?		1	2	3	50
11.15 "on top of the world"?		1	2	3	51
11.16 too restless to sit in a chair?		1	2	3	52
11.17 bored?		1	2	3	53
11.18 depressed or very unhappy?		1	2	3	54
11.19 very lonely or remote from other people?		1	2	3	55
11.20 upset because someone criticised you?		1	2	3	56

SECTION 12: SELF-CONCEPT.

How satisfied we are with ourselves is also a very important part of our lives. Do you agree that the following statements apply to you:

		Y	N	DK	
12.1 You feel that you're a person of worth, at least on an equal plane with others.		1	2	3	57
12.2 You feel that you have a number of good qualities.		1	2	3	58
12.3 All in all, you are inclined to feel that you are a failure.		1	2	3	59
12.4 You are able to do things as well as most others.		1	2	3	60
12.5 You feel you do not have much to be proud of.		1	2	3	61
12.6 You take a positive attitude toward yourself.		1	2	3	62
12.7 On the whole, you are satisfied with yourself.		1	2	3	63
12.8 You wish you could have more respect for yourself.		1	2	3	64
12.9 You certainly feel useless at times.		1	2	3	65
12.10 At times you think you are no good at all.		1	2	3	66

SECTION 13: GENERAL WELL-BEING.

During the course of this interview, you and I have discussed many of the conditions of your life and how you feel about them. Might we try and sum them up now?

13.1 Can you tell me how you feel about your life as a whole? (LSS) _____

13.2 This is a picture of a ladder. I would like you to imagine that the bottom of the ladder represents the very worst outcome which you could expect to have had in life. The top represents the very best possible outcome you could have expected. Can you please mark (X) where on this ladder you would put your life at present? (Ask client to MARK ladder!)

BEST POSSIBLE OUTCOME



WORST POSSIBLE OUTCOME

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USE ONLY

CARD 3

1

2-4



	FOR OFFICE USE ONLY
13.3 How happy has your life been over-all? _____	
a. very happy	
b. pretty happy	
c. not happy	5
d. don't know	
13.4 Can you name anything (s) which would improve the quality of your life?	
1. _____	6-7
2. _____	8-9
3. _____	10-11
SECTION 14: FINAL REMARKS.	
Thank you for having spoken to me in such an honest and open way about your life.	
14.1 It is possible that we may wish to contact you again in future, perhaps next year. Would you be willing to be interviewed again? YES / NO / DK	12
Thank you very much for your co-operation.	
FINISHING TIME: _____	
SECTION 15: INTERVIEWER COMMENTS.	
Before filing this questionnaire or proceeding on to the next interview, would you please complete the following section while your impressions of both the client and the setting for the interview are still fresh in your memory.	
15.1 How long did the interview take? _____ mins	13-15
15.2 How reliable or unreliable do you think the client's responses were? _____	16
a. very reliable	
b. generally reliable	
c. generally unreliable	
d. very unreliable	

FOR THE INTERVIEWER

15.3 Please complete the QUALITY OF LIFE UNISCALE now.

PLEASE MARK WITH AN X THE APPROPRIATE PLACE WITHIN THE BOX TO INDICATE YOUR RATING OF THIS PERSON'S PRESENT QUALITY OF LIFE.

LOWEST quality applies to someone completely dependent physically on others, seriously mentally disabled, unaware of surroundings and in a hopeless position.

HIGHEST quality applies to someone physically and mentally independent, communicating well with others, able to do most things enjoyed, pulling own weight, with a hopeful yet realistic attitude.

LOWEST QUALITY

[Empty box for rating]

HIGHEST QUALITY

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17-19

THANK YOU FOR YOUR HELP.

Please return completed questionnaires to:

Assistant Director (Development)
Social Services Headquarters

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File: LQOLP30



DAI-30

DRUG ATTITUDE INVENTORY

(Long Version)

APPENDIX 7

Scoring Criteria

The scale has fifteen (15) items that will be scored as **TRUE** and fifteen (15) items that will be scored as **FALSE** in the case of a fully compliant (positive subjective response). A correct answer to these items will be scored as plus one. An incorrect response will be scored as minus one. The final score is the sum of the total of pluses and minuses. A positive total score means a positive subjective response (compliant). A negative total score means a negative subjective response (non-compliant).

Below is our standard of completely compliant response profile (positive subjective response).

1	F	11	F	21	T
2	T	12	F	22	T
3	F	13	F	23	T
4	T	14	F	24	T
5	F	15	T	25	F
6	T	16	F	26	T
7	T	17	F	27	F
8	T	18	T	28	F
9	T	19	F	29	T
10	F	20	F	30	T

DAI-30
DRUG ATTITUDE INVENTORY
 (Long Version)

- | | | | |
|-----|---|---|---|
| 1. | I do not need to take the medication once I feel better. | T | F |
| 2. | For me, the good things about medication outweigh the bad. | T | F |
| 3. | I feel weird, like a "zombie", on medication. | T | F |
| 4. | Even when I am not in the hospital, I need medication regularly. | T | F |
| 5. | If I take medication, it is only because of pressure from other people. | T | F |
| 6. | I am more aware of what I am doing, of what is going on around me, when I am on medication. | T | F |
| 7. | Taking medications will do me no harm. | T | F |
| 8. | I take medications of my own free choice. | T | F |
| 9. | Medications make me feel more relaxed. | T | F |
| 10. | I am no different on or off medication. | T | F |
| 11. | The unpleasant effects of medication are always present. | T | F |
| 12. | Medication makes me feel tired and sluggish. | T | F |
| 13. | I take medication only when I am sick. | T | F |
| 14. | Medication is a slow-acting poison. | T | F |
| 15. | I get along better with people when I am on medication. | T | F |
| 16. | I cannot concentrate on anything when I am taking medications. | T | F |
| 17. | I know better than the doctor when to go off medication. | T | F |
| 18. | I feel more normal on medication. | T | F |
| 19. | I would rather be sick than taking medications. | T | F |

GO TO THE NEXT PAGE ➡

DAI-30

DRUG ATTITUDE INVENTORY

(Long Version)

- | | | | |
|-----|---|---|---|
| 20. | It is unnatural for my mind and body to be controlled by medications. | T | F |
| 21. | My thoughts are clearer on medication. | T | F |
| 22. | I should stay on medication even if I feel alright. | T | F |
| 23. | Taking medication will prevent me from having a breakdown. | T | F |
| 24. | It is up to the doctor when I go off the medication. | T | F |
| 25. | Things that I could do easily are much more difficult when I am on medication. | T | F |
| 26. | I am happier, feel better, when taking medications. | T | F |
| 27. | I am given medication to control behaviour that other people (not myself) do not like. | T | F |
| 28. | I cannot relax on medication. | T | F |
| 29. | I am in better control of myself when taking medications. | T | F |
| 30. | By staying on medications, I can prevent getting sick. | T | F |

If you have any further comments about the medication or this questionnaire, please write them below or overleaf.

DO NOT WRITE BELOW THIS LINE

CB _____

PC _____

VPCAT _____

BURDEN INTERVIEW

APPENDIX 8

INSTRUCTIONS: The following is a list of statements, which reflect how people sometimes feel when taking care of another person. After each statement, indicate how often you feel that way; never, rarely, sometimes, quite frequently, or nearly always. There are no right or wrong answers.

1. Do you feel that your relative asks for more help than he/she needs?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
2. Do you feel that because of the time you spend with your relative that you don't have enough time for yourself?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
3. Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
4. Do you feel embarrassed over your relative's behavior?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
5. Do you feel angry when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
6. Do you feel that your relative currently affects your relationship with other family members or friends in a negative way?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
7. Are you afraid what the future holds for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
8. Do you feel your relative is dependent upon you?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
9. Do you feel strained when you are around your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

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10. Do you feel your health has suffered because of your involvement with your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
11. Do you feel that you don't have as much privacy as you would like, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
12. Do you feel that your social life has suffered because you are caring for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
13. Do you feel uncomfortable about having friends over, because of your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
14. Do you feel that your relative seems to expect you to take care of him/her, as if you were the only one he/she could depend on?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
15. Do you feel that you don't have enough money to care for your relative, in addition to the rest of your expenses?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
16. Do you feel that you will be unable to take care of your relative much longer?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
17. Do you feel you have lost control of your life since your relative's illness?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
18. Do you wish you could just leave the care of your relative to someone else?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
19. Do you feel uncertain about what to do about your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always
20. Do you feel you should be doing more for your relative?
0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

21. Do you feel you could do a better job in caring for your relative?

0. Never 1. Rarely 2. Sometimes 3. Quite Frequently 4. Nearly Always

22. Overall, how burdened do you feel in caring for your relative?

0. Not at all 1. A little 2. Moderately 3. Quite a bit 4. Extremely

Appendix 9

Understanding of Medication Questionnaire.

I would like to ask you some questions about the medication you are currently taking by injection as a treatment for mental health reasons (sometimes referred to as antipsychotic medication). If you are unsure of any question, please feel free to ask.

- | | |
|--|---------------------------|
| 1. What is the name of your medication? | score 0 1 2
error 0 1 |
| 2. What is the dose of your medication? | score 0 1 2
error 0 1 |
| 3. For how long does this antipsychotic treatment usually need to continue ? | score 0 1 2
error 0 1 |
| 4. How frequently do patients taking antipsychotic medication need to be reviewed by their doctor? | score 0 1 2
error 0 1 |
| 5. How does antipsychotic medicate help patients? | |
| (a) General problem area (feel better/helps sleep/nerves)
Prompt: do you know of any general ways it can help? | score 0 1 2
prompt 0 1 |
| (b) Symptom relief (hallucinations, delusions)
Prompt: what problem does it help reduce | score 0 1 2
prompt 0 1 |
| (c) Diagnostic (schizophrenia, manic depression)
Prompt: what condition does it treat? | score 0 1 2
prompt 0 1 |
| 6. Do you know of any effects of stopping to take antipsychotic medication as shown by research? | score 0 1 2
error 0 1 |
| 7. Do you know of any side effects of antipsychotic medication? | Score 0 1 2 3 4 |
| <p><i>Scoring: 0 = no knowledge 1= aware of 'problems' unable to describe</i>
 <i>2= knows one side effect 3=two or more side</i>
 <i>4. knows three or more side effects, good account.</i></p> | |
| 8. Do you know of any special precautions patients are supposed to follow when taking this medication (alcohol/driving/machinery/sunlight/other drugs)? | score 0 1 2 3 |
| Prompt: are there any problems or things you should avoid when taking antipsychotic medication . | prompt 0 1 |

Scoring: 0 = no knowledge
1= aware of 'problems' unable to describe
2= aware of non specific precaution, minimal details
3=good account of two or more precautions

Knowledge scoring	Prompt and error scoring.	Total scores.
0 = no understanding	0 = absent	Total knowledge scores= /23
1= partial understanding	1 = present	Total prompt scores /4
2= full understanding		Total error scores /5
9. Understanding of tardive dyskinesia		
(a) have you heard of tardive dyskinesia		score 0 1 2
Prompt has anyone ever mentioned a side effect of abnormal movements.		prompt 0 1
		Error 0 1
(b) When does tardive dyskinesia occur?		Score 0 1 2
Prompt: how long after the treatment was started does it usually occur		prompt 0 1
		error 0 1
© What problems does tardive dyskinesia cause to patients with it		score 0 1 2
prompt: can the abnormal movements make people feel bad in any way		prompt 0 1
		error 0 1
(d) how is tardive dyskinesia treated		score 0 1 2
Prompt: can it always be treated		prompt 0 1
		Error 0 1
(e) Do you understand why antipsychotic medication is used despite the risk of side effects		score 0 1 2
Prompt: do you understand that the benefits of medication may outweigh the problems due to side-effects.		prompt 0 1
		Error 0 1
Prompt: does it effect muscles		prompt 0 1

**Teaching carers/Supportive persons to give depot injections;
interview prompt to elicit any change in relationships.**

Questions for the giver of the depot injection.

In your opinion has your relationship with the person you are administering the depot injection to, changed since you commenced administering the depot injection?

If yes, how would you describe these changes?

Do you see these changes in a positive or negative way?

Has your affection for the recipient of the injection changed in any way?

Do you talk to the recipient of the injection with concerns you may have about your ability to give the depot injection? If so, can you give any examples?

Are there any changes in the recipient's behaviour or feelings towards you since you learnt the skills to give the depot injection?

As a consequence of being able to give the depot injection, have you felt/thought about control/power changes within the relationship?

How burdened so you feel by having the skills/responsibility to give the depot injection?

Has the amount of time spent involved with the recipient changed?

How do you feel about being able to give an injection to a person you know?

Is there anything else I have not covered or that you would like to tell me?

Are there any questions you would like to ask me?

Thank you for your time and sharing your experience with me.

Questions for the recipient of the depot injection.

In your opinion has your relationship with carer/relative/supportive person changed since they learned to give you your depot injection?

If yes, how would you describe the changes?

Do you see these changes in a positive or negative way?

What are your thoughts/feelings about receiving an injection from a person you know?

Has your affection for the carer/supportive person changed in any way?

Do you talk to the carer/supportive person with concerns you may have about receiving an injection from a person you know?

Are there any changes in the injection givers' behaviour or feelings towards you since they learnt the skills to give the depot injection?

As a consequence of receiving the depot injection from your carer/supportive person, have you felt/thought about control/power changes within the relationship?

How do you feel about receiving an injection from your carer/supportive person?

Is there anything else I have not covered or that you would like to tell me?

Are there any questions you would like to ask me?

Thank you for your time and sharing your experience with me.

Within the study, all participants engaged with a range of information/educational material. This provided guidance on the administration of an intramuscular injection, medication, care planning about relapse indicators and information for children on mental illness. Their use with each dyad identified other important issues which need to be considered within an evolving training package. The training package is divided into 14 sections whose main headings include; having a rationale for taking on the role; questions to consider before you start; education resources which will be used during the training; skills which are necessary for the role to be undertaken; health and safety factors; communication; knowledge of support structures; working with children; developing a care plan and handing back the role to the health service if necessary. A column is left for comments as individual experiences will differ and recording these differences is important. The training package is designed for collaborative working between mental health services, practitioners and supportive persons who are interested in taking on the role resulting in some sections of the package appearing to be more relevant to one party or the other.

Rationale	Why might you want to take on this role?
Background and questions to consider	<p>Learning the skills, knowledge and language about giving a family member an intramuscular injection can take time – this may require home visits by the nurse who will bring equipment like needles, syringes and a manikin to your home. Or attendance at a clinic to learn the skills may be an option</p> <p>Deciding on the time and frequency of these training sessions is a matter for negotiation. For example, the sessions can be weekly for up to one hour or longer or a half days training to start with. The experience from the participants in the study averaged four sessions of between 40 minutes to 1 hour practice before supervised injection administration. Homework on administration an IM injection may be given for you to read between sessions</p> <p>It is helpful for the supportive person and recipient to attend some of the training sessions together. You will administer injections under the supervision of the nurse before administering unsupervised injections. The giving and receipt of feedback will be important to all parties in the learning process so it is useful to consider what the giving and receiving of feedback is like for you.</p> <p>Discussions and uncertainty are part of the learning process. For example, how much do you share with your supportive person about your mental illness? This information can evolve after you learn the skills of injection administration</p> <p>Discuss whether you want other household members informed and involved as knowing who is aware of the process is important. Disclosure</p>

	<p>and confidentiality are relevant factors for all parties</p> <p>Does the nurse attending your home with equipment cause you concern in relation to alerting other family members, neighbours etc of your mental illness?</p>
Education resources	<p>The chapter within the Royal Marsden Hospital Manual of Clinical Procedures (Dougherty & Lister) on intramuscular injection preparation and administration is core educational material</p> <p>Hunter's article (2008) Intramuscular Injection Technique useful supportive reading</p> <p>The diagrams from Hunter's article on identification of IM sites, when printed off in colour were found to be useful</p> <p>Photographs from university nursing websites on sites for IM injection administration used</p> <p>Literature on medication specific to recipient prescription ascertained from Trust website. Other sources used were the local pharmacist, MIND and Royal College of Psychiatrists</p> <p>Elements of the Early Warning Signs (Barker, Smith and Higbed; Worcestershire Mental Health Partnership) useful when discussing and planning relapse management plans</p> <p>Literature related to psychosis/schizophrenia from Trust intranet and from Mind/Royal College of Psychiatrists</p> <p>Trust policy and protocol related to depot injection, monitoring and record keeping</p> <p>For participants with children who wished to discuss mental illness with them, the literature from CAMHS and voluntary organisations such as Young Minds. One such book, Living with a Black Dog; (Johnson M), was identified and particularly valued by the children of one dyad</p>
Knowledge	<p>Knowledge of medication name, frequency and dosage. Rationale as to why given</p> <p>Knowledge of where to get further information about medication if and when required. For example, psychiatrist/ pharmacist/voluntary sector/online</p> <p>Some specific medications e.g Risperadol come with their own needle and syringe</p> <p>Clinical waste boxes for disposing of equipment used during the injection administration. Where to get a supply and where to dispose? The local pharmacy has a role in this procedure.</p> <p>Knowledge of site for the administration of an intramuscular injection-the upper outer quadrant.</p> <p>Knowledge of which two key anatomical features are to be avoided when administering injection; sciatic nerve and gluteal artery (use literature/photographs as reminder)</p> <p>Use the triangle of the greater trochanter, iliac crest and posterior iliac</p>

	<p>spine to identify site for IM injection administration</p> <p>Knowledge of equipment</p> <p>Needles – size 21 (green) and size 19 (white). Use white needle to withdraw medication from ampoule and green needle to administer medication</p> <p>Syringes – 5 ml or 2 ml syringes</p> <p>Retractable needles to administer the depot injection may be an option</p> <p>The depot administrator and patient will require knowledge about the medication and its side effects</p> <p>Use medication leaflets/local pharmacy/mental health services intranet/GP services/on line facilities</p> <p>The depot administrator and receiver will need to know who is prescribing the depot medication and where a supply of the medication will be gained from</p> <p>The cost of a prescription and whether payment required</p> <p>Safe and confidential transport of medication and equipment from clinic to home (e.g. a Ferrero Rocher chocolate box in a well known shopping brand bag was found by one study participant to be suitable)</p>
<p>Skills and process</p>	<p>The confidence and competence of the injection giver is important for both the recipient and mental health services</p> <p>Approaches used to develop skills include; familiarity with equipment, demonstration, observations, practice and feedback.</p> <p>A manikin and injection pads borrowed from the University to practice injection technique. These were particularly useful in IM site recognition and developing awareness of the resistance which may be experienced when entering muscle.</p> <p>An orange with cling film was useful in demonstrating and practicing the Z track technique</p> <p>Vegetable oil was useful in practising and feeling the resistance which is similar to that when aspirating viscous oil based medication</p> <p>Depot Administration skills.</p> <p>Injection preparation; opening ampoule, aspirating medication, getting rid of bubbles, changing needles, re-sheathing needle if absolute necessary (moving needle to sheath with sheath on tray, or holding the very tip of the sheath and moving it towards the needle - to avoid needle stick injury) see photograph/check list – Royal Marsden good practice page</p> <p>Checking medication ampoule for medication name, dosage and expiry date for example, Piportil 50mg in one ml – 3 weekly</p> <p>Wear gloves if necessary – if so, rationale for wearing gloves is the minimisation of potential air droplets from the syringe, with medication, landing on skin</p> <p>Administration; identify correct site – upper outer quadrant (see guidance knowledge and skills cell)</p>

	<p>When administering an injection, use dart like process to pierce the skin – direct 90 degree angle into muscle with smooth quick action. Leave 2 millimetres of needle showing. In the event of a needle break (very rare), calmly grab hold of protruding needle tip and withdraw from person – can use tweezers to grab tip Avoid slow drip administration style</p> <p>Use Z track technique. Aspirate for 10 seconds to check for any blood in the syringe. If blood appears, withdraw needle and dispose of medication and start again. May see some bleeding after administration- if so, clean with tissue and use plaster Blood may appear after administration due to the amount of capillaries that permeate the muscle and are punctured by injection needle</p>
Health and safety issues	<p>Hand washing before and after injection administration Knowing where to acquire a clinical waste box, where to dispose of used needles and syringes Storage of equipment and clinical waste box within the home, particularly with children, visitors and pets around Storage of equipment related to concealment and privacy within the home Management of needle stick injuries Clearing up after administration of injection</p>
Communication 1	<p><i>Communication between the recipient and administrator of depot injection, between family members and Mental Health team for ;</i> Appointments and support Direct telephone number of named CPN, psychiatrist and secretary GP practice; for prescription of medication and equipment Voluntary and support networks – Young Minds; Mind; Rethink: Carers UK or local carers network</p>
Communication 2	<p><i>Communication between supportive person and recipient;</i> To plan and deliver each injection – which room to use, which side of the body to give the injection, position of receiver during the injection administration, feedback after administration, recording of administration, and the maintenance of privacy The recipient of the depot injection can give support and guidance about selecting the specific site of administration</p> <p>Supportive persons/partners are required to have an understanding of the signs of distress and possible relapse symptoms, and a shared agreement about these symptoms with a response plan. For example, what might these symptoms indicate? Partner will alert recipient if something of concern is seen or heard and discuss concerns with them. Use published early warning signs (Barker et al) approach/assessment material to develop the personalised knowledge about relapse/distress symptoms and coping strategies</p> <p>Agreement between the giver and receiver of the depot injection about the time and day to give the depot injection. Does the medication cause a</p>

	<p>degree of drowsiness within 24/48 hours after administration? If so, the time and day of administration is important. For example, if the person receiving the depot injection is working Monday to Friday, then administering the injection on a Friday may be preferred</p> <p>Explore/discuss any possible impact on the relationship between the receiver of the injection and the supportive person– is the role impacting on relationships? Is the role of depot administration a stressor?</p>
Care plan	<p>This care plan can and should evolve over time and experience and in collaboration with the mental health and GP services A detailed and understood care plan on the actions to take should symptoms of distress be observed Where will you keep the care plan so that it maintains confidentiality but is accessible if needed?</p> <p>The care plan covers action to take if the person in receipt of the depot medication does not want to have the depot injection at the specified time. For example, the supportive person (who is administering the depot injection) may remind and seek consent on two further occasions in the seven days following the due date. The care plan should agree the timeframe and process through which the supportive person refers back to the mental health team if the patient does not wish to accept the depot injection Understanding the role of partner and the boundary between being a family member and a medication administrator</p> <p>Keeping a record of the prescriptions administered at home – including date, dosage of medication and site of administration. This record should be presented and discussed at clinic appointments Involving and informing others of home administration. It is important to value the role of supportive person administration If the out-patient clinic is the only or main link with services, it is important for both patient and supportive person to raise issues related to home administration with the practitioner you are seeing. Emailing or faxing the record of depot administration charts to the mental health team before or during an appointment so that the medical intervention can be reviewed and discussed Where to get a supply of home administration charts What to do with completed charts Where to store charts and other literature – guidance on administration of intramuscular injection/medication leaflets</p> <p>The care plan will identify strategies in place to identify medication due dates. For example, calendar, mobile phone, diaries Whose responsibility is it to remember the due date of the injection? Knowledge of who else needs to know within/outside the family</p>
Support	Support for the supportive person administrator is important

structures 1	<p>Once the depot injection is being administered unsupervised, a nurse from the local services will observe the administration of an injection at agreed periods. The recommendation is six monthly. This is an opportunity to update, refresh the skills and knowledge required and gain support. Being observed and given feedback may cause anxiety so it is important for the administrator and patient to be aware of this process.</p> <p>The family would want in place, through local mental health/GP services a supportive structure that is competent, supportive, has a monitoring role, who understands the role and is able to respond when a query is raised</p>
Support structures 2	<p>Supportive person and the recipient of the injection will have contact person/telephone number to relay concerns about client symptom change to the local health organisations. For example, mental health team or GP. The family will inform the services that they are home-administering a depot injection of, for example, Piportil 50mg, three weekly and request to be seen or have a prescription</p> <p>Awareness of local mental health service configuration, venue for such services and hours of operation. For example Duty and Home Treatment teams: how they differ and expectations of support they may offer Awareness of educational support networks – MIND, Royal College of Psychiatrists, personal support structures, Rethink, library, internet sources, carer groups Awareness of benefit and employment advice structures</p>
Issues to consider if children are involved	<p>Discussions with children and the provision of information when and where the parents feel is appropriate and when children ask questions about the injection or its purpose.</p> <p>Awareness of appropriate educational material and support networks- for example, Young Minds/ school support services</p>
Returning the role to health services	<p>The family can decide at any stage to return administration of the depot injection back to the mental health team or GP practice (if an option). Return to services does not have to be permanent – a break/holiday may be needed</p> <p>If the nurse has concerns at any stage of the process, then he or she will discuss these concerns and take back the role until the issues are resolved</p>
Comments	

Appendix 13

Research questions –staff interview codes and themes.

Research information leaflet -. questions to be answered.

Themes

How can a supportive person learn the skills to give a depot injection safely?	Entry/process/sustainability Choice and decision making Injection administration Concordance
How can the community mental health team acknowledge and resolve any difficulties that may arise between you and your supportive person on the issue of medication?	Communication/collaboration Risk Subjective attitude/feelings
Where would you get your medication?	concordance
How can the local community mental health team support you?	Trust Service delivery/ resources /policy
How can your doctor monitor your illness and medication?	Entry/process/sustainability
How can we develop an agreement and understanding with the doctor who prescribes your medication and the local community mental health team so that all parties know what to do and who to contact if difficulties arise?	Trust Decision making and choice Mental Health Carer/care
Explore and understand any changes that may arise in your relationship with the person who is giving the depot injection?	Owner/responsibility Emotional Relationship/Privacy power

Staff interview codes and themes.

Injection administration	concordance	Service delivery/ resources/policy 24 codes	Risk. 21 codes
Trust 23 codes	Mental Health 2 codes	Emotional 8 codes	Decision making and Choice 10 codes
Ownership – responsibility 12 codes	Entry/process/ sustainability 42 codes	Relationship/Privacy 17 codes	Care/carer 10 codes
	Power 7 codes	Communication – collaboration 5 codes	
Subjective attitude/feeling 7 codes	Change 7 codes	Leadership 3 codes	Nursing and roles 23 codes

Possible Interpretive themes;

1. Working with risk within a role sharing intervention;
2. Service provision- context and philosophy
3. There is always a level of uncertainty – moving from ‘offering’ to ‘involving’;
4. I am not rejecting- I need to understand the issues;;
5. Intramuscular injections – knowledge, skills and support.



Full Text

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FIGURE 1

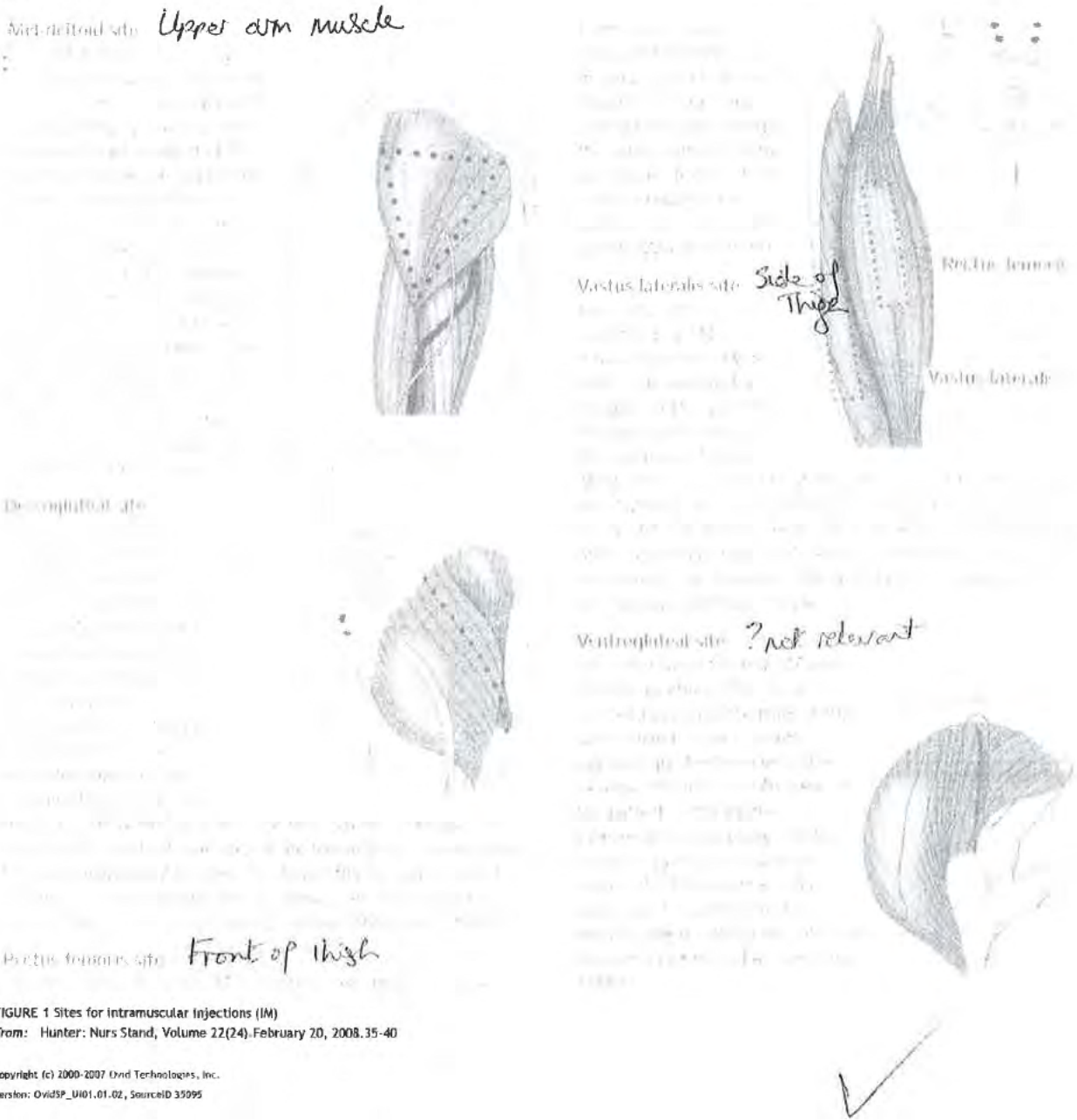


FIGURE 1 Sites for intramuscular injections (IM)
From: Hunter: Nurs Stand, Volume 22(24). February 20, 2008. 35-40

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Version: OvidSP_U01.01.02, SourceID 35095

Need to simplify

injections (Figure 1). The two recommended sites for IM injections are the vastus lateralis and the ventrogluteal sites (Donaldson and Green 2005, Nisbet 2006). However, when the patient is obese, the vastus lateralis is a better option (Nisbet 2006).

When choosing an appropriate site for administration, the nurse needs to ensure that the medication will be absorbed. The nurse needs to consider whether the patient is receiving regular IM injections because the site will need to be rotated to avoid irritation, pain and sterile abscesses. Choice will also be influenced by the patient's physical condition and age. Active patients are more likely to have a greater muscle

mass than older or emaciated patients, so individuals will need to be assessed to see if they have sufficient muscle mass. If not, the muscles may need to be 'pinched' up before the injection (Workman 1999, Rodger and King 2000). Any area or presence of inflammation, swelling or infection should be avoided (Workman 1999).

Patient preparation

It is important to explain the procedure so that the patient fully understands and is able to give his or her informed consent and co-operation. The discussion should include the choice of site for the injection and information about the medication, action and side effects. The patient can then express any concerns or anxieties relating to the procedure and the patient's knowledge can be

FIGURE 1

Sites for intramuscular injections (IM)

Not very clear - other page - avoid

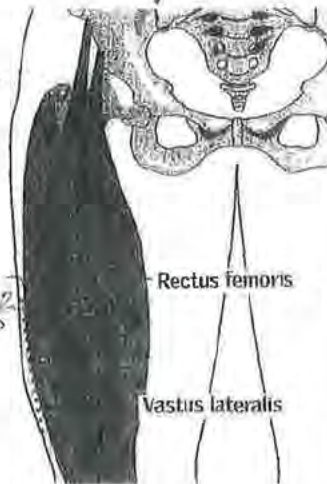
FIGURE 1 much better

Mid-deltoid site (Upper arm muscle)

The mid-deltoid site is easily accessible but due to the size of the muscle the area should not be used repetitively and only small volumes should be injected. The maximum volume should be 1ml (Rodger and King 2000). The denser part of the deltoid must be used. It is useful to visualise a triangle whereby the horizontal line is located 2.5-5cm below the acromial process and the mid-point of the lateral aspect of the arm in line with the axilla forms the apex. The injection is given about 2.5cm down from the acromial process, avoiding the radial and brachial nerves (Workman 1999, Rodger and King 2000).



1-5ml can be injected, although for infants this would be 1-3 ml. The rectus femoris is a large and well-defined muscle and is the anterior muscle of the quadriceps. It is located halfway between the superior iliac crest and the patella (Workman 1999).

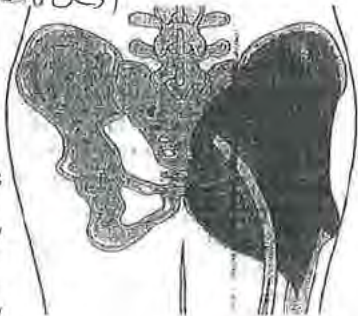


Vastus lateralis site (Thigh)

The vastus lateralis site: used for deep IM and Z-track injections. Up to 5ml can be administered (Rodger and King 2000). The muscle forms part of the quadriceps femoris group of muscles and is located on the outer side of the femur. It is found by measuring a hand's breadth from the greater trochanter and the knee joint, which identifies the middle third of the quadriceps muscle (Workman 1999). There are no major blood vessels or structures which could cause an injury in this area (Rodger and King 2000).

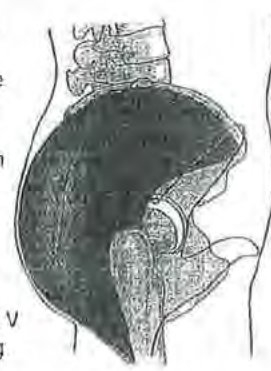
Dorsogluteal site (Buttocks)

This area is used for deep IM and Z-track injections. Up to 4ml can be injected into this muscle (Workman 1999, Rodger and King 2000). Commonly referred to as the outer upper quadrant, it is located by using imaginary lines to divide the buttocks into four quarters. To identify the gluteus maximus, picture a line that extends from the iliac spine to the greater trochanter of the femur. Draw a vertical line from the midpoint of the first line to identify the upper aspect of the upper outer quadrant. This location avoids the superior gluteal artery and sciatic nerve (Workman 1999, Small 2004).



Ventrogluteal site

This site is used for deep IM and Z-track injections. This site is located by placing the palm of the nurse's hand on the patient's opposite greater trochanter (for example, the nurse's right palm on the patient's left hip), then extending the index finger to the anterior superior iliac spine to make a 'V'. The injection is then given into the gluteus medius muscle, which is the centre of the V (Workman 1999, Rodger and King 2000).



Rectus femoris site (Thigh)

This site is used for deep IM and Z-track injections. Between



NHS Foundation Trust

Medication Home administration record.
(for research project)

Appendix 16a - case study 1 overall summary

December 2006 – May 2007 (17 weeks) Number of sessions 7		
Timeframe	Content of sessions	Learning/problems identified and resolved
12/06 – 3/2007	2 sessions on information and consent seeking. Specific action on mode and time of contact due to child not being aware of parent's illness. The family preferred meetings at health centre. Patient needed time to discuss with GP who was prescriber of the depot medication	Information sharing on project Engagement and contact strategies in view of child not being aware of mothers receipt of depot injection Liaison with prescriber of depot injection Consent signed during second information session
4/2007 – 5/07	<p>4 sessions on the skills of IM injection giving held at the health centre. The sessions covered familiarisation with equipment, sites of administration, education using video and literature (from renal unit), observation of practice and feedback and knowledge of prescribed medication. Royal Marsden's Clinical Nursing textbook (Dougherty and Lister 2006) guidance on the administration of intramuscular injections was used alongside a video on IM injection giving was watched and discussed as part of session 2. The video was borrowed from the fertility clinic of a local hospital which uses the video to teach partners IM injection skills.</p> <p>The feedback on the video was mixed as it led to confusion on identifying the upper outer quadrant when participants begun to understand the diagrams within the published literature. Patient and supportive person attended 2 sessions together. Supportive person attended 2 on his own as patient reported 'she did not want to know it all'. The patient felt she would like further illness information than what she currently held. Patient identified that husband may have some</p>	<p>Knowledge and skills required to give IM injection Usefulness of video as educational tool but resulting confusion on IM site identification led to an AR cycle in ascertaining further literature with participants (including diagrams) from nursing literature.</p> <p>Acknowledgement of 'power over' as an issue and what safeguards could be and would be necessary to implement. Not developed as participants moved. Illness specific information for</p>

<p>05/2007</p>	<p>'power' over her if he gained the skills of IM administration and may give her injection when not due Feedback from supportive person related to challenges of dexterity when aspirating viscous medication</p> <p>Depot administration at home by husband. Time negotiated when child was at school. Equipment delivered by researcher. Observation, recording and feedback discussion. The family had concerns related to informing their child about mother's illness and had differing views of how this could be done. Planned to discuss with their GP before moving out of the area.</p>	<p>participants from Trust website, MIND and R.C.Psych websites. Need to have spare vials of medication for practice – this was solved by other study participants later who used cooking oil.</p> <p>4 skills sessions could enable the supportive person to administer an IM injection under supervision. Patient had existing personal preferences that she liked to stand up and valued distraction during injection administration by discussing family and current affairs.</p> <p>Feedback suggested further sessions would be necessary on illness and medication knowledge and how and when to inform the child of parental mental illness.</p> <p>As a researcher I gained personal confidence in understanding wider issues related to injection administration besides skills and knowledge.</p>
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Appendix 16b - case study 2 overall summary

May 2008 – July 2013 (5 years)		Number of sessions/ contacts 74
Timeframe	Content	Learning/Problems identified and resolved
30/5 -31/7/08	15 sessions/contacts during this period. Of these 15 sessions, 2 were with depot clinic co-ordinator, 4 were with dyad on information gaining and giving; 9 were brief meetings or text/telephone contacts negotiating/cancelling and agreeing time to meet in view of dyad working and young children commitments. Texting was the agreed communication process. The dyad required time to consider a rationale for their children for my contact and the agreed rationale was it was related to supportive person's employment. On the 15 th session/contact, study consent form signed.	Engagement processes Communication channels Stigma Safety Rationale for participation by family members
1/8 – 10/10	Following consent, 5 sessions on completing research questionnaires. Importance of husband and wife titles and not use the word 'carer'.	Baseline on knowledge and expectations. Challenging the word carer.
10/10-16/11	4 sessions followed with supportive person on the skills and knowledge to administer IM injection, including- needles, syringes with a manikin to practice on. Literature on injection sites and administration-with photographs to illustrate. Pages from the Royal Marsden text on IM injection preparation and administration used as core alongside Hunters article (2008). Photographs from university nursing websites on sites for IM injection administration used. Feedback from other participants on literature and the use of vegetable oil to replicate depot medication viscosity for practice was used. Health and safety factors. Literature on medication specific to prescription ascertained from Trust website with family aware that they could discuss with local pharmacist if required. Internet access was available within the home and both patient and supportive person were competent users. The supportive	Skills and knowledge development Collaboration and liaison strategy with depot clinic Evaluation of literature - using AR cycle feedback from other participants Participant self-evaluation of skills and knowledge Educational approach

<p>16/11/08- 5/09</p>	<p>person wanted an educational approach that linked the experiences of the patient to the medication rationale.</p> <p>Demonstration of injection giving process from beginning to end. Observation, feedback and practice</p> <p>6 supervised depot administrations by supportive person followed by feedback and identification of areas for development. For the first two depot administrations, medication and equipment needed for one administration collected by researcher and disposed by researcher. For the remaining four depot injections, patient collected medication and equipment from the depot clinic on the week it was due and transported in a non-disclosing package. Safe and non-disclosing storage issues within the home became important.</p> <p>1 practice session with manikin followed the second depot administration with emphasis on aspects of administration identified and observed to warrant development – in particular site recognition, Z track and dexterity during the administration process</p> <p>2 further practice sessions, one following the fourth and one following the sixth supervised depot administrations. These sessions focused on feedback and observed competencies. AR cycle to progress skill competencies. Maintaining privacy by closing curtains and knowing where children were was identified.</p>	<p>AR cycle on skills and knowledge enhancement</p> <p>AR cycle on collection and transport of equipment Storage and disclosure issues developed through an AR cycle Stigma</p> <p>Privacy issues within a busy family home The status of depot within a busy family home where both parents have to behaviourally change to identify time to administer</p>
<p>30/5/09</p>	<p>First unsupervised depot administration by supportive person – timing of administration agreed when support from MH services and researcher were available if necessary. Dyad wanted clarification what action to take if the medication vial broke or became unusable. This was at a stage when only one vial was being collected at a time by the participants. Where to get a replacement. This had been identified by other dyads and a plan agreed with the depot clinic.</p>	<p>Researcher letting go AR cycle on time and action to take if difficulties arose Who and how to report</p>

<p>30/5- 20/12/09</p>	<p>Reporting strategies developed by which patient/supportive person would contact named person at depot clinic to inform them of date and time of depot administration.</p> <p>10 sessions following supportive person administration: these sessions focused on psycho-education about schizophrenia, relapse awareness and developing crisis care planning. Elements of the Early Warning Signs (Barker, Smith and Higbed; Worcestershire Mental Health Partnership) were used. Agreeing time of injection administration so that support was available and medication could be replaced if necessary, equipment access and clinical waste disposal, prescription from GP' feedback and monitoring. Medication absorption period becomes important in view of employment impact and this was also identified by another dyad</p> <p>Literature related to psychosis/schizophrenia was gained by the family from Mind and Trust information leaflets were provided by the researcher.</p> <p>Family felt empowered when equipment was accessed through GP after problem solving with mental health team. Problem solved with local pharmacist about collection and delivery of clinical waste boxes. Agreed with pharmacist how this could be done discreetly. Dyad agreed safe storage area within home. Decided that a smaller clinical waste box was more suitable for storage within the home. Participants administering depot injection unsupervised</p>	<p>depot administrations to Trust and researcher</p> <p>AR cycles on care planning</p> <p>Family problem solved accessing equipment through GP and disposing of clinical waste boxes</p> <p>Assessment of skills and knowledge</p>
<p>30/11/09</p>	<p>Fifth unsupervised injection – averaging 5 weekly instead of 4 weekly. Whose responsibility is it to remember and what strategies can be developed which would avoid disclosure to other family members and visitors. Depot being administered in bedroom at night time and at weekend when depot clinic services were not open. Bedroom used as storage of medical equipment.</p>	<p>A trusting dilemma for the researcher</p> <p>Medicalisation of bedroom</p> <p>Main problem is time and privacy -AR cycle with participants on privacy, time and opportunity to administer depot within busy family home</p> <p>AR cycle on strategies to remember due date</p>

3/1/10-3/9/10	3 sessions on enabling dyad to review information on mental illness suitable for children. Researcher collaborated with family members to gain and review literature from CAMHS and voluntary organisations. Felt empowered when literature (Living with a Black Dog; Johnson M) was identified and which children valued and read. They found the cartoons and language readable and understandable.	Parents' concern for disclosure and children safety AR cycle on accessing services and literature appropriate for children
1/2/10- 31/10/11	10 sessions on attending CPA/out-patient review meetings. Sessions on re-assessment of skills and knowledge and planning for closure. Closure involved support structures when study completed, equipment, monitoring and recording. Family led initiated contact with services involved support reduction and clarification of role and function of local mental health teams through AR cycles. The cost of paying for prescription from GP for depot medication was identified as an issue and discussed with pharmacy. Maximum of depot vials on any one prescription agreed by GP to be 3	Administration record keeping - AR cycles in developing, use and storage Re-assessment of skills and knowledge Prescription from GP – cost of prescription
18/11- 18/1/12	Evaluation questionnaires completed	Liaison with MH services AR cycle on closure and support strategies through and with other participants
3/12- 7/13	Six sessions – review of project and closure plan which covered access to equipment, relapse indicators and crisis planning, support structures, hand back project to mental health services options (linked with feedback from practitioners). Numerous short contacts throughout this period on clarifying issues, reassessment of skills and knowledge and updating researcher on progress	Family initiated problem solving with services Discharge from MH services Relationship with GP reported as supportive

Appendix 16c -case study 3 overall summary

Timeframe - October 2007 – December 2012 (5 years) -Number of sessions/ contacts: 50		
Time frame	Content of sessions	Learning/problems identified and resolved
16/10/07 -6/11	5 contacts negotiating access	AR cycle of engagement and negotiation
23/11- 19/12	3 sessions completing research questionnaires	Baseline of knowledge and skills Rationale for participation
8/1/08	CPA meeting with family and mental health team – consent forms signed	Key practitioners – expectations of process and collaborative working
1/2/08 - 8/2/08	2 sessions on assessment of knowledge and skills related to IM depot administration–practice with manikin (supportive person had previous knowledge and skills of injection administration). Diagnosis of schizophrenia was not to be mentioned within the home. Family words and understandings to be used. Medication specific knowledge from Trust website. Medication and equipment delivered by researcher to supportive person’s home and not patients home as issues related to disclosure and stigma were of concern. Storage within the home which preserved confidentiality was important.	Baseline of knowledge and skills Family disclosure concerns and language used within home. Headache and depression as diagnosis and not schizophrenia within home Storage of equipment within the home that maintained confidentiality. Stigma
29/2 -21/3	2 depot administrations observed – feedback, areas for development and practice. Needle stick injury problem solving with Trust’s infection control nurse. Discussion about infection raised potential issues of confidentiality and problem solving within home care was deemed different to clinic care as certainty of client status was known.	Needle stick injury management which AR cycle with infection control nurse AR cycle on developing care plan

11/4	Administered first depot injection unsupervised	which identified medication access and amount
11/4 – 20/8/08	<p>Depot medication viscosity was new to supportive person. This evolved into the use of vegetable oil as practice material and which was then used by other participants as practice material</p> <p>Reviewed literature on IM injection (Hunter J 2008) – written comments by supportive persons on which aspects of the article were readable and understandable. What language could be changed to make it non clinical.</p> <p>2 sessions specifically on reviewing literature related to IM injection giving – information identified from other participants and reviewed by dyad – written comments which were incorporated in the material for new referrals. Diagrams from this article were printed in colour and in black and white. The coloured version was deemed to be clearer in identifying the upper outer quadrant.</p>	<p>Letting go by researcher Trust identified by participants Time of administration agreed on</p> <p>AR cycle- used with other participants</p> <p>Diagrams within this article were useful and clear when printed off in colour ink. Used with other participants. AR cycle</p>
20/8- 31/9	5 sessions – CPA, prescriber and care co-ordinator interviews	Data from key practitioners which informed study
20/2/10-30/6	<p>3 sessions following family administration- review, feedback and practice. skills enhancement</p> <p>2 sessions of psycho-education; relapse signs, distress signs, care planning for crisis. The Early Warnings signs for psychosis (Barker, Smith and Higbed) were used to facilitate this discussion with family members completing homework. The care plan on support evolved over the study through an AR cycle as CPA status and personnel changed</p>	Strategies developed by family to aid remembering depot due dates but maintained confidentiality within the home

1/11 – 20/12	<p>5 sessions focused on home record keeping, prescription chart development, where stored and how integrated into CPA reviews. This followed feedback on home record charts not being asked for during appointments. Making home record chart an agenda item at CPA meeting. Moved from paper record to electronic evidence which was scanned by family and sent to mental health team for storage on Trust IT system.</p> <p>10 sessions; accessing equipment and collection of equipment; liaison with MH team; storage and disposal of medication –</p> <p>6 monthly CPA review meetings 3 monthly review sessions – on-going consent gaining, evaluation and problem identification and resolution</p> <p>3 sessions on completion of evaluative study questionnaires – closure of researcher involvement through service support and structure. AR cycle</p>	<p>AR research cycles with Trust and participants AR cycles following feedback on what worked, what did not work and Trust policy Evidencing home administration evidence to Trust system (AR cycle)</p> <p>Service led reduction in support levels – surprise to participant Sustainability of project Family problem solved support needs with MH services</p> <p>Closure and support from MH services planning</p>
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Appendix 16d –case study 4 overall summary

April 2007 – October 2007 (7 months) Number of sessions 12		
Timeframe	Content	Learning/problem identification and resolution
04/07	2 sessions on information and consent seeking; This identified medication specific guidance could be required as patient prescribed Risperadol. This was expensive medication which required storage in a fridge and had specific guidance on preparation. Discussion with patients CPN.	Participant rationale for engaging with project was holiday access - holiday booked for late august and hoped to have the skills by then. Dissonance between what information the patients CPN had given and researchers timeframe and expectations Paid carer relationship First study participant prescribed Risperadol
05/07	2 sessions completing research tools	Knowledge baseline
5/07 – 8/07	6 sessions involved liaison with services as prescribed medication was Risperadol. This was a new medication which had specific administration guidance attached to it which added a dimension of complexity for the supportive person. Agreement for this medication to be administered at home by supportive persons was required from pharmacist and manufacturer. These were the only study participants prescribed Risperadol. Problem solving the home care related to Risperadol around storage, access to specific equipment, safety within home fridge and mixing instructions. Samples gained from medication manufacturer which were necessary for developing administration skills.	AR cycle on problem solving the possibility of home administration of Risperadol. Successful outcome in that it was agreed Risperadol could be home administered. Medication samples acquired Collaboration and relationship with pharmacist and manufacturer developed.

<p>9/07</p> <p>10/07</p>	<p>The discussions and problem solving interactions with relevant groups were empowering for the participants and evidence of an AR cycle. Timeframe for participants and holiday were not likely to be realised.</p> <p>2 sessions on IM injection skills and medication knowledge focused sessions. Using Royal Marsden Manual IM injection guidance and Trust medication material.</p> <p>Researcher initiated CPA review following observed side effects of medication which resulted in depot being stopped (knowledge from previous role of nurse). Telephone call from patients psychiatrist to justify decision to change prescribed medication</p>	<p>Motivation discussion when holiday goal unlikely to be achieved.</p> <p>Researcher concern relating to patient and potential side effects of medication. Liaison with MH services</p> <p>Safety – role and knowledge of mental health nurse evidenced (bracketing) Potential conflict with patients CPN re monitoring of medication side effects Loss of participants to study Confidence and relationship with mental health team enhanced</p> <p>Researcher awareness of how study aims and expectations are being propagated by practitioners with the potential to underestimate the complexity of the role. This was taken forward in meetings and information sessions with other potential participants and practitioners.</p>
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Appendix 16e -case study 5 overall summary

December 2008 – January 2009 (6 weeks) Number of sessions 2		
Timeframe	Content	Learning/problems identified and resolved
12/08 12/08	<p>Contact from team manager re potential study participant</p> <p>1 meeting with mental health team to ascertain rationale for referral to study and identify key practitioners</p> <p>1 meeting with H and allocated CPN</p> <p>Discussed research study. H initially understood home administration to mean that the CPN would visit her home and administer depot injection. H stated that her family members lived far away and would not be able to learn the skills. H had understood the study to be about a CPN doing home visits to administer her depot injection. However, following discussion, H identified that she had a partner whom she trusted and he would be able to learn the skills to give an injection. H felt her partner would spend more time with her if he could take on the role. She identified that her partner had issues with alcohol intake.</p> <p>I decided not to take H on to the study.</p>	<p>Sources of and rationale for referral – how is study understood by mental health team</p> <p>Used knowledge gained form other study participants to give outline of study</p> <p>How expectations of what ‘home administration’ meant.</p> <p>Ethical and moral issues to do with H’s wellbeing</p> <p>Rationale for becoming participant</p> <p>I acted in ‘nurses’ role’ and made decision without organising joint meeting with H, myself and partner. This joint meeting would have linked with Linhorst’s empowering theory where the process is important.</p> <p>Service led referral to study. MH services wanted H discharged and saw this project as a discharge option.</p> <p>Differing agenda.</p>

Appendix 16f - case study 6 overall summary

December 2007 – February 2008 (3 months) Number of sessions 2		
Timeframe	Content	Learning/problems identified and resolved
Dec 07	<p>Contact from CPN who had given study information leaflet to potential participants.</p> <p>1 session focused on study information giving. Discussed research information leaflet. Participants surprised that they had this opportunity and expected to have to make a decision to become part of the study. Because they had more time to discuss and considered how best to gain a more comprehensive understanding of the study, a role play session was offered.</p>	<p>Dissonance between study information given by CPN and researcher</p> <p>As project was novel to CPN and potential participants, I had learnt that it was potentially difficult to conceptualise what might be involved in the study and role play was a decision-making enhancer based on my experiences with other participants. AR cycle</p> <p>Unblocking uncertainty by role play</p>
Feb 08	<p>1 session focused on role playing the potential knowledge, skills, equipment and process required within the study, with the aid of a manikin. This was designed to enable the dyad to conceptualise the project and what may be involved. Participants reported feeling informed and decision not to engage with study based on information gained. The concept of role play information-giving was offered to new participants.</p> <p>Participants identified that having injection equipment and medication in the home would raise issues about safety of grandchildren, visitors and pets. Participants had little confidence in existing MH services when crisis care was needed and how a novel project could give rise to uncertainties which they felt may not be understood by current services. Fear of being known as a ‘non complier’ by neighbours was relevant. The supportive person identified how knowledge of illness may make a person question the patient’s illness and how the patient would feel embarrassed if her husband gave her an injection.</p>	<p>Decision not to become study participants but reporting very satisfied with information and the opportunity to discuss in detail.</p> <p>Safety for pets and grandchildren (taken forward to other participants)</p> <p>Fears about existing services and how they might not cope with a crisis as this was a novel idea and pathway uncertain.</p> <p>The supportive person did not know about patients illness in depth</p> <p>Touch and caring within long term relationships</p> <p>Stigma and fear of getting known as a ‘non complier’.</p>

Appendix 16g - case study 7 overall summary

January 2006 – January 2009 (3 years) – number of sessions 5		
Timeframe	Content	Learning/problem identification and resolution
1/2006	<p>1 in-depth information gathering session on dyad experiences and expertise as they had taken on supportive person depot administration before the study acquired ethical approval. Supportive person was a registered nurse with no experience of administering depot injection within the home. Seen by mental health team as an educated dyad that they trusted. Participants were active engagers in CPA system.</p> <p>The patients CPN had observed 2 sessions of depot administration to assess knowledge and skills. Rationale for supportive person taking on the role was partner's employment and difficulties in getting out-of-hours depot injection. Both partners worked and had young children. The children were present and fully informed of parental illness.</p> <p>The patient had identified issues with drowsiness on Fridays following receipt of depot injection which was on a Wednesday, the standard clinic day. This drowsiness was identified as resulting from medication absorption which is recognised as being highest in the 24/48 hours following administration. This drowsiness resulted in employment warnings from employer. Following supportive person administration of depot on a Friday, the patient reported no further concerns about drowsiness at work. Family accepted that patient would be drowsy every third week-end.</p>	<p>How participants can problem solve along the journey and feel enormously empowered by this process.</p> <p>Status of 'educated' patient</p> <p>Meeting participants with children involved showed a different model to the other participants whose children were not aware of their parent's mental illness.</p> <p>Significance of depot administration and absorption leading to drowsiness which impacted employment. Family worked out Friday to be best day for administration</p>
1/2007	<p>4 update meetings with researcher– key action cycles were about negotiating service access and support. Developing a shared care plan with services and GP related to yearly review appointment with MH services and strategies for family led contact with services when</p>	<p>Importance and vulnerability of 'enabling niches' within organisations which facilitated this dyad to home administer. When key</p>

<p>9/2007</p> <p>6/2008</p> <p>12/08</p>	<p>required Medication access and disposal. Dyad led on these discussions with MH services and GP which were enormously empowering for them.</p> <p>Detailed relapse signs and crisis strategy following admission of patient to hospital (critical review of admission resulted actions being identified and amended in care plan). Patient requested supportive person to administer depot injection whilst he was in hospital. This issue was not concluded due to shortness of admission period.</p> <p>Detailed management care plan related to patient not accepting depot medication from supportive person. Following normal depot due date, if the patient did not want the depot injection, supportive person would ask on 2 more occasions during the next week. Supportive person clear that whilst she was happy to administer the depot for her husband, she was his wife and understood role ambiguity. Following hospital admission, the dyad identified a church pastor (patient request) who would encourage patient on two occasions over a one week period. If the patient did not want to accept, the depot administration was handed back to mental health services. Hand back role to MH services strategy developed with named person and action expected. This care plan evolved through an AR cycle.</p> <p>The process by which this dyad developed a collaborative care plan, particularly how they problem solved challenging events, how they developed role clarification, relapse indicators and understandings, service access points and action to be taken were noted as a model care plan and aspects of it were considered by other participants in the study. Following retirement the role of depot administration handed back to mental health services. Patient is an active member of local patient support groups.</p>	<p>practitioners left or changed, it resulted in dyad having to re-establish support structure</p> <p>Admission to hospital did not mean supportive person option was not viable – admission used as opportunity to develop care plan details and identify other options.</p> <p>Care plan development through AR cycle Relationship with mental health team (specific individuals) who responded to participants request with appointment at short notice because of their knowledge of home administration.</p> <p>How supportive person role can be handed back to mental health services when circumstances change.</p>
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