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‘Daring to peek over the wall’: A qualitative exploration of the concept of remission in the process of recovery for people with schizophrenia.

KEITH FORD

A thesis submitted in partial fulfilment of the requirements of the University of Northumbria at Newcastle for the degree of Doctor of Philosophy

Research undertaken in the School of Health and Life Sciences

December 2015

Declaration

I declare that the work contained in this thesis has not been submitted for any other award and that it is all my own work.

The word count for this thesis is: 78,246 words.

Name: Keith Ford

Signature:

Date: 7th December 2015

Abstract

Remission is synonymous within cancer care and with other physical disorders, but less known and utilised in relation to people with a diagnosis of schizophrenia. Following work by Andreasen *et al* (2005) the idea of remission in schizophrenia became more widely utilised as symptomatic remission and was employed as an outcome measure primarily addressing medication efficacy. Whilst remission may or may not be a useful concept, the language, perception and social construction of remission for people with a diagnosis of schizophrenia is also of high importance. To date, there has not been any published material with respect to consultation with service users who have a diagnosis of schizophrenia regarding their personal interpretations and possible concern of the concept of remission. This study explores and conceptualises the possible introduction of the concept of remission into the process of recovery for people with a diagnosis of schizophrenia. Therefore raising the question; *“Is remission a useful concept to facilitate transition back into primary care for people with a diagnosis of schizophrenia?”*

A qualitative approach using a grounded theory methodology was employed. The principal stakeholder groups of service users, carers and practitioners generated data. Participants were all connected with two community mental health teams in the North East of England. Data was generated via interview, initially from a variety of healthcare professionals [n=9] (Phase One) working in this field. The understanding and perspectives of this group went on to inform the language and questions posed in Phase Two which generated further data gathered from service users (people with a diagnosis of schizophrenia) [n=10] and their carers' [n=7]. Data was analysed using a constant comparative method to generate themes. These themes were mapped against each other and a conceptual map was established; from this conceptual map four possible trajectories were identified for service users as they progress through mental health services towards recovery. These possible trajectories are: i) 'Collaborative approach', ii) 'Self-fulfilling prophecy', iii) 'Pessimistic outlook', and iv) 'Inhibitive – Glass ceiling'.

Remission was not a concept that all participants were too concerned about using and recovery remains the favoured term to address progress for service users in addition to the service aim. This may be due to the feeling that remission denotes a 'medical model' approach. However, many issues stifle the transition back to primary care for people with a diagnosis of schizophrenia. This may often be viewed as reluctance to accept responsibility from Primary Care providers, but nevertheless results in some people being unduly 'maintained' in secondary mental health services. If personal recovery is to be advocated, whether it incorporates remission or not, then the door back into primary care should at the very least be seen as being ajar to instil the positive impression that recovery can be achieved. This would encourage and facilitate hope whilst reducing some of the therapeutic defeatism and disillusionment in service providers and service users and their carers'. Remission could be employed as a conduit to facilitate a route to primary care, but it must be better utilised to address more than symptom improvement as level of functioning and development of resilience are better indicators of overall recovery.

ACKNOWLEDGEMENTS

At times, the biggest distraction provides the greatest inspiration; and so I would like to thank my son Lewis, for being there throughout this journey. No better distraction a man could ask for!

To Julia, my wife, your continued support and belief has been unwavering. Thanks!

To my supervisory team: Dr Toby Brandon and Dr Michael Hill. Both different characters, with different approaches, but a shared goal of offering the best support and supervision. Thanks for allowing me to 'own' this work and for the pearls of wisdom and motivation when required. Thank you!

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“Psychosis, ladies and gentlemen, is the price we pay for being what we are. And how unfair, how bitterly unfair it is that the price is not shared around but paid by one man in a hundred for the other ninety-nine”

(Sebastian Faulks, 2006, p659)

Chapter 1:

Introduction

This thesis, and indeed the whole study, is based around consideration for service users with a diagnosis of schizophrenia. The true sense of the collaborative approach which is mooted so often from a service perspective is analysed. When concepts, pathways and care delivery is decided without due consideration of all stakeholders there can be no wonder when problems, hiccups, or issues occur. We can call these what we wish, but the principal issue has got to be one of fairness, respect and regard for one-another. The service user voice is becoming increasingly heard, but there are still areas and patches where less or little regard is afforded to the people for whom services are provided. Bill McKnight, himself diagnosed with schizophrenia, has expressed many points and insights through the medium of poetry;

Mental illness (a glimpse)

Mental illness,
What is it like?
Ever been self-conscious?
How do I appear?
I rub my nose;
I look at the toes
of my shoes.
Should I look to the right?
Should I look to the left?
Should I look up, down, around?
Perhaps a little too hot under the collar?
Perhaps a little redder in the cheek?
Perhaps a little too casual?
Perhaps a little too neat?
Is my voice too loud?
Is my voice too soft?
Am I being over-heard?
Perhaps a little too ... everything!
Mental illness
is like self-consciousness,
only worse.
And self-consciousness
is like
hell.

(McKnight, 2012, p14)

The nature of this poem speaks volumes and resonates with many sentiments within this study, and perhaps will do for many others too. The pathologising of behaviour once a diagnosis of schizophrenia is bestowed is very evident, as is the attempts to normalise mental

illness with the comparison with self-consciousness; which all people may appreciate. The reference to 'hell' is very symbolic, although as in so many instances within the field of mental health it can mean many things to many people. Ultimately understanding what a person is going through or experiencing is valuable but can only be derived from listening and communicating and this sadly is still missing from some elements in clinical practice. Sadly, another poem by McKnight, albeit brief, succinctly highlights the plight of many and the concern within this research study;

Terminology?

Schizophrenia

may not be an illness.

Nonetheless, for many

it's a life term.

(McKnight, 2012, p54)

It is well documented that approximately 1 person per 100 in the general population in the UK will be given a diagnosis of schizophrenia (Rethink Mental Illness, 2011; Bevan *et al*, 2013). The World Health Organization has ranked schizophrenia as the ninth leading cause of disability among all illnesses worldwide (*cited in*, Bevan *et al*, 2013, p7). As a consequence people with schizophrenia have a poorer mortality rate than the general population dying 15-20 years earlier in some cases (The Schizophrenia Commission, 2012). Schizophrenia has also been described as, "One of the most costly and debilitating disorders" (Brekke & Slade, 1998, p175). In terms of financial cost, mental illness accounts for 23% of the disease burden, in England alone it is estimated that the total cost of schizophrenia and psychosis to society is £11.8bn per year (The Schizophrenia Commission, 2012). As a consequence and a public health concern attention has been pointed towards improving treatment, physical wellbeing and outcomes (DoH, 2011; The Schizophrenia Commission, 2012).

Whilst remission has been well utilised for a myriad of illness' and disorders within the field of physical health it is relatively new to the field of mental health. Remission was initially utilised in mental health addressing depression and anxiety (Kelsey, 2001; Nemeroff *et al*, 2003). Following this an interest was taken with regard to utilising the concept of remission for people with a diagnosis of schizophrenia. When the Remission in Schizophrenia Working Group [RSWG] headed by Nancy Andreasen published a, somewhat influential, paper in 2005 this interest escalated. The paper by Andreasen *et al* (2005) introduced criteria as an outcome measure for remission and was utilised by many, but predominantly to address symptom

reduction and efficacy of medication. However, further work has since revealed an interest in 'functional remission' (Boden *et al*, 2009; Karow *et al*, 2012; Boyer *et al*, 2013) which addresses a broader focus than symptomatic remission. Despite this, remission had been viewed by Andreasen *et al* (2005) as part of the process or pathway to recovery. Recovery, viewed as the ultimate treatment goal by Andreasen *et al* (2005), is not without debate and some ambiguity either. Criticism has been rounded at 'professionals' for hijacking the term recovery and employing it as an outcome measure rather than a process as intended by the service user movement who originally developed the concept (Coleman, 1999; Deegan, 2002; and Frese *et al*, 2009). As yet, there is no consensus of a definition regarding recovery, despite there being some statements which are favoured more than others within the literature. Attempts at defining recovery have only satisfied some and certainly not all concerned.

From experience in clinical practice working towards recovery has, for a long time, been the primary impetus when working with people with a diagnosis of schizophrenia. This has been supported by local NHS Trusts as they have developed 'psychosis pathways' and 'recovery pathways' in order for people using services to be mapped and plotted upon. Pathways have encouraged and emphasised the use of psychosocial interventions and a collection of assessment tools, ultimately improving the drive for recovery through a collaborative approach with service users. Whilst these pathways may have traditionally assisted some practitioners, they are not to the liking of all practitioners, or indeed all professional groups within the multidisciplinary team approach. At times pathways have dictated only minimum standards to be met for the trust, it would then be up to individual practitioners or teams to develop this further to enhance and personalise the care for individuals.

Recovery is not without concern and for some it may not develop into the ideal it is purported to be. This can depend upon many things, however a personal concern is the manner in which it may be overstated what is being done or able to be done from a service perspective. This can often offer 'false hope' to service users and their carer(s) which is unacceptable practise. The notion of repeating the rhetoric of, 'recovery is what we are here for', 'we will do everything we can to assist in your recovery' can become empty promises, despite the practitioners wholeheartedly believing what they say. However this may be offered within restricting environments or services which inhibit progress in some instances. Recovery extends beyond secondary mental health services, yet there is often reluctance for people who have been given a diagnosis of schizophrenia to be discharged back to primary care. Reasons

for this will be debated within the thesis, but this creates the impression of ‘no escape’ or being held within a bubble, perhaps. Discharge from secondary mental health services has got to be a realistic option, otherwise all services are offering is a peek over the wall. The adhesive nature of the diagnostic label contributes to this major issue and can be forever haunting, and is epitomised in lyrics by David Sylvian;

“Just when I think I’m winning
When I’ve broken every door
The ghosts of my life
Blow wilder than before”

(Sylvian, 1981)

If the true sentiments of recovery are to be honoured for all individuals with a diagnosis of schizophrenia, taking into account ‘*all*’ aspects in a collaborative manner, then the truly inhibiting and restricting factors need to be addressed. The debilitating nature of the diagnosis and on-going ‘*need*’ for mental health service contact need to be acknowledged and addressed. Remission as a concept may possibly have an impact upon this, but it requires a good degree of exploration before certainty can be assured.

In 2008 a working group was convened in Birmingham, UK, by Janssen-Cilag, a pharmaceutical company. The working group was assembled to address the concept of remission for people with a diagnosis of schizophrenia in relation to the criteria suggested by Andreasen *et al* (2005). This group was attended by a number of Consultant Psychiatrists from around the UK, all of whom held a particular interest in people with psychosis. At that time I was employed as an Advanced Practitioner (MH Nurse) in a community team for people with psychosis. The weighting towards the medical profession, within this group, naturally swayed and dictated the emphasis in the discussions. However, the issue of whether this criteria, suggested by Andreasen *et al* (2005), with regard to remission could be applied in clinical practice was discussed comprehensively. The remission outcome measure or tool (see Appendix 1) is an abridged and adapted version of the Positive and Negative Syndrome Scale [PANSS] (Kay et al, 1987). Broadly, the premise being that if a person with a diagnosis of schizophrenia scored below a certain score continually for a period of six months then they would be deemed to be in remission. There was a general acceptance that there may be a place for remission in the overall pathway relating to recovery for an individual with schizophrenia.

Although this group has not been reconvened there was an agreement that we would share and exchange further ideas and write up what had been discussed for publication. I offered feedback and suggestions and co-authored two published papers that manifested from this; 'Managing schizophrenia in primary care: the utility of remission criteria as outcome indicators' (Fear et al, 2009) and; 'Resolution and remission in schizophrenia: getting well and staying well' (Yeomans et al, 2010). As these papers were aimed at a medical audience I decided to pursue my interest and relate this more towards nursing and perhaps a more multidisciplinary approach. Indeed, one of my concerns voiced at the working group was that I did not feel that we could presume that all psychiatrists in all areas would adopt the scale, despite the 'new ways of working' (DoH, 2007). As a consequence I feel that the role of assessing for remission would predominantly be taken on by the care-coordinator, who may be a nurse, social worker, psychologist or occupational therapist. With all of this in mind I submitted an abstract for the 2009 Royal College of Nursing (RCN) Mental Health Conference in Edinburgh, with the aim of addressing the reality of the applicability and understanding of remission in relation to the overall recovery for a person with schizophrenia. Following my presentation at this conference and after receiving some audience feedback I began to think more about how the service user and their respective carers may interpret this concept, as this had not been raised at the working group. This resulted in a further publication which focused on 'The concept of remission for people with a diagnosis of schizophrenia' (Ford, 2010). However, since commencing this research study there has been a growing list of impacts and outputs developed (for a full list see Appendix 2). The three aspects highlighted below were the main principles which fuelled this present research study.

- Input and representation from service users and carers to assist in overcoming barriers to implementation of the remission criteria into practice.
- Clarity of language and terminology to allow all stakeholders to feel united in the common goals of remission and recovery.
- The overall concept needs to retain a standardised approach, but with enough flexibility to allow for the unique nature of an individual's recovery.

(Ford, 2010, p25).

The existing gaps in theory and research in relation to remission tend to be around the lack of consultation with service users and carers in connection to the potential implementation of remission criteria. However, there is no consultation with practitioners demonstrated either. Ultimately these stakeholder groups will be the people most affected and influential if

remission criteria are to be implemented. Presently the research on remission for people with schizophrenia is heavily weighted towards positivist research methodologies by medics presented in areas predominantly read by other medics. The psychiatrist may have some knowledge around such outcome measures and concepts, such as remission, and perhaps from a primary care perspective the GP may have some insight too. However, the concept of remission for people with a diagnosis of schizophrenia is relatively new and untested in clinical practice. Concern from a personal perspective would be that remission criteria may be utilised and not explicitly explained to service users and carers, so that come the point in time where remission may actually be achieved it is either a surprise or confusing to people. The confusion would probably appear as a consequence of a 'new' word, in remission, being employed when perhaps recovery was the favoured term throughout treatment and interventions with the service user. Service users and their carer(s) may not comprehend the significance of such a term or how they may adopt this to be meaningful or advantageous in any sense.

Stakeholder groups need to be consulted in respect of new developments that impact so closely to the recovery of a person. As it stands remission criteria has been employed to evaluate efficacy of medication in the reduction of symptoms. It can offer more than this with shared understanding and a willingness to work towards people making a transition from secondary mental health services back to primary care. If it fails to offer this then we have to question the total utility of the remission criteria, other than the monitoring of medication efficacy which gathers almost an obsessive focus in some quarters of research. Whilst appreciating a broader approach and working collaboratively with service users towards their recovery, more understanding is required regarding the concept of remission and also the remission criteria. This may assist in gaining a clearer understanding of how this may be acknowledged or accepted by the people it will impact upon most.

This research study will explore and discover the thoughts and feelings that practitioners, service users and carers have in relation to the concept of remission for people with a diagnosis of schizophrenia. By addressing the area of possible transition back to primary care for people who have been diagnosed with schizophrenia and treated within secondary mental health services will increase the existing knowledge base. This research, therefore, extends the existing body of evidence in relation to this subject area. It adopts a fuller perspective than most research presently does in this area as it takes into account the views and opinions of major stakeholders involved in either implementing or encountering remission as a criteria.

During this research study some of the terms and language employed may be ambiguous or used differently by different authors. To clarify this the principle terms are defined as:

- ‘Psychosis’:** *This will be used to signify the ‘umbrella’ term for a variety of disorders or experiences. The causation may be varied and it does include people with a diagnosis of schizophrenia. Psychosis is a term within the field of mental health which, “Refers to the mental state of experiencing reality differently from others” (Moller, 2009, p334).*
- ‘Service user’:** *The term used to define a person requiring the interventions from mental health services is often a point of debate and frustration. However, the term ‘service user’ will be used throughout this thesis, with no intention of provocation or criticism.*
- ‘Carer’:** *As above, the term used to define a person as a carer may be open to scrutiny and debate. However, the word ‘carer’ is used in much of the literature and so is transferable into this thesis. The term carer as a participant (in this study) is a person who has a close relationship with a person with a diagnosis of schizophrenia.*
- ‘Participant’:** *The term ‘participant’ is synonymous with the research design employed and consistently covers all of the stakeholder groups. This will be used in their role of ‘participants’ in the research. Outside of this they will be addressed by other titles.*
- ‘Practitioner’:** *This term is used to define people who have a role within health services, either secondary mental health or primary care services. This refers to people with a professional qualification for example; nurse, social worker, or psychologist.*
- ‘Professional’:** *This term may be used interchangeably with ‘practitioner’ when defining a person or group of people (‘professionals’). It also defines a profession or professional group for example; psychologists, psychiatrists, or occupational therapists.*
- ‘Themes’ & ‘Codes’:** *These terms will also be used interchangeably, codes are used more so within the methodology chapter but within the findings and discussion themes will be employed.*

Other larger concepts and phrases utilised within this thesis will be explained at the point of their introduction. The use of acronyms has deliberately been avoided wherever possible to enable the flow of the writing, but also out of respect. Often within some literature and texts the service user is reduced to ‘SU’, or terms such as ‘consumer’ or the label ‘schizophrenic’ are utilised. Neither of these terms are respectful nor helpful and will not be used within the context of this work; unless when attributed to another author and necessary to make a point.

1.1 Thesis Design and Overview:

To capture the complexity and intricacies of the subject areas covered and addressed within this study, each chapter will build upon the previous in order to present a sequential approach. Throughout there will be a combination of pertinent supporting literature, opinion and narratives from all stakeholder groups combined with elements of personal reflection. This in order will provide the comprehensive approach that this area of healthcare warrants for the overall good of the people using these services. Despite being titled as a 'two-phase qualitative study' there will be a continuous presentation in order to facilitate clarity with less disruption or fragmentation of the study. However, as will become clearer data was generated from practitioners first in order to assist in ruling out any bias, prejudice or presumptions that may have impeded the data generation from service users and carers. A brief overview of each chapter will set the scene for 'this' thesis.

Chapter 1: Introduction.

This 'introduction' chapter sets the scene for the study by supplying some background information and context. The primary thrust of the research idea and personal sentiments are expressed to introduce the notion of potentially employing remission as a concept in this practice domain. The history surrounding the area of interest and generation of the research question is offered to contextualise this study. It concludes with this thesis design overview and chapter summaries.

Chapter 2: Research Questions and Aims.

This chapter explicitly maps the formation of the research question and consequentially the choice of methodology to be employed. This is a natural follow-on from the introduction and demonstrates how the question was constructed conceptually.

Chapter 3: Literature Review.

This chapter offers an understanding of how the literature was located in terms of searching via subject areas and concepts which link to the main topic areas. A diagrammatic representation offers some clarity on how this developed. The literature review addresses relevant literature in relation to the three primary topic areas of; schizophrenia, recovery and remission. There is naturally cross-over and synthesis but to aid clarity, where possible the

areas are explicit. A brief historical perspective is offered but this is contextual to frame the remainder of the chapter.

Chapter 4: Schizophrenia and Long-Term Conditions.

This chapter is an addendum to the literature review, although warrants being a chapter due to the need to contextualise where schizophrenia may sit in relation to other long-term conditions. Some elements which are considered exclusive to schizophrenia or mental health are addressed and examined in an attempt to demystify and perhaps 'normalise' these elements of schizophrenia.

Chapter 5: Methodology.

This chapter introduces the methodology employed within this study. The theoretical framework is established and justified and ethical considerations are highlighted. A reflective account of some of the issues and considerations during the research journey are also highlighted and this leads into the findings and discussion chapter.

Chapter 6: Findings and Discussion.

The findings and discussion are linked closely as the findings contribute to the discussion. These are presented by phase. Phase one, practitioners and then phase two, service users and carers. Themes are generated from the data and explained initially before being conceptualised in graphical format where possible. A conceptual map demonstrates the themes generated from service users and carers and from this four possible trajectories are discussed.

Chapter 7: Primary Care and the Management of People with Psychosis: The Complexity and Interface.

From the four possible trajectories extrapolated in the previous chapter the interface between secondary mental health services and primary care is a feature requiring a lot of discussion. This was felt to require an exclusive chapter in preparation for the conclusion. This chapter addresses the transition that service users may take and within that the concept of liminality is introduced to clarify some of the issues illuminated.

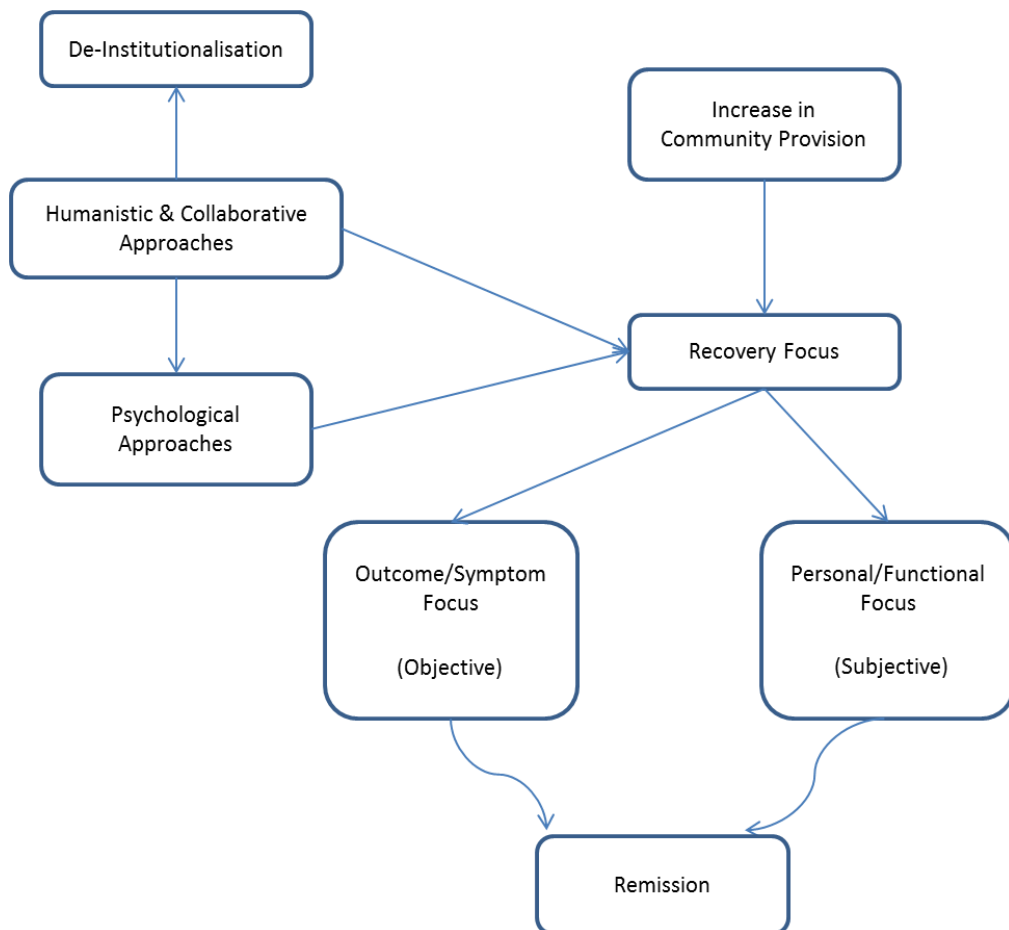
Chapter 8: Conclusion.

The thesis conclusion offers a summary and re-addresses the aims of the research study. A systematic approach discusses the impact of remission from a practitioner's perspective and then the perspective of service users and carers. This is followed by the overall social construction of remission with the final conclusion addressing the viability or remission for people with a diagnosis of schizophrenia.

Chapter 2: Research Question and Aims

The research question was developed as a result of the process discussed in the previous, chapter. The rationale for this chapter is to clearly state the research question and aims. The manner in which it is presented reflects the formation of the question following discussions and self-reflection of the main topic area. The question was also influenced by the beliefs and values of the researcher to gain clarity and understanding of this issue. As a consequence of discussion and feedback, primarily from peer groups at the time, ideas were conceptualised and explored. This resulted in the following process seen in Figure 1.

Figure 1. Formation of the Research Question



Within my clinical practice I became more aware of the beneficial impact for service users when adopting a humanistic and collaborative approach. This had been enhanced by education throughout my career, but I believe that it has always been a personal characteristic and possibly the reason I gravitated towards the role of working with people with psychosis.

The era of de-institutionalisation certainly contributed to this, and psychological approaches continue to emphasise this particular approach. This all feeds into the concept of recovery which is supported by the increase in community provision. This combination of influences contributes and promotes a recovery focused approach. However, the recognition of a bi-fold split in ideation surrounding recovery has come about. One which is predominantly outcome and symptom focused with attempts to be measurable ultimately offers an objective perspective. While conversely, a more subjective approach addresses the more personal aspects with a focus on functioning. Both of these, objective and subjective, perspectives are influences on remission and the potential introduction of remission criteria for people with a diagnosis of schizophrenia. This led to the formation of some preliminary questions such as;

- Will remission stabilise or de-stabilise present ideas around recovery?
- Can remission add to ultimate/overall recovery?
- What would be the 'real' impact of utilising remission?
- How might we make this 'work'?

The very nature of the questions being posed indicates that a qualitative methodology will be required to ascertain responses and possible answers. Following deeper scrutiny and looking at a more specific question resulted in;

“Is it viable to introduce the concept of remission for people with a diagnosis of schizophrenia?”

However, the question remained a little too generalised. Taking into account where, in the process, the remission criteria could play a potentially crucial role afforded more specificity to the research question. The research question for this study stands as;

“Is remission a useful concept to facilitate transition back to primary care for people with a diagnosis of schizophrenia?”

From this research question, the following aims were derived;

- To generate an understanding how practitioners, from different professional backgrounds, perceive remission in relation to people with a diagnosis of schizophrenia.
- To generate an understanding of how people with a diagnosis of schizophrenia and carers of people with schizophrenia perceive remission in relation to schizophrenia.

- To compare and contrast the perceptions of the stakeholder groups with the literature to inform and generate further theory.
- To gain a fuller understanding of how remission for people with a diagnosis of schizophrenia is socially constructed.
- To identify the potential viability of incorporating remission, or not, into the overall process of recovery.

Chapter 3:

Literature Review

3.1 Introduction & Rationale:

The first foray into the literature commenced after attendance at a working group in 2008 addressing the concept of remission for people with a diagnosis of schizophrenia and this was when the initial seed was sown for this research study, as highlighted in the rationale for this research study. Despite this interest the research idea for this study had not been fully formulated and as a consequence the literature initially searched and reviewed, by comparison, was fairly superficial. The reason for this disclosure is that there is much dispute and misunderstanding with regard to the literature review associated with a grounded theory study (Charmaz, 2014). Despite the perspective of 'classic' grounded theory being that the literature should not be reviewed until after the completion of analysis (Glaser & Strauss, 1967) it would be difficult to discount or not be influenced at all by this. In keeping with a theoretically sensitive approach when reviewing the literature, consideration will be given to what theory can be developed and applied in any given area as suggested by Gibson & Hartman (2014). It has been explained by Charmaz (2014) that there is concern around importing and imposing preconceived ideas upon your work. Having worked within mental health services since the early 1980s and being urged and encouraged to remain updated throughout ones career (Nursing Midwifery Council [NMC] 2008) it is inevitable and must be acknowledged that this may impact upon and influence the study from the perspective in which it is written.

The format of this chapter will initially highlight the search strategy, but in terms of the main topics (see Figure 2 below) there is no priority afforded to any topic, as all topic areas clearly warrant illustration. The fact that the topic of schizophrenia is being presented first is not to signify the dominance of the diagnosis but more so to set the pitch for the reader to understand what it is that people are recovering or in remission from.

3.2 Search Strategy:

Searching the literature continued throughout the duration of the study to continue to identify the most contemporary and useful literature. Initial searches were conducted utilising the following databases:

- Cumulative Index to Nursing and Allied Health Literature (CINAHL).
- MEDLINE.
- PubMed.
- ProQuest.
- Applied Social Sciences Index & Abstracts (ASSIA).
- University Library Access to search databases and library catalogue & Inter-library loans.
- ZETOC Alerts & RSS Feeds.
- Web of Science.
- Google Scholar internet search engine.

The searches were initially broad and based around four key areas of Schizophrenia, Remission, Recovery and Service Users (Figure 2). In conjunction with this bibliography searches were employed to follow up key citations and additional studies, this approach is advocated by Booth *et al* (2012).

Figure 2. Broad Literature Search Areas

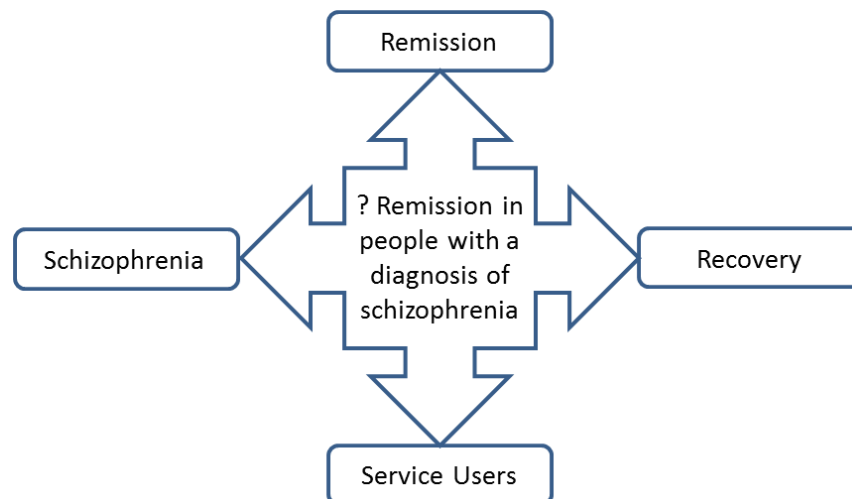
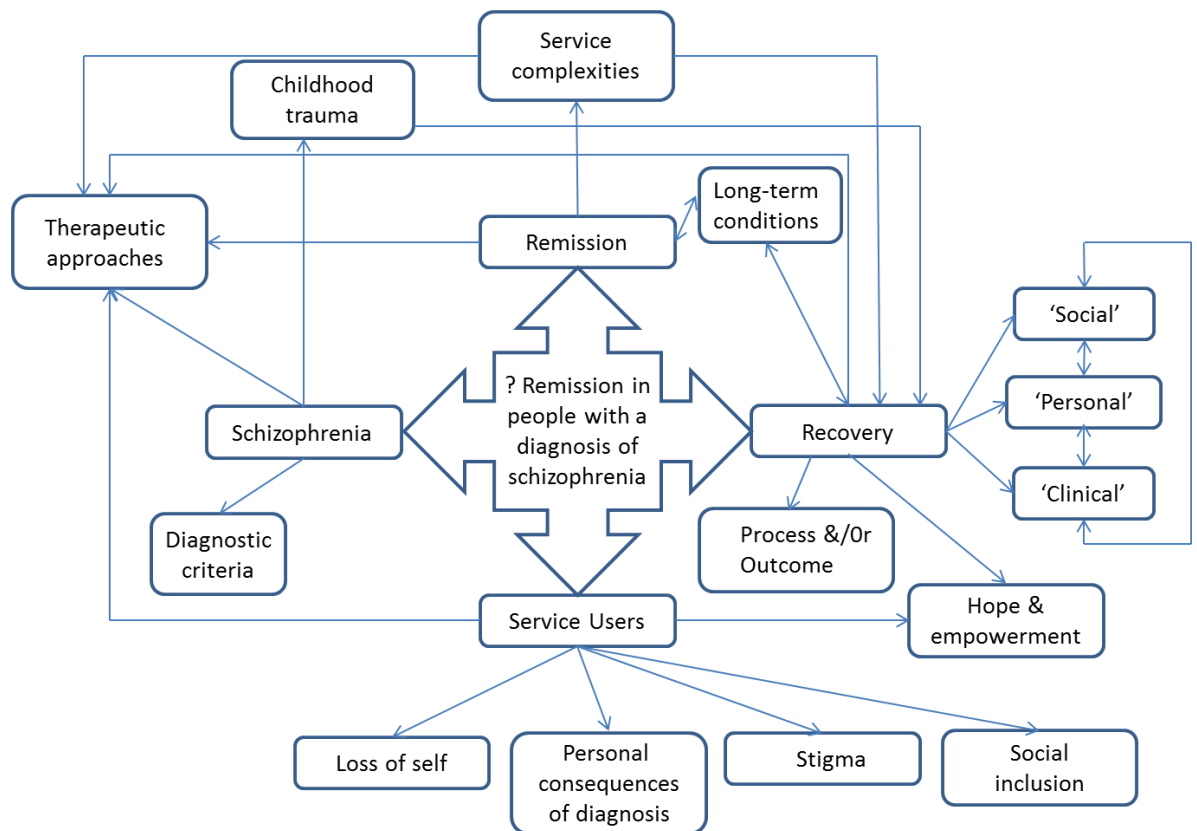


Figure 3. 'Exploded' Literature Search Areas



These four key areas were the obvious choice with their direct connection to the research issue. They also allowed for overlap and intersections within the literature to be recognised and acknowledged, Wellington *et al* (2005) recognise this as a possible method of organising related literature. However, whilst the four areas relate to the research issue, they also exploded somewhat when explored further. The further areas became more widespread and connections were made as further literature was uncovered as seen in Figure 3. This figure identifies the direction the literature collected had taken in their papers, articles, blogs and book chapters etc. When assembling the literature review not all of these areas could be covered to the same depth so some were limited to help maintain the focus of this research study. Despite identifying the four key areas of; schizophrenia, recovery, remission and service users; the first three will be employed as headings for this literature review. The rationale being that, service users are the main thread throughout all of the areas and as a consequence could not be isolated from any other areas. This also enables the use of 'funneling' as a structure to assist in organising the literature as described by Wellington *et al* (2005). Whilst not all literature could be included in this review, there was lots of literature appraised that has contributed to the overall direction of the review.

3.3 Schizophrenia:

Although this research study is situated within contemporary practice, it is important to review aspects of the historical perspective of the diagnosis of schizophrenia. Therefore, this literature review will offer a focused perspective to add context, rather than attempting to offer a full and comprehensive overview of every issue in relation to schizophrenia. The direction of writing will address a medical perspective introducing key authors to demonstrate how the concept of schizophrenia was developed and how this informs contemporary practice. The perspective of society, specifically the general public, will be introduced to apply the social context and finally the perspective of people with a diagnosis of schizophrenia will be introduced addressing the personal impact of schizophrenia.

The historical perspective of schizophrenia sets a pertinent rationale as reference continues to be made to the origins of the diagnosis and this continues to inform practice today in some quarters. However, debates and arguments around the validity and relevance of the diagnostic construct of schizophrenia continue to be contested and debated (Morgan, 2010). This debate continues to be recognised in most recent literature concerning the disorder and also when addressing aspects of working with people with this diagnosis. It was not until the 19th century that doctors began to take an interest in people regarded as ‘mad’; as beforehand this was largely in the domain of religion (The Schizophrenia Commission, 2012). Schizophrenia was the term introduced by Eugen Bleuler in 1911 and this was viewed as a development after Emil Kraepelin had previously employed the name ‘dementia praecox’ to describe what he initially considered a degenerative and irreversible condition (Busfield, 2011). The Latin interpretation of dementia praecox is ‘senility of the young’ and Bentall (2003) explains that this is exactly how Kraepelin viewed the disorder. Kraepelin had differentiated between good outcome (manic depression) and poor outcome (dementia praecox) and diagnosis would be verified or invalidated by the outcome (Harding & Zahniser, 1994). Morgan (2010) states that Bleuler’s concept was a specific intervention, against the understanding of schizophrenia being a purely cognitive experience, rather than a continuation of Kraepelin’s previous formulation.

The perspectives of many psychiatrists of the time including Kraepelin, was influenced by institutional experience (Burns, 2007a). In his writings Kraepelin had acknowledged the lack of reliability from his studies, however Boyle (1990, p58) points out that he, “... proceeded as if he had noted exactly the opposite”. Morgan (2010, p190) argues that “...many critics of the schizophrenia label flatten out the divergences, differences and complexities ... and merge

Kraepelin and Bleuler together in their account of the history of the concept". These comments by Morgan were aimed at people such as Boyle (1990) and Read *et al*, (2004). With such an unfounded beginning it may be of no wonder at all how we have continued to struggle with the concept concerning a collection of symptoms which people cannot agree on, for this reason Crow (1997, p128) refers to schizophrenia as an "elusive entity".

Bleuler, in his quest, had attempted to identify the underlying fundamental abnormality in schizophrenia (Andreasen, 1997) when he identified 'fundamental' and 'accessory' symptoms. The fundamental symptoms Bleuler felt were present only in schizophrenia, and were therefore 'pathognomonic' (Andreasen, 1997). The accessory symptoms were less characteristic and they could be seen in a variety of other disorders too. Bleuler also differentiated further between 'primary' and 'secondary' symptoms, however these were both seen as a result of the changes in brain structure and function of people called 'schizophrenic' (Boyle, 1990). Despite some initial optimism from Bleuler, he later concluded that there was never a full restoration to the original condition, or '*resituo ad integrum*' (Harding & Zahniser, 1994). Morgan (2010) puts forward the case that Bleuler's formulation of the schizophrenia concept was based around the notion of schizophrenia as a 'deadened life'. Morgan (2010) also adds that that the concept of schizophrenia as a deadened life needs to be revived as it is an important tradition and can contribute to the refinements of the diagnostic criteria for schizophrenia. This may have been developed from Laing's (1990) description of schizophrenia as a 'lifeless life', which Lysaker and Lysaker (2010, p334) interpret as schizophrenia being depicted as "... an experience of exile from oneself".

In the late 1950s Kurt Schneider developed his now renowned 'First-Rank Symptoms'. These first-rank symptoms remain important; they have been influential in UK mental health practice as they provided the criteria for diagnosing schizophrenia for clinicians (Gould, 2010). This began to exert a powerful influence on the concept of schizophrenia as it went some way to anchoring the perplexing flux of the phenomenon of schizophrenia (Andreasen, 1997). In fact first-rank symptoms are afforded enormous significance and value in diagnostics in both the International Classification of Disease (ICD-10, World Health Organization, 1992) and the Diagnostic and Statistical Manual of Mental Disorders (DSM-IV-TR, American Psychiatric Association, 2000). It is claimed that Schneider was attempting to improve diagnostic reliability (Burns, 2007a). Despite being initially un-opposed Schneider faced considerable criticism later (Mellor, 1982). First-rank symptoms are neither characteristic nor pathognomonic of

schizophrenia according to Idrees *et al*, (2010). This may be due to the fact that Schneider asserted importance on the 'form' rather than the 'content' of the patient's experience (Bentall, 2003). Studies by Kluft (1987) and later Ross *et al* (1990) both asserted that first rank symptoms are more characteristic of multiple personality disorder than schizophrenia. Schneider's first rank symptoms are predominantly positive symptoms¹ and as a consequence will prove less useful in early stages of schizophrenia (Idrees *et al*, 2010). This is particularly pertinent as Hafner *et al* (1992) found schizophrenia commences with negative symptoms² in 70% of cases.

Despite these criticisms, there were positive comments of first rank symptoms. Chopra and Gunter (1987) stated that when diagnosing schizophrenia first rank symptoms could be relied upon. Whereas, Burns (2007a, s2) asserts, "This 'Schneiderian' approach lends itself to modern treatment trials". The comments which are supportive of Schneider's work have a tendency to develop from studies and commentators inclined to be addressing diagnostic measures and utility (Burns, 2007a; Saddichha *et al* 2010) as opposed to addressing the psychological and/or humanistic aspect (Boyle, 1990; Bentall, 2003). It is no strange occurrence to observe dichotomous opinion in the literature surrounding schizophrenia. In fact, it is maybe symbolic of the 'sane' or 'insane' conundrum. A contributor to this way of viewing mental illness would be Laing (1990) who when describing people experiencing delusional thinking stated they would rightly be regarded as crazy.

Definitions appear to be the primary problem of ambiguity according to Koehler (1979) as clinicians and researchers fluctuate from Schneider's original definition (see Appendix 3, for comparison between two studies), also with variation in methodology when comparing studies. Saddichha *et al* (2010) concur that limitations affect the diagnostic utility of first rank symptoms and as a consequence the prevalence of first rank symptoms in other disorders has lessened their importance in diagnosing schizophrenia. Boyle (1990) postulates that Schneider had further compounded the confusion caused by Kraepelin and Bleuler as he also used different criteria to diagnose schizophrenia in different people, thus reducing validity in his work. Idrees *et al* (2010) state that as a consequence first rank symptoms should be employed

¹ Positive symptoms are "so-called because they represent experiences that are qualitatively different from normal or behavioural exaggerations of conventional social conduct" (Keen & Barker, 2009, p214). These include hallucinatory phenomenon, delusion thinking and incongruity.

² Negative symptoms are so described as they represent "an apparent loss of normal function or a diminution from social norm" (Keen & Barker, 2009, p214). These include apathy, anhedonia, avolition, and blunted or flattened affect.

cautiously when diagnosing schizophrenia as only one third of people diagnosed utilising the DSM-IV (APA, 2000) criteria demonstrated any first rank symptoms. Boyle (1990) is less forgiving in relation to criteria for diagnosing schizophrenia when she points out that neither Kraepelin, Bleuler nor Schneider presented data relevant to their assumption justifying the introduction of the concept they were advocating (dementia praecox & schizophrenia); “They presented instead their own beliefs, backed up by authority” (Boyle, 1990, p75). Due to the lack of consensus and the many interpretations of the work of Kraepelin, Bleuler and Schneider we remain without any certainty in relation to a clear diagnostic criteria or construct of schizophrenia. Brekke & Slade (1998, p158) highlight that, “Schizophrenia is one of the most perplexing and scientifically investigated mental disorders”. In the 1970s Smythies (1973) highlighted that there has been many years of heated debate concerning the aetiology of schizophrenia, and this still shows no signs of abating.

There has been a long history of attempts to categorise diseases, disorders and illnesses (Ceusters & Smith, 2010) and since its existence, there has never been a professional consensus regarding schizophrenia (Keen, 1999). Alarming around 30 years ago we were still being informed of the catastrophic nature of receiving a diagnosis of schizophrenia from the textbooks available. An example of this negative view of schizophrenia was highlighted by Lyttle (1986, p221) “Of all mental disorders, schizophrenia probably causes more fear and misunderstanding than any other. It resembles most closely the layman’s concept of *true madness*”. To think that this definition was an exception would be erroneous as texts continued to freely propagate the negative aspects of schizophrenia. The person receiving a diagnosis of schizophrenia may also receive different information about their ‘illness’ and the two definitions below demonstrate the negativity that is easy to find:

“Schizophrenia, a mysterious and potentially devastating mental illness strikes apparently healthy young people without warning and knocks them (and their families) for six!”

(Jenkinson, 1992, p17).

“Schizophrenia is notorious for being the most frightening, disabling, and misunderstood of mental illnesses, historically sentencing the sufferer to an existence of terrifying experiences such as hearing voices, and thwarting hopes and dreams for the future”

(O’Reilly, 2011, p153).

Symptoms of schizophrenia are diverse and have long been identified as problematic as two persons may be diagnosed with schizophrenia yet share no symptoms, as previously highlighted there are still no pathognomonic symptoms of schizophrenia (Glynn, 1998). In agreement Harding & Zahniser (1994) had signified that 'substantial heterogeneity' is present in every group of patients. Moller (2009, p335) also asserts that, "Schizophrenia is one group of related disorders that are heterogeneous".

Previously, symptoms of schizophrenia have been described as 'florid' or 'productive' and 'defect' or 'deficit' and these roughly reflect the more contemporary and popular terms of 'positive' and 'negative' symptoms (Haro *et al*, 2003). As mentioned, symptomatology is currently differentiated into categories identified as 'positive symptoms' ("exaggerated normal behaviors" Moller, 2009, p336) and 'negative symptoms' ("diminished normal behaviors" Moller, 2009, p336). Despite Nettle (2001) employing a third category he called 'schizophrenic thinking' the former terms are employed with more frequency. Brennan (2004) only utilised the two, choosing to subsume the 'thought' elements into the positive symptom grouping, this is also the case for Rethink (2011). O'Reilly (2011) identifies his third category as 'cognitive symptoms' which is predominantly the same but employing a more pathologising language, it could be argued. Moller (2009) utilised a fourth category specifically for 'mood symptoms' and then drew reference to their impact upon social and occupational dysfunction. Andreasen (1997, p106) makes the noteworthy point; "Neither Kraepelin nor Bleuler actually used the terms positive symptoms or negative symptoms". The reason for the pre-occupation with symptoms of schizophrenia may be that, due to the lack of a specific laboratory tests schizophrenia has to be defined by symptomatology (Leff, 1992). The categories of symptoms demonstrate that further confusion may exist within attempts to ascertain a diagnosis of schizophrenia. Bentall (1990, p26) highlights that, "Given the auspicious beginnings of the schizophrenia concept it is not surprising that there have been frequent disagreements about the symptoms of the hypothesized disorder", and this also creates difficulty in differentiating schizophrenia from other psychiatric disorders. Put quite simply "There is no single symptom picture that is unique to schizophrenia" (Bevan *et al*, 2013, p23).

Formal diagnostic criteria and location also play a part in determining whether a person would receive a diagnosis of schizophrenia or not. In 1973 Smythies reported great disparities between psychiatrists diagnosing schizophrenia in different countries, an example was that the same people diagnosed with schizophrenia by American psychiatrists were diagnosed with

affective disorders by British psychiatrists. The two formal diagnostic criteria presently employed are; The Diagnostic and Statistical Manual of Mental Disorders, of which the Fifth Edition (DSM-5) was released by the American Psychiatric Association [APA] at their annual meeting in May 2013. The other is the International Classification of Diseases [ICD-10] from the World Health Organization [WHO] (1992). The 11th revision of the ICD is due for publication in 2017. Both of the criteria here take a different angle on schizophrenia;

Diagnostic and Statistical Manual of Mental Disorders (DSM-5):

“Schizophrenia is characterized by delusions, hallucinations, disorganized speech and behavior, and other symptoms that cause social or occupational dysfunction” (APA, 2013).

International Classification of Diseases (ICD-10):

“The schizophrenic disorders are characterized in general by fundamental and characteristic distortions of thinking and perception, and affects that are inappropriate or blunted” (WHO, 1992).

The newer criteria of the DSM-5 have eliminated the subtypes of schizophrenia (paranoid, disorganized (*sic*), catatonic, undifferentiated and residual). The ICD-10 continue to utilise subtypes; paranoid, hebephrenic, catatonic, undifferentiated, post-schizophrenic depression and residual. However, the newer DSM-5 is not without criticism. It is postulated by Thomas *et al* (2013) that the controversy around the role of psychiatric diagnosis, such as schizophrenia, has been reinvigorated by the introduction of the DSM-5. More broadly the DSM-5 has been criticised for over pathologising everyday life (Laurance, 2013). Busfield (2011, p31) feels that these formal diagnostic criterion deliver a binary contrast between the psychoses and the neuroses. There have been many calls for the term schizophrenia to be abolished and newer terms introduced in diagnostic criteria such as the DSM-5 and ICD-10 (Sato, 2006; Kingdon *et al*, 2007; George & Klijn, 2013). Despite this, the Schizophrenia Commission (2012) predicted that the DSM-5 would recommend keeping the diagnosis of schizophrenia and also that the ICD-11 is likely to follow suit. Perhaps all of the on-going debates reduce the validity rather than strengthen any cohesion, as Bentall (1990) highlights that for schizophrenia to be a valid scientific concept the psychiatrists should agree on a singular set of criteria. To emphasise this point Bentall (1990, p25) states with some frustration that, “One psychiatrist’s schizophrenic must be another psychiatrist’s schizophrenic”. Thomas *et al*, (2013) suggest that there is little evidence of psychiatrists moving away from schizophrenia being viewed as a brain disorder with a poor prognosis, rather akin to Kraepelin.

Guidelines have attempted to reduce confusion in order that care may be enhanced and standardised for people diagnosed with schizophrenia. The National Institute for Health and Care Excellence [NICE] in Clinical Guideline 82 offer; “Schizophrenia is a major psychiatric disorder, or cluster of disorders, characterised by psychotic symptoms that alter a person’s perception, thoughts, affect and behaviour” (NICE, 2009, p3). This again acknowledges that differences will occur between people with a diagnosis. A ‘factsheet’ from Rethink (2011) initially offers a one-dimensional approach. “Schizophrenia is a mental illness which occurs when parts of the brain responsible for emotion and sensation stop working properly” (Rethink, 2011, p2). This presents a very biologically determined perspective and one that some may find unhelpful. As Bentall (2003) highlights that according to many psychiatrists a biological explanation should take precedence over psychological accounts. Rethink (2011) do go on in their ‘factsheet’ to list other causes of schizophrenia, as ‘Genetic’, ‘Abnormal brain development’, ‘Birth complications’, ‘Psychological triggers’ and ‘Substance misuse’.

Whilst there appears to be a poor prognosis accompanied by therapeutic defeatism for a person diagnosed with schizophrenia (Ford, 2010), there are signs of reassurance in the literature. Even in 1973, Smythies reported radically changed views regarding a ‘gloomy prognosis’. However, this was less than convincing, when he added, “Many cases improve significantly to be discharged from hospital but a relapse soon occurs – which is usually due to the failure to take the tablets” (Smythies, 1973, p280). Thomas (1997, p86) reminds us that “... psychiatric wisdom holds that deterioration is a core feature of schizophrenia, and this has played an important part in attempts to validate the diagnosis”. This brings to the fore the question, If deterioration is to be contested, would this further invalidate the diagnostic criteria for schizophrenia? Warner (1994, p57) feels that, “Many researchers have formed the impression that recovery rates in schizophrenia have improved in comparison with earlier times”. However, Warner (1994) comments that this is attributed to new treatment methods. Brekke & Slade (1998) also advocate against such deterioration by suggesting, “... the prognosis for schizophrenia is better than has previously been thought” (Brekke & Slade, 1998, p172). Professor Robin Murray in his ‘Foreword’ in the report (‘The Abandoned Illness’) by The Schizophrenia Commission (2012, p5) stated, “... we have learned that a diagnosis of schizophrenia does not predict inevitable decline”. There is, however, divergence in the statistics demonstrating this; Andrews and Jenkins (1999) indicate that 25% of people given a diagnosis of schizophrenia will ‘recover completely’, 40% experience ‘recurrent episodes’, while 35% remain ‘chronically disabled’. The Schizophrenia Commission report (2012) chose to

go with statistics from Barbato (1998), who suggested; 40% 'recover after one or more episode', 20% have 'unremitting symptoms' and 35% alternate between 'periods of remission and relapse'. Other studies demonstrating rates of recovery will be offered in the following section of this literature review.

The general sway of opinion in contemporary practice by and large is that schizophrenia would come under the broader label of psychosis (Warner, 1994; Moller, 2009). Holloway (2011, p6) postulates, "Psychosis is a relatively new word, which initially meant any kind of disordered mental state". However, Healy (1997) stated that Psychosis, as an alternative to insanity and mania, is not new and had been used in 1845. Yet some would favour the term psychosis over that of schizophrenia. In respect of this Bradshaw & Mairs (2011, p184) suggest that they prefer the term psychosis as it is less stigmatising in their view, however they concede that at times they have been 'forced' to use the term schizophrenia. This indicates a preference to move away from the term schizophrenia and the connotations that arrive with it, predominantly stigma. However, Bird (1999) raised the fact that, psychosis affects approximately 3% of the population if we include bi-polar disorder, chronic psychosis and schizophrenia and Lester (2009) raises the fact, for interest sake, that this then makes a diagnosis of psychosis as common as a diagnosis of insulin-dependent diabetes. The Schizophrenia Commission (2012) realistically reinforce the point that schizophrenia continues to be the term traditionally utilised for people with more severe psychoses. According to Bentall (2006) many people researching the field of psychosis feel that it is currently undergoing a 'paradigm shift'. This indicates that long-standing beliefs and assumptions about schizophrenia are being questioned and approached employing new strategies. This feeling may be as a consequence of the prominence of studies and research evidence around issues such as the links between childhood trauma and the development of schizophrenia (Spataro *et al*, 2004; Janssen *et al*, 2004). Read *et al* (2005, p331) highlights that, "... it was not until 2004 that sophisticated; large-scale studies addressed the still contentious issue of whether childhood trauma can cause psychosis". Whilst trauma did feature in what Bentall (2006) was referring to, he also indicated environmental influences and their impact upon the person psychologically. Whilst Bentall is recognised for his discomfort with diagnostic criteria and labelling, he adds;

"It is only by understanding the processes involved in normal cognitive, emotional and social development that we can hope to understand why some people arrive at adulthood handicapped by delusions, hallucinations and other psychotic experiences" (Bentall, 2006, p17).

3.3.1 The Perceptions of the Public Towards Schizophrenia:

The rationale for the inclusion of the public perception of schizophrenia in the literature review is due to the impact this can have for a person with a diagnosis of schizophrenia. With an emphasis on recovery and perhaps including concepts such as remission it is felt that a brief awareness needs to be made.

Negative attitudes and stigma towards people with mental illness is widespread (Penn & Martin, 1998; Lee, 2002; Lauber *et al*, 2006) and van Zelst (2000) points out that people with a diagnosis of schizophrenia face this on a regular basis, placing them among the most stigmatised groups in western societies (Corrigan, 2005). The 'Time to Change' campaign led by 'Mind' and 'Rethink Mental Illness' (2008) which is working towards tackling discrimination, state that 87% of people with a mental health problem have been affected by stigma and 71% have stopped doing what they wanted to do due to this. Lysaker *et al* (2008) identify that self-esteem is negatively affected by the stigma and stereotypical beliefs about people with severe mental illness, Corrigan *et al* (2011) also support this adding that hope is affected too.

One concern with regard to discriminatory behaviour stems from the portrayal of mental illness and in particular schizophrenia in the media. Mullins (2014) reinforces that the mass media in its various forms can divide, change or shape public opinion due to their powerful mechanisms. Rose (1998) identifies that the portrayal of psychosis in the general media is not always clear and indicates that people with psychosis are unstable and a threat to others. According to Sieff (2003) this may be due to the remit of most programmes being firmly focused on entertainment rather than education. It was reported by Ferriman (2000) that the director of programmes at Carlton Television had said of newspaper reporting that it is always easier to reinforce readers views rather than challenge them. Wilson *et al* (2000) conducted a study of children's television programmes and reported that viewers are being socialised into stigmatising people with a mental illness. Thornicroft (2006) adds that the broadcasters follow a commercially tried and tested formula as this has been proven to work for them. Films such as 'Psycho' from 1960 and 'One flew over the cuckoo's nest' from 1975 are well known and provoke negative perceptions of mental health issues (Mullins, 2014).

Newspaper reporting has often come under criticism for its portrayal of mental illness too (Duckworth *et al*, 2003; Chopra & Doody, 2007). The word schizophrenia attracts reporters to

use this as a metaphor within their articles. A study by Duckworth *et al* (2003) addressed this in newspapers within the United States [U.S.] and found 28% of the articles sampled used the word 'schizophrenia' as a metaphor; compared to 11% in a similar study performed in the UK by Chopra & Doody (2007). "This suggests that schizophrenia is less likely to be used as a metaphor in UK than U.S. newspapers" (Chopra & Doody, 2007, p425). In Italian newspapers 'schizophrenia' or 'schizophrenic', "...was used far more frequently as a metaphor (73.7%) than in reference to people actually with the diagnosis (19.2%) or to the disorder itself (7.1%)" (Magliano *et al*, 2011, p1019). Chopra & Doody (2007) report that in the UK the use of metaphor was not limited to one particular area, with 'fashion, arts and literature' being the most common followed by 'sport' then 'politics'. Chopra & Doody (2007, p425) offer the example of a celebrity describing the designer Armani as being "... versatile and flexible enough to adjust to my sometimes schizophrenic personality", this was taken from the Daily Mail 3rd February 2005. In Italy the term schizophrenia was used more in political articles and then in culture, entertainment and sport sections (Magliano *et al*, 2011). An example from the U.S. offered by Duckworth *et al*, (2003, p1403) is; "[Los Angeles] this unique schizophrenic city" from the Los Angeles Times. One point of interest in the UK context is that there is no statistical difference in the use of the terms when comparing broadsheet and tabloid newspapers (Chopra & Doody, 2007). Whereas Duckworth *et al* (2003) discovered that the metaphor rate in the U.S. did not differ by region, but it did by newspaper with *USA Today* offering the highest use (52%).

Sontag (1978) describes the use of metaphor in illness and states how this develops more in illnesses regarded as mysterious, such as leprosy, AIDS and schizophrenia. The development of a metaphor occurs when people are identified with the disease, then the disease itself becomes a metaphor, resulting in the name of the disease being imposed on other things, usually in a negative manner (Sontag, 1978). Chopra & Doody (2007, p426) make sense of this by stating that the use of schizophrenia as a metaphor of contradicting elements contributes to the stigma of the illness, therefore an illness which carries such stigma is more likely to encourage metaphors. Chopra & Doody (2007) support the study by Duckworth *et al* (2003) by stating that schizophrenia is the new 'illness as metaphor'. Magliano *et al* (2011, p1020) also support this but add; "schizophrenia may represent the illness as a metaphor of the twenty first century, a role that cancer played in the mid to late twentieth century and tuberculosis in the nineteenth century". Some argue that using these terms metaphorically is a joke, whereas

others warn that this serves to further mystify conditions which are stigmatised and misunderstood (Kelly & Winterman, 2011).

We are now in a situation where it is not uncommon to read about schizophrenia out of its correct context and this may develop into outright derogatory remarks in the press. Despite an unprecedented amount of information in the public domain with regard to mental health, the level of general knowledge about mental health is 'meagre' (Thornicroft, 2006). This may manifest in two-directions, with the most benevolent public attitudes characterising people with mental health problems as 'helpless or child-like' (Corrigan & Watson, 2002); or derogatory comments emblazoned on the front page of popular media sources. "Bonkers Bruno locked up" was a front-page headline from *The Sun* (23rd September 2003) in reference to ex-boxer Frank Bruno who was detained under the Mental Health Act. This is a sportsman, who to some is regarded as a 'National Treasure' as reported by Sam Coulter for the *Top Class Boxing* website. Following public outcry this was immediately altered and another batch of newspapers sent out with the new headline, "Sad Bruno in mental home". Gary Nunn writing in *The Guardian* states that we have moved on since this incident, but still need to watch our language despite mental health being so ingrained in our everyday vernacular (Nunn, 2014), as Chopra & Doody (2007) stated, the immense power that words have can create stigma. Klein & Lemish (2008) state the high use of schizophrenia as a metaphor should be taken within the context of the high use of 'madness' in mass communication. According to Duckworth *et al* (2003) the metaphorical use of schizophrenia cannot be eliminated from media discourse and we could no more expect this than we can any other term. Mullins (2014, p35) states that should the question be raised, "Would you like to be judged unfairly on the basis of an illness? The answer should be a resounding 'no'". It is the misleading metaphors and encouragement and recognition of positive achievements which staff should be obliged to work towards (Duckworth *et al*, 2003). Chopra & Doody (2007) warn that awareness to differing views by different stakeholders may be prudent. Lauber *et al* (2006) had previously warned that mental health professionals must improve their attitudes and be aware of their stigmatising feelings. The lessons are there for us all to learn as Sartorius (2002, p1471) stated; "How should we convince others that most people with mental illness retain many of their capacities and that their rights are often not respected if we do not show the way by our own behaviour?" An example of negative behaviour was offered by Sartorius (2002) when he stated that psychiatrists in some countries (including Europe) had requested longer holidays and higher

salary because they had to work with mentally ill patients who are dangerous; this was totally incongruent with their arguments that mental illness is no different to other illnesses.

3.3.2 The Personal Impact of Schizophrenia:

For the context of this literature review it is important to consider the personal impact for the person receiving the diagnosis of schizophrenia. A lot may be assumed by 'professionals' in their roles, but if there is no clear consensus in relation to causation and diagnosis, as highlighted above, then this may too transmit confusion for service users. Chopra & Doody (2007, p423) remind clinicians that there needs to be awareness demonstrated due to the fact that, "patients, carers and the public might have a different understanding of the word we use to diagnose". Concern had previously been expressed by Strauss *et al* (1983, p9) that there are difficulties in presenting definitions and concepts which equally represent the disease and the person simultaneously. Whilst Schneider (2003) addresses concern that there are implications for social identity when receiving a diagnosis of schizophrenia. These implications may be associated with a sense of loss and grief as being given a diagnosis of schizophrenia deeply affects the lives of people (Mauritz & van Meijel, 2009). Differentiation is made between 'internal loss' and 'external loss' as Mauritz & van Meijel (2009, p257) define internal loss as, "Living in a different world" and external loss as, "Not belonging".

Deegan (2002) highlights that prior to being diagnosed with schizophrenia she was a whole person, however, this altered as professionals saw her as fundamentally ill and broken by viewing her through 'distorted glasses'. The concern here is that this view perpetuates into a view of 'them' and 'us' between service users and those working within mental health services. If a person receives a diagnosis of schizophrenia this may be regarded as a label. Repper and Perkins (2009) state this, labelling, is usually followed by the linking of negative attributes and as a consequence rather than being a person with schizophrenia they become a 'schizophrenic'. This is the distinction between 'them' and others in society which can create many issues. As Leete (1989, p199) explains; "Your label is reality that never leaves you; it gradually shapes an identity that is hard to shed". This is strongly echoed by Deegan (2002) as she states that the diagnosis was what mattered most to the many staff working with her, to identify that she was 'schizophrenic'. Whilst people with a diagnosis of schizophrenia may talk about staff and others that have been helpful, the difference may be due to whether the

'professional' relates to them as an abstraction by calling them a 'patient' or 'schizophrenic' as opposed to seeing them as a 'real person' (Topor *et al*, 2011).

Estroff (1989, p189) succinctly stated that "Schizophrenia is an '*I am*' illness", in so much that unlike having other conditions such as cancer or heart disease receiving a diagnosis of schizophrenia entails "becoming a schizophrenic". Langeland *et al*, (2007) concur that many experience themselves as only patients or a diagnosis. It is highlighted by Schneider (2003) that one manner in which we establish our identity is through narrative, if this narrative is consumed by pathological reasoning it may be of little wonder that the person describes themselves as such. Sass (2001) states that schizophrenia can be understood as a particular kind of 'ipseity'³ disorder. In his work Sass was attempting to integrate the interpretations of three phenomenological psychiatrists (Minkowski, Blankenburg & Kimura). Sass (2001, p254) acknowledges that "Much phenomenological philosophy and psychiatry is written in highly technical or abstract prose that can be off-putting". Despite this the work of Sass is supportive of Estroff in the manner of viewing schizophrenia as a disorder that is adopted, and taken ownership of, by the individual given the diagnosis. Those experiencing psychosis failed to separate the disease entity from themselves; as a consequence, the illness would be blamed for any limitations to functioning, experience or behaviour and making any sense of this experience would be a struggle (Kinderman *et al*, 2006). When differentiating between schizophrenia and other 'illness' House (2013) explains that schizophrenia is a disease of constitution, this is because we do not state one has *a* schizophrenia unlike one has *a* fever or *a* tumour; instead we state one *is* schizophrenic. This is more due to the fact of our lack of scientific understanding of causation and cure rather than a quality of the disease (House, 2013).

A study by Haghighat (2008) addressed the discourse of schizophrenia and discovered that a higher percentage of patients were happier to call themselves 'schizophrenics' compared to their relatives. However, there were a higher number of both patients and relatives preferring the term 'schizophrenia sufferer' as opposed to 'schizophrenic'. Haghighat (2008) found that reformulating the diagnosis was a tactic employed by service users to gain some personal understanding of the condition and in addition some control and hope for recovery. The alteration to the self's sense of wholeness, integration and the cultural boundaries that afford coherence are altered in schizophrenia and result in feelings of passivity, lack of control and

³ *Ipse* is Latin for "self" or "itself" (Sass, 2001, p253).

social alienation (Fabrega Jr, 1989). Therefore it becomes imperative that practitioners heed the advice from Strauss and Estroff (1989) in relation to this, as they state that a patient's subjective experiences and sense of self must be attended to, otherwise there is something seriously missing from the area of mental health.

Howard (2001) identifies that John Turner's (1987) theory of 'Self-categorization' focuses on the components of social identity and this may well be affected negatively by seeing oneself in the guise of a 'schizophrenic' as the personal and social self-categorisations are compromised. Goffman (1963) describes such a person may be viewed as 'thoroughly bad, dangerous or weak' and therefore "...reduced in our minds from a whole and usual person to a tainted, discounted one" (Goffman, 1963, p12). If this discrediting effect is very extensive it can be regarded as stigma and as confirmed by Turner (1987) this creates a discrepancy between virtual and actual social identity (Goffman, 1963). However, despite this and even when a patient's acceptance of the medical explanation is recognised this does not inform anybody how the person is coping with the diagnosis (Williams, 2008). The cumulative aspects associated with a diagnosis of schizophrenia can be damaging and suspend thoughts of clinical improvement and recovery for all concerned. Overall, in a study by Thomas *et al* (2013) after being given a diagnosis of schizophrenia people described a wide range of negative impacts on their lives with one person told not to have children. Andersen & Larsen (2012) state that medical constructions have been made to attempt to make sense of personal experiences that people have in relation to being mentally ill and this is unsuitable for the person themselves. By stating that mental problems are painful phenomena rather than disease may prove more helpful (Andersen & Larsen, 2012). Cleary *et al* (2012) addressed therapeutic optimism in nursing, but this could certainly be transferred to all professional groups working in this field, when they state that it is important to explore ways to foster optimism. This in turn would be more facilitative and in keeping with a recovery-focused approach.

3.4 Recovery:

Within this research study the overarching theme of recovery is very much at the fore, for a person with schizophrenia the relationship between remission and recovery may be seen as part of the same process with recovery being the ‘ultimate goal’ as highlighted by Andreasen *et al* (2005). In the preceding fifty years, as a society, we have evolved to a position where people with a diagnosis of schizophrenia are ‘expected’ to demonstrate some form of recovery (Frese *et al* 2009). Table 1 below highlights long-term follow-up studies demonstrating international recovery rates for people with schizophrenia;

Table 1. Recovery Long-Term Follow-up Studies (Harding and Keller, 1998, p135)

Investigator	Location of study	Number in cohort	Length of follow-up years	% significantly improved/recovered	% socially recovered
M. Bleuler (1972)	Switzerland	208	23	53-68	46-59
Huber et al (1975)	Germany	502	22	57	56
Ciampi & Muller (1976)	Switzerland	289	37	53	57
Tsuang et al (1979)	Iowa (USA)	186	37	46	21
Harding et al (1987)	Vermont (USA)	82	32	62-68	68
Ogawa et al (1987)	Japan	105	24	56	47
Desisto et al (1995)	Maine (USA)	45	36	42	49

The table demonstrates a spread of studies that span more than twenty years, and the studies themselves are all over twenty years in length of follow-up with a good sample size in each cohort. These studies are indicative that recovery does indeed occur and it is not confined to one country, also that the number of people recovering appears to be significant in all studies. However, caution should be heeded, despite each study having their own merits certain factors reduce the accuracy for the sake of comparability. This also includes the diagnostic cultures of initially diagnosing a person with schizophrenia. Whilst we can observe the range in social recovery between 21 and 68%, this may be attributed to the studies employing different sample selection, treatment differences and also different methods of data collection (Harding & Keller, 1998). As a consequence we find ourselves in the position where recovery, very much like schizophrenia, propagates debate regarding the lack of an agreed definition. Bonney & Stickley (2008) have stated that generally, there is no clear consensus regarding recovery and it remains very much contested. Many authors state that there is not yet a definitive definition

of recovery (Kopelowicz *et al*, 2005; Onken *et al*, 2007; Kogstad *et al*, 2011). However, the most commonly cited definition was encapsulated by Anthony (1993) who according to Shepherd *et al* (2008) was one of the intellectual founders of the recovery movement;

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

(Anthony, 1993, p15)

Roe & Davidson (2008) identify that the idea of recovery in schizophrenia was ‘cherished’ by a small group on the fringe of the field of mental health for over 20 years. Therefore, “Recovery is not a new concept within mental health, although in recent times, it has come to the forefront of the policy agenda” (Bonney & Stickley, 2008, p140). Generally, “The concept of mental health recovery has been evident in consumer/survivor self-help since the 1930s” (Onken *et al* 2007). Spandler & Stickley (2011) report that since its inception the service user/survivor movement have raised concerns surrounding, what feels like, a lack of compassion in mental health services.

Recovery from schizophrenia has evolved considerably since its recognition as a psychiatric condition (Frese *et al* 2009). “Despite the enduring legacy of pessimism ... a majority do recover” (Deegan, 2005, p1). The role of the ‘mental health consumer’ movement in the USA in the late 1980s raised the profile of recovery from schizophrenia to mental health providers, researchers and policy makers, internationally (Roberts & Wolfson, 2004; Andresen *et al* 2006). The dissatisfaction with the traditional medical model has partly driven the advent of recovery (Ahmed *et al*, 2012). Such dissatisfaction was due to the historic view that traditional systems had fostered disability, alienation and marginalisation (Jacobsen & Curtis, 2000). Longitudinal research studies had led to the concept of ‘*recovery from schizophrenia*’ with its emphasis being the eradication of clinical symptoms, whereas the service user movement embraced the concept of ‘*recovery in schizophrenia*’ which allows service users to retain some degree of control over their lives despite the possible presence of symptoms (Gordon, 2013). The traditional medical model was seen as lacking in long-term perspectives on the coping strategies for service users (Skuse, 2012). It was recognised by Frese *et al* (2009) that the medical model, in conjunction with deinstitutionalisation, began to address the functioning of former patients and consequentially the notion of recovery from schizophrenia began evolving, initially under the guise of rehabilitation. According to Deegan (1988) the recovery

process is the foundation of rehabilitation services. For service users like Pat Deegan it took time to overcome the insult she felt to her personal identity in relation to being given the diagnosis of schizophrenia, the term she used is 'dehumanized' (*sic*). "Dehumanization is an act of violence, and treating people as if they were illnesses is dehumanizing" (Deegan, 2002, p9). Pilgrim (2009, p477) emphasises, "The structural shift from large institutions, and the possibility of citizenship for those previously dehumanised and shut away, encourage optimism in a different form now than in the past". This is in comparison to the 'eugenic axiom of degeneracy' that existed within institutions (Pilgrim, 2009). It cannot be denied that people seen to have a mental illness were treated abhorrently and no consideration of recovery was offered in the past. Kelves (1985) reminds us of the eugenics movement of the late 19th and early 20th centuries, when genetic explanations for stigmatised characteristics like mental illness and low intelligence were governed by policies and resulted in marriage restrictions, sterilisation and even extermination.

In the late twentieth century there was a policy shift for countries that had employed large scale institutional containment (Pilgrim, 2009). Countries in Europe, North America and Australasia dismantled their asylum systems that had been inherited from the nineteenth century, in what was called 'deinstitutionalisation', 'desegregation' or 'decarceration' (Scull, 1984). Deinstitutionalisation and community care became common place in the twentieth century although one does not imply or lead to the other (Pilgrim, 2009). This is a polite reference to the fact that during 'community care' some people felt a state of abandonment as they slipped between the cracks in service configuration or were overlooked by this regime. As a consequence of this, Sayce (2000) highlights the fact that in the public mind 'community care' was associated with failure. Allott *et al*, (2002, p18) commented that; "Within the UK ... the majority of people served by the mental health system are given little hope of recovery from their experiences". The staff also came under fire from Allott *et al*, (2002) as it was pointed out that staff were lacking in knowledge with regards to recovery and how service users could be supported in the process. Despite this paper being published in 2002 it is unclear how many years previous Allott *et al*, (2002) are drawing reference from, as they state that the introduction of key policy documents by the Department of Health will change the situation. The documents referred to are: 'Modernising Mental Health Services; safe, Sound and Supportive' (1998), 'The National Service Framework for Mental Health: Modern Standards and Service Models' (1999) and the 'NHS Plan: A Plan for Investment' (2001) which had all preceded their own paper. However, in fairness it may be the rate of adoption into

clinical practice which is problematic. The Chief Nursing Officer's Review on Mental Health Nursing (Department of Health, 2006) states nurses should use recovery principles in every aspect of their practice. Although things are changing and we have a much clearer structure for community services in England, Boardman & Shepherd (2012) state that improvement is still required in respect of the quality and content of these services. Despite this, in 2014 Slade *et al* report that; "An understanding of recovery as a personal and subjective experience has emerged within mental health systems" (Slade *et al*, 2014, p12).

The language of 'recovery' has become a common feature in mental health policy and practice in the UK and the agenda of recovery encompasses diverse perspectives from policy makers, service users and professionals (Spandler & Stickley, 2011). People who have experienced mental illness have been increasingly vocal in communicating what their experiences are with mental illness and also what assists in moving on beyond mental illness (Slade, 2010). These narratives and service user perspectives have assisted everyone in attempting to tailor interventions to facilitate an individual's recovery. However, these opinions within the literature about recovery are wide-ranging and whilst they cannot be characterised uniformly they do provide valid indicators of what recovery looks and feels like from the inside (Slade, 2010).

Lehman (2000, p329) advises caution and states, "Recovery has become a loaded word in the mental health field". This may be due to recovery being a dichotomous proposition, as some people take recovery to represent hope that they may go on to pursue a fulfilling life. In contrast, others view 'recovery' as rhetoric for people who have been oppressed victims of the system; these feelings gave rise to a philosophy of anti-psychiatry⁴ and people wishing to be free of professional treatment. The lack of consensus and the abstract nature of the concept of recovery was attributed to the lack of clarity around the definition of mental illness (Onken *et al*, 2007). In attempting to clarify this ambiguity Schrank & Slade (2007) stated that the term recovery has two meanings which are: 'Service-based recovery definitions' and 'User-based

⁴ There have been many authors within the 'anti-psychiatry' movement. Siebert (1999) highlights eight reasons why the 'brain disease hypothesis of schizophrenia' is not valid. Siebert also states that it is unethical how psychiatrists misrepresent what is known about schizophrenia. His eight reasons are: 1) Schizophrenia is not a single disease; 2) Evidence for the brain disease hypothesis is weak; 3) The brain disease hypothesis cannot accommodate solid evidence that many people completely recover from schizophrenia; 4) No brain disease has ever been cured with psychotherapy or the passage of time; 5) Some people diagnosed with schizophrenia progress beyond recovery; 6) The cause of schizophrenia is unknown; 7) There is no universal recognition that schizophrenia is a brain disease like all other brain diseases; 8) Treatments for schizophrenia are often worse than the disease.

recovery definitions'. Service based recovery definitions rely on symptom remission and reduction in use of medication, whereas user based recovery definitions address personal growth and development in overcoming the experience of being a mental health patient.

The concept of recovery has been defined in countless ways and Silverstein & Bellack (2008) organised them roughly into two groups. The first group reflect recovery as an 'outcome' this addresses the descriptions that desire operationally defined criteria to be achieved; the second group are those that refer to recovery as an on-going 'process' of identity change. Therefore it is easy to distinguish, again, the areas where service providers and service users may have a differing stance and similarities can be drawn against the work of Schrank & Slade (2007). However, this may have developed from Bellack (2006) who had identified viewing recovery as an outcome developed from the search for clinically meaningful and psychometrically reliable outcome measures, whereas appreciating recovery as a process developed primarily from service users attempting to raise the profile of their perspective within practice and research. Liberman & Kopelowicz (2005a) argued there is difficulty in separating 'process' and 'outcome' due to the elements of these two perspectives 'reverberating' with each other. Gordon (2013) adds that despite service users often claiming to reject the idea of 'outcome', their descriptions generally embrace both process and outcome; and as examples Gordon cites Deegan (1988) and Anthony (1993). Atterbury (2014) notably points out that measuring outcomes is not 'unimportant' but individually outcomes do not to afford the ethical justification for a recovery-orientated approach. Gordon (2013) had expressed disappointment that the many recovery-focused outcome measures available are not being adopted and applied by researchers, academics and the pharmaceutical industry. "This is especially perilous given that outcomes measures often drive the types of service provided" (Gordon, 2013, p271). This is viewed as 'perilous' by Gordon (2013) as recovery as an outcome implies people are condemned to hopeless unending journeys which may also encourage apathetic services which would continue to be determined by symptom-focused outcome measures. This may be viewed as a regression to a maintenance approach for people with a diagnosis of schizophrenia.

Another similarly contested factor is whether recovery is an approach, a framework or a model with different authors putting their own interpretation on proceedings. Warner (2009) favours the term '*The recovery model*'. This may be derived from earlier opinion by Andresen *et al*, (2006, p972) who state that "... there is a need for a model and a method of measuring

recovery as the concept is described by service users". Thornton & Lucas (2011) 'sketch' some of the issues and articulate a possible recovery model for mental health. However, they state clearly that the aim is to "clarify the options rather than defend the model that emerges" (Thornton & Lucas, 2011, p24). Whilst many issues are raised and discussed from other perspectives within their paper it is difficult to ascertain the level of conviction that the authors have in the 'model'. In a position statement by consultant psychiatrists in two merging London NHS trusts it was stated that, "Whilst some people refer to a 'Recovery Model', it is probably better to speak about Recovery ideas or concepts. A model would suggest that there is a manual somewhere" (South London & Maudsley NHS Foundation Trust and South West London and St George's Mental NHS Trust, 2010, p11). Kogstad *et al*, (2011) predict that the recovery approach needs to go beyond attempts to construct models for recovery-orientated practices and should therefore be a 'non-linear' process. Perkins & Slade (2012) identify recovery as a 'journey' but it was Unzicker (1989) who was one of the first to generate the idea of recovery being a journey. As a self-confessed 'survivor' of services Unzicker's drive and determinism was developed from the rejection of the medical model. Many view recovery, and the recovery movement in particular, as a challenge to the medical model (Coleman, 1999; Deegan, 2002; and Frese *et al*, 2009).

Pilgrim & McCrainie (2013) state that, whether rhetorically or otherwise, the personal journey approach to recovery has found a strong presence for all stakeholders. Mountain & Shah (2008, p241) worryingly identified that, "... many psychiatrists seem detached from this approach [recovery]. Sceptics suggest that it underplays the value of psychiatric treatment and services and offers false hope". Mountain & Shah (2008) go on to defend the medical model and state that it has a part to play as objectively defining 'what works' is a medical model approach and therefore is not divorced from the recovery approach. This may be a case of self-preservation given that Mountain and Shah are both consultant psychiatrists offering a strong rallying cry to defend their profession. In doing so, they admit that in response to the recovery movement, "There has been a confusing range of responses among psychiatrists. Some have been bemused, dismissive or defensive" (Mountain & Shah, 2008, p244). There is also concern that psychiatry may be re-badged or the medical model be distorted by the recovery movement and that the medical model itself need not be questioned but more the manner in which it informs current psychiatric practice (Mountain & Shah, 2008). Andresen *et al*, (2006) had already identified that symptom measurement, functioning and hospitalisation are based on the medical model, but these are often in conflict with service user or consumer

perspectives of recovery. Pilgrim & McCranie (2013, p44) illustrate the growing complexities associated with the notion of recovery;

“... we have seen recovery in a number of either/ors: an internal versus an external process, a process versus an outcome and a clinical goal versus a socio-political goal. One might be discussing recovery-as-experience, recovery-as-evidence, recovery-as-ideology, recovery-as-policy or recovery-as-politics”

Whether recovery is defined as a process, outcome or staff training philosophy it is important to increase efforts to evaluate areas which promote recovery (Silverstein & Bellack, 2008). In an attempt to progress and operationalise the literature around recovery Andresen *et al*, (2006) developed a ‘stages of recovery’ instrument. This was developed from a consumer-orientated definition of ‘psychological recovery’ from their earlier work in 2003 and this was described as; “... the establishment of a fulfilling, meaningful life and a positive sense of identity founded on hopefulness and self-determination” (Andresen *et al*, 2003, p588). The whole premise of recovery is based upon finding a new self and position as opposed to rediscovery of the former, premorbid, self (Deegan, 1988; Anthony, 1993, Allott *et al*, 2002). Andresen *et al* (2003, p589) developed what they described as, “Four component processes of recovery; i) Finding hope, ii) Redefining identity, iii) Finding meaning in life, and iv) Taking responsibility for recovery”. At this period in time other studies had also identified stages or phases in the recovery process but with regard to the exact delineation there was no consensus. A much earlier study from Davidson and Strauss (1992) addressed the sense of self in respect of recovery and whilst this study did not specifically address people with schizophrenia per se there were 25 participants from the total of 66 with this diagnosis. Davidson and Strauss (1992) developed ‘four aspects’ which are; i) Discovering the possibility of the self as an agent, ii) Taking stock of strengths and limitations, iii) Putting aspects of self into action, and iv) Using the enhanced sense of self as a resource in recovery. The significance of personal change is not missed here as these aspects adhere, to some degree, to Kurt Lewin’s (1951) three-step model of change management⁵. Andresen *et al*, (2003) drew comparison between five studies prior to drawing up their own 5-stages of recovery. These five stages consisted of; Moratorium, Awareness, Preparation, Rebuilding, & Growth. These stages are not necessarily a linear progression that all go through, but are best viewed as aspects of engagement within the process of recovery (Shepherd *et al*, 2008). Components,

⁵ Kurt Lewin devised a three-step model of change management, which initially appears simplistic in nature. It does however provide the necessary steps to facilitate and consolidate change. The three-steps are; ‘*Unfreezing, Movement and Re-freezing*’. The work of Davidson and Strauss (1992) resembles this using aspects i, iii and iv. Aspect ii (taking stock of strengths and limitations) resembles another feature of Lewin’s work, the *Force-field analysis*.

aspects or stages of recovery highlighted and suggested by various authors have contributed to a drive towards an understanding of recovery, even though not always adding clarity in every case.

In 2005 Laurie Davidson identified that we cannot implement programmes of recovery taken from physical illnesses in the field of mental health. This is due to the notion that 'self-management models' and 'service user experiences' have more value than models originating from physical health (Davidson, 2005). In respect of definitions around recovery, Davidson was in support of and utilised the notion of recovery previously highlighted by Anthony (1993) whilst also utilising the work of Andresen *et al*, (2003) in developing a clearer understanding for the UK perspective. This work was beginning to signify the direction for recovery in the UK as Davidson developed his work in the Devon Recovery Group to identify 'The Principles of Recovery' (Davidson, 2008). These principles have been replicated and advocated by many including Shepherd *et al*, (2008)⁶, Manchester City Council & Manchester Mental Health and Social Care Trust, Dorset Health Care University NHS Foundation Trust, Falmouth Recovery Support (Cornwall) and even as far as The Mental Health and Recovery Board in Ohio, USA. Those mentioned above also advocate the definition of recovery by Anthony (1993) and the 'four component processes of recovery' (Andresen *et al*, 2003) for an illustration of The Principles of Recovery see Appendix 4.

We are reminded by Deegan (2002) that recovery is not the privilege of an exceptional few clients, but as empirical data indicates most do recover. Atterbury (2014) asserts that if the promise of recovery and recovery relationships are withdrawn from service users it is an injustice and a moral violation. To be able to transfer recovery focused-approaches into practice it is useful to comprehend the regular themes that arise from people who have recovered. Table 2 below compares three studies illustrating the themes of people who have recovered. The study by Schrank & Slade (2007) identifies components of the recovery process as defined by service users, the other studies are themes derived from the literature.

⁶ According to the 'Rethink Mental Illness' website Making Recovery a Reality (Shepherd *et al*, 2008) is the most downloaded document ever by the Sainsbury Centre for Mental Health. <http://www.rethink.org/about-us/commissioning-us/100-ways-to-support-recovery> [accessed 30/12/14].

Table 2. Comparison of Recovery Themes

Kelly & Gamble (2005)	Schrank & Slade (2007)	Slade (2009)
Hope	Hope	Hope
Mentorship		
Spirituality	Spirituality	
Growth		
	Responsibility & Control	Personal Responsibility
	Empowerment	
	Connection	
	Purpose	
Being an Individual	Self-Identity	Self-Identity
	Symptom management	
	Stigma	
		Meaning

Hope remains a central tenet of recovery and this is reported widely in the literature (Deegan, 1988; Allott *et al*, 2002; Repper & Perkins, 2003; McCabe *et al*, 2007; Hobbs & Baker, 2012). Repper & Perkins (2003) appreciate that this is not without challenges to the mental health worker, as they face the ‘twin challenge’ which address the impact of the mental health problem on a person’s life and also fostering a positive future vision. In an earlier paper and also following consultation with ‘consumers’ (*sic*) Jacobson & Greenley (2001) introduced the concept of recovery referring to both *internal* and *external* conditions. The internal conditions referred to; hope, healing, empowerment and connection. The external conditions defining recovery are; human rights, a positive culture of healing and recovery-orientated services.

Langeland *et al*, (2007) highlights that within the recovery process, three healing factors have been identified as being important. These factors are that participants i) perceive themselves as something other than just a diagnosis or a disease, ii) explore themselves with respect to their whole person, and iii) take control of their own lives (Langeland *et al*, 2007, p276) . To enable service users to do this mental health staff need to appreciate the concept of salutogenesis. Improving all aspects of life simultaneously through holistic healing was proposed by Antonovsky (1985). Atterbury (2014, p184) is very much in agreement and states; “A more holistic view of mental health offers recovery as the hopeful protagonist in a narrative of health not illness”. This is the basis of salutogenesis as opposed to the traditional perspective of health which is regarded as pathogenic, as its emphasis is more on disease and

biological mechanism. The diagnosis becomes secondary to the story of the person, with the person understood as an active system that interacts with the environment utilising both internal and external conditions (Langeland *et al*, 2007), very much in alignment to those described by Jacobson & Greenley (2001).

Lindstrom & Eriksson (2006) state that one of the questions puzzling Antonovsky was how come we can survive in spite of all of the chaos and stress that forms part of our lives? In relation to this Antonovsky (1985) regarded health as relative and on a continuum and his questions were regarding what causes health (salutogenesis) as opposed to what are the reasons for disease (pathogenesis). The presence and ability to utilise salutogenesis was illustrated in a study by Ventegodt *et al*, (2008), addressing clinical holistic medicine in the recovery of working ability. In their conclusion Ventegodt *et al*, (2008, p221) exclaim; “The patients are motivated for human development and engage in existential therapy in spite of this being highly emotionally painful at times where old trauma are confronted and integrated”. This is a chord that will resonate for people with a diagnosis of schizophrenia, as a potential for approaching recovery. The theory base has two ‘core concepts’; a Sense of Coherence [SOC], and General Resistance Resources [GRR] (Antonovsky, 1985). The sense of coherence is relative to the role of stress and human coping with the person who copes well seen as having a high SOC. General Resistance Resources are crucial to SOC and defined as; “Any characteristic of the person, group or environment that can facilitate effective tension management” (Langeland *et al*, 2007, p278). Antonovsky (1987) identified five therapy principles in this intervention; 1) the health continuum model; 2) the story of the person; 3) health-promoting (salutary) factors; 4) the understanding of tension and strain as potentially health promoting; and 5) active adaptation.

Overall, the concept of salutogenesis may have informed many other approaches to recovery, including most of the recovery processes identified in Table 2. In respect of delivering recovery approaches, the literature explored indicates that there is a move more towards person-centred and service user defined methods rather than solely clinical outcomes. The benefit of a salutogenic approach is increased when service users are prepared to assume responsibility for their own life (Ventegodt *et al*, 2007). This has been appreciated for some time as Liberman & Kopelowicz (2005a) postulate, due to the fact that schizophrenia is often associated with dependence on others recovery should include a dimension associated to independent functioning. This has a big impact upon mental health services and approaches, as Copeland &

Mead (2000), who use their own experiences to suggest that mental health workers have to 'be human' and regard recovery orientated relationships as real and authentic despite changes in roles. As for Repper & Perkins (2003) the central issue in effective relationship formation is the ability to value people as equals. Silverstein & Bellack (2008) argue that a lot of the terms, such as hope, empowerment and self-determination are often used in a vague manner. This may be part of the rationale that Kogstad *et al*, (2011) discovered in recent studies that recovery factors experienced by service users are not always compatible with professional approaches. There can be many possibilities speculated for this but Beck *et al*, (2012, p564) hypothesise, "People appear to hold an individual representation of what it means to be recovered". It may be difficult to argue against this, but to what degree this interferes or inhibits recovery may be easier to question. Rufus May (2000) from his personal experience states that recovery from social expectations was a bigger challenge than the psychosis itself and as a consequence he sees that "Recovery lies in the social contexts within which this process occurs" (May, 2000, p10). It needs also to be acknowledged that there will be many subjective views of recovery with one reason for this being due to personal understanding of recovery altering over time (Slade *et al*, 2014).

It is evident that the individual and personal journey of recovery for service users necessitates services to alter the focus of care and treatment (Lloyd *et al*, 2008). There have been attempts over the years to meet the needs of people recovering from schizophrenia and this continues. The Quality Standards developed by the National Institute for Health and Care Excellence (NICE, QS14) highlights fifteen statements in relation to user experience in adult mental health services (see Appendix 5). These statements are to be employed by Trusts as guidance to assist the facilitation of positive approaches to recovery with the first three identifying the need for optimism; empathy, dignity & respect; and shared decision-making (NICE, 2011). A study by Gould (2012) was designed to explore how effective service users found the 2008 Care Programme Approach [CPA]. Initially Gould (2012) reports that the concept of recovery was a welcome challenge to the idea of a 'life sentence' within the maintenance approach built on the medical model. Service users in the UK have generally welcomed professional bodies and the government's endorsement of recovery approaches, however it was felt that this was still 'patchy' at this time (Gould, 2012). Within this study by Gould (2012) the service users developed a checklist of good practice for professionals (see Appendix 6).

Atterbury (2014) indicates that the difference between traditional mental health practices and recovery-orientated approaches is that if we are utilising a recovery focus then the locus of control should remain with the service user to the greatest extent possible. This will, hopefully, avoid the traditional paternalistic approach based on maintenance. Aston & Coffey (2012) warn that without understanding of the concept of recovery mental health staff will struggle to deliver a recovery-orientated service. This may be problematic and continue to cause some conflict as Stickley & Wright (2011) indicate from their review of recovery literature that the necessity for therapeutic relationships is a strong component of recovery; as it is for all interactions within mental health (Barker & Buchanan-Barker, 2009).

Slade *et al*, (2012) conducted an analysis of 30 documents from six countries addressing international perspectives and practice guidance on supporting recovery and found four overarching levels of practice; promoting citizenship; organisational commitment; supporting personally defined recovery; and working relationship (Slade, *et al*, 2012, p101). Yates *et al*, (2012) explored the social and environmental condition in which recovery occurs, with their paper concluding that recovery seems unlikely and can never meet the needs of the people if the environment is structured in a manner that damages, excludes and discriminates against them. To further compound some of the issues Aston & Coffey (2012) identified that, within their study, nurses were uncertain of their role in relation to recovery and felt that, despite rhetoric to the contrary, the concept had been imposed upon their profession in conjunction with challenging the notion of therapeutic optimism. In spite of this concern, some service users remain positive and Mayes (2011) states that whilst choice is important, the combination of self-help and mainstream services can offer the best approach. According to Slade (2010) aspects of individuals engaging or re-engaging in their life are recurring features from the recovery narrative that allow people to discover meaning and purpose through valued identity and social roles. This is indicative of 'personal recovery' which involves working towards better health, regardless of the presence of symptoms as highlighted by Deegan (1988); Coleman (1999); and Frese *et al*, (2009). One of the main indicators of personal recovery according to Giusti *et al*, (2014) is cognitive insight. Cognitive insight refers to the ability to evaluate and correct distorted beliefs and assumptions and the increase in ability to do this presents a positive correlation with personal recovery (Giusti, *et al*, 2014). This approach is indicative of wellbeing rather than the treatment of illness. Slade (2010,) illuminates the fact that 'positive psychology' is devoted to the promotion of wellbeing.

Seligman *et al*, (2005) states that in its broadest sense *positive psychology* addresses positive emotions, positive character traits and enabling institutions, all of which would be conducive to recovery. When considering recovery in the context of wellbeing as opposed to the best possible life it can be suggested that people share a common set of needs which provide a basis for a life worth living (Papadopoulos *et al*, 2013). This is regarded as a 'eudaimonic' approach which would have an impact on the values of all concerned. It was from Aristotle's philosophy of happiness which the eudaimonic tradition is derived (Ryan *et al*, 2008). In relation to recovery Thornton & Lucas (2011) remind us that the goal is of a life that is valued by the service user and the values would be best if eudaimonic rather than hedonic. Ryan *et al*, (2008) identify that both eudaimonic and hedonic perspectives have different targets, with the focus of hedonia being happiness as experiencing pleasure and eudaimonia as happiness as living well. Seligman *et al*, (2005, p413) raises the point, "One nonobvious reason to be interested in interventions that build happiness is that happiness is not an epiphenomenon". This indicates that the phenomenon of happiness for service users experiencing personal recovery is not a by-product and may induce an overall sense of recovery. Slade (2010) suggests that valuable lessons may be learned in utilising a bilateral approach towards the 'fundamental aims of recovery' and 'positive psychology'; and whilst the name [*positive psychology*] may be unhelpful and misleading 'well-being' would be a better focus for many disciplines.

A study by Wood *et al* (2013) specifically explores service user's perspectives of recovery from psychosis. Due to recovery being a poorly defined concept and minimal impact of service user definitions this study was performed by Wood *et al* (2013). The results revealed four distinct perspectives as important factors to be considered and addressed; 1) Collaborative support and understanding, 2) Emotional change through social and medical support' 3) Regaining functional and occupational goals, and 4) Self-focused recovery. These factors were developed by service users in groups for the purpose of the research study. It led to the authors concluding that despite 'common elements' it is the number of idiosyncratic perspectives which need to be taken into account when conceptualising and delivering recovery through service provision (Wood *et al*, 2013).

In a 'special article' by Slade *et al*, (2014) addressing 'uses and abuses of recovery' they identify seven abuses of the concept of recovery. These 'abuses' are identified as;

- 1) Recovery is the latest model
- 2) Recovery does not apply to 'my' patients

- 3) Service can make people recover through effective treatment
- 4) Compulsory detention and treatment aid recovery
- 5) A recovery orientation means closing services
- 6) Recovery is about making people independent and normal
- 7) Contributing to society happens only after a person is recovered

(Slade *et al*, 2014, p14).

The purpose of this overview was to highlight areas where services and teams had perhaps adopted a ‘knee-jerk’ response to providing recovery orientated approaches without thinking them through clearly. To add balance, within the same article ten empirically supported pro-recovery interventions were highlighted;

- | | |
|--|--|
| 1) Peer support workers | 2) Advance directives |
| 3) Wellness recovery action planning | 4) Illness management and recovery |
| 5) REFOCUS ⁷ | 6) Strength model |
| 7) Recovery colleges or education programmes | 8) Individual placement and support |
| 9) Supported housing | 10) Mental health dialogues ⁸ |

The emphasis by Slade *et al*, (2014) is on the implementation of recovery-orientated practices and facilitating inclusion. It is acknowledged that this type of recovery will involve transformation within, and impact upon mental health services and will not be easy to transform as it impacts upon human systems.

Recovery-orientated practices are viewed as ethical by Atterbury (2014) as they recognise and respect every person’s personhood and dignity. Extending beyond a reductionist view of symptomatology recovery orientated services help individuals reconstruct their lives in a meaningful way (Mathur *et al*, 2014). The culture of care that underpins how service users are valued, understood, related to and position within the organisation should be central to the delivery of interventions and service systems (Papadopoulos *et al*, 2013). An initiative in the UK is ImROC (Implementing Recovery through Organisational Change); it was established in 2008 by the Department of Health in England and is a joint initiative between the Centre for Mental Health and the Mental Health Network NHS Confederation (Shepherd *et al*, 2014). One of the main tenets of ImROC is;

⁷ The REFOCUS programme was a 5 year research study which aimed to understand what is meant by personal recovery and to find effective ways of increasing the recovery support community-based adult mental health services offer to service users (Fortune *et al*, 2015 p3).

⁸ A mental health dialogue meeting is a community forum of service users, carers, friends, mental health workers and others with an interest in mental health participate in open dialogue (Slade *et al*, 2014).

“While the ideas of recovery and recovery-oriented practice have the potential to transform mental health services, we need to look beyond what is provided by these services and examine the whole range of resources and opportunities that can support quality of life, full citizenship and human rights for people with mental health problems.”

(Boardman and Friedli, 2012)

The ImROC programme is based on a framework of ‘10 key challenges’ (Boardman & Shepherd, 2009). Some of which goes beyond the therapeutic approach and utilises an educational approach (recovery colleges) to support people on their recovery journey (Perkins *et al*, 2012). There is increasing pressure on service providers to ensure that the services offered to people with mental health problems are recovery orientated (Meehan *et al*, 2008). This concern can be addressed as not only do recovery colleges assist people whom they serve in their personal and collective journeys of recovery, but they also address organisations and services to enable them to become more recovery-focused (Perkins *et al*, 2012). Approaching recovery and utilising approaches as suggested by ImROC would also go some way to ensuring that services employed a more ‘practice-based evidence’, in doing this the voice of the service user would be privileged and given equivalent status with the more conventional models of presenting evidence as suggested by Ramon *et al*, (2009). However, caution must be exercised that the case made by Roe *et al*, (2007, p173) does not become true, when they state that; “If recovery can be taken to mean anything, then it comes to mean nothing at all”. A similar statement had been made earlier by Lester & Gask (2006) when they commented upon how broadly the term recovery was being made that it bordered on becoming meaningless. However, despite advances since these comments there is a lot of work to be done to enable services to be more effective in enabling recovery for people with a diagnosis of schizophrenia. Hobbs & Baker, (2012) commented more recently that despite the increase in number of services adhering to the recovery approach, they continue to be in the minority. Although, as awareness increases and the emphasis of user-defined goals continues, utilising strengths approaches and educational supports (such as recovery colleges) then it can only be hoped that the impetus continues to deliver improved services and approaches.

One of the most recent developments has been as a consequence of the REFOCUS programme, which is primarily aimed at promoting recovery in adult mental health services. It resulted in the REFOCUS manual now in its second edition (Bird *et al*, 2014). This manual addresses the implementation of pro-recovery interventions by staff and these interventions impact in two ways; *Recovery promoting relationships*, and *Pro-recovery working practices*

(Bird *et al*, 2014). A summary of findings from the REFOCUS programme was published by Fortune *et al* (2015) and this offers a clear demarcation between clinical recovery (emerging from mental health professionals) and personal recovery (emerging from people with lived experience). Importantly, there is clear reference made by Bird *et al* (2014, p8) that “... recovery can take place within, partly outside or wholly outside the mental health service”. This is a clear message that people should be encouraged to recover in a fitting environment, not just within mental health services.

3.5 Remission:

Exploring and examining the literature in relation to remission will highlight where commentators, academics and clinicians alike stand on the idea of the usefulness of this concept in relation to people with a diagnosis of schizophrenia.

Remission is a term that may be synonymous with certain medical complaints or illness, such as multiple sclerosis (Juliano *et al*, 2008), rheumatoid arthritis (Ma *et al*, 2010), cancer (Tait, 1993) or Crohn's disease (Kast, 1998). In this context remission is used to signify either the absence of a disease (complete remission) or significant improvement and reduction in the clinical and subjective characteristics of a chronic or malignant disease (partial remission). This, however, is not always as straightforward in the field of mental health despite the concept of remission being employed here for well over a decade. Remission was predominantly employed in respect of people with depression and anxiety (Kelsey, 2001; Nemeroff *et al*, 2003; Nierenberg *et al*, 2010), with depression being described as the 'vanguard' of remission in psychiatry and other areas being poised to benefit from this (McIntyre *et al*, 2006). Within anxiety disorders remission was not designed or intended to infer the complete absence of symptoms but minimal symptoms with mild disability (Doyle & Pollack, 2003), therefore more in line with the notion of partial remission and perhaps less in keeping with what the layperson may view as remission. Fischer & Carpenter (2008) postulate that schizophrenia will pose unique challenges if we are to employ the same criteria as for depression and anxiety. Within depression, recovery is often equated to remission (Frank *et al*, 1991). Han & Wang (2005, p568) add that, "Recovery may also be defined as remission for an extended period of time or the complete absence of symptoms". Within the Report of National Audit of Schizophrenia (2012) remission is defined as; "When someone is not currently suffering from the symptoms of an illness that has affected them they are said to be in remission" (Health Quality Improvement Partnership & Royal College of Psychiatrists, 2012). Although simplistic, this is suggestive of complete rather than partial remission. This reveals the nebulous nature of the concept of remission in aspects of mental health and the multifarious application of it.

There have been other studies within the field of mental health, such as that by Fritsch & Ingraham (2003) addressing the plausibility of remission in patients with 'borderline' (*sic*). This study by Fritsch & Ingraham (2003) illustrated some interesting points, and whilst people with a diagnosis of borderline personality disorder cannot be directly compared to a person with a

diagnosis of schizophrenia there are shared learning points. One such point concentrates on the aspect that those people who demonstrated remission may be representative of a subset regarded as 'atypical borderline patients' (Fritsch & Ingraham, 2003). This is also prevalent for people with schizophrenia as sceptics may use this argument to dismiss remission or recovery due to issues with perceived initial misdiagnosis. Other similarities occur around the aspects of specific diagnosis of borderline personality disorder and categorical diagnosis in general, which certainly resonates with parallel issues being raised in relation to schizophrenia and Fritsch & Ingraham (2003, p127) point out that "... being labelled borderline cannot predict the course of the disorder ... perhaps BPD as currently diagnosed by DSM-IV is merely an admixture of nonhomogeneous people who happen to have similar symptoms at one point in their life". One further and important aspect highlighted by Fritsch & Ingraham (2003) is that they discovered that remission was associated with important alterations in the subjects' experiences of themselves and others. Given that schizophrenia may be internalised and regarded as an 'I am' disorder (Estroff, 1989), the value of self-perception cannot be underestimated in achieving remission and indeed working towards recovery.

Historically, in relation to schizophrenia there was a sense that over time people with this diagnosis would 'burn out' and symptoms would reduce as a consequence. This phenomenon has been heard around clinical areas for some years. Shultz *et al* (1997) highlight that age impacts on neurotransmission and the dopaminergic responses may be affected by this too. Prior to this Bridge *et al* (1978) published a study examining evidence for a 'burn-out' process which may transpire in patients with schizophrenia in their middle to late years. It was recognised and documented that those that "survive to the involuntal years do experience a symptomatic diminution" (Bridge *et al*, 1978, p839). However, it was concluded that as there was little systematic investigation into the phenomenon of 'burn-out' further psychiatric research should examine, "both the onset and the diminution/remission of schizophrenic phenomena" (Bridge *et al*, 1978, p839). Hence, in the literature the impetus shifted from addressing 'burn-out' to focussing more on remission. Papers began to appear addressing remission such as Ho *et al* (2000) who addressed symptom remission in first-episode schizophrenia. However, it was illuminated by Auslander & Jeste (2004) that the reported rates of remission for schizophrenia were so disparate due to the different and, in some cases, questionable criteria utilised. Auslander & Jeste (2004) highlight that due to employing strict criteria for remission the rates they were able to report were low by comparison with some others. The criteria employed initially stipulated that a person must have met the DSM-III-R or

DSM-IV criteria for schizophrenia. This eliminates, or at least minimises, the argument of misdiagnosis if the results appear favourable. However, this research did not go without scrutiny as Liberman & Kopelowicz (2005b, p1763) demanded more clarity in relation to "...the criteria for defining sustained remission in terms of quantitative levels of symptoms". Overall, the findings of this study (Auslander & Jeste, 2004) indicate that even in chronic cases sustained remission can occur; they go on to state that, "Our results show that true recovery from schizophrenia is an exception rather than the rule" Auslander & Jeste (2004, p1492). Whilst this statement may initially appear innocuous, it introduces unnecessary subjective language that is ambiguous in relation to 'true recovery'. When definitions are unclear or have no consensus, in relation to definite outcome, they may be viewed as superficial or reaping little actual benefit to the service user. Unfortunately this has been a case in point throughout all aspects of this literature review, in relation to schizophrenia, recovery and also remission.

Central to the concept of remission in schizophrenia was the, somewhat seminal, paper by Andreasen *et al* (2005). Interest has increased around the area of remission and recovery as this research provided new insights (Tsang & Chen, 2007). This paper by Andreasen *et al* (2005) was the main impetus that, perhaps, remission could be considered and utilised as a concept within the more overarching term of recovery for people with a diagnosis of schizophrenia. The rationale offered for this paper was due to previous studies addressing the goal of prognostic factors rather than establishing operational criteria for remission. Nancy Andreasen had been involved in the studies previously highlighted by Shultz *et al* (1997) and Ho *et al* (2000) and it was Andreasen who was instrumental in the development of the Remission in Schizophrenia Working Group (RSWG). This RSWG was convened in 2003 with the purpose of developing a consensus definition of remission as applied to schizophrenia; and this was derived after developing operational criteria for remission using the work around remission in mood and anxiety disorders from the previous decade (Andreasen *et al*, 2005). The definition of remission is as follows:

"A state in which patients have experienced an improvement in core signs and symptoms to the extent that any remaining symptoms are of such low intensity that they no longer interfere significantly with behavior and are below the threshold typically utilized in justifying an initial diagnosis of schizophrenia"

(Andreasen *et al*, 2005, p442)

The definition by Andreasen *et al* (2005) resembles very closely that generated by Kupfer (1991) in relation to long-term treatment of depression;

“Remission is defined as the attainment of virtually asymptomatic status and return to pre-morbid social function, such that syndromal criteria are no longer met” (Kupfer, 1991, p29).

The principal similarity in relation to both definitions is that symptoms would have to reduce below the point where the original diagnosis, be it depression or schizophrenia, would be given to the person. Andreasen *et al* (2005) emphasise the point that there are also examples in ‘nonpsychiatric illness’ whereby remission only indicates a reduction in symptoms rather than removal or elimination. Some considerations were made when addressing the definition of remission and Andreasen *et al* (2005, p443) identify these ‘important features’ as “applicability to clinical practice across a wide range of treatment settings, utility in research settings and incorporation of both symptom severity and time components”. Despite the ongoing surge of recovery-focused approaches, within mental health, remission has not really been adopted in terms of its clinical application. It was stated by the RSWG (Andreasen *et al*, 2005) that one of the reasons an operational definition of remission was required would be that it would provide opportunity to elevate and articulate expectations of patients, caregivers and providers of mental health services in respect of the long-term outcome in schizophrenia.

In respect of service users, there is some recognition in relation to the use of remission for people with a diagnosis of schizophrenia. Ashley Smith, a service user with a diagnosis of schizophrenia, writes a Blog entitled ‘Overcoming Schizophrenia: How I am living with it’ and has a thread entitled ‘What is remission?’ In this she writes;

“Remission is the absence of symptoms for at least six months with the support of medication. In other words, a doctor who has never seen you before may not diagnose you as a person with schizophrenia anymore... However, this does not mean the patient is cured or the illness has went away, the illness is still present, however, under control. Remission is achieved with the assistance of medication” (Smith, 2009, Posted 1/2/2009).

This explanation is almost identical to that of Andreasen *et al*, (2005) with the addition of a personal perspective. This Blog did provoke some responses; whilst some were supportive there were others who held stronger views regarding their condition and treatment. Smith (2009) is obviously very accepting of her medication regime, but a response to her Blog from a fellow service user (calling herself Francesca Allan) stated;

“Your definition of remission: ‘absence of symptoms for at least six months with the support of medication’ seems unnecessarily restrictive. What about absence of symptoms without medication? Why would that not be considered remission? (Posted 15/7/2009).

Another respondent on the Blog, remaining anonymous, expressed feelings of being restricted and tied to the services due to receiving a diagnosis of schizophrenia. This person had suffered sexual abuse and had been forcibly detained and medicated in the four years they had been known to services. Despite not adhering to the prescribed medication regime they stated;

“...I have rebuilt every aspect of my life and an (sic) symptom free. Yet I still have the heavy stigmatising label of schizophrenia in remission attached to me. I feel angry that my choices and rights are tied up to the psychiatric system and in the hands of others, to a large extent, due to this label and system which depowers vulnerable people who have experienced abuse, illness of which is a natural reaction, not as implied by the medical/pharmaceutical model of brain dysfunction” (Posted 25/7/2011).

The point made with regard to ‘schizophrenia in remission’ being a negative label is an interesting one as most would assume this would suggest that improvements had been achieved. This Blog entry is clearly expressing displeasure and frustration at a system that is containing a person who feels that their ‘remission’ is perhaps not acknowledged by others and is therefore not a beneficial label. Despite this person being given the label ‘in remission’ other indicators emphasise that a recovery focused-approach has not been utilised to support them.

The publication by Andreasen *et al* (2005) also provoked responses, predominately researchers, interested in this particular field. Whilst it encouraged and enabled some to pursue further work utilising the definition offered, it also raised more questions for some. Remington and Kapur (2005) picked up on the fact that Andreasen *et al* (2005) had confined the criteria for remission to three dimensions of psychopathology (positive, negative and general psychopathology symptoms) and did not address domains that are critical to functional recovery. It was also postulated by Remington and Kapur (2005) that there may be an issue with comprehension of the language employed by Andreasen *et al* (2005). However, it is interesting to note the language chosen to challenge this;

“The problem is that the majority of the specialists and lay users of this term from here on in will not have the nuanced sophistication of its authors. This

is more than semantic quibbling because nomenclature is not just a matter for psychiatric researchers anymore” (Remington & Kapur, 2005, p2393).

Perhaps the crux of this open letter by Remington and Kapur (2005) is that they oppose Andreasen *et al*, (2005) being the ‘group’ offering authoritative approval of the use of the term remission. Remington and Kapur (2005, p2393) advocating more for the case of functional recovery stated; “We are wary of reifying a decrease in a subset of symptoms without any reference or measure of real improvement in functional outcome or quality of life with the rather bold imprimatur of ‘remission””.

Another contributor in this area is Jim van Os, although he was not a contributing author to the paper published by Andreasen *et al* (2005) he is a member of the RSWG, and together with other members of this group he published a paper in 2006 attempting to demonstrate the utility of remission criteria in schizophrenia. This paper (van Os *et al*, 2006a) employed a comparison of the literature to support the use of remission in schizophrenia and was able to add a little more clarity around the scoring to acknowledge the presence of ‘symptomatic remission’. The criterion consists of two elements; symptom-based criterion and a time criterion. The symptom criterion is based upon “... eight diagnostically relevant symptoms” (van Os *et al*, 2006a, p92). The symptoms chosen were taken from the Positive and Negative Syndrome Scale [PANSS] (Kay *et al*, 1987);

1. Delusions (P1)
2. Unusual thought content (G9)
3. Hallucinatory behaviour (P3)
4. Conceptual disorganisation (P2)
5. Mannerisms/posturing (G5)
6. Blunted affect (N1)
7. Passive/apathetic social withdrawal (N4)
8. Lack of spontaneity and flow of conversation (N6)

Despite Muller & Wetzel (1998) previously expressing concern regarding the inter-rater reliability of the PANSS, the criteria were selected from the three components of the PANSS; Positive symptoms (P), Negative symptoms (N) and General Psychopathology symptoms (G). The original PANSS tool contains 7 positive symptoms, 7 negative symptoms and 16 general psychopathology symptoms (30 in total). As can be seen in the criterion for symptomatic remission there is a significant reduction in symptoms being rated to assess for remission (P 3, N 3 and G 2). There is also a factor of time that is required in amalgamation with the symptoms. Initially there needs to be a general low score achieved (3 or less on each

component) over a time period of six months to determine whether symptomatic remission is achieved, or not. van Os *et al* (2006a) are clear to assert here that remission is distinct from recovery, despite being an important step towards it, recovery is seen as a “higher hurdle and longer-term goal” (p94).

In another study, Van Os *et al* (2006b) attempted further validation of the criterion for symptomatic remission by conducting a retrospective study employing over 300 service users who had been in mental health services at some point since 1998. They concluded the study by stating, “The proposed symptomatic remission criterion has clinical validity and represents the right balance between parsimony and inclusiveness” (van Os *et al*, 2006b, p2000). Nasrallah (2006) also agreed that this proposed definition is conceptually viable and feasible in both research and practice. It was strongly advocated by van Os *et al* (2006b) that the symptomatic remission criterion could be used in research such as randomised controlled trials. This may raise slight concern as during their study van Os *et al* (2006b) included, in the remission criteria, items of ‘suicidality’ and ‘depression’ from the Brief Psychiatric Rating Scale [BPRS] (Overall & Gorham, 1962) and they also did not take into account the time (duration) criterion. Whilst it is suggested by Andreasen *et al* (2005) that the BPRS criteria may be used and then complimented by the use of the Scale for Assessment of Negative Symptoms [SANS] (Andreasen, 1984a), this may possibly reduce the validity within clinical trials and practice as not all researchers or practitioners may be familiar with the miscellany of tools. However, as highlighted by Mortimer (2007) due to its limited coverage of negative symptoms the BPRS is less useful in determining remission, so as a consequence would benefit from being augmented with the SANS. The lack of criteria for negative symptoms has since been criticised and Levine & Leucht (2013) cite the fact that at the time that the remission criteria was formulated antipsychotic medication targeted positive rather than negative symptoms. Levine & Leucht (2013) conclude that as a consequence perhaps the remission criteria are not intended for people with predominantly negative symptoms. This is despite Andreasen *et al* (2005) stating that the criteria are applicable across all stages of the disease course.

Within an exchange of open correspondence between Haro and van Os, a debate developed regarding the use of scales for assessing remission. Haro *et al* (2007) stated that despite van Os *et al* (2006b) commenting that the use of remission would be conceptually viable, using a serial assessment with this scale would prove costly. Haro *et al* (2007, p163) went on to advocate; “The evaluation of remission with reliable but easier to administer severity scales could

facilitate its measurement in usual practice". The response from van Os (2007) was to remind Haro *et al* that the entire PANSS, or entire BPRS would not be employed and that only the eight diagnostically most relevant items of the PANSS would be applied; "The administration of which would neither be lengthy nor costly and easily included in clinical practice" (van Os, 2007, p164). In further response Haro (2008) suggests that van Os had not followed his own recommendation when he used another scale to report remission rather than that recommended by Andreasen *et al* (2005). This may have served as a cutting reminder to van Os who had stated as his previous parting shot; "...if worldwide the concept of remission is going to be used, why not make sure we talk about the same thing?" (van Os, 2007, p164). This, again, fuels the arguments around inconsistency in outcome measures, in a lot of aspects, for people with a diagnosis of schizophrenia.

A familiar trend has developed using the term remission and the remission criterion as the standard in testing efficacy of medication in comparison studies by re-analysing existing data (Mortimer, 2007). This trend has continued and as a consequence the concept of remission has taken on a virtually singular dimension of signifying medication induced improved outcome. John Kane (a co-author with Andreasen *et al*, 2005 in drawing up the criterion for remission) and colleagues addressed symptomatic remission for people with a diagnosis of schizophrenia using either aripiprazole or haloperidol (Kane *et al*, 2007). Six of the co-authors working with John Kane on this paper were employed by pharmaceutical companies with a vested interest in the outcome. This is not an exception as the development of the concept of remission criteria has excited pharmaceutical companies to compare and advertise their products. Other examples include Buckley *et al* (2007) addressing symptomatic improvements in people with a diagnosis of schizophrenia who switch to ziprazidone, this research sponsored by Pfizer, the company producing and distributing ziprazidone. Emsley *et al* (2008) addressed remission in patients with first-episode schizophrenia using risperidone long-acting injection in a study funded by Janssen-Cilag, who produce this injectable antipsychotic medication. Peuskens *et al* (2010) addressed long-term symptomatic remission for people with schizophrenia using quetiapine fumerate. A very short conclusion highlights the effectiveness of the medication in achieving symptomatic remission in this study funded by Astra Zeneca, the producers of the medication in the study. Ashton (2007) states, the pharmaceutical industry is 'slowly strangling' the medical profession. In the conference paper which Ashton delivered in 2007 she explains' how this may occur, "[pharmaceutical companies] sponsor drug trials which are published in high impact medical journals ... Positive results from the same trial are published

in multiple journals, giving them added weight. Drug companies will often purchase thousands of reprints of an article, giving the journal a profit margin of 70%" (Ashton, 2007, p5). Some researchers, such as Helldin *et al* (2007) chose to make an explicit point of there 'not' being pharmaceutical or treatment intervention provided for the purpose of attaining remission within their study.

There is a common understanding around the use of the remission criteria that it is the symptomatic elements which are utilised, whereas the time criterion (duration) is rarely used and often neglected (Beitinger *et al*, 2008; AlAqeel & Margolese, 2012). Beitinger *et al* (2008) suggested that one of the reasons behind the lack of consistency in use of the time criterion (duration) and the emphasis on the symptomatic part of the criteria was as a consequence of the high dropout rates in the antipsychotic drug trials. Due to such inconsistencies Beitinger *et al* (2008, p1651) "... feel that a consensus on the analysis of the time criterion should be developed". Leucht *et al* (2008, p11) state succinctly; "The main advantage of the remission criteria is that they reflect how many patients are no longer symptomatic at endpoint". This 'endpoint' is more likely to infer the conclusion of the study as opposed to the six month duration criteria proposed by Andreasen *et al* (2005). According to Fischer & Carpenter (2008) reported outcomes of percentage improvement in symptom scores or the percentage of people crossing the threshold for improvement "...have no relation to remission or recovery" (p560) and this has been criticised as settling for improvement rather than pursuing remission. A concern expressed by Eberhard *et al* (2009, p200) is that despite some of the symptomatic criteria not being 'schizophrenic-specific' it may maintain some clinical relevance, however; "We must be aware of the risk that the connotation of the word could induce too much focus on symptom control". This is supported by Oorschot *et al* (2012) who highlight that remission may be an overly restricted goal due to the focus on symptomatology.

Haddad (2007) reminds us that there has been several attempts to define remission in schizophrenia, but as a consequence of utilising different criteria there are difficulties in comparing results of these outcomes. Kurihara *et al* (2011) reiterate this point and add more specifics in relation to the range of percentages reported achieving remission from studies utilising the standardised remission criteria by Andreasen *et al* (2005), see Table 3.

Table 3. Comparison of Remission Outcomes (taken from Kurihara *et al*, 2011)

Remission 'Type'	Range of people reportedly achieving remission (low & high)
Symptomatic Remission	Between 24% to 55%
Functional Remission	Between 13% to 46%

From their own study Kurihara *et al* (2011) reported findings that 27% achieved symptomatic remission, 32% achieved functional remission and complete remission (symptomatic combined with functional remission) was achieved by 27%. Whilst this offers similar results to other studies Kurihara *et al* (2011) concur with Haddad (2007) that different study designs and sample characteristics also make comparison difficult. A few years following the standardised remission criteria (Andreasen *et al*, 2005) there were more studies emerging that attempted to improve and compete in this area. Alonso *et al* (2008) used a short form of the SANS (Scale for Assessment of Negative Symptoms, Andreasen, 1984a), and the SAPS (Scale for the Assessment of Positive Symptoms, Andreasen, 1984b), as in the original criteria they also used 8 items in total. Alonso *et al* (2008) felt that they were able to accurately identify people in an outpatient setting with schizophrenia who had attained remission. Llorca *et al* (2009) developed the Functional Remission of General Schizophrenia (FROGS) scale. Using an expert consensus the FROGS was developed using 3-stages; (1) selection of functional dimensions in the literature, (2) generation of relevant items reflecting the different domains (3) construction of the scale to measure functional aspects of remission (Llorca *et al*, 2009). The complete tool contains 19 questions based on a five-point scoring scale. Llorca *et al* (2009) propose that this scale may be a step towards the development of an international definition of functional remission for people with schizophrenia. Barak *et al* (2010) addressed 'psychosocial remission' and developed the Psychosocial Remission in Schizophrenia (PSRS) scale. The PSRS is also an 8-item scale and this quantifies psychosocial remission in a manner that Barak *et al* (2010) describe will compliment symptomatic remission and serve as useful for both research and clinical evaluation.

Although Helldin *et al* (2006, p743) remarked that "Remission appears to be a clinically relevant phenomenon", more literature has expressed the significance of the differences between symptomatic remission and functional remission (Boden *et al*, 2009; Karow *et al*, 2012; Boyer *et al*, 2013). In fact the amalgamation of both symptomatic remission and functional remission has been termed 'complete remission' (Kurihara *et al*, 2011; Prikryl *et al*, 2013). However, the problem commences again regarding generally accepted criteria. Boyer *et*

al (2013, p1020) stated that, “There are no generally accepted criteria for functional remission unlike symptomatic remission”. This was in spite of efforts by Kurihara *et al* (2011) to define the criteria for functional remission as;

Patients were required to attain the three criteria simultaneously:

- [1] Vocational functioning (paid or unpaid work for more than half-a-day),
- [2] Independent living (without supervision by family members),
- [3] Peer relationships (meeting with non-family members more than once a week).

Llorca *et al* (2009) had previously identified the several dimensions that functioning encompasses, and these included; activities of daily life, social interaction, relationships, work and education. All of which appear to have influenced Kurihara *et al* (2011). Boden *et al* (2009) suggest symptomatic remission should be aimed for as an intermediate treatment goal prior to attempts to attain functional remission. Llorca *et al* (2009) identify that functional remission is an important treatment goal as they explain that “...independent living and reintegration of patients into the community and the workplace is the ultimate goal of any treatment” (Llorca, *et al*, 2009, p218). A study by Alenius *et al* (2010) identified that people who had not achieved functional remission lacked knowledge and insight. Braw *et al* (2012) suggested people in full symptomatic remission had intact executive functioning. Karadayi *et al*, (2011) observed significant differences in relation to quality of life and functionality between people with schizophrenia who were ‘in’ or ‘not in’ remission. The deficits that people may have in different areas of functioning, symptoms and well-being emphasise the need for combined outcome criteria (Karow *et al*, 2012). Brissos *et al* (2011) had earlier called for areas of symptoms, functioning, quality of life and neurocognition to be assessed simultaneously. The rate of symptom remission within the first year following hospital admission is much greater than the rate of recovery and therefore suggests that interventions addressing employment and social functioning are required to raise the chance of recovery (Ventura *et al*, 2011). However Robinson *et al* (2004) had outlined that during the early years the overall rate of recovery is low, but importantly that shorter duration of psychosis predicted symptom remission and recovery.

Within a UK perspective a journal supplement sponsored by Janssen-Cilag Ltd in 2007 ignited this topic closer to home. The lead article within this supplement was authored by Tom Burns (who was part of the RSWG) and stated that; “This supplement is concerned with how clinicians can use the remission concept” (Burns, 2007*b*, p3) and it posed four questions:

- How useful is it to those who work with individuals suffering from schizophrenia over long periods?
- Can it help focus on meaningful levels in the process of improvement which can often be imperceptible from day to day?
- How useful is it when talking with both the patients and their families and carers?
- How does it translate across the various disciplines in our multi-disciplinary teams?

The supplement is appreciative from all angles of the multi-disciplinary approach and as a consequence has contributions from many professionals' perspectives and also from a service user. Not surprisingly all contributors are favourable in their view of remission for people with a diagnosis of schizophrenia. Burns offers a perspective of the psychiatrist and states, if it reduces the pessimistic view of schizophrenia and introduces greater discrimination and attention to the course of schizophrenia then remission will be a good thing (Burns, 2007b). Robert Hunter (a Consultant Psychiatrist and Director of Research) also contributes by advocating the use of remission. Focussing on those with complex needs and with systematic assessment of clinical needs and outcome forming part of the service model, Hunter (2007) adds that psychiatrists and other team members will need to respond by using more structured and clinically meaningful assessments such as remission criteria. Despite on-going debates regarding specific criterion and the inclusion of functional remission to compliment symptomatic remission Hunter (2007, p6) stated that; "Early reports are encouraging in that clinicians, carers and patients appear to value the clarity that remission brings". It is important to add that this was a personal view and not referenced to any previous research.

From a nursing perspective, the manager from an early intervention team contributed to the debate in this supplement. Due to some psychiatrists previously holding modest aspirations for patients with schizophrenia, "Nurses may be pleased that medical colleagues are embracing the concept of remission in schizophrenia" (Gillam, 2007, p7). It is not quite clear what Gillam intimates when he states that if the community mental health nurse and psychiatrist agree that a person is in remission "...an inappropriate switch or cessation of medication might be avoided" (Gillam, 2007, p7). Although initially pleased about remission being embraced, Gillam has concern around remission remaining within the realms of a medical model, unlike recovery; therefore the concern being that psychiatrists focus on achieving remission rather than aiming for recovery. From a primary care perspective Lester & Shiers (2007) wish to challenge the belief that primary care only deal with milder mental illness, and explore the new focus remission may provide for people with schizophrenia and their families in primary

care settings. The sentiment from Lester & Shiers (2007, p10) is that the incentives offered to GPs should encourage them to think beyond the “sick note and procyclidine mentality” shifting to a more health improvement perspective as opposed to disease maintenance. Lester & Shiers (2007) admittedly state that GPs are possibly more prone than psychiatrists to hold on to Kraepelinian notions of inevitable decline for a person receiving a diagnosis of schizophrenia and unfortunately this pessimism generates low expectations for health and social outcomes. Lester & Shiers conclude with challenges to the uptake of remission as a viable concept. They stipulate that finding a language which is understandable to both primary and secondary services, education and training to practitioners on both sides of the interface and shifting ‘hearts and minds’ to acknowledge that for people with schizophrenia that there is hope of remission and recovery would be the primary challenges (Lester & Shiers, 2007).

The penultimate contributor to the supplement is from a service user from the Sheffield User Support and Employment Services (USES) and he remarked that as a concept remission can be viewed as a positive way forward for service users (Cockshutt, 2007). Cockshutt (2007) explains that within Sheffield, service users and many occupational therapists have been working with a ‘remission type model’ for a long time, as they operate within a social model perspective as an alternative to the medical model. Although not clear what is meant by the remission type model this would have preceded the work by Andreasen *et al* (2005). This work was not without issues as Cockshutt (2007) explains frequent problems have been from medical staff that view ambition as a ‘nonstarter’ for those with psychosis. Sadly Cockshutt (2007, p12) reports that; “...people find it difficult to accept that remission and recovery are reality and not just another delusion”. The establishment of remission criteria would encourage more positive attitude from practitioners, service users and families whilst importantly helping people move in the right direction (Cockshutt, 2007). Peter James, a psychologist adds the final perspective in this supplement and takes the opportunity to advocate for the role of psychological interventions for people working towards remission. Whilst James (2007) does not evaluate the benefits or challenges to adopting remission criteria, he jockeys for a position to state that psychologists are best placed to deliver the interventions for people with a diagnosis of schizophrenia. Despite admitting that remission would offer hope and the setting of realistic goals, this remains in the context of therapy. This is perhaps demonstrated here:

“Furthermore, the concept of being ‘in remission’ supports the idea of continued vulnerability to a mental health problem and the need for continued work to maintain improvement after any therapeutic input has ended (in contrast to the complacency of recovery). This is very much the essence of psychological interventions” (James, 2007, p15).

The benefit of going through this supplement in such a manner was to offer a flavour of how the picture is progressing in the UK from different disciplines and also from a service user. This supplement was well distributed and fuelled more activity in the UK, primarily under the impetus from Professor Tom Burns.

In September 2008 a group was convened in Birmingham UK, to address remission criteria, principally addressing the criteria proposed by Andreasen *et al* (2005). The group agreed that the addition of a Social Inclusion Index [SIX] (Priebe *et al*, 2008) would be beneficial as an addition to the original criteria. For the full criteria including SIX see appendix 1. This was seen at the time as possibly the tool to be employed in the UK if remission was deemed a realistic factor in the course of people with a diagnosis of schizophrenia. This meeting fuelled a further three publications. Fear *et al* (2009) addressed the notion of managing schizophrenia in primary care utilising the remission criteria to monitor outcome and stated that until the remission criteria was met; the service user would remain with the secondary mental health services. Overall it is proposed that remission provides the basis for meaningful clinical pathways to be developed and this can also facilitate shared care and social inclusion for people with schizophrenia (Fear *et al*, 2009). Yeomans *et al* (2010) addressed the aspect of the people in symptomatic remission going on to achieve increased well-being and improved functional outcomes. Yeomans *et al* (2010) also illustrated some realistic limitations to adopting the assessment of remission in clinical practice, Box 1:

Box 1. Limitations of Adopting Remission Criteria (Yeomans *et al*, 2010)

* Many psychiatrists do not value standardised measurement of outcomes
* It is not clear whether remission assessment is valuable to patients
* Managers may be unfamiliar with remission or wellness assessment as a measure of service effectiveness
* Relapse has yet to be operationally defined

The final concern is particularly relevant as to most people relapse may be signified when the criteria for remission is no longer achieved, but again there is not a consensus on this. Yeomans *et al* (2010) do identify the potential benefits of remission in Box 2;

Box 2. Potential Benefits of Remission (Yeomans *et al*, 2010)

* It is a standardised outcome measure
* It can be applied swiftly in a clinical setting
* It could help to demonstrate good-quality care
* It could help demonstrate limitations of care

This list given may be viewed as very broad and lacking in specificity which could prove off-putting if wishing to incorporate it into practice. Although, the main concern regarding application to clinical practice may be due to the observation by Yeomans *et al* (2010) that routine outcome measurement is rare. This is not a new revelation as Gilbody *et al* (2002) addressed this phenomenon and found that the majority of psychiatrists do not use outcome measures.

The third paper to be published following the group meeting in 2008, was by Ford (2010), this is an informative paper offering an overview for practitioners within clinical practice. The main point made was that if remission was to be accepted and adopted as a feasible outcome measure in clinical practice, three main aspects that have not yet been addressed require attention, and these are:

- Input and representation from service users and carers to assist in overcoming barriers to implementation of the remission criteria into practice.
- Clarity of language and terminology to allow all stakeholders to feel united in the common goals of remission and recovery.
- The overall concept needs to retain a standardised approach, but with enough flexibility to allow for the unique nature of an individual's recovery.

(Ford, 2010, p25)

The three aspects highlighted above were the main principles which fuelled this present research study.

Remission is generally synonymous with a medical perspective following its introduction to medical conditions a long time before it was seen in mental health. Despite the concept of remission being employed in depression there are challenges to adopting this for people diagnosed with schizophrenia. Symptomatic remission appears to be more readily accepted as

easier to measure, whereas by contrast functional remission is seen to be similar to recovery and a more nebulous concept to define and create criteria for. Research utilising the remission criteria has predominantly addressed the efficacy of medication and heavily sponsored and supported by the pharmaceutical industry. Those concerned more with the well-being of service users and making closer links to recovery are making attempts at an accepted criterion that incorporates social functioning and well-being.

3.6 Chapter Summary:

The literature continues to demonstrate that schizophrenia is a problematic diagnosis to live with for many people and for many reasons. Stigma, discrimination and negative societal views all add to and further compound difficulties already faced by an often complex array of symptoms. Despite lots of views highlighting increased hope regarding recovery for people after receiving such a diagnosis there continues to be a lack of consensus around so many issues. These differences and debates commence at the initial stage of diagnosis and continue throughout the lifespan once a diagnosis of schizophrenia has been bestowed.

A recovery approach is being advocated and utilised by many working with and supporting people with a diagnosis of schizophrenia. But, again consensus cannot be agreed on the specifics, such as a definition. It is however agreed, in most cases, that recovery means different things to different people and the service users' view should be paramount. This promotes a person-centred individualised approach developed upon a collaborative framework. The literature around recovery brings together research and clinical perspectives which throw up debates around whether we aim for clinical, social or personal recovery. Measuring recovery as an outcome can be viewed differently to recovery as a process and this is sometimes not explicit in the papers published.

Remission and its utility have been debated in much the same way as recovery. The idea that people reach a state of remission during the journey of recovery appears to be widely accepted; however it is still a strongly held view that recovery can be achieved without remission ever being reached. Again this causes some disagreements and also impacts on the recovery journey and/or treatment route taken by the service user. Remission was initially utilised to monitor and highlight symptomatic remission for the benefit of demonstrating drug efficacy. With remission similar debates have developed to those in recovery regarding

symptomatic remission and functional remission. There is the danger that the concepts of remission and recovery may tread on each other's toes adding to the confusion. Remission for the purpose of monitoring symptomatic outcome reinforces the Schneiderian perspective as diagnostic criterion is employed for comparative purposes. This in turn compliments a very service-based ideology and a possible move away from a service user based outlook. The concern expressed by some is that psychiatrists concentrate on remission rather than recovery, which would be seen as the bigger picture and more fulfilling for the service user.

Gaps have been revealed within the literature around remission and its relationship to schizophrenia. Primarily, service users, carers and front-line clinicians within the multidisciplinary team had not been consulted with regards to remission and its potential application into practise. This was perhaps not an issue initially as it was psychiatrists who were the principal professional group utilising remission within the barrage of outcome measure principally addressing efficacy or comparison of antipsychotic medication(s).

The notion of 'functional' remission has broadened and developed this concept beyond purely symptomatic remission and in addition the Remission in Schizophrenia Working Group's impetus for introducing remission into everyday practise further encouraged this direction too. Therefore, questions need to be addressed in relation to the potential introduction of remission. The utility and acceptance of remission in schizophrenia would be a primary issue and would address how service users, carers and front-line clinicians understood and choose, or not, to adopt this.

The following chapter addresses the issue of schizophrenia often being grouped or related to other long-term conditions. Also the perspective of schizophrenia and diagnostic overshadowing will be highlighted. This chapter will be an addendum to the literature review.

Chapter 4:

Schizophrenia and Long-Term Conditions

In order to contextualise aspects of schizophrenia in relation to healthcare, it is important to address its relationship with and against other conditions often termed as 'Long-Term Conditions' [LTC's]. Whilst we may initially believe or protest that Schizophrenia has exclusive elements to it, upon exploration we may be able to appreciate similarities with other conditions and also discover how they are managed in a healthcare setting. Some books around the subject of LTC's have included specific reference to mental health issues (Chang & Johnson, 2014), whereas others may mention the risk of developing mental health problems as a consequence of other, physical LTC's (Carrier, 2009). "The term long-term condition, long-standing disorder, chronic illness and chronic disease all refer to those health problems that are prolonged, do not resolve spontaneously, and are rarely completely cured" (Dowrick *et al*, 2005 *cited in* Margereson & Trenoweth, 2010). Although it has to be recognised that the Department of Health (2004) had expressed this view when they stated that medical interventions cannot cure, but can only control chronic disease, with the life of the person altered there is no return to 'normal'. This primarily raised the notion that this chapter, through some exploration could set the scene a little clearer and therefore was required to add further depth to this study.

Despite Davidson (2005) stating that we cannot implement programmes of recovery taken from physical illness there may be some similarities and associations with other LTC's. In an article from 1988, Janice Stevens suggests comparisons can be made between schizophrenia and multiple sclerosis. Stevens (1988) suggests that schizophrenia and multiple sclerosis may belong to a similar class of disorder due to the parallels in clinical course, age of onset, geographical distribution and immunological responses. These biologically determined assumptions by Stevens (1988) are based on the premise that both schizophrenia and multiple sclerosis may both be of infectious or immunological origin; this assumption has created some difference of opinion as neurologists have widely accepted this hypothesis for multiple sclerosis and yet for schizophrenia it has been regarded with some incredulity. The initial difficulty in identifying multiple sclerosis is identified by Sharman (1987) as it begins with intermittent episodes of attacks which are often quite mild. When considering the prodromal phase of schizophrenia the same concern may be offered too. The overall heterogeneity of both conditions is a feature which requires acknowledgement, as individually the

disparateness has been highlighted in both schizophrenia (Moller, 2009) and in multiple sclerosis (Grytten & Maseide, 2005). However, Stevens (1988) identifies that there are some polarised differences especially with regard to the onset of these conditions, as an early onset of schizophrenia would predict a worse prognosis whilst for multiple sclerosis the opposite is the case.

One major social impact for people with either schizophrenia or multiple sclerosis is stigma. However, Grytten and Maseide (2005) highlight many other long-term conditions that have been researched in relation to stigma, such as lung cancer, epilepsy, HIV/AIDS, hearing loss, body weight and diabetes. Given that stigma is attributed to individuals on the basis of difference between them (Kennedy, 2011), then it becomes clear that long term conditions can produce such differences. When considering schizophrenia and multiple sclerosis there are visible attributes in both which contribute to social exclusion, stigma and derision. People with schizophrenia may experience distressing symptoms but often it is the visible side effects of medication which draw attention from the general public; such as muscle stiffness affecting ones gait, restlessness and also movements of the jaw, lips and tongue (Rethink Mental Illness, 2015). For people with a diagnosis of multiple sclerosis there are also difficulties with gait due to spasticity, slurred speech (often leading to people being wrongly accused of being intoxicated), dizziness and fatigue (The National Multiple Sclerosis Society, 2015). Whilst these issues that mostly give rise to stigmatising behaviour from others are not necessarily the same, there may be a shared appreciation of the effects suffered. Grytten and Maseide (2005) identify that people with multiple sclerosis purposefully conceal the condition to prevent being deprived social belonging. Due to the nature of schizophrenia having an impact upon a persons' 'insight', which is often a debatable point, there are differences in the manner of coping. Whilst the concept of insight has been used for a long time in clinical practice, it has by comparison had a shorter history in the research literature (Osatuke *et al*, 2008). This is possibly due to the lack of validity when assessing insight (Mintz *et al*, 2003). When progressing towards recovery people with a diagnosis of schizophrenia have tendencies "...to either integrate their illness experiences into their wider life situation, or 'seal over', or keep them separate" (Thompson *et al*, 2003, p31); these are used for a similar reason as people with multiple sclerosis conceal, to protect themselves from the stigma associated with the disorder. McGlashan and Levy (1977) had highlighted 'integration' and 'sealing over' as typical recovery styles for people with mental health problems and this is primarily for self-preservation.

Many of the long term conditions utilise remission, including rheumatoid arthritis. Aletaha (2012, p116) states that until recently, the concept of remission was “illusionary and far out of reach for rheumatologists”. The definition of remission for rheumatoid arthritis describes a ‘state’ which represents an absence of disease activity; however it has to be acknowledged that to require a complete absence of disease activity would not be realistic for this disorder (Felson, 2012). There is little known about how often sustained remission can be achieved in rheumatoid arthritis and the associated time requirements for this (Aletaha, 2012). This degree of ambiguity is somewhat similar to that associated with remission in schizophrenia, yet at first glance it may appear that disorders with a physical component would be easier to apply remission criteria to. Again, multiple sclerosis would be an example as NICE (2014a) state that the most common pattern of the disease is relapsing remitting, with remission described as periods of ‘stability’. However, giving rise to concern that remission will be followed by periods when symptoms will exacerbate in the form of relapse (NICE, 2014a).

The way forward, postulated by Carrier (2009), for people managing people with long-term conditions in the UK is by utilising;

- Protocols
- Registration/Recall/Review
- Teamwork and Referral Criteria
- Audit

There may be many benefits in this style of approach, especially when managing huge numbers of people; as 60% of adults in England reportedly had a chronic health problem in 2004 (DoH, 2004). Although, this approach could be perceived as restrictive for some people with a diagnosis of schizophrenia who are attempting to continue their recovery outside of secondary mental health services. Again, at first glance we may be guilty of assuming that only people with severe mental health problems are retained within secondary services. Conversely, this approach would ensure that people with many other forms of long-term conditions are in similar positions, with some welcoming this and others perhaps resenting it. A study by Mendel *et al* (2011) addressed the manner in which recommendations of physicians’ influenced and impacted upon the choice that service users made in respect of treatment options. Mendel *et al* (2011, p28) found that; “Almost half of the patients with schizophrenia and more than a quarter of the patients with multiple sclerosis followed their physician’s recommendation and were thereby steered away from their initial treatment

preferences". Whilst this cannot be termed coercive practice there is a strong influence that healthcare practitioners need to be aware of in relation to true collaborative approaches.

In relation to the comorbidity of physical wellbeing and mental health there has been a lot of interest and recognition of neglect, with people with a mental illness having higher morbidity and mortality rates, in relation to chronic diseases, than that of the general population (Robson & Gray, 2007). The Schizophrenia Commission (2012) report that people with schizophrenia die around 15 to 20 years earlier than the general population and this neglect of people's physical health cannot be allowed to continue. 'Diagnostic overshadowing' is a term employed to denote how people with mental illness receive worse treatment for physical disorders (Thornicroft, 2011). Examples of this are offered by the Schizophrenia Commission (2012) as they highlight, the prevalence of type-2 diabetes is 2-3 times higher for a person with schizophrenia, people with schizophrenia who develop cancer are three times more likely to die and people with severe mental illness are twice as likely to die from heart disease. Thornicroft (2011) postulates that physical illness is treated less thoroughly and less effectively in people with mental illness because medical staff are guided by negative stereotypes and often the physical symptoms are misattributed to a mental disorder. Jones *et al* (2008) illuminate the fact that other studies in relation to diagnostic overshadowing have taken place addressing bias or discrimination with other minority groups particularly race, age or gender. Bailey *et al* (2012) also discovered in their study that clinicians had been dismissive of cardiovascular changes of young people with severe mental illness.

However, the recognition that diagnostic overshadowing in patients with mental illness had been under-investigated (Jones *et al*, 2008) has driven the agenda that has developed 'Parity of Esteem'. Based on the notion of equality and fairness, parity of esteem is the principle which addresses equal priority between mental and physical health and this was adopted in law within the Health and Social Care Act 2012 (Centre for Mental Health, 2013). Thornicroft (2011) points out that if such differences in mortality rates were present in a less stigmatised section of society then the outcry against this socially unacceptable impact upon this group would have been heard much more. This remains an issue for practitioners' in secondary and primary care settings as it cannot be disregarded in any area. In relation to comorbid cardiovascular disease in young people Bailey *et al* (2012, p377) state, "As GPs and psychiatrists, our medical training and our role in prescribing give us a unique responsibility to actively intervene to promote physical well-being ... for the thousands of young people with

severe mental illness". Zipursky *et al* (2013) also and importantly state that everybody concerned, including the public, need to recognise that the deterioration that many may experience is not an inevitable part of the illness course for schizophrenia.

It would be erroneous not to be reminded that there are problems with mental illness being viewed as illness like any other. According to Tew (2015, p72) "Psychiatry has been keen to promote, as a normalising idea, the notion that mental distress is an illness like any other". This however, has been warned against due to the fact that identifying people as ill serves to reify differences causing and inflaming the positioning of 'them' and 'us' due to the nature of people with mental distress being labelled as 'other' (Dietrich *et al*, 2006; Read *et al*, 2006). Mills (2015) adds that by considering mental illness as, being like, any other illness may be an attempt to calculate and compare the burden of these disorders alongside other disease categories, which may have an emphasis on financing and resourcing such 'disorders'. Despite the awareness that all aspects of mental health and mental health service delivery are value-laden Mills (2015, p211) asserts that there is a presumption that, "... physical illness and the medicine that intervenes on it is somehow objective and value-free", and this adds to the socio-political complexity. According to Sayce (2000) the social model offers the best option for progress for people with schizophrenia in relation to overcoming discrimination and social exclusion and Sayce (2000) is critical of attempting to place mental illness on a par with physical illness thereby treating it as a disease of the brain.

Chapter 5:

Methodology

5.1 Introduction:

This chapter will address the theoretical framework and conceptual development of this study. Personal reflective accounts will also be utilised throughout this chapter, to personalise what may traditionally be viewed as the “concrete techniques or procedures” (Crotty, 2013, p6) and this will also contribute to an explicit view of the research journey undertaken.

According to Blaikie (1993) the two broad ontological approaches to social enquiry are described as ‘realist’ and ‘constructivist’. These are often simplistically known, or referred to as quantitative (positivistic) and qualitative (naturalistic) research approaches and these research terms are often used to contrast forms of research that emphasises enumeration or produces descriptive or narrative information (Fossey *et al*, 2002). This over simplification can be viewed as a disadvantage in relation to paradigm-based approaches (Grbich, 1999), due to the additional complexity inherent in both approaches. Collins (2010) contrasts the positivist paradigm with alternative paradigms, which include constructivism, interpretivism, critical theory and phenomenology.

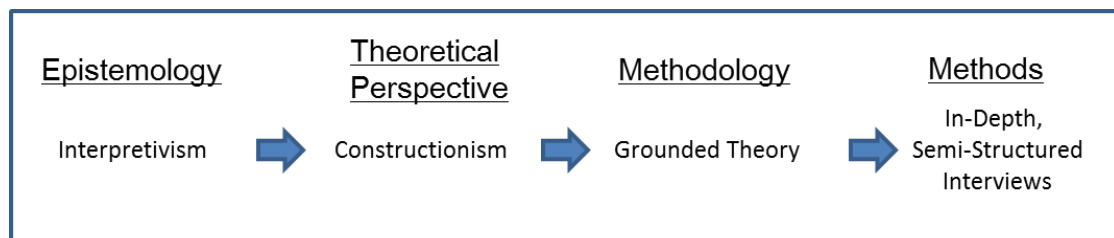
Within the realist ontology the assumption is that social reality exists independently for the observer and the activities of social science (Norton, 1999). Positivism is an example of a paradigm which supports a realist position. Positive is often seen as being an opposite of negative, but in this case positivism relates to what is ‘posited’; it is a given rather than being open to speculation (Crotty, 2013). Despite positivist approaches being employed predominantly in the research papers around remission in schizophrenia; their emphasis is in total contrast to the emphasis and focus of this study. Given the research question being addressed for this study a qualitative approach has been adopted. There is a long history of qualitative methods being utilised within the social sciences (Pope & Mays, 1995). Starks and Trinidad (2007) highlight that qualitative research is enabling for health science researchers, in so much, that researchers can address questions of meaning whilst also examining institutional and social practices and processes. By comparison, to the realist paradigm, within constructivist approaches constructions of reality are formed by individuals (Norton, 1999). This then culminates in the world being viewed as consisting of multiple individual realities

which are influenced by context (Mills *et al*, 2006). The impact of the context bears utmost significance and non-more so than in the use of a grounded theory approach. Progressing from observed instances to the development of a law or model of action, grounded theory is an analytic inductive technique (Grbich, 1999). According to David and Sutton (2011) grounded theory is widely employed in social enquiry and more generally 'grounded' implies that an idea which is either located in context or has emerged from active engagement with the real world of empirical enquiry. The nature of the research question assisted and reinforced the choice of approach employed in this study. The further details in respect of this methodology and its intricacies will be elaborated upon in the remainder of this chapter.

5.2 Theoretical Framework:

The link between common sense and scientific enquiry was emphasised by John Dewey (1937) and the methodological considerations in relation to this study utilise both of these components as this is closely connected to the research question. Within the construction of meaning, emotional and intellectual involvement is expected to play a part, which includes collaborative dialogues between the 'researcher' and the 'researched' within the given context (Grbich, 1999). Constructionism claims that meanings are constructed by humans as they engage with and interpret the world (Crotty, 2013). Within this research study the participants have constructed the meaning of remission for people with a diagnosis of schizophrenia. The participants all had different contexts in which to apply this, resulting in the formation of different realities; as service users and service providers. This subjectivism is far removed from the objectivism found in the majority of research previously performed in relation to remission and people with schizophrenia. The whole premise being that meaning is not discovered, but constructed (Crotty, 2013). A clear, although simplistic, overview of the approach adopted within this study can be seen in Figure 4 below;

Figure 4. Overview of the Research Approach (after Crotty, 2013, p5)



Rather than reporting objective reality, interpretivism is a method of gaining an understanding of the world as experienced by and made meaningful by people (Collins, 2010). As alluded to, this perspective has not been addressed in other research papers on this specific subject area. However, interpretivism is seen as the right fit to extrapolate the data required for analysis in relation to the research question in this present study. Social constructionist approaches take a critical stance towards taken-for-granted knowledge, they acknowledge cultural and historical specificity; agree that knowledge is sustained by social practices; and agree that knowledge and social action go together (Burr, 1995). This therefore indicates that social practice shapes and constructs knowledge. Research or clinical intervention can never be viewed as objective or neutral when it constitutes part of this constructive process and as a consequence

reflexivity in theory and practice is essential (Ussher, 2000). Reflexivity will be addressed later in this chapter.

This visual overview (Figure 4) of the research approach illuminates interpretivism as the epistemological stance and this is consistent with the overall perspective of the study. From the theoretical perspective, Crotty (2013) suggests that constructionism makes the unambiguous assertion that there is no single true or single valid assertion. The nature of knowledge, known and developing, within this field and the inherent inability to separate ourselves from what we know aids the justification for this choice. This will therefore provide the 'lens' through which we view the world. "Different lenses necessitate different assumptions about the nature of the world and the ways in which we should attempt to understand it" (Collins, 2010, p38). The opinion of Charmaz (2008, p402) epitomises the principal drive of this study when stating, "...constructionists see participants' views and voices as integral to the analysis-and its presentation". Gathering and interpreting these views and voices, this 'discourse'⁹, is imperative if we are to comprehend the area being scrutinised. Parker (1992) explains how 'discourses' allow us to see things not really there, and that once an idea has been elaborated in a 'discourse' it is difficult not to refer to it as if it were real. This has been described as an ontological illusion (Harre, 1986). That is, we cannot have direct knowledge of ontological objects because they are perceptual, linguistic and constructive in process which mediates between the object and the knowing. To give an object epistemological status we can call the object into being by prior conceptualisation, talking about it in iteration with others. For some participants, the idea of remission in schizophrenia had not been recognised or appreciated, but by discussing this brings it into existence for them, an aspect which had not been applied fully in previous research on this subject. This demonstrates, as highlighted by Hughes (1980), that there is clearly a connection between the ontology and epistemology issues regarding what exists and how this may be known.

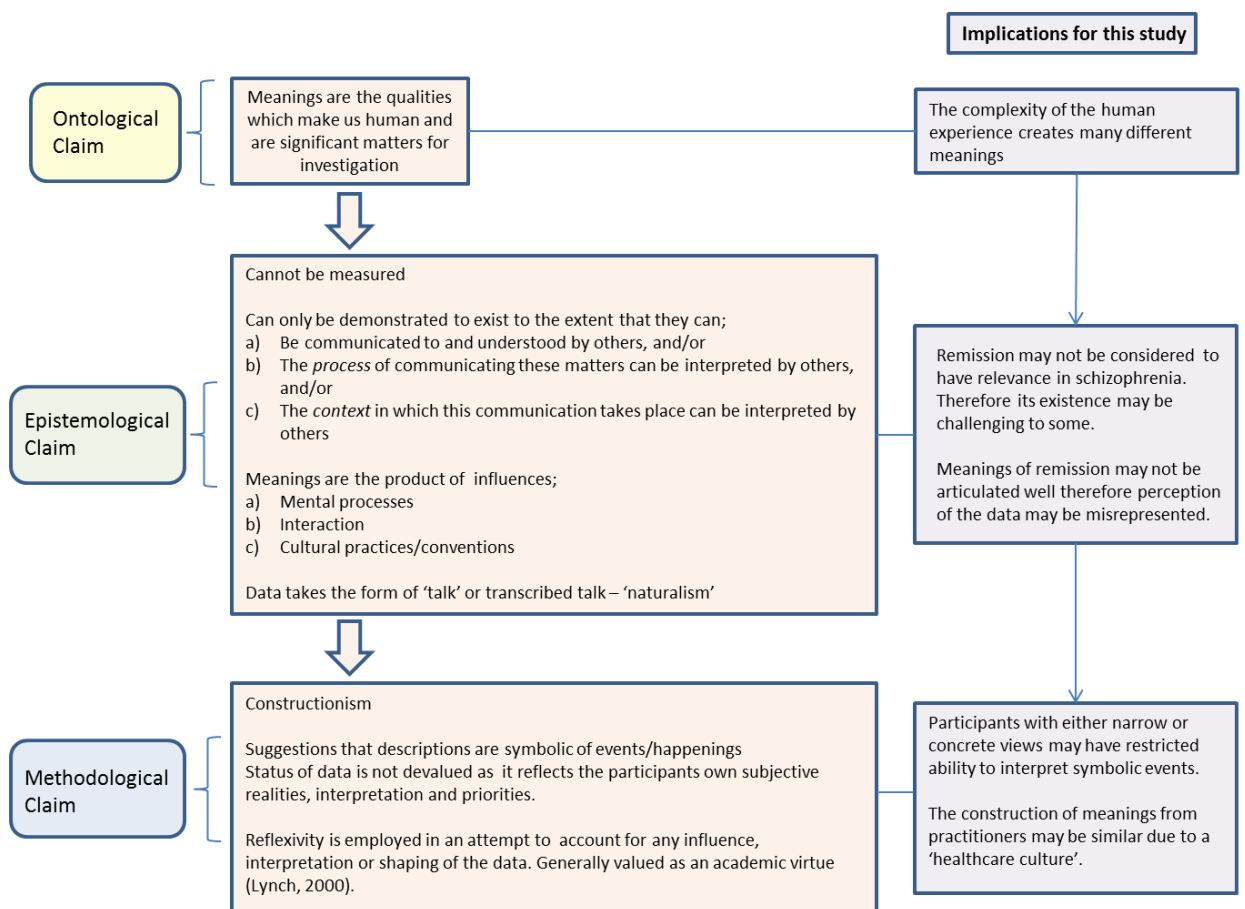
Within the disciplines of psychology, education and nursing, constructivist grounded theory is a popular research method (Mills *et al*, 2006). This may be due to the conversational style and holistic approach which could be employed in each of these disciplines. This methodology seeks to construct theory concerning the issues of importance in the lives of people (Glaser, 1978; Strauss & Corbin, 1998). This is achieved by human interaction (Hutchinson, 1993) and

⁹ Discourse(s) in this sense is referring to language and how people may use language to make the point of what they perceive, much rather than the formal definitions of discourse embedded in versions of Discourse Analysis.

social interactions defining their version of reality (Stern *et al*, 1982), with the researcher having no preconceived ideas to prove or disprove (Mills *et al*, 2006). Within this research study the conceptualisation of adopting remission is held in abeyance by the researcher, so not to influence or predict any version of reality offered by participants.

Figure 5 below illustrates the position of the study in relation to the, ontological, epistemological and methodological concerns. This offers a snapshot of the philosophical framework whilst also making the connection with potential implications for this study.

Figure 5. The Position of the Research Study



Symbolic interactionism is linked to the philosophical perspective of interpretivism according to Hughes (1980) and grounded theory is “Rooted in symbolic interactionism” (Cutcliffe, 2000, p1477). George Herbert Mead is often credited as a founder of symbolic interactionism (Charon, 2001) with Blumer continuing this methodological stance. Blumer (1969) views symbolic interactionism as a down-to-earth approach to human group life and conduct, which derives its interpretations from naturalistic studies. Mead’s belief was that we

need to understand the mind, symbols and self in order for human behaviour to be understood (Charon, 2001). Symbolic interactionism is informed by pragmatism (Collins, 2010), which is a theoretical perspective which assumes that society, reality and self are constructed through interactions such as language and communication (Charmaz, 2006). This therefore resonates strongly around this research study, as the features mentioned by Mead are integral components within this inquiry. Symbolic interactionism also rejects the fundamentals of a research approach which is based on positivism and the search for an objective, measurable truth or reality (Blaikie, 1993). Symbolic interactionism was employed in this study to facilitate the generation of a theory which contributes to understanding the social world of stakeholders in relation to remission for people with a diagnosis of schizophrenia.

Grounded theory philosophically reflects pragmatism and symbolic interactionism (Collins, 2010). This therefore facilitates a strong research design, due to choosing a research paradigm with congruence with the researcher's beliefs about the nature of reality (Mills, *et al*, 2006). Clarke (2005) describes grounded theory as being an epistemologically sound approach, offering empirical approaches to social life through qualitative research. Developed in the 1960's from a background in sociology '*The Discovery of Grounded Theory*' was the original text by Glaser and Strauss (1967). Clarke (2005) describes how grounded theory was further elaborated by Glaser and Strauss and others too including Clarke herself. There has been criticism from some aimed at the increasing complexity of this as a research method, and Melia (1996, p376) makes the comment that this leads to a position where "the technical tail is beginning to wag the theoretical dog". The methodology for this research project follows one of these elaborations in 'constructivist grounded theory'. Kathy Charmaz is the author most frequently referred to in relation to constructivist grounded theory (Gibson & Hartman, 2014). The view of Charmaz, with regard to grounded theory generally;

"consist(s) of systematic, yet flexible guidelines for collecting and analyzing qualitative data to construct theories from the data themselves" (Charmaz, 2014, p1).

Since the early 1990's scholars have moved grounded theory away from the positivist leanings of early versions such as that by Glaser and Strauss (1967), and people such as Charmaz (2000, 2008) and Clarke (2003, 2005) have introduced a more overtly constructivist approach. This constructivist approach, whilst still developing to some extent, continues to embrace some of the ideologies of the work in Glaser and Strauss's original work. The inductive, comparative, emergent and open-ended approaches are some of the aspects retained. The pragmatist

tradition of the dual emphasis on *action* and *meaning* is also retained, whilst in constructivist grounded theory there is increased emphasis upon the flexibility of the method and a resistance to its potential for mechanical application (Charmaz, 2014). Mills *et al* (2006) argue that variations of grounded theory exist on a methodological spiral reflected by the epistemological underpinnings; therefore choice of approach is dependent upon the relationship between the researcher, participant and what can be known. The suitability of a constructivist grounded theory approach is justified for this research project, as it positions the researcher as the author of a reconstruction of experience and meaning, as explained by Mills *et al* (2006).

An interpretation of grounded theory which also influenced this research study is ‘*Situational Analysis*’ by Adele Clarke (2003, 2005). Clarke (2005) offers situational analysis as a more contemporary approach following the postmodern turn. There are differences between this and the former grounded theory approach and Clarke (2005) highlights these (see Table 4).

Table 4. From Traditional/Positivist to Postmodern/Constructivist Orientations to Grounded Theory (Adapted from Clarke, 2005, p32)

<u>Traditional/Positivist Grounded Theory</u>	<u>Postmodern/Constructivist Grounded Theorizing</u>
Positivist/realist	Constructivist/relativist
Dualism of subject & object	Continuities of subjects & objects
Discovering/finding	Constructing/making
Naïve objectivity	Noninnocent subjectivity reflexivity
A <i>priori</i> rejection of contradiction as possible	Representation of contradiction(s) as analyzed/interpreted
Simplification desired	Complexity represented
Seeks to be conclusive	Tentative, opening, jarring, troubling
Authority of author/“expert” voice dominant	Multiple voices, perspectives, intensities, reflexivities
(False/overdrawn) clarity	Ambiguity of representation
Tacitly progressive; linear	Doubtful; reads against the grain
Metaphors of normal curve	Metaphors of cartography
Goal: To delineate a basic social process (BSP) and formal theory	Goal: To construct processes, sensitizing concepts, situational analytics and theorize

According to Clarke (2005, p32) these comparisons identify the “...more problematic *in practice* tendencies”, rather than fully describing grounded theory. Clarke has clearly advanced in a

direction of postmodern/constructivist grounded theory from that of the traditional/positivist approaches once seen. The main characteristics of this movement being the shift away from formalised authoritative orientations and more towards hearing all stakeholders, despite this potentially adding complexity and confusion. The primary aspect of this approach employed within this study is around the use of cartographic mapping for emerging ideas and also to conceptualise developing ideas, examples being the *'Head &/or Heart Debate'* and the *'Situational Map of Service User Transition with Themes Plotted'* both in Chapter 6.

Other theoretical influences that had a diminutive influence on this research study should be mentioned as the nature of social research often invites such complexities. People portrayed as social 'actors' is an example and may be seen in different methodological approaches. Mitrovic (1999) highlights that Habermas, an exponent of the phenomenological approach, believes that both speech and communicative community involve 'actors'. Habermas (1984), with his long-standing interest in pragmatism (Aboulafia, 2002), identifies three ways in which social actors relate to the everyday world; objectively, socially and subjectively. This developed from the 'dramaturgical action' which is one of the four components of the 'communicative action theory'¹⁰ developed by Habermas (1984). This highlights that the relationship between the actors and their world results in different dimensions of understanding which is gained due to these interactions. The relationships between service users and their own (personal) world may be somewhat different to the relationship with the world of mental health services. Erving Goffman (1959) highlights that 'actors' work the system for the enhancement of self. This then points towards the 'teleological' or strategic action highlighted by Habermas. Goffman (1959) identifies that dramaturgical action¹¹ depicts a subjective world where actors' self-presentation is important in order to be visible to their audience. Habermas (1984, p93) reiterates this dramaturgical action stating, "The actor is orientated to his own subjective world in the presence of his public". These considerations are important and extremely relevant in relation to interpretivism and the methodological approach within the research study. Although not typical, this does share some congruence within a grounded theory approach and supports this as a considered choice of the methodological approach.

¹⁰ Communicative action theory identifies four types of actions namely; 'teleological action' 'norm-regulated action' 'dramaturgical action' and 'communicative action' (Habermas, 1984).

¹¹ In Goffman's work the dramaturgical aspect is developed from the metaphor of 'life as theatre' where reality is socially constructed through interaction, resulting in a 'collective conscience' being maintained.

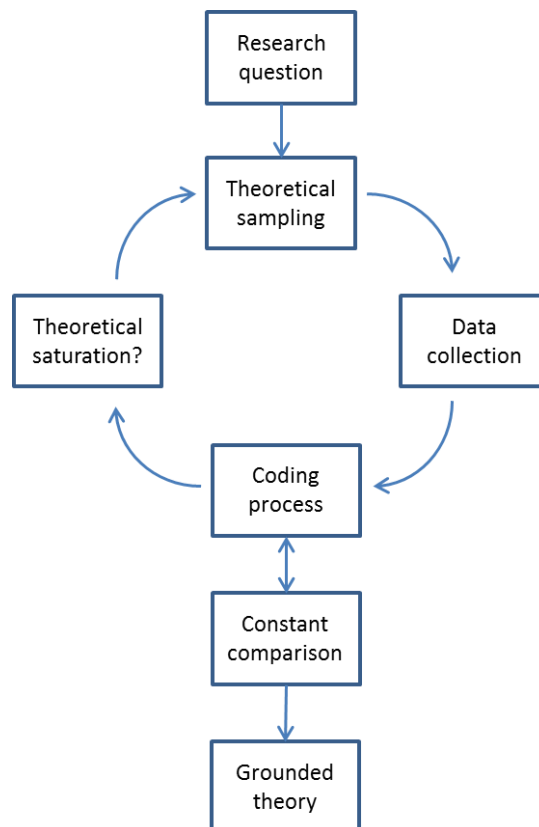
Participants will be offering their perceptions and interpretations of reality and understanding and interpreting reality calls for awareness or consciousness. Searle (1995, p6) states, “With consciousness comes intentionality, the capacity of the mind to represent objects and states of affairs in the world other than itself”. Intentionality is highlighted by Husserl as the fundamental property of consciousness and a prime feature in phenomenology (McIntyre & Woodruff Smith, 1989). We all put things into a context in an attempt to make sense of them and the world, and being conscious, aware and with the ability to contextualise represents intentionality. Understanding any phenomenon requires that we know the facts about that phenomenon, as inquiry necessitates description and likewise description necessitates interpretation (Sandelowski, 2000). The phenomenon under scrutiny in this study is that of remission, within the context of people with a diagnosis of schizophrenia. Searle has been criticised only viewing a ‘single world’ in comparison to other philosophers such as Popper or Habermas who view categorically different worlds (Heidemann, 1999). The points highlighted are of theoretical salience only and it is important to state that this study remains on the last instance a grounded theory study.

This present research study will allow the participants to develop and demonstrate their own interpretation of the world as they see it through their own ‘lens’ without any interference or bias from a potentially overbearing philosophical perspective. Overall, a major difference in grounded theory, as opposed to phenomenology, is that a grounded theory will be developed to have relevance for more specified groups rather than just an individual. Therefore, people with a diagnosis of schizophrenia can be considered in relation to remission and the analysis of its ultimate utility. As the philosophical framework for this study has been highlighted the remainder of this chapter will focus upon the design and the research journey.

5.3 Design:

In practice grounded theory research is not a linear process as some may think (Charmaz, 2014), despite grounded theory guidelines describing the steps and offering this as a path through it (Charmaz, 2006). A grounded theory approach has a strong emphasis on data collection and analysis and this can be seen in Figure 6 below.

Figure 6. Key Steps in Grounded Theory Research Design (Rose *et al*, 2015, p127)



The fieldwork and analysis process is depicted as a cycle consisting of four components within this Figure and this emphasises the iterative process which is crucial to constructivist grounded theory (Rose *et al*, 2015). This is very much in keeping with the close nature of these four elements as postulated by Dick (2003), who stated that data-collection, note-taking, coding and memo writing should be performed simultaneously. This Figure is for illustrative purposes and was not followed with any great precision, although all of the primary aspects of the research design will be discussed and the relationship to this study explored and explained.

5.3.1 Sampling and Initial Data Analysis:

This section will be presented in a manner which combines the aspects of sampling and the initial data analysis. This is due to the nature of a grounded theory approach highlighting the inter-relationship between theoretical sampling and data collection and analysis (Rose *et al* 2015), as seen in Figure 6. According to Charmaz (2014) grounded theory is distinguished from other types of qualitative inquiry due to a method of theoretical sampling.

Grounded theory is the generation of innovative theory from real-life circumstances relevant to the research question, the contributions to knowledge are grounded in the data collected rather than from existing theory (Gasson, 2004). With the research question for this study being;

“Is remission a useful concept to facilitate transition back to primary care for people with a diagnosis of schizophrenia?”

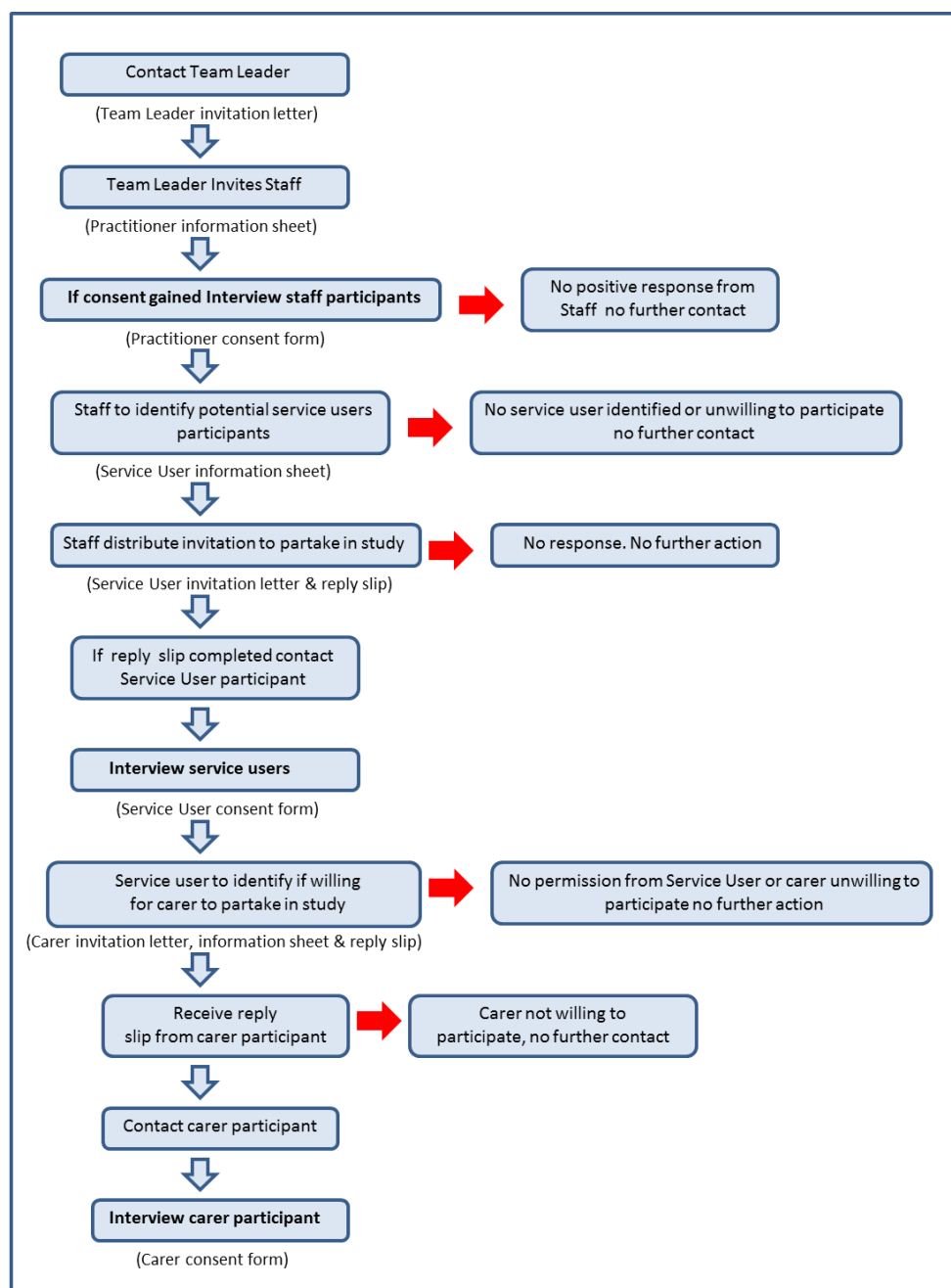
The sample required to generate data around this question needed to be a purposive sample. People were required to have an understanding around the issues being explored and two community Mental Health Teams were selected from which to gain the sample of participants. These teams were selected on the basis that the researcher had awareness of these teams and that it would be a rich area to gain willing participants. As suggested by Morse (1991) it is best to ascertain who will be appropriate prior to beginning interviews. So, despite Lincoln and Guba (1985) stating the characteristics of the participants should not be pre-determined. This study will follow the suggestion from Starks and Trinidad (2007, p1373) that the sample should consist of “Those who have experienced the phenomenon under different conditions”.

This research study was conducted in two phases, with the first phase consisting of practitioners from within these two mental health teams; after this the second phase was to access service users and carers. In keeping with this methodological approach, and in comparison to other methods, this would offer the participants a privileged voice (Fossey *et al*, 2002). This voice, for all participants, was afforded through the data collection method of in-depth interview utilising a semi-structured format. Charmaz (2014, p85) suggests that interviews are a good fit with grounded theory approaches due to similarities which include them both being “open-ended yet directed, shaped yet emergent and paced yet unrestricted”. The interviews of practitioners, in the first phase, allowed for the modification to the interview schedules for the second phase. In particular, the language employed and links between

recovery and remission. This enabled a more objective positioning and less influence from the researcher during the interviews.

The actual process of gaining access to the participants within this study can be seen in Figure 7 below; the 'Accessing Participants Algorithm'. The initial contact with the Team Leader was followed by a quick introduction at the respective team meetings. This briefly introduced the research study and raised awareness in preparation for the practitioners to decide whether or not to partake. A selection of the forms, listed in the algorithm and utilised in this study can be viewed in Appendices 7-13.

Figure 7. Accessing Participants Algorithm



The manner in which the sampling was performed adheres to the notion of theoretical sampling as advocated by Glaser and Strauss (1967). The goal of theoretical sampling is to seek pertinent data and this assists in the emerging theory. This study followed the suggestion by Hodkinson (2008) in commencing a discrete analysis stage as soon as the initial interviews had been transcribed. The analysis being concurrent with data collection is a central feature of grounded theory (Duffy *et al*, 2004). This is also seen in the key steps in grounded theory approach (Figure 6, p85) by Rose *et al* (2015).

In phase one the participants utilised were practitioners, all qualified in their respective professions. The table below highlights the participants by their respective teams, professions and gender (total = 9).

Table 5. Participants for Phase One

<u>Team 1</u>	<u>Team 2</u>
Social Worker (F)	Social Worker (F)
Mental Health Nurse (M)	Mental Health Nurse (M)
Psychologist (F)	Psychologist (F)
Occupational Therapist (F)	-----
Consultant Psychiatrist (F)	Consultant Psychiatrist (F)

As can be seen in the table of participants there is a good spread in relation to professional background, but a higher ratio of female participants. This is due to the selection method, which was voluntary and could not be predicted by the researcher. The make-up of the participants for phase two are highlighted in table 6 below.

Table 6. Participants for Phase Two

<u>Team 1</u>	<u>Team 2</u>
Service Users (F) x3	Service Users (F) x1
Service Users (M) x1	Service Users (M) x5
Total = 4	Total = 6
Carers (F) x1	Carers (F) x3
Carers (M) x3	Carers (M) x0
Total = 4	Total = 3
Combined Total = 8	Combined Total = 9

Whilst the sample was not gender significant, the gender is identified in order to demonstrate that there was representation from females and males as service users and carers. The total participant numbers for the study were; Phase One = 9, Phase Two = 17 giving an overall total of 26. Which resulted in 13 from each team, this turned out to be a fortuitous balance as the selection was random as participants had responded voluntarily.

The value of transcribing one's own interview recordings assisted greatly in this process and enabled the commencement of the data analysis. "As we learn how our research participants make sense of their experiences, we begin to make analytic sense of their meanings and actions" (Charmaz, 2006, p11). Whilst performing this process it was possible to gain a clearer perspective of whether more data was required. One issue that became very apparent in this process was that the initial practitioners that had been interviewed disclosed a lot about the medical perspective and their thoughts on this, yet there was no representation at this time from any medics. It was at this juncture, through the use of theoretical sampling that another brief contact was made to the respective team leaders to ascertain if the medical staff had been included or felt that they were eligible to partake in this research study. Theoretical sampling proposes that participants are not only selected according to the criteria determined by the research purpose, but also determined by the unfolding theorising (Miles & Huberman, 1994), this is also seen as pursuing analytically relevant distinctions (Emerson, 1981). As a consequence two consultant psychiatrists, one from each team, consented to be interviewed and were able to contribute to the overall balance of this study. This is an example of the interplay between analysis and data collection, as can be seen in Figure 8 below.

Figure 8. Simplified Illustration of Interplay Between Analysis and Data Collection

(Hodkinson, 2015, p86)

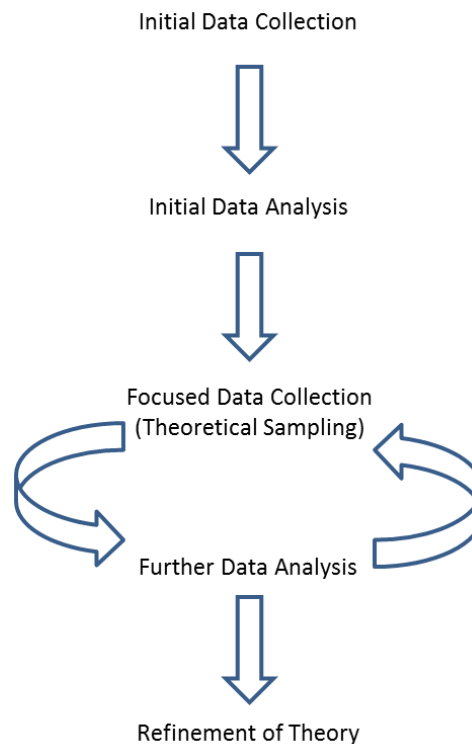


Figure 8 illustrates how this study adheres to theoretical sampling to gain the most from the sample and data analysis. Initial analysis from phase one (practitioners) then informed the second phase when service users and carers were interviewed to collect data. This process was repeated until a state of data saturation was believed to be achieved. Mason (2010) highlights that if there is to be fidelity to the principles of qualitative approach the concept of saturation should generally be followed. Whilst the process of data collection (via interviews) had been progressing, analysis in the form of writing on-going memos and coding had continued. The point then became apparent that further collection of data was not going to significantly add or contribute to the development of the grounded theory; this is the point of saturation in accordance with Gibson & Hartman (2014).

5.3.2 Data Collection; Interviews:

The importance of the interviewing process cannot be underplayed and as the method of data collection for this research study a lot of preparation and thought was placed on it. Simplistically the process involves an interviewer and an interviewee discussing specific topics in depth, in order to motivate the interviewee to share their perspectives (Hennink *et al*, 2011). Utilising a semi-structured approach within the interviews remains congruent with a grounded theory methodology as it allows the researcher to maintain some consistency, whilst at the same time facilitating a degree of flexibility in the sequencing and in-depth exploration (Fielding, 1994). Whilst allowing for exploration and clarification of comments made by participants, a semi-structured approach also allows the interviewer to utilise prior knowledge during the process (Rose, 1994). As the prior knowledge of the researcher could not be discounted totally there were times during the interview process when experience and knowledge facilitated further disclosure from participants in both phases of the study.

Offering some theoretical account of social life is the task of the social scientist according to Hughes (1980). This theoretical account needs to be built throughout the study. Within constructivist grounded theory the mutual creation of knowledge by the viewer and viewed is recognised (Charmaz, 2000). This collaborative approach to theory generation is very much in keeping with the study and the area of mental healthcare. Humans have a tendency to explain their social conduct using the ‘vocabulary of action’ (Hughes, 1980, p92). The emotive and sometimes provocative content contained within the data generated from the interviews in this study is testament of this. However, Silverman (2013) warns that the data from interviews needs to be analysed correctly in order to offer the best representation of the participant. Silverman (2013, p54) also adds that many interviewers lose sight of how “sequence is consequential for what we say and do”. Without the acknowledgement of this sequence value may be reduced from the data generated in the interview. Purely using answers from the interview to substantiate or support claims made by the researcher (Silverman, 1980) would also be erroneous and not in keeping with the methodology of this research study. There are strengths and limitations to utilising in-depth interviews and Hennink *et al* (2011) summarise these in the table below:

Table 7. Strengths and Limitations of In-Depth Interviews

<u>Strengths</u>	<u>Limitations</u>
Gain information on people's personal experiences Useful for sensitive topics Gain in-depth information	One-to-one interview, No feedback from others Need skills to establish a rapport, Use motivational probes, Listen and react to interviewees
Get contextual information React to interviewees	Flexibility needed to change topic order in interview guide Following interviewees story
Get personal stories, experiences of people	A lot of transcription is needed

(From Hennink *et al*, 2011, p131)

Following consideration of the above it was decided that semi-structured interviews would be the best option to generate data for this study. Duffy *et al* (2004) identify that in semi-structured interviewing the interviewer requires more focused information and uses specific questions to gain this using a style which opens discussion, listens and then uses prompts to guide the participant. The interview guide would generally include 'introduction, opening questions, key questions and closing questions' (Hennink *et al*, 2011). The information sheet given to participants provided some of the introduction so the interview guide employed moved promptly into the opening questions, following a short preamble. Questions from the interview guide are detailed below:

- What is your general impression of the term remission, outside of the field of mental health? *Have you heard of this before? What images does this conjure up? In what context do you think remission applies to patients/service users?*
- Do you feel that this (the concept of remission) could be applied in the area of mental health? *Have you heard of it being applied in the area of mental health previously? Broadly speaking do you think remission is suited to the area of mental health?*
- Do you think remission may be applied to or beneficial to people with a diagnosis of schizophrenia? *How do you think that using the concept of remission may benefit people? Have you read or heard anything about remission in schizophrenia?*
- How do you presume people (practitioners, service users & carers) may be able to utilise the concept of remission? *Do you think the concept could be embraced? Is there any group or profession that may use it more than others?*
- Do you foresee any issues/barriers to introducing such a concept into clinical practice either personally, locally or nationally? *Would you feel comfortable discussing remission with service users and carers? Are you familiar with any tools or measurements used to assess remission?*

The questions in italics were used to elicit further information from participants and depended upon the response or ability to answer the initial questions. At the end of each interview opportunity was given for the participants to ask questions. This provided some fruitful insights as it allowed the participants to offer their perceptions and perspectives and say something which was not necessarily asked of them in the interview. As mentioned the language and responses offered from the practitioners here prompted the direction of the questions for the interview guide for phase two.

The modified interview guide for phase two is detailed below; the questions here are aimed at service users. The version for carers was worded slightly differently, but only to reflect that they were not the person with a diagnosis of schizophrenia and were the person caring rather than receiving care.

- What things do you need to do, or to be in place for you to stay well?
- What would your thoughts be if you were deemed well enough to be discharged back into the care of your GP?
- Who is involved in deciding if you are well or not?
- What does the word remission mean to you? *Generally? In relation to mental well-being? Do you consider yourself to have been/or presently be in remission? Did you or anybody else use the term remission?*
- What kind of things/areas does your care coordinator look at when carrying out assessments/questions? *Is there anything you feel this fails to cover or misses?*
- Do you still see your GP from time to time or do mental health services cover all of your needs?
- What might be your idea of the 'perfect scenario' if we had a magic wand?

Personal insights and reflection with regard to interviewing will be detailed in the section on the research journey. As interview transcripts were being developed note-taking and memo-writing commenced, Lewins (2015) identifies that this is an important aspect of the management and continuity of analysis and this will be explored further.

5.3.3 Formal Data Analysis:

Qualitative analysis involves working with rich data in an intensive manner (Bazely & Jackson, 2013). Whilst there are computerised methods of analysing data, with programmes such as NVivo, all of the data analysis for this study was performed manually by the researcher. Hennink *et al* (2011) bring the aspect of data analysis into context with a grounded theory methodology by stating;

“Grounded theory provides a set of flexible guidelines and a process for textual data analysis that is well suited to understanding human behaviour, and identifying social processes and cultural norms”
(Hennink *et al* 2011, p206).

The decision to analyse the data manually developed as this data was being generated. Analysis began in phase one whilst key points that were developing into themes were written onto flipchart sheets (see Appendix 14). During phase two the amount of data and material made this method increasingly difficult and the computer was utilised combined with word-processing software. Transcripts were colour-coded as themes emerged and used for further analysis deeper into the process. Figure 9 is an example of the initial coding of data.

Figure 9. An Example of Initial Coding of an Interview Transcript

Excerpt from interview with participant S5510

22 *OK, so just hypothetically what would your thoughts be if you were deemed well enough to be*
23 *discharged back into the care of your GP?*

24 *Hmmm ... I don't know if I would like that, for the simple reason I like to keep, I am a very neat and*
25 *tidy person I like things to be compartmented so going back to me GP to discuss mental health*
26 *problems errrr would take up the time that I like to spend with him, for instance when I go, I don't*
27 *go to my GP very often (right) for the simple reason because I have a mental health problem I think*
28 *to myself that he'll be looking at me err thinking to himself "oh she's errm she's got a mental health*
29 *problem and everything's like a big drama" so I have to be absolutely dying before I go to my GP for*
30 *anything (yeah) ...*

Excerpt from interview with participant S5510 (highlighted during coding)

22 *OK, so just hypothetically what would your thoughts be if you were deemed well enough to be*
23 *discharged back into the care of your GP?*

24 **Hmmm ... I don't know if I would like that, for the simple reason I like to keep, I am a very neat and**
25 **tidy person I like things to be compartmented so going back to me GP to discuss mental health**
26 **problems errrr would take up the time that I like to spend with him, for instance when I go, I don't**
27 **go to my GP very often (right) for the simple reason because I have a mental health problem I think**
28 **to myself that he'll be looking at me err thinking to himself "oh she's errm she's got a mental health**
29 **problem and everything's like a big drama" so I have to be absolutely dying before I go to my GP for**
30 **anything (yeah) ...**

As this method was not compatible with the data of phase one, this data was also later transferred onto a computer via the same method. With this compatibility now resolved the data from phase one and two could be compared with much more ease. Examples of this comparison are to be found in Chapter 6 (Findings and Discussion) of this thesis.

When analysing the data the grounded theorist creates 'qualitative codes' by defining what is seen in this data (Charmaz, 2006). This is the method simplistically referred to as 'coding'. Coding may be seen as the 'critical link' between data collection and their explanation of meaning (Charmaz, 2001). According to Saldana (2013, p3) a 'code' is;

“often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based visual data”

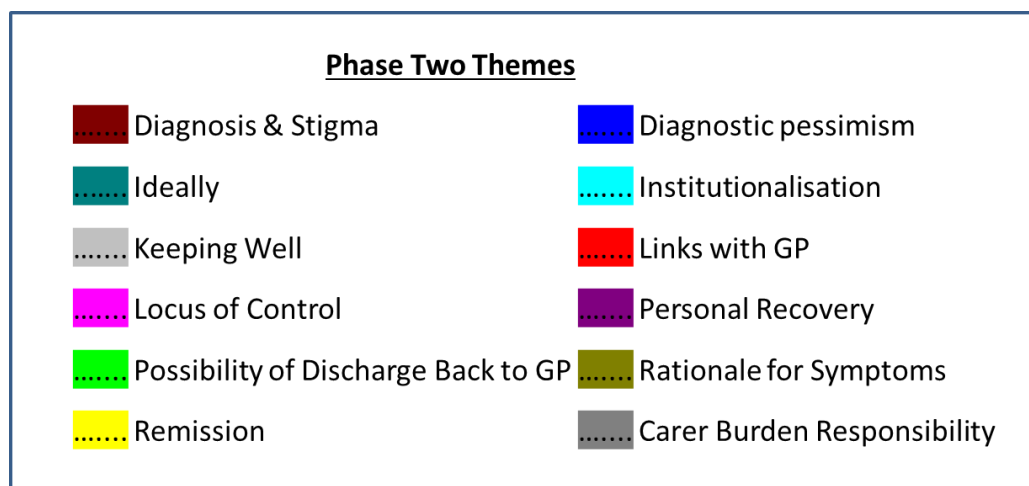
Charmaz (2008) points out that we can gain an interpretive understanding of the phenomenon whilst accounting for the context. There are differences of opinion with regard to how coding may evolve, with Glaser and Strauss (1967) advocating the format of Open coding, Axial coding and Selective coding. Saldana (2013) advises careful consideration when choosing the coding method adding that this needs to be based on the research question to enable the best open coding outcome. Preparation is crucial and to enable the interview transcripts of this study to be traced throughout all of the stages of analysis participants were given an identification code and all interview transcripts were individually line numbered. Each time data was moved to form codes/themes these two identifying components were present. This was especially pertinent for phase one when moving data manually onto flipchart paper and can be seen in Appendix 14. Saldana (2013) recommends the use of coding methods whether employing either 'classic' (Glaser & Strauss, 1967) or 're-envisioned' (Charmaz, 2006) grounded theory.

Following a constructivist grounded theory approach the coding format suggested by Charmaz (2006) was adhered to in this study, although Saldana (2013) offers caution regarding mixing potentially incompatible formats advising to choose one purposefully. The format selected by Charmaz has four stages of; 'Initial', 'Focused', 'Axial' and 'Theoretical' coding. Charmaz (2006) states that line-by-line coding assists to fulfil the criteria of 'fit and relevance'. Figure 9 is an example of using individual line numbering to assist in this and also illustrates the highlighted text as part of the initial coding process. Charmaz (2006) highlights that initial grounded theory

coding should adhere closely to the data and as a consequence can prompt people to identify where data is lacking; such as lack of a medical perspective in phase one.

Further analysis by way of ‘focused coding’ offers a more directed, selective and conceptual approach (Glaser, 1978). Without sacrificing any detail contained within the initial coding focused coding advanced the analysis as suggested by Charmaz (2014). Recognition of key concepts became more apparent at this point and the theoretical direction progressed quickly. This allowed the codes to become, or at least appear, more stable. The figure below illustrates the colour coding utilised in phase two to identify the themes.

Figure 10. Colour Coded Themes for Phase Two



At this stage ‘axial coding’ was utilised and this assisted in the formation of sub-categories and the dimensions of the codes/themes further acknowledged. This stage allows the fractured data to be brought back together to enable coherence (Strauss & Corbin, 1998). An example of this analysis can be seen in Chapter 6, Figure 12 ‘Representation of Head and Heart’. This is supported by Charmaz (2014, p148) who reports from personal communication with Adele Clarke that she views axial coding as a way to elaborate a category by utilising diagramming. The following stage of ‘theoretical coding’ is seen as being generally more sophisticated. Elliott and Jordan (2010) state that a common error in grounded theory may be not moving data beyond the narrative stage, to avoid this they suggest theoretical coding as this succeeds in generating theoretical conceptualisation. Charmaz (2014) states that if used wisely theoretical codes can be employed to specify relationships between the categories developed. Comparisons between the themes in both phases and the development of conceptual maps assisted in this development of theory for this study. It is stated by Corbin and Strauss (2008)

that our ability to demonstrate the inter-relationship between these themes and concepts leads towards the development of theory. Concept mapping is a very useful method for assisting in the organisation and translation of complex qualitative data in a way that advances knowledge about the topic and practical implications (Johnsen *et al*, 2000). Throughout this study illustrative, or cartographic representation has been utilised to graphically represent some of the theory and/or notions into a more simplistic or understandable format. Fossey *et al* (2002) advocate this conceptual level process and exploration of meaning as being more meaningful than simply just coding the data. . In order to add clarity around the process of coding undertaken Table 8 (below) illustrates the aspect of coding and its interpretation and application.

Table 8. Interpretation and Application of Coding Typology

Coding Typology (Charmaz, 2006)	Interpretation and Application
<i>Initial</i>	Generation of themes/codes from the initial transcription. Finding the main aspects, in some cases reflecting the primary topics covered at interview.
<i>Focused</i>	Codes generated with more depth and significance from initial coding, becoming more selective and conceptual in appearance. Generated during repeated analysis in exercises, seen for example in Appendix 14.
<i>Axial</i>	Codes become more elaborate through the use of diagramming and cartographic representation, see Figures 11, 13 & 15 for examples.
<i>Theoretical</i>	More sophisticated conceptualisation is demonstrated in theoretical coding through the analysis of the relationships between the codes, see Figures 12, 14 & 20 for examples.

A grounded theory approach strongly advocates the method of constant comparison and theoretical sensitivity, throughout the data analysis and coding process this was adhered to. Glaser and Strauss (1967) identify four stages to the constant comparative method. The four stages are;

- The comparison of incidents within categories,
- The integration of categories,
- Delimitation of the theory, and
- The writing of the theory.

Examples of the constant comparative method can be seen within the discussion and findings (Chapter 6). This follows guidance from Elliot and Jordan (2010) who emphasise the importance of re-examining data and identifying links between concepts so that the relative

positions appear in the emerging theory. The use of the constant comparative method contributes substantially to methodological rigour (Cooney, 2011) and this is concerned with 'best practice' in research (Fossey *et al*, 2002). Theoretical sensitivity and coding are also closely linked, with theoretical sensitivity being the ability to comprehend and explain phenomena in abstract terms to demonstrate relationships (Charmaz, 2014). Gibson and Hartman (2014) state that the concept of theoretical sensitivity is often misunderstood, but the key to it is the attitude of being open. Through the use of the detail offered and comparisons made resulting in conceptual maps the notion of being 'open' is evident within this study.

Another component of being open and practising theoretical sensitivity within a constructivist grounded theory approach is that of reflexivity. The reflexive stance informs how the researcher conducts the study, relates to the participants and represents them in the written report (Charmaz, 2014). Reflexivity is inherent throughout this study as the position of the researcher is openly disclosed whenever and wherever the opportunities for this arise. In respect of investigator triangulation with the codes generated, this was achieved within the process of supervision. Codes and reflections of these codes were discussed at supervision sessions to avoid them being solely at the whim of the researcher. As a consequence justification was provided for each of the codes generated through the research and compared against the data generated within the transcripts.

Conflicting advice has plagued grounded theory in respect of the application of prior knowledge (Morse, 1994) and this also includes previous experiences. According to Holton (2007) there are sources of prior knowledge other than literature for example accumulated experiences and preconceptions arising from the persons discipline or profession. This study would not have come about if it were not for the prior experience of the researcher which raised concerns regarding the issue being investigated. Also the relationship with all of the participants was enhanced due to the previous experience of the researcher. Lincoln and Guba (1985) stated the admission of tacit knowledge offers more opportunity for the researcher to apprehend and adjust the phenomenon in context, whilst also enabling the emergence of new theory. This is very much the sentiment of Charmaz (2008) who believes that reflexivity is central to grounded theory, but does not believe that prior knowledge and experiences should be either discounted or bracketed from the study. Prior knowledge and experience contributed to the ability to reflect upon the research process and journey throughout and this can be seen explicitly in the next section.

5.4 Ethical Considerations:

Official ethical clearance for this study was provided in the first instance by the University of Northumbria at Newcastle and then by the Research Ethics Committee at the National Research Ethics Service. Within the study all considerations have been made to apply an ethical approach to this research.

Establishing safeguards that protect participants is the primary aim with the study as suggested by Bloomberg and Volpe (2012). This includes concern with regard to informed consent, confidentiality, risk-benefit ratios and the rights and welfare of the participants (Murphy *et al*, 1998; Houghton *et al*, 2010; Bloomberg & Volpe, 2012). A social science researcher therefore, is responsible for informing and protecting participants (Bloomberg & Volpe, 2012). In this study appropriate paperwork such as 'information sheets', 'Invitations with reply slips' and 'consent forms' were utilised and had gained approval prior to their use (see Appendices 6-11). All participants were reminded verbally about their rights prior to the interview; reminding them of their right to withdraw without recrimination should they choose. Polit and Tatano Beck (2006) identify that informed consent allows the participants to play a role in the decision making regarding their on-going participation.

All interview materials, including audio and written materials were dealt with sensitively and utilised individual identification codes to maintain confidentiality on all corresponding materials. Signed consent forms were also kept by the respective team leaders as on-going proof of consent. An honorary NHS Trust contract and research passport was granted and used by the researcher for the time spent collecting data within the trust. These ceased to be effective after data collection and once the 'research close-down report' had been returned to the research and development unit for the NHS Trust sites.

During all interviews there was an awareness of the risk-benefit ratio. This draws attention to weighing up the benefits and potential harm (Orb *et al*, 2001). The experience of the researcher in this field may lead to the idea that the interviews would not cause undue distress for the participants, but this cannot be taken for granted. As mentioned earlier some interviews became emotional and during these interactions it was assessed whether the benefit of the interview was going to outweigh the harm to the participants as suggested by (Houghton *et al*, 2010). On both of these occasions the participant was asked if they were

comfortable to continue in view of the upset it appeared to be causing, on both occasions the response was that the participants were more than happy to continue, with one disclosing how grateful he was to be given opportunity to recount his story. This was reported verbally to the care coordinator after the interview in case there were repercussions or after effects, again on both occasions there was another person present during and after the interview was completed.

The role of the researcher is imperative to safeguard the participants and therefore awareness needs to be acknowledged with regard to the ethical theory applied. There may be a dual role or conflict of interest between professional interest and the study topic (Houghton *et al*, 2010). This was not particularly the case in this study, however terms derived from linguistic studies may explain the position of the researcher. The terms 'Etic' and 'Emic' were coined by Pike (1954) and are used to denote an observer who is not in the culture (Etic) and an insider who is a member of the culture (Emic). The researcher would very much embrace the emic position in this study and an awareness of the influences this may have needed to be addressed. This may be a superficial explanation to make the point, but Nelson and Prilleltensky (2010) state the relevance is more in keeping with cultural research, but nevertheless define an 'insider' 'outsider' position. With people with a diagnosis of schizophrenia suffering prejudice from other aspects in their life, careful attention needs to be paid to this in the research field.

Overall, a deontological ethical theory was applied. As opposed to a utilitarian or consequentialist ethical theory which assesses actions in terms of outcomes or consequences (Murphy *et al*, 1998). Deontology serves to demonstrate respect for people by never treating them solely as a 'means', not violating autonomy and also prohibiting exploitation (Macklin, 1982). This theoretical approach corresponds with the research ethics and elements of healthcare too. Nolt (2015) states a weakness of deontology concerns the problem of conflicting demands, but it would not be envisaged as a problem in respect of this study.

5.5 The Research Journey (Reflections):

Although the conception of the research idea occurred a while ago following a working group in 2008, this section will be a record of the specific research journey undertaken since the study itself commenced. Whilst there is a clear and precise format to the research process this section will report on recorded incidents and reflections throughout the research journey.

It would be fair to say that the whole research journey has been illuminating for many reasons. The first dilemma came to the fore once the format of the study had been set and concerned phase one; the collection and analysis of data from practitioners. The dilemma centred on the issue of ethics and convenience. The study had gained clearance from the University of Northumbria ethics board. There was an acceptance of the requirement that due to utilising service users as participants in phase two clearance would be sought from a Regional Ethics Committee (REC). However, phase one could be 'badged' as a possible service evaluation, which would not require clearance from the REC and the study could commence earlier. There were issues to consider in relation to this and to avoid making a rash decision, which may impact negatively later in the study; some consideration was afforded to this. Identifying phase one as a 'service evaluation' would mean;

- A potentially reduced or 'narrow' focus
- Potentially reducing options for publication (different readership)
- Would I be 'true to myself' as a researcher (taking an 'easy option')
- Convenience – it would be quicker to avoid the ethical 'red tape'

By comparison, identifying phase one as qualitative research would mean;

- Fuller, richer and more informed
- Wider options for publication
- Despite ethical 'red tape' it would be viewed as good practice

Overall the decision was to demonstrate fidelity to the research methodology throughout the full study. Personally, this would feel as though corners had not been cut and although it would take longer to gain ethical clearance the full study could gain ethical clearance in one-step.

In keeping with the methodology and in particular utilising a reflexive approach note-taking (memos) and reflections were kept throughout the process. Cooney (2011) identifies that grounded theorists utilise memos to record methodological and analytical decision rather than utilising an audit trail. The build up to the first interview was anxiety provoking due to the partial handing over of control. This feeling came about as the team leaders were given responsibility to contact the potential participants. The progress of the study had been taken from the researcher at this point whilst awaiting contact for potential participants. It was also up to the team leaders how they articulated the information to recruit participants. Following the first interview with a mental health nurse the following notes were made;

“First Interview:

3.12.12 – Overall feeling, it went well. Duration 42 mins – no recording mishaps.

During the interview I was mindful of links to theory and experience from my practice – this enabled me to ‘see’ the issues raised by the participant...

Feelings – Excited to hear language pertinent to study – satisfied I had commenced generating data – relief procedure was going well and yielding quality data (although not listened back or transcribed yet).

Thoughts – Must let participant use his words and not suggest or pre-empt too much. ‘Seeing’ (identifying) links to theory and practice experience prompting further questions – are they pertinent? Keep on track!

Result – Added questions gained more valuable data – do I use same questions again or personalise each interview a little?

Considerations for next interviews –

Do not ask multiple questions ... keep it simple

Keep it as succinct as possible when making points and asking questions

Do not talk-over people, try not to cut beginning or end of dialogue of participants.”

There were a few challenges during interviewing, one participant in phase one felt ill-prepared and mentioned that they were disappointed not to be able to offer more information. This was challenging as the interviews were not designed to make any of the participants feel uncomfortable or under scrutiny.

In preparation for phase two, the same feelings returned in relation to recruiting willing participants, overall the team leaders and team staff were useful but in the wait the following diary entry was made;

“Recruitment of participants for phase two:

This relied on team leaders and care coordinators understanding what was required & then being able to put that across to the service user & carers before I was able to approach them.

Not knowing what the care coordinators said to potential participants was difficult as there were some refusals to participate, also not knowing what the care coordinators understanding or bias was also created some anxiety”

Some care coordinators had thought that the service user and carer both needed to consent, whereas the reality was if the service user or carer consented then I would interview the person consenting and respect the choice of the other person. There were some cases when this occurred from both perspectives and no issues resulted.

Only one service user consented to being interviewed without being recorded. This was not problematic as permission was gained to take notes throughout the interview and due to the level of distraction the participant experienced this was not one of the longer interviews. On two occasions the carer wished to be interviewed at the same time as the service user. This created additional issues at the transcription stage, but was overcome due to using underline and colours to decipher the different participants. Analysis then took the same process as all other transcripts.

Despite all attempts to offer service users and carers a voice during this study, there are some that would not regard people with mental health issues and in particular schizophrenia as reliable and trustworthy participants. Potential bias may also be a consideration as the participants may only represent a “subset of all persons meeting the schizophrenia criteria” (Dworkin, 1992, p46). However, the participants within this study are representative of the population being investigated, as people with a diagnosis of schizophrenia presently involved within secondary mental health services. People who have recovered and no longer require input from mental health service, who had a diagnosis of schizophrenia at some time are not part of this study. However, the point made by Dworkin (1992) that some ‘patient samples’ may be appropriate for treatment outcome studies resonates with previous research around medication efficacy and its relationship with remission. The comments by Carpenter and Hanlon (1986) regarding the difficulties establishing a rapport with a person with psychosis may have spurred Dworkin (1992, p60) into stating that “The decision about the appropriateness of interviewing a psychotic patient is formidable”. The interviews conducted in this study were all fruitful and relevant with some extremely articulate responses which

were able to offer a wealth of data. On a couple of occasions the experience was cathartic in nature and service user and carers being interviewed cried and laughed, at appropriate times as they recounted their stories. This offered another potential challenge; although not problematic it was a consideration all the way through the interviews in phase two. As a mental health nurse with over thirty years of experience there may have been the temptation to offer therapeutic intervention. During contact with participants, for the purpose of interviewing, communication skills were utilised to facilitate a good rapport and to facilitate a degree of disclosure. The interview schedule was predominantly adhered to and participants were not encouraged to state anything they felt uncomfortable about or anything that may be construed as voyeuristic and off the point. This was stated clearly and feedback was given to the care coordinator where necessary.

The decision to personally transcribe all of the interviews conducted was taken and proved valuable at the commencement of data analysis. Easton *et al* (2000) point out that you can never assume that an interview has been transcribed correctly if performed by somebody else. Due to the nature of interviewing service users and carers simultaneously on a couple of occasions the format of transcription could be standardised and understood. The biggest advantage during transcription was the close scrutiny paid to the data. The speed, or lack of it, during transcription allowed for deeper scrutiny. At times the dialogue between researcher and data became very evident as the initial stage of coding. As highlighted by Saldana (2013) this allowed for new discoveries, insights and connections to be made.

5.6 Chapter Summary

This chapter draws emphasis and clarity upon the methodological approach for the study. An overview of the ontological and epistemological position is stated and justifications given. The theoretical framework demonstrated is congruent with the research question and therefore suitability is established. Cooney (2011) emphasises that researchers should trust the grounded theory methodology and have confidence that the study will be rigorous if the methodology is applied correctly.

The research design illustrates the practicalities of the approach and further supports the justification for it being chosen. The research journey is covered in a manner of reflection and illuminates some key areas as the process ensued. Ethical considerations are covered and along with an attitude of reflexivity display the attributes of beneficence and respect for the participants in the study.

The principal reason for selecting constructivist grounded theory as the methodology for this study stems from Charmaz (2001), who provides the guidance in the construction of meaning from the data which renders the experiences of participants into legible and coherent theoretical interpretations. The following chapter will demonstrate this with the findings and discussion.

Chapter 6:

Findings & Discussion

6.1 Introduction:

This chapter is approached in a manner to present the findings and discussion in a logical sequence. This is to provide clarity and cohesion and to clearly illustrate how the findings were generated. In doing so direct quotes from participants demonstrate how the codes are relevant and linked to the data generated. Discussion is coupled with the findings within this chapter in order to maintain cohesion of the salient points. Therefore the discussion will supplement the findings to allow comprehensive coverage within this chapter.

The data for this study has been generated over two phases;

- Phase One: Practitioners working with people with a diagnosis of schizophrenia.
- Phase Two: Service users (with a diagnosis of schizophrenia) & carers of people with schizophrenia.

The data was analysed one phase at a time initially. The primary rationale for this order of proceedings was to gain insight into the language utilised and the feelings expressed, with regard to remission, by people (practitioners) working in the current clinical environment. By doing this it offered the researcher opportunity to modify and adjust the format for the interview schedule prior to generating the data for phase two, from service users and carers. Following the individual analysis of the data from each phase the data was then mapped against each other and then synthesised. This chapter will therefore report the key findings from each of the two phases individually prior to combining the two to form the discussion. Excerpts from transcripts will be cited as confirmatory evidence of the data generated and to add context wherever required. Each of the excerpts cited will include the participant number and line number from the original transcript within brackets following the citation. A systematic format is employed to aid clarity and to reformulate the theory as it developed through analysis, as suggested by Backman and Kyngas (1999). This will demonstrate how the data had been managed.

6.2 Phase One (Practitioners):

Data generated within this phase originated from 9 semi-structured, in-depth interviews with practitioners with different professional backgrounds/training from two community mental health teams working specifically with people with a diagnosis of schizophrenia. Responses from participants, in some cases, echoed an influence of their professional background and training. The overarching philosophy within both of the mental health teams is one of working collaboratively in a manner that facilitates a recovery approach with service users and their respective family and/or carers. The emphasis is not necessarily on 'illness' but more concerned with the reduction of 'distress'. Obviously, practitioners held differing roles but all worked (the majority taking the role of care coordinator) with people with a diagnosis of schizophrenia, both of the teams utilised a multidisciplinary team approach but differences were demonstrated due to staff approach and service interpretation and also local needs; this was despite both teams belonging to the same NHS Trust. Atwal & Caldwell (2005) illuminate the important point that the function of the team ideology is only successful when the team members embed this into practice. In the case of the two teams utilised for this study there were no issues highlighted that would lead me to believe that they were not all striving for the same goal. However, in striving they may be utilising different approaches based upon their professional background, clinical experience and exposure to this ideology.

Initially 17 themes were generated during the process of 'initial coding'. It became apparent that these themes were adhering closely to the data as suggested by Charmaz (2006). Themes were further analysed and condensed to 12 themes with two of the themes containing sub-themes (Box 3). This reduction was achieved during the second major phase in the coding process; 'focused coding' (Charmaz, 2006). During focused coding the themes became more conceptual and advanced the theoretical direction of the study.

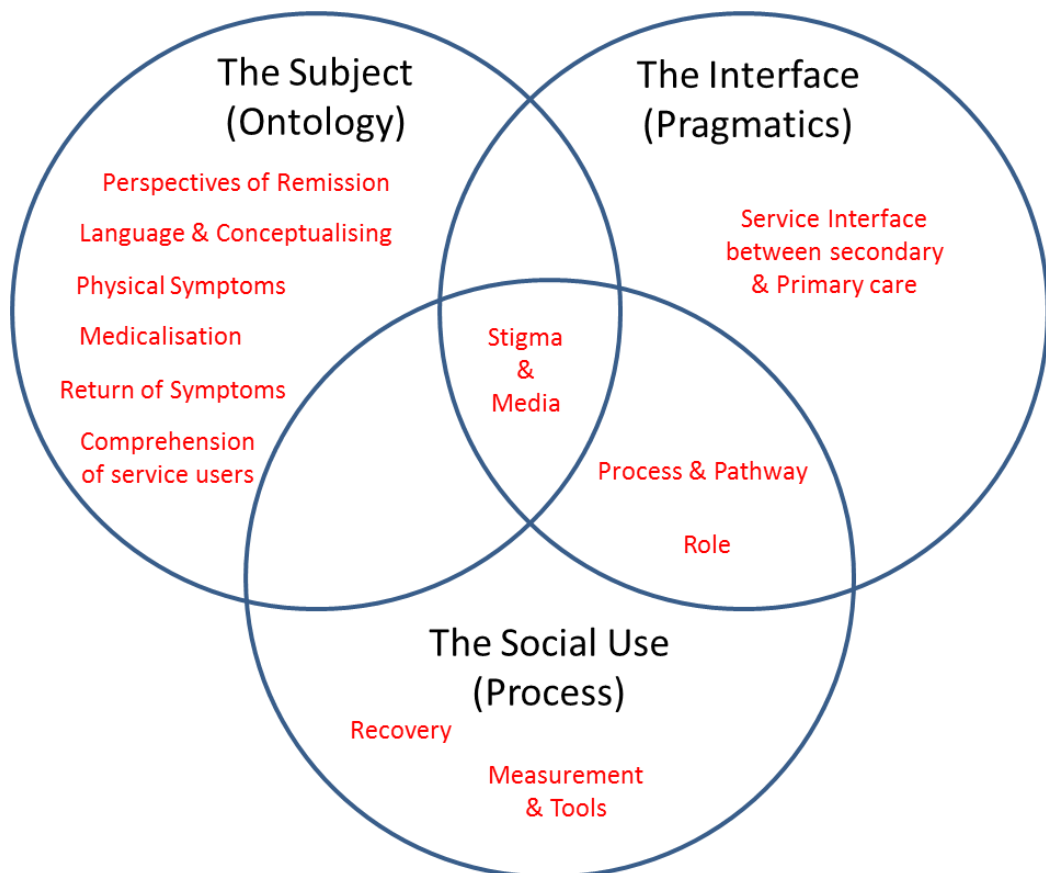
Box 3. Phase One Themes and Sub-Themes

Phase One Themes and Sub-Themes

<u>Perspectives of remission</u>	<u>Role</u>	<u>Comprehension of service users</u>
Application		
Formal use	<u>Stigma & media</u>	<u>Return of symptoms</u>
Illness/symptom orientated		
Making sense of	<u>Medicalisation</u>	<u>Service interface</u>
Remission & recovery		
<u>Recovery</u>	<u>Language & conceptualising</u>	
Individual		
Professional issues	<u>Measurement & tools</u>	
<u>Process & pathway</u>	<u>Physical symptoms</u>	

Further scrutiny of themes enabled the identification of three areas where the themes tended to congregate (Figure 11).

Figure 11. Congregation of Themes



Firstly, the area of the Subject, this represents the 'Ontology' as it is concerned with 'what is' (Crotty, 2013, p10). What is remission? How might people interpret this term? Practitioners in the field of mental health may have heard of or encountered the term remission from either professional or personal dealings. It has been postulated by Gerring (1999) that it matters 'how' we define our terms, rather than merely defining them. All of the themes within this area contribute to an overall understanding and clarity of the subject area. Nonetheless, this is derived from the participants' insights, as highlighted by Alexander *et al* (2008) within interpretivist research it is the participants that provide the researcher with their interpretations to assist in the development of the ontology.

Second is the Interface area, this is concerned with the practical relationship between secondary mental health services and primary care services and as a consequence represents the 'Pragmatics'. Pragmatics in this sense refers to the realistic practical application rather than any theoretical considerations. The issues around this interface between secondary mental health services & primary care and professional role have been illustrated in the literature (Lester *et al*, 2005; Roberts *et al*, 2007; Reilly *et al*, 2012). Difficulties and tensions may occur if service users wish to become more independent from mental health services (Ford, 2010). These areas also became apparent from data generated in the interviews.

The third area is The Social Use which represents the 'Process'. This aspect is the delivery of remission. It does have some overlapping themes with the pragmatics and revolves around how practitioners feel that they may deliver remission in the context of their present practice and service delivery systems. None of the practitioners had seen the paper by Andreasen *et al*, (2005) describing the potential process and as a consequence it was refreshing to see how this process was interpreted by the participants without having specific prior knowledge or information.

6.3 Detailed Findings by Theme (P1):

Here the themes will be explored in detail under their respective headings.

Perspectives of Remission:

Within the theme of ‘perspectives of remission’ it became apparent that there were sub-themes. Whilst some of the sub-themes could have been subsumed within other main themes, or even as themes in their own right, it was felt that they were discussed in the sense of practitioners contextualising their perspectives of remission. Exploration into this theme was deliberate within the interviews in order to allow for deeper exploration from participants’ regarding what remission means to them. For many this was the first opportunity they had encountered to explore this. The sub-themes are:

- Application
- Formal use
- Illness/Symptom orientated
- Making sense of (clarifying)
- Remission & recovery

Application:

This sub-theme refers to the actual application of the term remission in practice. When eliciting understanding of the application of remission in relation to people with a diagnosis of schizophrenia there was a sentiment from most participants that remission would not be a word they would use when working with a service user.

“I prefer to use ‘recovery’ if I am talking with clients” (88110-29)

“I would never describe someone as in remission – I would always say they are currently well” (88103-49)

Out of the nine participants employed in this phase it was generally felt that the doctor would be the one to apply the term remission in their role and practitioners from other professions would be less likely, if not totally opposed, to applying and using the term remission.

“If the doctor says it’s in remission then that’s what goes on the documentation it’s up to whatever the doctor writes” (88101-320)

Deciding to utilise a term, such as remission, if it has not been prominent or previously employed in the profession may be a big step to take for some practitioners. This step may feel

onerous and beyond the realms of the responsibility for the individual practitioners, except for doctors maybe. Atwal & Caldwell (2005) describe that in their study that within the multidisciplinary teams the doctors/consultants held a more dominant role. This could also be a factor within this study which makes it an easier choice for some practitioners to state that remission is more readily aligned to a medical perspective rather than something that they would be happy to discuss with service users and their carers'. In a similar vein a participant who is a Social Worker differed slightly in opinion but still expressed a feeling that remission carries physical and/or medical orientated connotations and offered:

"Well you automatically think of nurses I suppose, 'cos that's what you think, you think the more physical aspects of things like cancer and stuff"
(88112-111)

Given the comments from other participants it became important to obtain the perspectives from the psychiatrists in relation to this, as the majority felt that they would be the people applying the term remission more readily. Perspectives from the psychiatrists indicated that they were perhaps not as ready to use the term generally as expected by their respective colleagues;

"... in fact the only time I really use it [remission] is to convey to err on a letter to a GP if somebody is so well that I think they are not going to need us, ... the way I would use it to convey from one medic to another that pretty much everything has gone and there is no need for the secondary care bit anymore" (88115-40)

There was an indication that other areas of speciality in the medical profession may employ the term more readily;

"I don't think we use it [remission] in mental health in the same way as you probably would do for other, other medical conditions I think"
(88116-14)

The general feeling is that with regard to the application of the term remission some participants assume it to be used by the medics but they in fact would use it more with medical professionals possibly more outside the remit of mental health.

Formal use:

The fact that remission is formally mentioned in the ICD-10 (World Health Organization, 1992) was not overlooked and some participants highlighted this;

"ICD-10 uses it" (88103 – 21)

As the people utilising the diagnostic tools such as the ICD-10 and also taking more responsibility for diagnosing people, the consultant psychiatrists were the participants raising this most. There were no other references to the formal use of remission within either of the two teams utilised for this study.

Illness/symptom orientated:

Some participants could relate remission to that of illness or symptoms and almost all of the participants were able to relate to remission in this manner. This demonstrates an indication of general feeling or understanding with regard to the word remission. Due to this link towards illness there is a great sense of therapeutic negativity attached to this sub-theme. Health is viewed as a positive state to which we should aspire (Jones, 2012). Therefore, if we have an absence of health this can simplistically be viewed in a negative manner. As a consequence to have any illness in the first instance and to have the worry regarding its return were the main concerns expressed;

“To be in remission you’ve got to have had an illness in the first place – so in that way it is negative” (88103 – 13)

Retrospectively viewing illness as a negative has potential to further compound issues for service users and may also impact upon the practitioner’s ability to assist in the identification of strengths that are present in the service user.

“Could be negative as symptoms may return ... Not an altogether positive term – something left hanging over them waiting for something negative to occur again” (88110 – 15)

Again, this is another negative perspective which may permeate healthcare teams and reach the service user with the possible consequences of reducing hope for the future. The negative outlook persisted but for one participant a wider, sociological perspective was offered;

“Because you’re symptom free does not mean that your life is returning to normal ... if somebody goes into remission, their symptoms may have gone but they may have lost a job, house, their life hasn’t recovered” (88106 –76)

This comment may be borne from experiences of seeing and working with people affected by the impact of schizophrenia or it could be as a consequence of what Cohen & Cohen (1984) describe as the ‘Clinician’s Illusion’. This is a bias in thinking which contributes to this phenomenon as clinicians will see the most severe service users and those with a poorer prognosis more frequently. This can create the illusion that this is how it applies to all service users with the same diagnosis.

Making Sense of (Clarifying):

When attempting to clarify remission participants relied on the sentiments and values from either their professional background and training or the ethos of the team in which they work. The idea of remission having to be tailored to the individual was prominent, as this is synonymous with the principle of recovery (Deegan, 2005).

“Remission would be individually determined” (88114 – 67)

Despite this suggestions were not offered how this would be performed, other than stating that it is individual and therefore different for each person. This may, unfortunately, be part of service-led recovery rhetoric rather than a clear understanding by individual practitioners. Some participants expressed a feeling that remission could be useful and a positive concept to adopt.

“For certain individuals remission is a useful concept” (88106 –244)

This does recognise the individual nature of the person and removes the idea that remission may be a ‘blanket’ term utilised for everyone. Service users should be empowered within mental health services and their strengths recognised (Atterbury, 2014).

“There is the idea that things are getting better for the person... I think it is a positive thing for the person” (88107 – 23)

The true nature of individualised care was recognised in the comment below;

“Possibly the only person that knows if they are in remission is the patient. It’s subjective, so individual, so personal – we can only measure in objective ways” (88115 – 215)

This comment would certainly further question the present tools employed within mental health services in attempting to understand if a person is in remission, especially as presently this is only performed using objective measures of clinical symptoms (Andreasen *et al*, 2005; Alonso *et al*, 2008; Levine *et al*, 2011). Another big question this would raise would be concerned with people from mental health services listening to service users and acknowledging what they have a say in respect of remission. This may be challenging for some practitioners and the cause of conflict with the manner in which they presently practise.

Remission and Recovery:

Throughout the interviews it was apparent that there is a strong belief from all of the practitioners that recovery should be a central principle and would be the preferred language to use rather than remission. All practitioners expressed that the term remission should not replace the term recovery, despite this not actually being a direct question from the researcher, participants were eager to vocalise this point.

*“Recovery and remission are inextricably linked – but they are different”
(88106 –87)*

Again, the quote below identifies the negative overshadowing that appears with a term such as remission;

“It [remission] doesn’t suggest recovery it suggests that you’re getting a break but it will be back” (88103 – 14)

The fear of symptoms returning may be synonymous with historical negativity attached to the diagnosis of schizophrenia. Whilst this may be inevitable for some service users the practitioners did not wish to subscribe to anything that may be seen to support this view, again this could be in-keeping with a recovery focused ethos from mental health services. Therefore, the more positive sounding term recovery would be more likely to be employed;

“I prefer recovery (right) If I am talking with clients remission isn’t a term that I would use I prefer to use recovery errm I think it just sounds a lot more positive” (88110-29)

The participant cited below encapsulates this overall sentiment by stating;

“I think recovery is quite a positive word and that’s why we use it isn’t it?... We do use the word remission, we have got the word remission on the new documentation and it is a word that’s used not like the word recovery we don’t use it as often as the word recovery” (88101-297)

This theme of ‘perspectives of remission’ comprises of the sub-themes covered above and is an attempt for practitioners to make sense of remission within the context of what they already know and the manner in which they practise. During the generation of this data at the interviews some participants were comfortable and appeared relaxed in deciding how to articulate the concept of remission. Other participants were a little unsure, but all attempted to describe what their thoughts and feelings were in relation to the concept of remission.

Recovery:

When analysing the data within this theme it became apparent that participants were discussing the issues in relation to two main aspects; individual aspects of recovery and the professional issues associated with it.

Individual:

The concept of recovery advocates a nature of individualism (Deegan, 2005) and this was strongly echoed by most of the participants.

“You’ve got to kind of say to them, look as part of your recovery you need to develop your independence” (88103-286)

Whilst the idea of promoting independence may be present, perhaps there are hints in the language used that there may be a ‘them’ and ‘us’ view by some practitioners. This could unfortunately support the concept of separation discussed by Estroff (1989); in this concept people with a diagnosis of schizophrenia would be identified as ‘schizophrenics’. Repper & Perkins (2009) add that any other, perhaps positive, attributes of the person would be eclipsed by these identities. Despite this emphasis towards the development of independence it does not appear to foster a collaborative, therapeutic relationship that might facilitate a true move towards independence as advocated by Pratt *et al*, (2005), and Atterbury (2014). The mental health charity *Mind* (2008) expressed concern that the recovery agenda was being re-articulated and therefore colonised by mental health services. Unfortunately this statement may be regarded as confirmation of this.

“The picture of it [recovery] must be what the individual has a picture of really” (88106-174)

This sentiment has been laid out by the Department of Health since 2009 in the document ‘*New Horizons*’; “... focused on recovery, as defined in discussion with service users” (DoH, 2009, p7). However, the degree to which practitioners can specifically assist service users to exercise their right to individual recovery was not expanded upon. Although, efforts were attempted to articulate this;

“...do it collaboratively ... saying ‘what would you like to be different, these are the options of how we can achieve that, what can we agree together’ ermm and that’s what drives the recovery bit really because recovery for a patient might mean something quite different” (88115-185)

The issue of consistency in approach may be of slight concern as practitioners have different approaches between themselves. Yet, a practitioner may have their own values and beliefs in relation to recovery, also be influenced by the concept of recovery postulated by the service or team and also take into account the individual nature of the service user and their expectations regarding this. In this vein, Davidson & Roe (2007) highlight that recovery is not just one thing, but many; with Pilgrim (2008) adding that recovery is a 'polyvalent concept'.

Again a social perspective was raised and acknowledged as an important component in relation to recovery;

"Recovering from a mental health problem isn't just about the mental health itself for me because I would work from a social model so it's about looking at social inclusion it's about looking at employment it's about looking at ermm opportunities like that" (88112-44)

"When I talk about recovery I am talking about not solely recovery from symptoms and not solely recovery from social issues" (88106-294)

This was reinforced a little more and expressed utilising a positive outlook by some too, almost to the point of asserting that the 'Clinician's illusion' (Cohen & Cohen, 1984) would not be an influence in the matter;

"You need to be clear that you don't necessarily have to be acutely unwell for the rest of your life, people do have schizophrenia, they do have jobs, ... they do have a social life, they do have wives and children it doesn't necessarily mean that because you've got a diagnosis of schizophrenia that you are unwell for the rest of your life" (88101-47)

The view by Burti & Mosher (2003) is that clinician's may develop a pessimistic view of the outlook for people with mental illnesses if they keep contact with people who are unwell, but selectively stop seeing people who have recovered.

Professional Issues:

Whilst the concept of recovery is adopted in both of the mental health teams some participants expressed a little concern and this may be a cause of ambiguity;

"I think recovery can be an unhelpful word for people because I think people find it very difficult to imagine what recovery means to them and a professional's told you have to go with what the person sees as recovery" (88107-55)

It may be that once the diagnosis of schizophrenia is placed upon a service user that this initiates a problem for some practitioners in relation to their vision of possible recovery, given that historically schizophrenia carried negative connotations (Lyttle, 1986; O’Reilly, 2011). Mental health services also utilise their respective take on recovery, which is perhaps more systems lead, and this may or may not be truly conducive to a recovery approach for some;

“... as soon as they are given that label [schizophrenia] so I think that that label in itself prohibits anything about recovery or about remission I think” (88107-210)

It is apparent that not all practitioners hold the same beliefs regarding recovery, much the same as service users. However, the professional issues may be the cause of incongruity or confusion for some practitioners. This may be due to issues highlighted by Meehan *et al* (2008) such as recovery not being delivered in a consistent manner and service delivery not being systematic. Le Boutillier *et al* (2011, p1470) suggested that “Recovery offers a transformational ideology for services” this may be an issue if this ideology is not perceived or adopted in the manner intended by the practitioners working with the service users.

Process and Pathway:

In their paper on ‘Remission in schizophrenia’ Andreasen *et al* (2005) outlined a linear style pathway which positioned remission along the pathway before the ‘ultimate goal’ of recovery. During the interview the participants were asked where they, themselves, may see remission in the context of the recovery pathway, to aid clarity some of these responses were matched against the pathway by Andreasen *et al*, (2005). None of the participants acknowledged seeing this pathway prior to interview.



(Andreasen *et al*, 2005)

Recovery, as a concept, now carries such a strong emphasis and the Trust strongly advocates a recovery approach. In order to gain consistency in both approach and care delivery, processes and pathways have been devised and implemented, which practitioners have been made aware of;

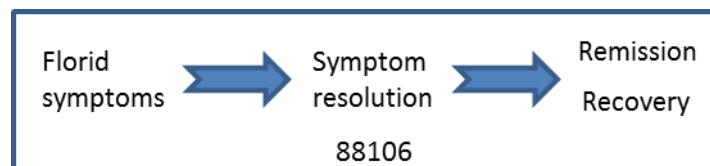
“From somebody coming into services we start a point of recovery, now that might be an assessment, ermm cos we have a ‘Superflow¹²’ so that

¹² ‘Superflow’ is the Trust’s battery of assessments within the recovery approach.

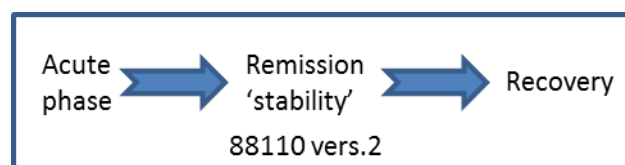
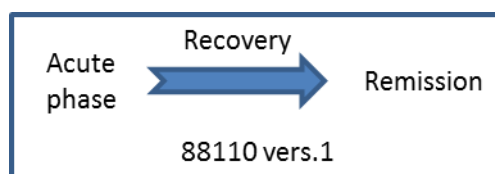
would be an assessment a gathering, ... what that persons needs are, what they think their needs are, what we think their needs and how we can work together” (88101-82)

To illicit a fuller understanding of the pathway participants were asked ‘where remission may sit in relation to recovery’. With some of the participant’s responses it was straightforward and visual representation was utilised for ease of comparison.

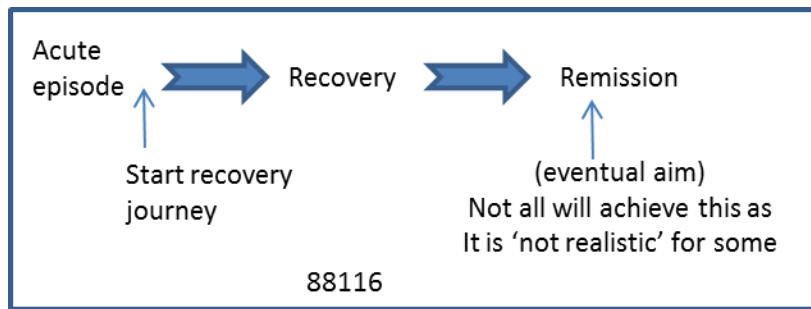
“... really debilitated by the symptomology, there needs to be a reduction in that before any sort of meaningful recovery can start to move forward, hence we have in-patient hospital I guess” (88106-120)



“I think remission ... would be looked at more towards the end after a period of involvement when the recovery is taking place where as recovery I think is something you can be looking at right from the very beginning ... but remission is a term and what it encompasses would come later on further down” [Version1] (88110-72)

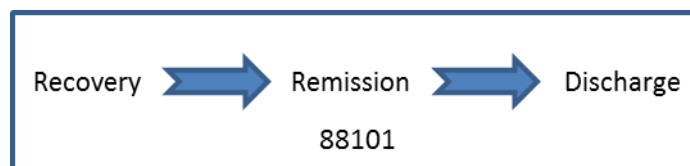


Whilst discussing the process this participant (88110) revised his thinking to come up with an altered approach (Vers. 2). This typifies the unsure nature of the practitioners with regard to processes associated with recovery being utilised into practice. When addressing practice guidance Le Boutillier *et al* (2011) highlight the complex nature of translating recovery into practice.



“Your eventual aim I think is for remission and for people to get better and but you know for a lot of people that isn’t necessarily realistic so I would see remission as being at the end ermm or sort of towards the end of that journey” (88116-200)

There is a cautious element to the pathway postulated above. The caveat that ‘not all will achieve’ recovery may be as a consequence of the challenge that the guiding philosophy of recovery brings, as it challenges ideas and beliefs about aetiology and treatment (Le Boutillier *et al*, 2011).



“We have recovery then we get a point where things plateau and people become in remission if you like, and then we start to walk, work towards discharge” (88101-86)

The element of subjectivity was also apparent whilst employing a process and this could possibly contradict previous statements made regarding service users deciding what recovery means;

“A patient might think they’re in remission and they don’t need services anymore, might be quite different to what I think” (88101-179)

Some participants were not able to be as straightforward but made some interesting points in relation to process and pathways;

“It has to be something that isn’t just a one-off otherwise you can’t really gauge anything by it” (88115-169)

Overall, this theme identifies that there are differences in opinion between practitioners of where remission may fit into any process or pathway, making interpretation and consistency of delivery a possible issue of ambiguity. Even when there was a consensus that remission may indicate being symptom free there were still inconsistencies in responses regarding where it may be placed in the pathway. This may be the result of confusing recovery as an outcome as

opposed to viewing it as a process. Silverstein & Bellack (2008) identify that recovery is easier to operationalise when defined as an outcome as opposed to a process. Ultimately, these differences could have a negative impact on the delivery of recovery focused services.

Role:

The theme of role was not large by comparison, but the most interesting point was that it was both of the psychologists that made strong reference to their roles. Coming to terms with the role was a prominent aspect within a medical orientated organisation;

“I find that the hardest people to work with are the people who hold a very strong medical model about their illness” (88107-105)

A major concern from hearing this response above may be that, if the concept of remission for people with a diagnosis of schizophrenia was to be introduced, would this enhance or cement the medical perspective that the service users might view the diagnosis being part of? Therefore, the opportunities for practitioners to deliver psychological-based approaches may be reduced if concern from the practitioner is to be generalised. Within the multidisciplinary team cohesion is required (Caldwell & Atwal, 2003) and team members will be required to understand the roles of others. Barr (1998) highlighted members must be competent to collaborate. The psychologist making the following statement did not take on the role of ‘Care Co-ordinator’ for service users, but were a much utilised team member;

“You spend a lot time looking at psycho-education and normalisation and those types of things ... the most contact anyone ever has is with their care-coordinators so it’s actually thinking about getting care coordinators on-board with that idea” (88107-125)

The psychologists in both teams do not take the role of care coordinator for service users but are utilised when care coordinators refer service users to them for psychological therapies. For the point of clarity the only other practitioner in the team not taking on the role of care coordinator are the consultant psychiatrists. Despite the psychologist(s) working within the same team(s) some practitioners may adopt a different philosophy;

“I sit uneasily alongside the idea that our job as mental health practitioners is to get rid of err symptoms of schizophrenia, when often for people things like voice hearing can be a generative and transformative experience and an absence of them wouldn’t be wanted” (88114-83)

It may be inevitable that within teams that contain different disciplines from different professional backgrounds that issues may arise concerning divergent views in the delivery of care. Warning must be heeded as the working professional relationship can affect the health care provided (Zwarenstein *et al*, 2009). The ideology (of recovery) needs to be consistent and put into practice in order for it to become successful (Atwal & Caldwell, 2005). Therefore, consistency, a shared philosophy (ideology) and cohesion are required.

Stigma and Media:

Some participants expressed belief that remission could be less stigmatising as it is synonymous with physical disorders and not exclusive to mental health.

“In some ways maybe remission ‘cos it is quite a medicalised word maybe it would help with stigma ‘cos if you medicalise things a bit then maybe if mental health is more viewed as a medical issue then does that reduce the stigma ‘cos there isn’t any stigma around physical health issues” (88103-61)

The acknowledgment of the potential iatrogenic harm caused by administering the diagnosis of schizophrenia is still held today with concern that service users may stigmatise themselves. This perception may be based on the work by Corrigan & Penn (1999) stating that members of stigmatised groups stigmatise themselves as they internalise the public stigma. However, it would be imprudent to consider that other, perhaps physical; disorders do not face similar issues of concern in relation to stigma. People with a diagnosis of multiple sclerosis also experience stigma (Grytten & Maseide, 2005), as do people with lung cancer (Chapple *et al*, 2004), epilepsy (Troster, 1997) and hearing loss (Erler & Gartecki, 2003).

“The diagnosis of schizophrenia in terms of language I think it’s the most dangerous thing [smiling] for someone ever to be given that a label like that because, because of the media portrayals of schizophrenics as murderers ... I think that people stigmatise themselves I think that they see themselves as really broken and that actually a future isn’t possible” (88107-188)

Self-stigma infers that service users believe and internalise the negative stereotype and this leads to negative emotional reactions (Cavelti *et al*, 2012a). This should be picked up by practitioners when working with service users but could also be reinforced unknowingly if the practitioner is not fully understanding or appreciative of a recovery approach. This needs to be addressed swiftly as it can detrimentally affect a persons’ sense of hope and self-esteem (Corrigan *et al*, 2011).

The concept of media coverage was more in relation to remission generally than that of people with a mental health problem. This was portrayed as a normalising experience rather than negative;

“Again for certain individuals it’s a useful concept [remission] because it’s a phrase that is out there in the media, it’s out there in general conversation people talk about remission ... you hear about celebrities that have had illness that go into remission” (88106-244)

Perhaps this kind of coverage, in spite of negativity, the media may serve to offer hope as they inadvertently go some way to possibly normalising the experience. However, this would be best acknowledged from a service user perspective.

Medicalisation:

Some participants made inference to adopting a medicalised approach whereas other comments in this theme are around the link to remission and ways to avoid and overcome a medical perspective. Broom & Woodward (1996) claim that for several decades the concept of ‘medicalisation’ has the sociology of health and illness. There are strong arguments and feelings among commentators in mental health, particularly from the service user movements, regarding the over-use and reliance on the medical model and medicalised approaches (Unzicker, 1989; Wallcraft *et al*, 2003; Boyle, 2013). Within this theme the term medicalisation refers to the use of the medical model and over-use of medical terminology. This is more in keeping with the definition offered by Busfield (2011, p121) who states, “ ... medicalization (*sic*) is commonly used to refer to the expansion of medicine into aspects of daily living ... as well as mental life, where formerly it had played little part”. However, some participants recognised that pressure to acquire the correct diagnosis in the first instance is important for some;

“I think actually getting the diagnosis right is a key thing because actually you can’t say somebody’s in remission unless you have got the correct diagnosis for them in the first place” (88116-99)

For others the ambiguity around this may be an issue;

“it’s a bit like the debate about is a diagnosis beneficial or not, some people really value that and some people hate ... I suppose it’s similar there that some people ... might feel better to kinda think ‘oh this is remission’ it’s almost like ... it’s quite a medicalised word and I think some people might like that better ... It’s quite a medicalised word” (88103-57)

The idea continues to pervade that a medical word would be more readily accepted by service users than a word more synonymous with mental health connotations. The view of remission being a medical term instantly makes practitioners from professional disciplines other than medics believe the medical staff would be the people to apply this approach more readily;

“I think it is quite a medicalised term so yeah I would say more the medics the doctors errmm the fact that they work in, within those diagnoses as well in which it is an intrinsic part of the ICD 10 information and things like that” (88103-68)

The feelings regarding the use of a medical model and medicalised views often fuel strong debate and this sometimes enhances or cements polarised approaches. Blakeman & Ford (2012) highlight that for practitioners the medical model continues to pose challenges, due to the dangers associated with relying on a single therapeutic approach. The education offered within the NHS Trust in respect of recovery enhances the strengths of a ‘biopsychosocial’ model and whilst acknowledging the role a biological (medical) perspective adds the emphasis has somewhat shifted. This is very much in keeping with the sentiments from the recovery movement initiated by service users. As postulated by Boyle (2013) our attention is shifted from people’s lives to their brains if the medical model is employed. Boyle’s sentiment is that we need to view the wider perspectives including psychological and social perspectives, rather than minimising our views with the idea that the brain (as an organ) is solely responsible.

Language and Conceptualising:

The language employed in any profession can be said to be important and also the way this is conceptualised. Some participants had looked for information prior to being interviewed, once they had received the information leaflet, they admitted that this was to raise their knowledge of the subject area;

“I looked for information on remission in schizophrenia when I got your information leaflet – there is nothing in psychology literature what I found was psychiatry and medication focused” (88114-40)

Due to the perceived dearth of information on remission in schizophrenia for specific healthcare disciplines participants will have relied on their own judgement and presumed that others would have the same ideas too;

“It’s a word that people hear, it is not one that is used in general day-to-day conversation if you’re well and fit but non-the-less it is a word that

probably a lot people will have heard of and understand the concept thereof” (88106-249)

Some participants felt that alternative language or the indirect use of ‘remission’ may already be present in mental health services;

“Just because the word remission might not be used, does not mean that we don’t use -‘having no symptoms” (88106-253)

The quote above is suggestive that alternatives are employed in practice and therefore remission is employed, but by using other words. This assumption may lead to further misunderstandings between healthcare practitioners and ultimately impact on the service user. The quote below suggests further ambiguity and fails to state that if service users were asymptomatic would they then use the term ‘in remission’?

“I’d always tend to say you’re currently well or currently recovering well if they are not asymptomatic” (88103-48)

The idea that practitioners were more in-tune to detect differences in the language employed was raised and also the desire to make this consistent;

“Patients don’t see the difference between the language – but I can see the difference it can make” (88107-75)

“It would be better if we all shared our terms of reference” (88114-130)

Most participants suspected that it would be within the primary care setting that a term or language such as remission would be employed most;

“GPs would be comfortable using ‘remission’ it’s a language they make sense of” (88110-148)

This theme illustrates differences between participants. As all participants are qualified healthcare workers, within their own speciality, it may have been assumed that there would be more of a consensus. However, due to the term remission not being used regularly this may have been the causation for some of the ambiguity around this.

Measurement and Tools:

The literature around the use of remission (Andreasen, *et al*, 2005) advocates the use of a tool to ‘measure’ remission. So the question was asked, if participants or teams are using a specific tool to measure remission. The responses were consistent in stating that they were not using anything specific to measure remission. However, many participants highlighted other on-

going assessment tools that were presently employed which could, perhaps, contribute to understanding if a service user may be in remission but were nevertheless not specifically designed for this process;

“We use the likes of the BPRS¹³ here which is used to monitor you know the symptoms ... the Belief About Voices¹⁴ ... there’s the KGV¹⁵, Camberwell¹⁶” (88110-93)

In spite of more objective rating scales it is acknowledged that subjectivity accounts for the components that these tools may not address. Given that the comment below is from a consultant psychiatrist it may be experience or perhaps an issue of power which permits them to make such judgements;

“Obviously we have assessment parts of the ‘Superflow’ but ... it often goes on ermm clinician’s global impression of whether somebody is in remission, you might do symptom ratings” (88115-140)

Some participants were not in favour of using formalised assessment tools. Whilst this may reduce validity in the formal tool it may perhaps lend itself more towards a fuller understanding by utilising a narrative perspective (Davidson, 2003) from the service user to gather rich information;

“You know I prefer assessment that allows you to tailor your conversation to the patient, rather than just follow a set ... structure” (88103-162)

There was also concern that the service users do not value some of the assessment tools utilised by practitioners;

“... and when she had finished she went “What a load of crap that was!” (88101-188)

Assessment and measurement is inevitable within the teams in this study, however there is immense value in understanding how participants utilised and related to these. Overall, the NHS Trust advocates certain assessment tools to assert minimum standards, utilising tools beyond this are at the practitioners’ discretion and as a consequence may not facilitate a consistent approach if not employed or understood by other team members. If this is the case elements of subjectivity may be introduced.

¹³ BPRS (Brief Psychiatric Rating Scale) is a global symptom rating scale for people with psychosis. Originally developed by Overall & Gorham (1962) and later revised and updated by Ventura *et al* (1993).

¹⁴ The Belief About Voices Questionnaire - Revised (BAVQ-R) an assessment designed to gain deeper understanding about voice hearing developed by Chadwick *et al* (2000).

¹⁵ The KGV is another global symptom rating tool for psychosis developed by Krawiecka *et al*, (1977).

¹⁶ Camberwell Assessment of Need (CAN) is another assessment used to identify need in people with severe mental illness (Slade *et al*, 1999).

Physical Symptoms:

This theme does not address any links between physical health and mental health. It centres on the concept of remission being synonymous with physical illness rather than an attribute of recovery in mental health terms. The relationship identified with remission was one with physical disease, with cancer being the predominant disease mentioned;

“I suppose cancer is the one that you often hear but it could be any physical condition” (88110-10)

This connection to cancers and terminal illness may be a rationale for some not being in favour of such a term being employed in mental health;

“The association with cancer and terminal disease would put me off using the word remission” (88101-266)

Some participants were attempting to balance out the factors when considering that value of remission being employed for people with a diagnosis of schizophrenia;

“I might not be massively keen on it as it is linked with illness’ that scare people like cancer and suggests that it could come back anytime but it’s a functional term and not ambiguous at all” (88103-107)

Part of this balance was seeking a more positive outlook from some participants;

“With cancer remission would bring a sense of relief” (88107-27)

“If you’re looking at people with cancer ‘in remission’ the treatment is finished – you don’t need anything more – away you go” (88115-38)

These two comments above are in contrast to earlier, negative, comments (from different participants) in relation to having illness in the first place and potential relapse hanging over them.

Remission is undoubtedly linked with cancer and physical illnesses and would deter some participants from utilising it, but others identified some positive aspects in this. None of the participants drew reference to conditions other than cancer, disorders such as Multiple Sclerosis, which are also seen very much as a remitting and relapsing disorder that also share other characteristics and have elements of stigma attached (Stevens, 1988).

Comprehension of service users:

Practitioner's views of how they perceive service users comprehending such a phenomenon as remission generated some differences. It was appreciated that practitioners need to offer more information to service users;

"I think, well the more transparent we are with the patients the better it is and the more involved in the discussions the better it is" (88115-173)

The service users understanding was questioned and it was presumed by this participant that as long as symptoms were reduced as a consequence of adhering to the medication regime, then all would be well;

"Remission is a bit more 'well people don't have this anymore' but whether the service user understands that in the same way, they're just getting on with their life or whatever and they're not, as long as they take the tablets they're not getting the voices or whatever" (88116-70)

There was supposition that the service user would have awareness of being in remission, even if the terminology employed was not the same;

"... if they are truly in remission they should have some awareness of that themselves, 'obviously you know I am really quite well at the moment' [spoken in a Jovial voice]" (88103-168)

All of the points raised were assumptions by practitioners as service users have not been exposed to the language of 'remission' in the respective community mental health teams and this was echoed;

"It would be interesting to see, to find out what the patient perspective would be on this or whether they would see it as un-diseased"(88107-103)

Despite practitioners not having had first-hand experiences of talking to service users, or their carers', about remission explicitly there were some assumptions made in respect of this. Whilst this may be done with the best of intention, nevertheless, it is possible that it may provoke a prejudgement from practitioners towards service users.

Return of Symptoms:

In most aspects of the literature this is viewed as 'relapse' however, to simplify what is meant in this theme 'return of the symptoms' is utilised to avoid other operational definitions of relapse. In relation to a person's recovery worrying about symptoms returning may be an inhibiting factor;

“We can never promise someone that lapses or relapses won’t happen ever again, ... I guess there is also that little thing in their head where, they are aware that something like this could happen again but it doesn’t necessarily seem to stop people from being able to move forward” (88107-59)

Utilising the term remission may be a way of preparing service users that there may be times when things do not go to plan and this was viewed as being realistic by this participant;

“yeah, in terms of set-backs because sometimes you can have a period when things go really quite smoothly and things improve that are really satisfactory sort of rate but I guess it’s being realistic and preparing people as well that there may be at times set-back and planning for them” (88110-106)

The inevitability that people will have relapses was made clear, but confusion or uncertainty was expressed around the link with remission, with a concern that it cannot be as clear as we may hope. This participant is expressing more of a continuum approach as opposed to the dichotomous ‘well – unwell’ phenomenon;

“but it’s very rare that people have full resolution if you look at all aspects of their life (88115-23) ... but remission is so individual and so personal that ermm I think it would ...I can think of that as being a barrier to ermm the discussion in that it forces you to a ‘yes’ or ‘no’ when that’s not really what you are trying to discuss and at what point do you not stay in remission, if you are showing signs of relapse are you still in remission? But you’re heading towards a relapse, have you left remission? When do you cross the line?” (88115-216)

As health care practitioners the participants were wishing to say that service users would ultimately achieve recovery but realistically had to concede that symptoms may return for some people and that this may throw up confusion in relation to distinct categories of ‘in’ or ‘out’ of remission.

Service interface:

This theme developed as practitioners spoke about the interface between secondary mental health services, which they are all employed within, and primary care. Primary care includes general practice and this would be the area that service users may be discharged to if they were deemed well enough, regardless of whether we call this recovery or remission. There are differences between the two community mental health teams despite working within the same NHS Trust and examples of this were generated from the collection of data. Initially the perceived response of GP’s was highlighted;

“If I was in like a GP surgery or something and I got a letter through saying that this person has been discharged back to me ‘cos they are currently in remission’ then I would read from that they are currently well ... So yeah I think that the GP’s would probably like that term (88103-104)

But to counteract this statement the same participant did not feel that remission was a positive term to use as it may prevent people being discharged who have some residual symptoms;

“I don’t know whether it would facilitate discharge really ... ermm ... because essentially if we were looking at discharging somebody what we’re saying is that they are quite well they don’t need us so you could just say that ‘You’re very well!’... you know you might have somebody who’s recovered very well still has some residual ermmm sort of hallucinatory experiences but excellent insight and manages them and no associated distress” (88103-203)

The processes and pathways previously alluded to by participants was felt to have eased the transition back to primary care for some. The response below is only from one of the community mental health teams and does not readily apply to the other;

“What really swayed it with GP’s is the changes that we’ve made to the whole structure allows a flow through ... so as part of the ‘Superflow’ process that we have there’s a discharge bit ermm which is really looking at preparing the patient and the family and the GP for the fact that they are going to be discharged” (88115-53)

At some point there may need to be a question raised regarding whether the GP necessarily needs to see or hear the word remission at all to accept transfer of a person back into primary care. Would a thorough discharge summary suffice and then the GP and primary care team could read between the lines and assume remission had been achieved. The reassurance afforded to primary care services by this community mental health team is seen as assisting in the process for one of the teams utilised in this study;

“They can quickly come back through if it doesn’t work out that way, so by and large the GP’s will be happy with that they’ve had enough time to see that if they do refer they’re back through quickly” (88115-74)

One of the major issues in discharging service users from secondary mental health services is that of medication and this was highlighted predominantly by the psychiatrists although other participants did mention issues around this;

“Usually the ones that I would discharge back are on some form of medications psychotropic not necessarily antipsychotic” (88115-61)

It was not clear which medication within the specific 'psychotropic' group, but these would not be administered by injection.

"I think they [GPs] just, yeah look at whether they are on Quetiapine or Olanzapine or something like that and make a decision about whether they want to continue prescribing that ... and without support from secondary mental health services" (88116-144)

The two medications mentioned in the comment above are antipsychotic medication, quite often the view may be that if people are taking this medication then they must be closely monitored in a manner that only secondary mental health services can manage. Medication for people with a diagnosis of schizophrenia can be and is often administered in intramuscular injection format, also known as 'depot' medication. This has often been a contentious issue, in relation to discharge, for some people who could be discharged may have to remain in secondary services due to requiring these regular injections of the medication.

"Sometimes we do discharge them and the GP's will take over the depot, we have a number of those ... if they are on a depot which cannot be changed and the GP is not willing to take over the prescribing of that then we are pretty much stuck with them" (88115-246)

In relation to this issue, one of the mental health teams does have GPs in the area who are notoriously reluctant to accept service users if depot injections or, in some instances any antipsychotic medications are involved;

*"Aahh well depots [laughter] as you'll probably be aware in **** [place name disclosed] we can't get rid of those people even if they are in remission so that wouldn't facilitate us at all (yeah) saying in remission or even if we put in recovery, you know in recovery (hmm) I don't know if ... they really understand what that means in mental health terms" (88116-152)*

From the other mental health team there is an awareness of the difficulties faced by their counterparts in the Trust and it is almost a sense of relief that it is not the same in their area too;

*"In this patch we don't have a problem, I know in **** [place name disclosed] then pretty much if you're on antipsychotics it's very hard to get discharged back but that isn't the case here" (88115-73)*

However, even within the team thought to have improved links with more accepting GPs a participant raised the issue that perhaps the practice nurses within surgeries are resistant to the idea of administering depot medication;

"I remember having the conversation with the practice nurses and they were terrified at the thought of having to administer an IM injection –

really! But yeah there is definitely some resistance to it as it stands at the moment” (88106-380)

Whilst we are reminded by Lester & Glasby (2010) that mental health forms a significant proportion of work for practice nurses, this is predominantly dealing with people with depression and anxiety. One principle adopted to assist in discharge is to attempt to ‘normalise’ issues in relation to general aspects of health and to educate primary care workers:

“They’re [GPs] happy with the advice on medication and really it’s just about ermm reminding GP’s that mental health is no different from any other speciality and that once somebody has recovered from an episode of illness and they have a plan and that is manageable for them and manageable at primary care level then off they should go they shouldn’t get stuck in the system” (88115-91)

One of the key initiatives that is to be considered when discussing where a service user may receive care is ‘Payment by Results’ (PbR). This is a payment system in England where commissioners pay health care providers for the treatment a service user receives, determined by currencies and tariffs, and this takes into account the complexities of the healthcare required (NHS Confederation, 2011). This was brought up by two participants who took a slightly differing stance;

“especially with Payment by Results now coming in that whether GPs would be more keen actually for us to identify people who are in remission or who are you know well enough, you don’t really need secondary services ermm so they wouldn’t then have to pay us for our input really” (88116-251)

In relation to the same issue the other participant was wishing for consistency to enable an improved approach in which remission may be included;

“If you have a remission tool that stands alone ermm what are you measuring against so it needs to be a repeatable thing that you can actually track because the other thing that links in with the pathways and all of the cluster and the Payment by Results stuff that it has to be something that isn’t just a one-off otherwise you can’t really gauge anything by it” (88115-165)

Overall it was felt that there are differences recognised between the teams within this Trust and that this may be based on the confidence and perhaps contact that staff in primary care have in secondary mental health services;

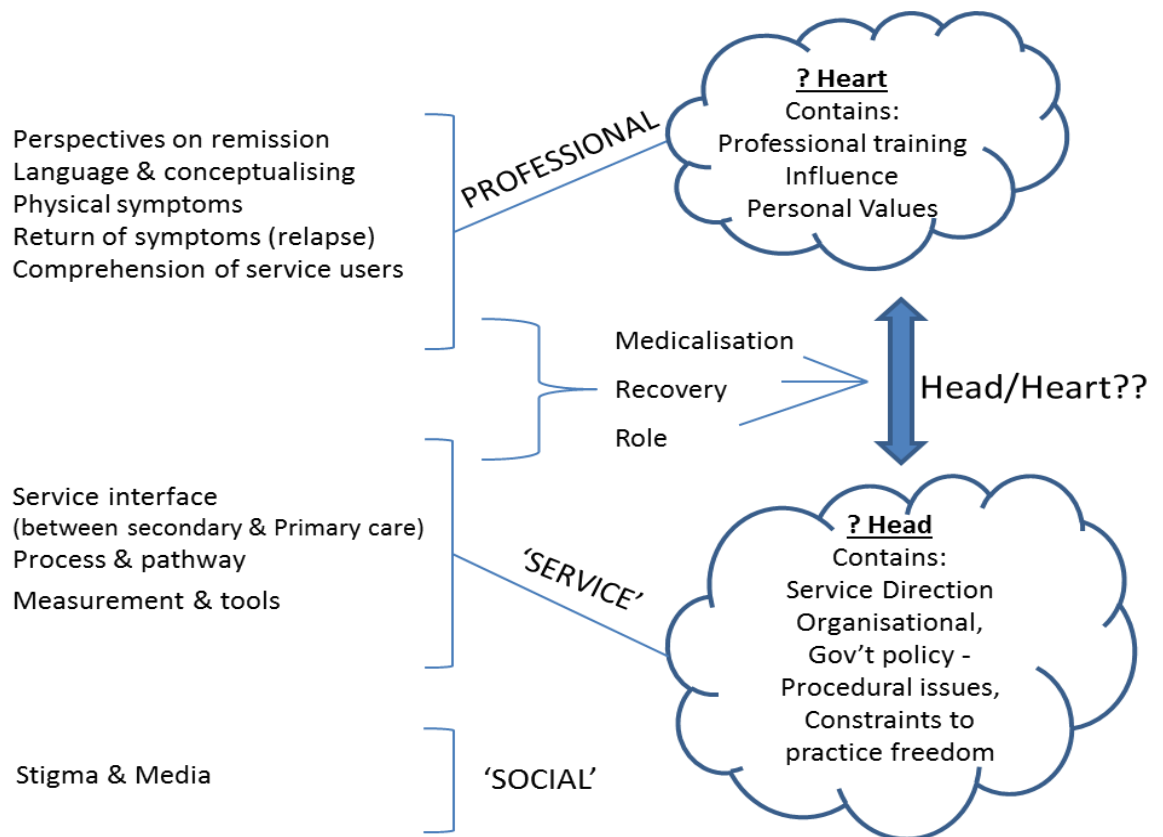
“I think in certain areas having worked on different patches in the Trust ermm I think it is different in different areas and I think that some of it comes from the trust that primary care has in the mental health services that are servicing it (88106- 365)

When this theme was introduced it was acknowledged that there are differences within the teams regarding their interface with primary care. This theme is very important in relation to what can be achieved for service users if remission is applied as a criterion in respect of the recovery journey for a person.

6.4 Head &/or Heart Debate:

In further analysis of the data a method of constant comparison¹⁷ was employed. Whilst employing this method, of constant comparison, with the data from phase one a diagrammatic representation was developed in an attempt to develop further clarity (Figure 12).

Figure 12. Representation of 'Head and Heart'



The representation in Figure 12 illustrates a similar grouping of themes under the three headings of Professional, Service, & Social, as initially observed in the Venn diagram (Figure 11). Displaying the themes in this format allowed them to be appreciated as derivations from either 'the head' or 'the heart'. It has been suggested by Goleman (1995) that we have two minds, a rational mind that thinks and an emotional mind that feels. However, philosophers, Hegel and Dewey were opposed to dualistic and dichotomous thinking, including that between cognition and emotion despite this characterising the mainstream of ethical theory beforehand (Miller *et al*, 1996). Upon reflection, it is perhaps a more colloquial expression or

¹⁷ The constant comparison method is "A method of analysis that generates successively more abstract concepts and theories through inductive processes of comparing data with data, data with code, code with code, code with category, category with category and category with concept" (Charmaz, 2014, p342).

discourse within healthcare to refer to the aspects of the head and the heart. This may be consequential as little of our lives are governed by logic alone, generally, as our emotional world motivates our decisions and actions (Freshwater and Stickley, 2004). Baker (2013) associates the head with 'knowledge' and 'science' whereas; the heart is associated to 'feelings' and the 'art'. The same can be appreciated in this figure as; the themes allied to the head are derived from service direction, organisational perspectives including government policy and procedures, and constraints to practice freedom. When employing the term 'practice freedom' it is in the context of the practitioner utilising autonomy and having authority to be creative and flexible in their delivery of interventions and approaches with service users and carers in the respective teams, as opposed to being stifled and contained by the procedural restraints imposed by the organisation or team. This can then be akin to Bakers' (2013) concept of knowledge and science as they are driven more from the head in a cognitive manner. The themes allied to the 'heart' are derived from professional training, influence of colleagues & peers, and personal values and could be aligned to 'feelings' or 'art'. One cannot describe the art and science of nursing without reference to emotions (Freshwater & Stickley, 2004). Whilst only a small number of the participants in this study are nurses this would be applicable across all areas of healthcare, especially when working with people with a diagnosis of schizophrenia, due to the challenging nature of this role. Social conduct is required in all aspects of healthcare and as described by Gerth & Mills (1978) we conduct ourselves in order to meet the expectations of others. This could be performed using the head, heart or a combination of both, but if strongly driven by the head then it could well be the expectations of the organisation that are more influential. In this case the practitioner may succumb to a bureaucratic approach. Max Weber states that bureaucracy maximises uniformity and secures continuity and its pyramidal structure implies a career ladder (Poggi, 2005). In addition Weber (1922, *cited in Poggi, 2005*) described three forms of social action and this may share some resemblance with the head/heart representation;

- Traditional Action (motivated by customs and tradition) =? Head
- Effective Action (motivated by emotions and impulses) =? Heart
- Purposive-Rational Action (motivated by conscious methodical calculation of available means of achieving desired ends) =? Combination of Head & Heart

Weber's hermeneutic tendency allowed him to postulate that in order to survive human beings strive to make sense of the world, this is achieved by attaching meaning to the innumerable, contradictory aspects which reality presents (Poggi, 2005).

Baker (2013) suggests that when we attend to our own head and heart we then have increased ability to care effectively for our patient's head and heart, and they should be treated as both and 'not either or', again perhaps rejecting the dualistic approach. From the perspective of ethical theory this may be viewed differently. The 'head' or 'science' aspect could be seen as a development of deontology. Contemporary deontologists are less inclined to suggest or demand 'moral law within' as postulated by Kant, but nevertheless social contract theories are developed and often expressed as rights, an example being the right that everyone has not to be harmed without good reason (Nolt, 2015). By contrast and in accordance with the 'heart' or the art perspective would be consequentialism. Rather than objectively determining what is right consequentialism is influenced by the good or bad that would be the consequence of our actions (Nolt, 2015), including those felt by the service users when in receipt of care or input.

6.5 Phase Two (Service Users and Carers):

Data generated from phase two originated from 17 semi-structured and in-depth interviews with people with a diagnosis of schizophrenia (10) and carers of people with a diagnosis of schizophrenia (7). The quotations utilised from the interviews are distinguished between service users and carers by the use of 's' (service user) and 'c' (carer) prior to the participant code and line number from the original transcript. The participants were all associated with the same two community mental health teams as the participants (practitioners) from phase one of the study. The data yielded 12 themes with eight of these containing sub-themes as can be seen in Box 4 below.

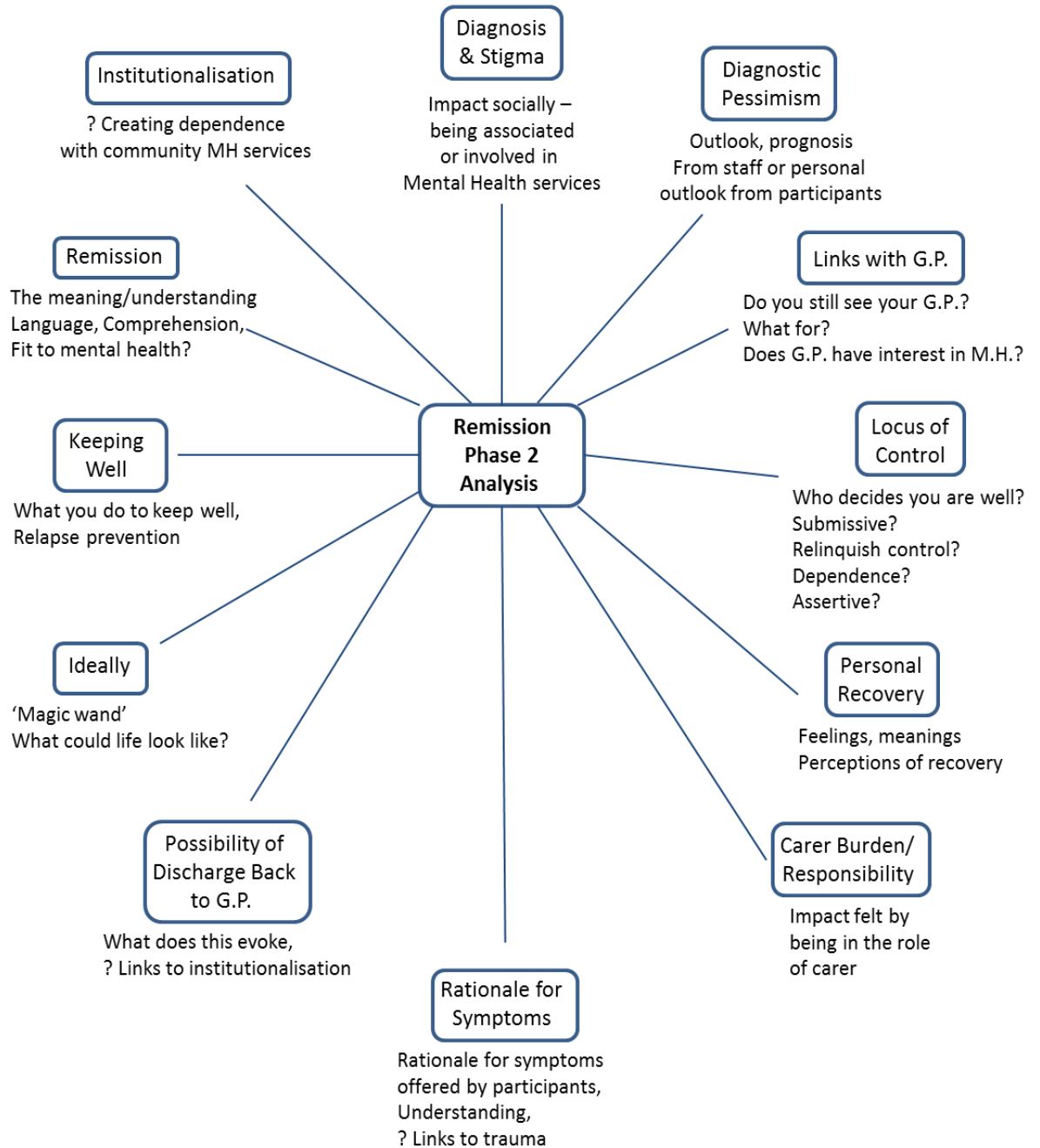
Box 4. Phase Two Themes and Sub-Themes

<u>Phase Two Themes & Sub-Themes</u>		
<u>Remission</u>	<u>Diagnosis & Stigma</u>	<u>Carer Burden/Responsibility</u>
Care team using the word 'remission' Have heard of 'it' but vague/confusing Heard of it & got a conceptual rationale In relation to mental health In remission?	Employment Social stigma	
<u>Possibility of Discharge Back to G.P.</u>	<u>Ideally</u>	<u>Links with G.P.</u>
Accepting Resenting	Social (vocational) Status Quo Symptoms	
<u>Institutionalisation</u>	<u>Locus of Control</u>	<u>Personal Recovery</u>
Practitioner as a friend Completeness Discharge Anxiety	Healthcare Team Self or Others	
<u>Keeping Well</u>	<u>Diagnostic Pessimism</u>	<u>Rationale for Symptoms</u>
Carer & Family Intervention Medical & Service Intervention Personal Coping & Management Strategies Social Intervention	Self Service	

In order to understand with a little more clarity what areas were explored within each theme Figure 13 (below) illustrates some of the areas and aspects investigated within each theme, this will be explored in much greater depth theme by theme.

Figure 13. Initial Themes from Phase Two (with detail)

Initial Themes From Phase Two Analysis



6.6 Detailed Findings by Theme (P2):

The themes will be explored in detail under their respective headings.

Remission:

As in phase one, the main issue of remission needed to be addressed and whilst it was naturally a theme it contained the sub-themes of;

- Care team using the word remission
- Have heard of it but vague/confusing
- Heard of it & got a conceptual rationale
- In relation to mental health
- In remission?

Care team using the word remission:

The content of this theme supports that highlighted by practitioners, that remission is not so much a word employed directly and that the preferred option would be to use the word recovery with service users. One carer denied hearing the term remission or recovery used by the staff who visited the person she cared for. As a consequence it would appear that if the concept of remission was to be employed, in relation to people with a diagnosis of schizophrenia, it would be new to service users, carers and practitioners.

Have heard of it but vague/confusing:

The meaning of remission is covered by this and the next sub-theme, as some service users and carers had heard of remission. Some were able to articulate what it means to them and a few were less able and perhaps a little confused by the term.

"I've heard of the word but ... I, I don't know what it means" (S4405-47)

"... remission, is it when you get, you're getting off with something, you get caught but you're getting off with something, that's remission to me" (S4402-81)

"Sounds like releasing you, freeing you, does that mean getting free?" (S5507-204)

Heard of it & got a conceptual rationale:

This sub-theme is illustrated by people who have an idea of what remission means and have a view of it in their own mind. The view that was expressed in relation to remission was closely associated with cancer.

"Its people recovering isn't it, is that what the word means?" (S5509-79)

This response above may be one of the principal misconceptions among literature but for the layperson it may appear to be a common sense view. Others relate it straight to the most heard of examples, that of cancers;

"Is that people who have cancer and try to get better and there's things like that aye" (S5511-108)

"Yeah, it's like cancer when it goes into remission and it's not causing you a problem but it can come back again, but yeah it, it's a temporary recovery as far as I know" (C2204-40)

A number of participants had observed a closer relationship with people experiencing remission, and in these cases it was in relation to cancer, as one participant identified;

"My sisters friend she had cancer and she went through remission for about two or three years, but then it came back and obviously it happened, she died" (C2205-75)

In relation to mental health:

Generally participants had not heard of remission in connection with mental health. However, in relation to whether they felt that remission could be applied to mental health some participants agreed;

"I think that remission is a good idea ... I would feel if I was classed as that I suppose, in remission, that there was some progress" (S5510-136)

Only one carer responded in a positive manner when asked if remission may be applied to mental health;

"Yeah, I don't see why not [Yeah?], Yeah, I don't see why not" (C2204-42)

In remission?:

Ascertaining the feelings of the participants in regard to whether they feel as if they were or had ever been in remission was relevant following the discussions within the interview around general aspects of remission. Some participants were able to articulate this, although all had a different perspective as the comments state;

"It's hard to say whether my condition is in remission 'cos sometimes ... the negative symptoms can be worse" (S5512-161)

"I think that for instance, especially with myself with me having long periods of wellness and I do think that I do have ... long spells of wellness I think that they could be classed as remission stages in my mental health" (S5510-92)

"Aye, I think the nearest I can say to remission is when I first started the hearing voices ['hearing voices' group] ... that sort of gets you into that remission where you are not staying in bed all day" (S5511-106)

One participant was able to feel as though they were in remission, but not recovered;

[Interviewer] So would you feel like you are in remission now?

"Yeah!" ...

[Interviewer] And in terms of recovery then would you say you've recovered?

"No not fully" (S4407-113)

Other participants were clear and in some cases adamant that they had not been in or experienced remission. Carers also commented upon service users going into remission;

"Yeah, she's been fine for what? ... months now, yeah, yeah"

[Interviewer] So would you call that remission? ...

"Yeah ... schizophrenia is probably something that you are going to have for the rest of your life, I don't think it can be cured ... I think it's just something in your makeup, in your genes or whatever" (C2204-43)

This comment highlights a very interesting perspective, that; schizophrenia is a non-curable disorder yet despite this there are periods where the service user may be asymptomatic. Therefore, as a consequence relapse must be expected, otherwise this would progress to be symbolic of recovery (and it has already been stated that it is not curable).

*"I don't know whether ***[name withheld] goes into remission or he's ... with the physical as well as the mental health side you don't know which*

bit's coming out of kilter...There are periods when he is better but I wouldn't say that he's in remission" (C2205-98)

This comment raises the issue of confusion as to the primary causation of illness, is it physical or psychological? But either way this would not be classed by the carer as remission. It is maybe not surprising that there are differing views of remission and what this means to people at a personal level. Remission is not a word that has been utilised with service users, as was suggested by the practitioners too. Therefore only a few could state that they had experienced anything resembling remission at any time since being diagnosed.

Diagnosis & Stigma:

According to Penn *et al* (1999) the negative views held by the general public towards people with schizophrenia is well documented. Goffman (1963, p13) refers to 'stigma' as "... an attribute that is deeply discrediting". The issue discrediting people is the diagnosis of schizophrenia and having to admit to needing involvement of mental health services. This theme was split into two sub-themes;

Social Stigma:

For one participant the diagnosis was welcomed but the social aspect of stigma was a concern;

[Interviewer] And that was the first time they said you have schizophrenia?

That's right, yeah. It was a bit of a relief actually when they said that, you know"

[Interviewer] Was it?

"Yeah, because they didn't know what was wrong with me and I just said to the doctor 'what is wrong with me?' and the doctor said you've got schizophrenia ... so there you go"

...[Interviewer] Did you have any other thoughts when he said that?

" Yeah, what people are going to think about you, you know are you mad or something"

[Interviewer] ... and has that been true? Do people think that?

"My mates from school don't bother with me now since they knew, nobody bothers. I have got one friend that's the next door neighbour, they all disown me type of thing, you know" (S5509-99)

In this manner, it has been highlighted that people with a diagnosis of schizophrenia have to tolerate much more than the illness itself (Hocking, 2003). Social inclusion has been recognised as an important aspect of recovery (Clifton *et al*, 2013). Therefore social exclusion would be expected to have the opposite effect and be the cause of relapse rather than recovery. If admission to hospital is necessary and becoming an in-patient a requirement, this too can cause anxiety and worries regarding stigma and fear of being labelled;

"It's not a natural environment for people is it? [a hospital ward], you know and it can ..." (S5507-171)

[Carer interjects] *"See, well I know him, the way he is and you are going into them places you see them all shaking and stuff like that"* (C3307-173)

"There's one [other service user] said what are you in here for drugs? I said I am not, I have had a nervous breakdown!" (S5507-174)

The element of self-preservation is apparent in this case, as a diagnosis of drug abuse may appear to be less acceptable than a 'nervous breakdown'. Nevertheless, most people with a diagnosis of schizophrenia will unfortunately receive some degree of stigmatisation (van Zelst, 2009; Rusch *et al*, 2011).

Employment:

Pilgrim and McCranie (2013) illustrate that key indicators, such as employment, have come to the fore to monitor 'functional remission'. One participant was able to articulate how she felt in relation to employment and stigma;

"I'd like all the circumstances around my mental health to be totally deleted and me never ever to have anything like that on my record ever, so that I could actually go to an employer err yeah an employer and say I have never suffered with mental health issues ... I would actually like to work in the mental health field or in child protection" (S5510-187)

This participant felt that disclosing information about previous mental health problems was reducing her opportunities for employment. She goes on to explain her strategy for this;

"... getting to know people and then eventually revealing to them that I actually have a mental health illness [yeah] and I will always do that but I let them get to know me first before I actually tell them and some people you can see are totally shocked" (S5510-211)

Stigma continues to have the negative impact that has been documented as the participants shared their views. Some made attempts to overcome this by employing strategies that attempts to preserve and enhance a degree of dignity or self-preservation.

Carer burden/responsibility:

“Mental illness is, by its nature, a familial experience” (Kinsella, *et al* 1996, p24). As a consequence carers and family members will be affected by having a person around who has been given the diagnosis of schizophrenia. Lefley (1987) identifies that symptoms and time in hospital can be a source of burden for families. Despite this there were not a lot of issues expressed by carers, but a male carer (husband) felt a little restricted to perform his own activities;

“... She’s clingy aren’t you? You’re clingy you know errm I go out to work and she doesn’t see anybody else until I get back home” (C2207-149)

Another aspect highlighted from a female carer (wife) was having to ‘suss’ out how her husband was before planning the day;

“I have to get him up first ... if he’s in a good mood, if he’s feeling OK we can go somewhere” (C3306-232)

By comparison a male carer (partner) expressed anxiety and strong concern that he may ‘sleep through’ if he is needed in the night as he and his partner sleep in separate rooms due to both having different healthcare needs. A female service user acknowledged the role her husband plays, and states;

“When I was bad, I was really bad, I mean I don’t know how my husband really coped with me at home, I mean I take my hat off to him because I think if, had the boot been on the other foot I don’t know if I would have been strong enough to have him at home” (S5510-105)

Mental illness continues to have an impact upon family and carers as the participants have highlighted. This is also acknowledged in the literature; Considerable stress is experienced if there is a family member with schizophrenia (Keen & Barker, 2009).

“Sometimes I lose my temper, and last year I really did lose it but there was lots of things of my own going on. I had been diagnosed with a bad heart and that, that takes its toll until you get your head around it doesn’t it?” (C2205-167)

Carers are, obviously, not without their own healthcare issues and this too can compound the problem and the associated stress of caring.

Possibility of Discharge Back to GP:

Some participants were more accepting of the idea of being discharged back to their respective GP when it was raised in the interview. It was made clear, when discussed, that this was a hypothetical proposition and this had no bearing on any care they were continuing to receive or plan of care presently in situ. The participants that were more resenting of being discharged back to the care of their GP demonstrated traits that may be indicative of institutionalised behaviour although this correlation was not assessed directly as part of this study. As a consequence there are two sub-themes identified; *Accepting* and *Resenting*.

Accepting:

Both service users and carers expressed some positive feelings to being discharged to their GP's, however they were in the minority compared to those resenting potential discharge. Participants expressed it as a step in the right direction, in respect of their desire to recover. Another participant stated in response to being asked about potential discharge to the GP;

"I'd probably feel okay to be honest" (S5512-67)

The rationale behind this was that the GP held mental health as their special interest and the participant felt that they had a good relationship with the GP. However, there was a little anxiety highlighted by the participant when they added;

"...but I probably, I probably prefer to have a contact with my CPN even if it's only occasional just to know the support is there really" (S5512-69)

One participant, who is a carer, exclaimed it would be *"Brilliant!"* (C2201-80) as this would be indicative of movement in the right direction.

Resenting:

Some of the reasons provided for resenting the possibility of discharge back to the GP appear to be that the participants do not perceive themselves as being well enough presently. Emotional responses to illness, health-related behaviour and relationships with health-care providers are shaped by beliefs that are held by the person in relation to their illness (Salmon, 2002). This may account for some of the responses offered. It does become a cause for contention as, illness beliefs incorporate social interactions in addition to psychological dimensions and overall in mental health 'disease labels' are much more controversial

(Kinderman *et al*, 2006). The participants may well have missed the point of 'if deemed well enough' in the question. This may also have been caused by anxiety around potential discharge. The responses are varied as participant's attempted to describe how they perceive it would affect them;

"Couldn't be. Impossible ... I would end up in hospital again" (S4402-29)

"Oooh phew, [draws breathe through teeth] Well, it would be a log falling on top of my head I think" (S5511-38)

"No, it would solve nothing" (S5506-50)

Concern was expressed regarding the competency of the GPs in relation to mental health too;

"... I don't think he is trained enough in that particular field" (S4407-52)

"I don't think that the GPs have much training in it" (C3306-173)

These responses were from unrelated participants from different areas despite the similarity in response. Some participants are happy with the present package of care and have been affected by unsuccessful previous attempts at discharge;

"...well I am happy now at the moment" [Service user] (S5507-60)

"I think he would be more disappointed" [Carer] (C3307-62)

"I'd be disappointed" (S5507-63)

"Yeah he would because it happened to him a few year, I am going back a lot of years and it did make him go back over, so he ended up ..." (C3307-64)

"... Oh I flipped again, didn't I?" (S5507-65)

"Yeah he ended up back in hospital" (C3307-67)

For carers some of the concern regarding possible discharge back to the GP is around the perception and ability of coping and two responses identify this;

"I would be scared" (C2205-31)

"Oh, I would be worried" (C3309-23)

This theme was particularly pertinent as historically this issue has not been discussed with service users or carers. It would also be foolhardy to attempt to pre-empt any response in advance of asking the person concerned. Another consideration may be, after years of being encouraged to 'engage' with services and strong messages regarding the need for 'compliance' and 'concordance' it may be no wonder that service users remain in that particular frame of mind and see it as something strange to be offered discharge.

Ideally:

This theme was generated from responses based on the ‘Miracle Question’ which is based in Solution-Focused Brief Therapy¹⁸. In essence, it asks what things could look like in a perfect scenario. It offers the participants an opportunity to look into the future and share any desires they may have in respect of how life may be. This generated three sub-themes of status quo, symptoms and social (vocational).

Status Quo:

One participant did not want to change the way things were, it was not wholly clear what the benefits were of his partner staying the same and as a carer his wishes were;

“... just for her to stay like she is” (C2204-103)

The partner of this carer also feels presently that she is well, which may account for his feelings in respect of this. Daring to dream of something better can prove difficult for some people and the fact that at present things are going OK may mean that some people adopt a ‘fingers crossed that it does not get any worse’ approach to life.

Symptoms:

The removal or reduction of symptoms is something that participants felt would be indicative of an ideal scenario, a little more emphasis was placed on the positive symptoms in particular that of hearing voices;

“Life without the voice I think ... life without mental illness” (S5509-152)

“... just get rid of the voice” (S5511-204)

One participant was more explicit and disclosed about the torment that the voices cause her and how in an ideal scenario she would be free from this;

“I would like to go to bed on a night and sleep, you know, never be woken up with the fear that something is happening to one of my kids or the voice telling me that, you know, something’s happening to one of them and me having to ring them. I would like to have no voices ever, that would be great!” (S5510-198)

¹⁸ Solution-Focused Brief Therapy is one of the most popular and widely used approaches in psychotherapy. Previous solutions and exceptions to the service users’ problems mean that this approach is based on resiliency (Trepper *et al*, 2006).

Negative symptoms were also mentioned;

"I guess to be able to concentrate more ...those two things I would like to get back is my concentration and thoughts not to race" (S5512-272)

This participant was aware he was referring to negative symptoms and added;

"... so ideally have less negative symptoms really, so I can get on and do a little more" (S5512-275)

Social (Vocational):

It has been strongly advocated that employment, worthwhile activity, and social interaction has a positive impact upon recovery (Davidson, 2003; Artazcoz *et al*, 2004). This was also a sub-theme generated by the participants of this study. Some of the responses also made reference to paid employment;

"I would be out working, wouldn't I?" (S4402-172)

"... I would like to be back in the work, ... to be back in the workplace" (S5510-195)

For other participants being able to return to enjoyable activities, whilst this is characteristic of anhedonia it can have a great impact on social activity;

"... to do my artwork every day, which I obviously love doing. It would bring a lot of enjoyment from life to be able to do that" (S5512-271)

Others, perhaps due to their age, may be looking at regaining the social aspect of activity but this came more from carers than service users as it may be easier to view the impact from an objective standpoint ;

"I'd want to see her back to normal like she used to be ... and get her out of the house" (C2201-153)

"Oh, it would be great wouldn't it? We would go out together ... it would be like years ago" (C3309-109)

The responses for this theme were practical and not fanciful or un-realistic in nature, most participants had a good idea of what they would like the future to look like for them. This would bode well in terms of recovery as the true goal is moving forward (Pilgrim & McCranie, 2013).

Links with GP:

This theme unearthed some interesting comments regarding continued links to the GP despite being in secondary mental health services. It has been clearly reported and acknowledged that people with a diagnosis of schizophrenia may not receive some general health checks, compared with people who do not have this diagnosis (Roberts *et al*, 2007). This is now part of a campaign by the organisation Rethink Mental Illness (2014) who states that less than 30% of people with schizophrenia receive a basic annual physical health check. This is not solely the responsibility of the GP or primary care but nevertheless this is an alarming statistic. The majority of participants still went to see their GPs at some point, but the majority also acknowledge that this is primarily for physical issues, rather than mental health. There were a variety of responses indicating this;

“He [GP] goes by my shakes; if I am shaking he knows that I am not so well ... it’s just the tablets, he said” (S4402-160)

Some participants found that the GP was happy to leave the mental health aspect to secondary mental health services and did not address this at all. In one instance the GP had felt that the area of mental health was not an area he felt comfortable with;

Well ... one of the doctors once said to me..., we were talking and I mentioned it about the sort of voices and he said ‘Woohoo hoo woo! That’s out of my league’“(S5511-176)

This statement echoes a finding from a research study by Lester *et al* (2005) who found that most healthcare professionals felt that the care of people with serious mental illness was too specialised for primary care.

One participant felt comfortable and able to talk to the GP;

“You are able to say things... as well about your mental health, anything that’s troubling you” (S4407-65)

Overall there are differences in the services that people receive from their GP and also the way this is interpreted by service users and carers. Some service users appear less interested in approaching the GP while mental health services are involved, primarily as they feel that the GP does not know or understand them as well as the care coordinator or mental health team. If the service user feels that the GP does know them well enough this fosters a better relationship;

*“... so I went to see Dr *** [GP] ... because he knows me, he knows I’ve got a good understanding of my condition, you know what I mean” (S5512-260)*

Perhaps the feelings expressed are not so exclusive to service users with schizophrenia but could be a common feeling across all communities.

Institutionalisation:

Despite all of the service users who participated being in a community setting, and not in hospital, the responses continued to hold aspects that allowed this theme to develop. The theme was further divided into three sub-themes.

Practitioner as a friend:

This sub-theme developed due to practitioners being encouraged to 'engage' with service users to work in a 'collaborative' manner (Chapman & Chessum, 2009). This may be misconstrued by some service users as friendliness rather than a therapeutic relationship;

"Yeah, she does everything for us ... helps sort things out" (S4402-54)

Service users do not embrace all practitioners in the same manner as this participant added;

"She makes you feel comfortable ... the one before, she used to talk to you like you were a five year old kid ... it used to irritate me" (S4402-96)

I am sure that practitioners appreciate the aspect of professional boundaries within their roles, but sometimes it may be required that they check the perception of the service user in relation to this 'therapeutic' relationship so as not to foster dependence or induce reliance on services. Benner & Wrubel (1989) describe this role taken by the practitioner as the 'omnipotent rescuer', whereby the practitioners would be over zealous in anticipating the problems and dealing with them, whilst at the same time failing to perceive the resourcefulness of the service user. However, Stein-Parbury (2014) describes this as a 'connected relationship'. This indicates that both the practitioner and service user would appreciate each other as people initially and this could lead the practitioner to work 'above and beyond' the call of duty (Morse, 1991); and the service user would therefore describe this kind of relationship as 'friendship' (Fosbinder, 1994).

Completeness:

The sub-theme of completeness describes the feelings that participants made about having or keeping secondary mental health services in their lives, otherwise it would appear to be or feel incomplete.

*"I like coming to *** House [Community Team Base] you know ... I do mate to be honest" (S5509-35)*

So if that wasn't here you feel as if there was something missing?
[Interviewer] *"Something missing in my life, Yeah!" (S5509-40)*

Even when considering parting from secondary mental health services when well, one participant expressed an attachment;

"No, I wouldn't, I think a little bit more about them and I am quite attached to all of them ... and I think more of them than just getting rid of them when I am OK. I still like them in my life" (S4407-190)

Discharge Anxiety:

The interview provoked some concerns from participants that there may be an ulterior motive, a way of facilitating discharge in an underhand manner. These questions and anxieties were quickly addressed and reassurance was offered. One of the participants' asked;

"I am just wondering with the questions ... there's nothing in the pipeline with the Hearing Voices [group] going to be scrapped is there?" (S5511-260)

Some participants had experienced discharge from secondary mental health services previously, yet this induced further anxiety should it occur again;

So when services ... discharged you then it wasn't a good thing?
[Interviewer] *"No!"* What was it that made it a bad thing? [Interviewer]

"I don't know I just used to get agitated and stuff didn't I?" (S5507- 74)

It was not only the service users who felt this anxiety, a carer commented;

So, being monitored by mental health services gives you that reassurance? [Interviewer]

"Oh Yeah!, Yeah I think if they were going to do that they would have to monitor her fairly regularly" (C2204-25)

Practitioners are encouraged to engage service users and form therapeutic relationships (Barker & Buchanan-Barker, 2009) but unfortunately sometimes this may be misperceived by

the service users and/or carer. This in turn can foster dependence and reliance on services and perhaps also particular practitioners. This is in turn a form of institutional behaviour that is not conducive in the long-term and does not foster the sentiments of a recovery focused approach.

Locus of Control:

It became apparent during the interviews that participants would express who they felt or perceived to have the locus of control over their wellbeing. Locus of control is the attribution of the state of their health to either themselves, powerful others or chance (Marks *et al*, 2011). This is derived from Rotter's (1966) original conception of the locus of control, from his social learning theory. This was subsequently reconceptualised by Levenson (1974) and the concept dissected into control by powerful others and control by chance or fate. Whilst there were no clear references, made by participants, of leaving the state of their health to chance. The clear sub-themes of 'healthcare team' and 'self or others' were generated and this is more in keeping with the outline by Marks *et al* (2011).

Healthcare Team:

As suggested by the heading, participants identified members of the healthcare team as the people they felt held the decision whether they were well or not. The responses were not hostile or negative in any way; participants were resigned and accepting of the fact that in their opinion these people (healthcare staff) made the decision. This may be based on the notion suggested by Davidson (2003) that historically people were 'lost to the illness' and as a consequence others have assumed responsibility to make decisions and speak on behalf of that person.

Some examples, when asked who is responsible for deciding if you are well or not;

*"I think ... what's she called ... oh yes Dr ***** [consultant psychiatrist]"*
(S4405-27)

*"That would be errr ***** [Community Mental Health Nurse]"* (S5509-52)

Carers also expressed similar views;

"You know what I mean, when you go to the doctors or the police they decide if he's well or not" (C3306- 189)

*"It's errr the CPN, the doctors at ***** House [Community Team Base] you know"* (C3309-42)

Self or Others:

None of the service users expressed strongly that they took control and decided if they were well or not. One participant identified himself as being in control, but the language employed did not demonstrate true conviction in this belief;

"... I hope it's myself you know" (S5511-89)

Another participant alluded to this but was resigned that others were also involved and family were an important consideration too;

"Well, err Hmmm I would like to say me [laugh] I don't think I am totally top of the tree, I would say the first port of call is my family, because I'm within the family unit" (S5510-76)

The participants did not mention whether the practitioners concerned with their healthcare made attempts to promote independence and autonomy for service users. This may have had an impact upon the perceptions of who decided whether they were well or not, as in a truly collaborative approach by practitioners this could ultimately facilitate increased responsibility for the service user. Davidson (2003, p61) states that we could ask, "In what ways do you influence the course and outcome of your disorder?" Davidson (2003) adds that we do not ask this for a variety of reasons. Irrespective of the reasons, this may have been asked of participants to allow further interpretation from the issues in this theme.

Personal Recovery:

The theme of personal recovery is pertaining to the thoughts and feelings of the participants themselves rather than aligning the comments to that of a definition of personal or any other type of recovery. Some participants expressed a feeling that they had recovered;

"I think I've recovered ... I honestly do" (S4405-108)

This participant did not explain further the context in which recovery is viewed; otherwise one could ask why they are continuing to be involved with mental health services.

Some participants had a different view to others around them in relation to recovery;

"Some people think I've recovered [very light laugh] but in theory I haven't really, 'cos I've still got problems I just ... I'll push myself because I am actually very driven" (S5512-168)

Sometimes it is the healthcare system and treatment that has a major role in whether people may feel as though they have recovered or not;

“At the end of the day who wouldn’t want to be classed as being well ... it’s what’s classed as being totally recovered, I meant to take, to stop taking your tablets to me would be ... my ultimate goal” (S5510-150)

In some instances, and this case a carer, people develop a belief that enables them to progress, despite being informed that things may not improve;

Where does that belief come from ***** (name withheld) that she will get better? Is it something you have read? [Interviewer]
“No, no just something I feel for myself ... That I believe in myself ... Although I have been told different!” (C2201- 47)

Sullivan (1994) identifies that people in recovery use faith and belief that can be spiritual in nature and this appears to also be adopted, in some instances, by carers &/or family too. There are many aspects associated to recovery, and the views expressed by participants support the notion that recovery is an individual issue and is characterised by a hope for improvement (Pilgrim & McCranie, 2013); however it cannot be forgotten that there is also an impact felt by carers and family members.

Keeping Well:

As this theme developed from the data generated it reflected aspects of relapse prevention/management and resilience. The theme title ‘keeping well’ does however encapsulate the fuller aspect of responses. This theme generated four sub-themes: Carer & Family Intervention; Medical & Service Intervention; Personal Coping & Management Strategies; and Social Intervention.

Carer & Family Intervention:

The family are important and can be “highly facilitative in the recovery process” (Stacey *et al*, 2012, p153). Therefore it is understandable that comments from participants echoed this too;

“If it wasn’t for her [wife] I would be in hospital now” (S4402-17)

“Just the support of my family ... she [partner] always reads up on different things like when I was diagnosed with schizophrenia ... so she knows what it’s about” (S5506- 47)

Sometimes, as in life generally, family can be estranged and this can cause tensions;

I guess one of the most important things is like access to my children, because I have got two boys” (S5512-3)

However, not all participants shared information with the family;

“I haven’t really told them about ... my family you know. I haven’t told them about my illness really” (S5509- 15)

Carers highlighted some of the interventions they delivered and general ways of coping;

“I try and take her out as much as possible, even if it is just going down to Pacitto’s and having an ice cream” (C2204-4)

“I just errm look after him the best I can” (C3309- 6)

Medical & Service Intervention:

This sub-theme generated some responses in connection with medication and the belief of compliance. This could possibly be that service users are informed of this being ‘good practice’ since receiving the diagnosis of schizophrenia. Kinderman *et al* (2006) reports researchers are studying illness beliefs of people with mental health issues using approaches developed from physical illness. If this is the case then it may be understandable that from a clinical perspective where symptoms may be over pathologised that medication is seen as the primary option or hope of improvement.

“I think it’s the tablets you know what helps” (S4405-4)

“Well the main thing is my regular supply of tablets and me taking the right dosages” (S4407-3)

This was reinforced, by some, due to previous experiences coming off medication;

“The only time she has been really unwell is once when she wanted to come off Clopixon and another occasion it was an Asian doctor decided she’s been on them too long and she took her off Clopixon” (C2205-6)

Group activities such as the ‘Hearing Voices Group’ are seen as beneficial to service users. Longden *et al* (2013) state that self-help groups, such as the Hearing Voices Network, are beneficial and provide supportive relationships which are of considerable value as discussions can take place without fear of censure or prejudice.

“The hearing voices group, I go once a week” (S5509-4)

It was also identified that the healthcare staff assist in keeping people well too;

“They are very supportive there, whenever I need one of them one of them will be there for me” (S4407-33)

Personal Coping & Management Strategies:

Generally the coping strategies expressed and employed by participants are methods in which they keep occupied. People must be able to maintain a sense of self-esteem throughout an illness, but this is often threatened (Stein-Parbury, 2014). Resilience is often seen as the key to overcoming life events such as illness, and is seen as the process of adapting to traumatic events (Shackman, 2009). It has also been found that resilience is more of a common response than initially envisaged (Wessely, 2005). Some responses by participants may be seen as more adventurous than others;

“It’s just keeping myself busy ... So if I am busy then I am not thinking about the voices and things like that” (S5506-19)

“Just living a normal life in a normal environment ...and do a degree course at University...a BA in English” (S4407-9)

“I try and go out every day, I make myself go out...I have just come back from Rome ... it was only four nights and I really pushed myself to do it because I still have negative symptoms” (S5512- 22)

Social Intervention:

The recognition of being involved in some form of social activity/intervention was the tenet of this theme. Social networks are good predictors of overall health status and not just mental health (Milne *et al*, 2004). However, the responses from participants indicated more of the desired rather than actual interventions;

“When you’re in hospital everything gets taken away from you ...you lose your identity almost... but it’s gaining that back ... you can be part of the normal community again, you’re going to be normal, whatever normal is! [laughter]” (S5510-16)

“He used to go on a walking group and that calmed him down, but what he’s like now he can’t go on a walking group. I know it sounds daft but a sense of being as if you’re here to do something” (C3306-151)

Participants discussed and highlighted many things to enable them to ‘keep well’. Some of these things were accessible and some were less so. The primary issues raised were synonymous with present recovery focused literature.

Diagnostic Pessimism:

This theme came about from responses alluding to reasons and feelings that once given a diagnosis of schizophrenia that people were not going to recover. Perhaps influenced by the archaic concept proposed by Kraepelin, many people still have a view that schizophrenia results in an inevitable decline in all aspects of a person's life (Cavelti *et al*, 2012a; Lysaker & Lysaker, 2010; Crow, 1997). This theme is sub-divided into two further themes 'self' and 'service' which are the areas covered in the responses from participants.

Self:

Not all participants expressed a negative outlook but there were some that did and they painted a very bleak outcome;

"I don't think you ever recover ... not fully from that schizophrenia it's always there looming away in the background it never goes anywhere"
(S4407-132)

This was also echoed by this particular participants' carer who was also interviewed and added;

"You don't recover" (C2207-132)

This collective view may mean that there is less domestic conflict as service user and carer share the same opinion and may not come into conflict over this. It also allows both people to attribute feelings or 'blame' onto an impersonal property. Opportunity to alter this perception may face difficulty due to this being the 'household' view in this instance.

Another service user demonstrated how fragile one may feel with these views. We began discussing his beliefs regarding aliens, which at times he appreciates is a delusion or 'unshared belief'¹⁹ for him, he continues to find talking about this rather upsetting;

"It's not going to change ... It gets to me man! [Crying] ... I just want it to go, I want rid of it" (S5507-403)

¹⁹ 'Unshared belief' refers to an expression used as an alternative to the term delusion, which is contested by some as pathologising in nature. 'Unshared' refers to the notion that others will not share the same belief, rather than it not being shared by the person experiencing this phenomenon. It is referred to by Read & Bentall (2013) 'Debates about delusions' (Box 11.4, p261) in Cromby *et al*, (2013).

Service Pessimism:

Some service users did not receive or believe the message that recovery is a possibility for them;

Does **** [care coordinator – name withheld] mention the word recovery or anything? [Interviewer] *“For me, doctors seem to think that I am never going to recover!”* (S4401-195)

Some of the pessimistic views (often couched in terms of prognosis by the practitioners) are given to the carers, almost in a benevolent manner so as not to raise expectations;

“Because you see now that she is errr like I say not very easy to errr I’ve been told as time goes on she will get worse ... she’ll get harder”
So who told you that? [Interviewer]

*“They told us that at ***** [in-patient unit] ... it was a few months ago”*

So how did that make you feel? ... [Interviewer]

“It made me feel sick really ... I believe really ... that she will get better”
(C2201-17)

Some of the pessimism may also be used as a coercive method of ensuring that people continue with a medication regime; this continues to reinforce a strong medical approach from a biased biological perspective;

*“I think that was Dr ***** [name withheld] had sort of said, if you don’t take the tablets it’ll come back”* (C2205-122)

There may be many reasons for a pessimistic outlook regarding potential recovery once given the diagnosis of schizophrenia, but it needs to be appreciated that this is not conducive for a recovery focused approach and that it can speak louder than the ‘recovery rhetoric’ voiced by services and practitioners alike.

Rationale for Symptoms:

Quite often people will develop a rationale for the symptoms they exhibit. Heider (1958) identified that the manner in which people explain the onset of disease, and in this case symptoms, derives from attribution theory. We develop our own personal theories about what is wrong when we become ill, this may be due to the ambiguity of symptoms and the elusive nature of the aetiology of the illness (Margereson, 2010). Despite symptom focus being a common orientation for practitioners involved in mental health (Graham, 2013), for some it takes time to develop an understanding. The generation of this theme developed from

discussing, in a relaxed and casual manner with service users and carers, the symptoms and when they first began. The responses offered were not reduced further into sub-themes as they are all very individual in nature and therefore held no common links, although trauma featured in some cases; which is in keeping with psychological theories of psychosis (Pilgrim, 2014).

“the first attack [of symptoms] was when I was 16 years old, I was just doing my exams at school like you normally do and I had troubles at home as you normally do when you’re at that age ... I went to pieces and errr I heard voices and stuff like that but it wasn’t checked out or dealt with then because nobody understood what was going on with me” (S4407-207)

Untreated symptoms of psychosis were probably more prevalent at those times, but fear of being incarcerated in the asylums was also a major concern if symptoms were disclosed. This fear could compound the experience;

“when I was 14 I was hearing voices ... I didn’t want any help but I could still hear the voices because they would have put me in the mental hospital and just forgot about me” (S5506-32)

People often had different ways of trying to make sense of the brain and parents may influence the way in which youngsters view things;

“Sometimes my mind runs away with itself like my Dad said, you’ve got two sides to your brain and it gets the better of the other side doesn’t it” (S5507-272)

Other traumatic events were mentioned, such as losing someone close and later having a family member dying bringing back the pain and grief. One participant described her husband’s traumatic rationale for his symptoms;

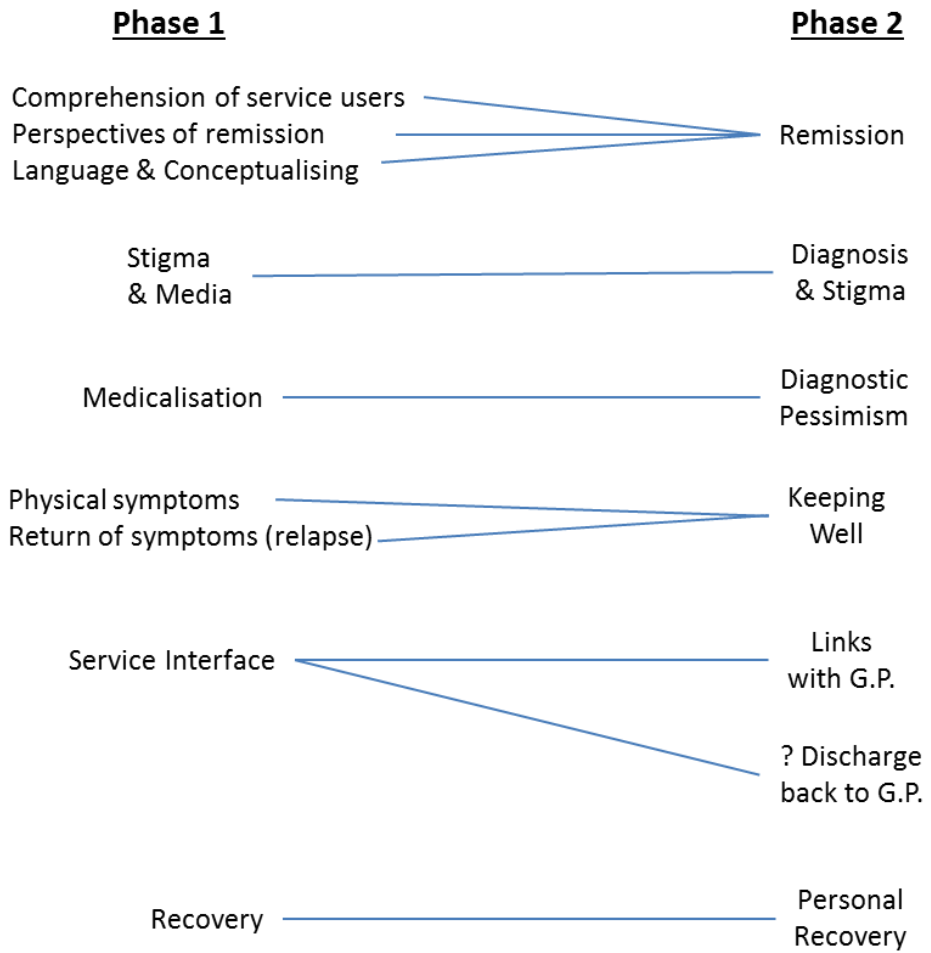
“He had a bit of anxiety before he got knocked down [ran over by a Land Rover] and he could control it but when he errm got knocked down it got worse and he was even getting spiders in his mouth at one time and he was screaming” (C3309-127)

All of the rationales offered for the onset of symptoms were different, with a good proportion coming from stressful or traumatic events. All contribute to the narrative accounts that service users are able to share, but do not always get the opportunity to do so.

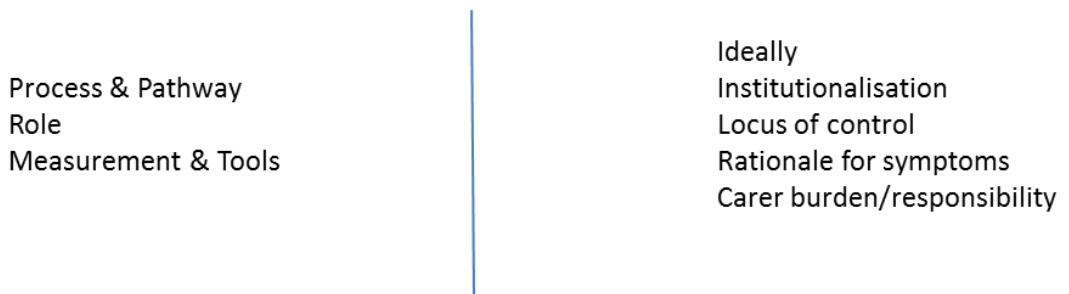
6.7 Comparative Analysis of Themes:

The themes generated from both sets of participants (phase one and two) yielded valuable insights around remission for people with a diagnosis of schizophrenia and beyond in many instances. Despite there being, coincidentally, the same number of themes generated in each phase there was a mixture of similarities and differences between them. The differences may be obvious and stem from the fact that one group of participants work with people in mental health service whilst the others are 'served' by these mental health services. Further analysis generated a comparative map of the themes as such in Figure 14 (below). Comparisons are drawn in relation to themes of a similar character; although the language may be different similar elements are present in these themes. There are also independent themes that could not be closely linked with themes from the other set of participants. Themes for practitioners that may be viewed as independent are; 'process & pathway', 'role' and 'measurement & tools'. Service users and carers may not have been exposed to these in the same way that practitioners would have been. Likewise, the independent themes from phase two ('ideally', 'Institutionalisation', 'locus of control', 'rationale for symptoms' and 'carer burden/responsibility') are more personal and carry subjective elements to them in a manner that practitioners may not have experienced at first-hand.

Figure 14. Map of Comparative Themes & Independent Themes



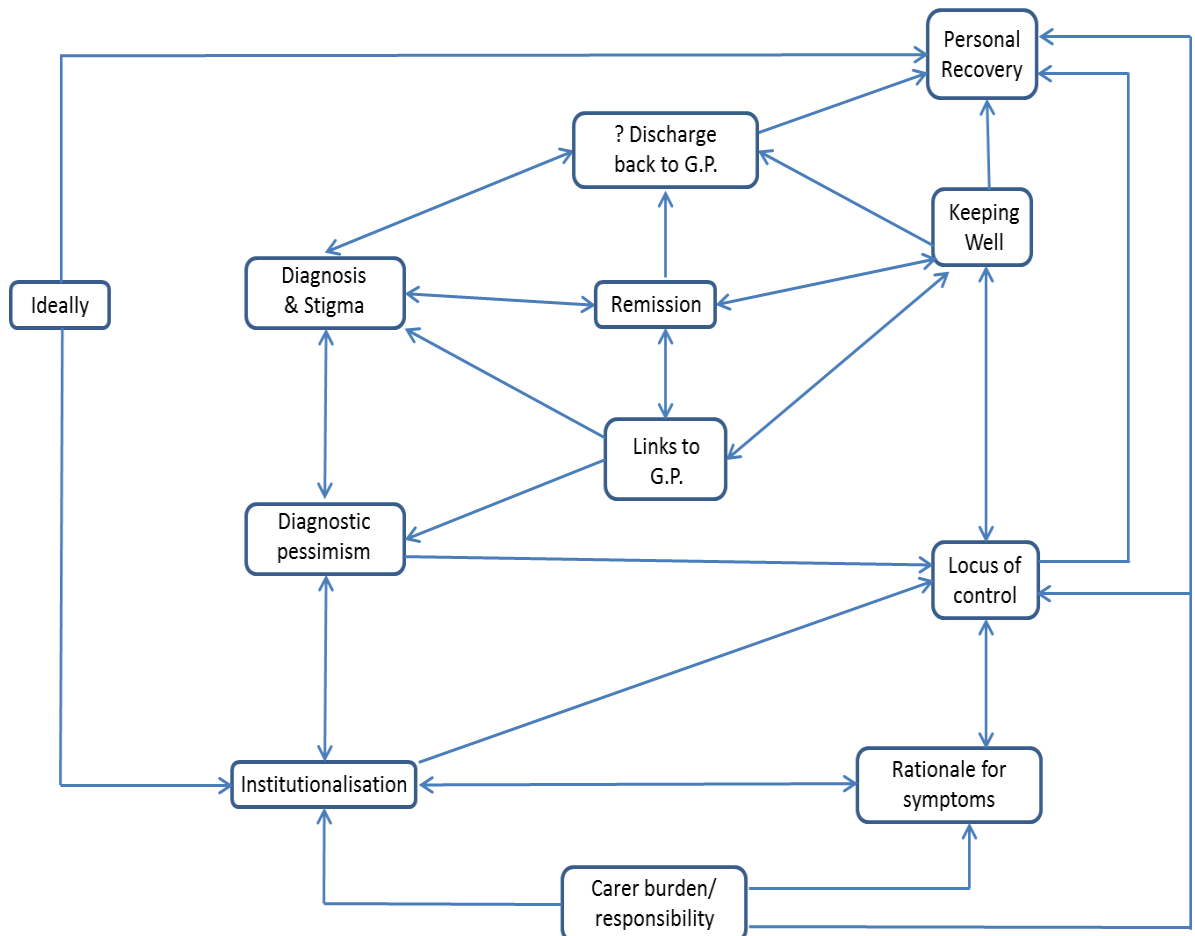
Independent Themes



6.8 Conceptual Mapping & Trajectories:

The analysis of the themes continued to produce connections and interconnections between the themes. Due to the less technical nature (in terms of language) of some of the themes generated from service users and carers they became more comprehensible and fluid and it was these themes that generated a conceptual map (Figure 15).

Figure 15. Conceptual Map of All Themes from Phase Two



This cartographic representation of the themes from service users and carers is symbolic of the relationship of the themes and the manner in which service users may navigate through mental health services. This map also resembles the analogy of a ‘snakes and ladders’ game board which was previously used within a poster presentation of this study (see Appendix 15). Sometimes the unpredictable nature of stressors which trigger relapse in schizophrenia can influence the course of the illness (Warner, 1994). Concern about possible relapse and the diverse range of symptoms experienced contribute to the conundrum of how best people may steer through services. Care pathways have been devised, applied and revised and despite

assertion by Tsang (2012, p39) that “Mental health services have been leading the way in using a pathway-based approach as a means of achieving a move away from hospital-based care”. This has had little impact upon people gaining discharge back to primary care. The ‘Superflow’ approach utilised by one of the community mental health teams in this study remains a case in point. Despite introducing this ‘pathway tool’ and standardising tools, such as assessments, and procedural elements of the process there has not been a formal recognition or acceptance that people who are ready to be discharged from secondary mental health services will or can be. However, we must be reminded that this is the team that has discharged some people. Whereas, the other team within the Trust has had much less success in this venture.

With the issues, mentioned above, in mind, this conceptual map of themes was further scrutinised and analysed resulting in the generation of four possible trajectories which service users ‘may take’ or end up following. These four trajectories are routes that are embedded within the conceptual map of the themes and are supported by the narratives from the participants in order to further validate each of the themes. Each of the four trajectories will be presented:

Possible Trajectory 1 – ‘Collaborative Approach’

The concept of collaboration as a beneficial approach within mental health services has been well documented (Ryan & Morgan, 2004; Keen & Lakeman, 2009; Baldwin, 2012). As Mills (2000) infers there is a role to play for both the service user and the practitioner in the development of coping methods and new understandings around psychosis. This can be a beneficial alliance and Lipczynska (2011) asserts that effective collaboration and communication with service users may possibly improve diagnosis, treatment and recovery. This possible trajectory would be able to demonstrate a positive collaborative approach that would fully utilise the concept of remission for a person with schizophrenia. Remission would be a shared concept that would be discussed by practitioners in secondary mental health services with the service user from an early point and worked towards as part of the personal journey to recovery. It has to be said that of the four possible trajectories this would be the most desirable, in that it would ultimately facilitate discharge and allow the service user to take the next steps beyond mental health service input on the journey to ‘full’ or ‘personal’ recovery.

Figure 16. Collaborative Approach Trajectory

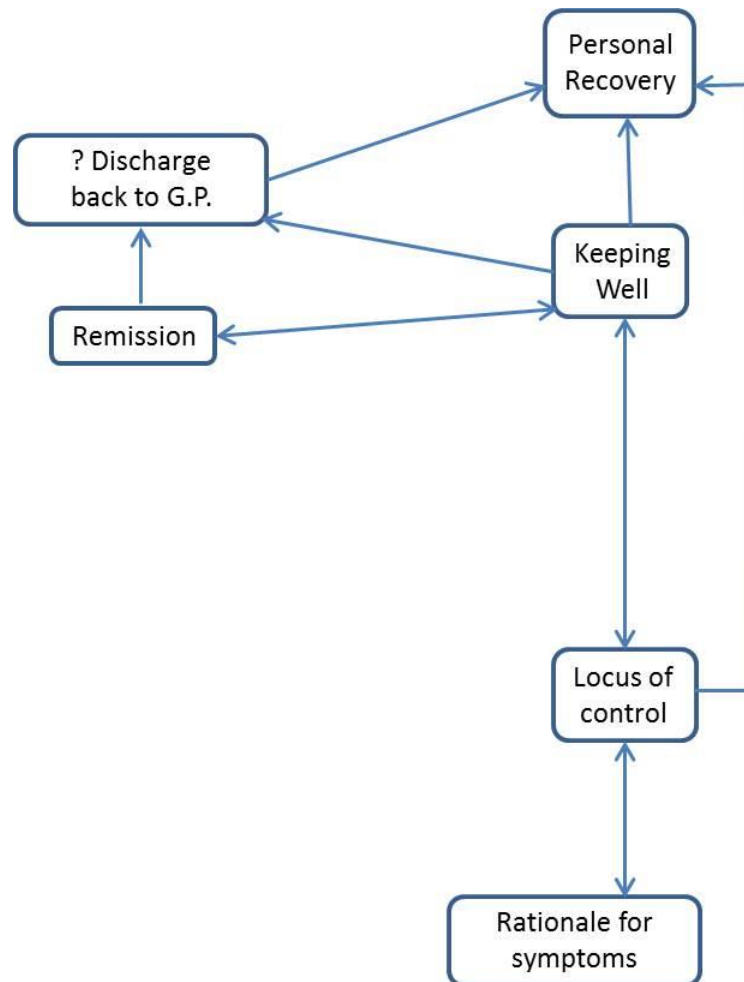


Figure 16 illustrates the themes extracted from the conceptual map (Figure 15) in the manner of facilitating a collaborative approach.

'Rationale for symptoms' – Ideally the service user develops a positive approach to their symptoms which is supported by the practitioners and healthcare team involved too. It is not just the disorder itself which determines the long-term course and outcome of schizophrenia, but the relationship or interaction between the person and the disorder (Hoffmann *et al*, 2000). It can be surmised that if this interaction (between the person and the disorder) is positive then the outcome can be too. Consequentially this would be a good starting point when adopting a recovery focused approach. Bentall (2003) is dismissive of the constructs of psychosis by Kraepelin in support of sentiments by Ludwig Wittgenstein. “Madness need not be regarded as an illness. Why shouldn’t it be seen as a sudden – more or less sudden – change of character?” (Wittgenstein 1980, *cited in* Bentall 2003, p95). Bentall’s (2003) contemporary

take is that psychosis should be seen as a component of human variation as opposed to a negatively viewed disorder. If practitioners can adopt and work with a psychological approach to arising issues this may prove beneficial. As offering explanations and working collaboratively with service users in a manner that may 'normalise' symptoms they experience rather than catastrophising them may reduce distress and increase understanding (Nelson, 1997; Turkington *et al*, 2009). Destigmatising and normalising the symptoms adopts a cognitive, behavioural approach which Nelson (1997) advocates practitioners should adopt.

'Locus of control' – Warner *et al* (1989) stipulate that it is both a combination of accepting a diagnosis of mental illness and adopting an internal locus of control that is associated with improved outcomes in psychosis. Therefore, if this trajectory is to be realised then the locus of control has to be acknowledged by the service user. Also, importantly, there has to be no objection or resistance to this from practitioners who may be tempted to assume that they 'know best'. This may not be automatically borne from a negative perspective, as the practitioner may adopt an attitude of assuming responsibility to solve the problems for service users. Until recently service users have been universally perceived as passive recipients of care (Lester & Glasby, 2010). However, this reflects issues of control and power (Stein-Parbury, 2014) despite being developed through meaningful relationships that may have been well-intentioned.

'Keeping well' – The ideal scenario would be that the service user understands what is keeping them well and therefore able to demonstrate factors of resilience to protect against relapse. It is understandable that people who have had psychotic experiences do have concerns about becoming unwell again (Gumley *et al*, 1999). If the mental health team manage this well, in a collaborative approach, and enable service users to understand difficulties, know what the treatment options are and ultimately make better choices as suggested by Turkington *et al* (2009) then they need not be in constant fear of relapse. Again this adds to the overall feeling for service users that they are establishing some control over their life again. Deegan (2009, p58) makes the point, "Recovery refers to the lived or real life experience of persons as they accept and overcome the challenge of the disability". Hopefully, this would be facilitated at this point with the input from mental health practitioners.

'Remission' – If a person has managed to 'keep well' for a period of six months, according to the criteria by Andreasen *et al* (2005), then they should be deemed to be in remission. There

may be value in utilising the concept of remission at this stage. The rationale for stating this is due to the possibility of 'remission' being utilised as a conduit or potential route to primary care for a person deemed well enough. Ideally, a service user would identify an improvement over a period of time accompanied by a reduction in symptoms. This improvement would also be assessed and acknowledged by the care team and consequentially the GP and primary care team would be accepting to receive the person into primary care.

'? Discharge back to GP' – Given that the person has evidence of being in remission then the primary care team as a whole should be accepting. It has to be appreciated that this would be facilitated with sensitivity for all stakeholders and to assist the person to embrace this further step in their quest for recovery. The GP and primary care team would be made fully aware of the plan including contingency planning and offered advice and a quick route back if required. All healthcare needs would be taken over by the primary care team.

'Personal Recovery' – The service user is fully integrated into, and accepted into society. Thus the person can go on to regain a sense of citizenship (Sayce, 2000) which would also be enhanced by being free of the diagnosis previously attached. Remission would signify that people would be; "...below the threshold typically utilized in justifying an initial diagnosis of schizophrenia" (Andreasen *et al*, 2005, p442).

As suggested this possible trajectory would provide the ideal scenario to facilitate discharge the person back to primary care as all stakeholders would be content with arrangements made.

Possible Trajectory 2 – 'Self-Fulfilling Prophecy'

This possible trajectory would not, in terms of recovery, be considered ideal. There would be the attempt at collaborative working from practitioners but this may be refused or rebuffed by the service user as they feel that they are unwell or could not attempt, the perceived, big steps towards recovery. This relates to 'perceived self-efficacy' which is a concept defined by Bandura (1994), these are the beliefs we hold with regard to the capability we have to perform and exercise influence over events that affect our lives. If this 'event' is the diagnosis of schizophrenia, then we may appreciate a logical construction of this belief. If we accept that the diagnosis of schizophrenia is a classical notion of madness with issues of power lying at its

heart (Coles, 2013), then it becomes comprehensible that the person receiving this diagnosis may develop undesirable feelings such as being powerless or hopeless. Marks *et al* (2011) highlight that one of the sources of self-efficacy is ‘vicarious experiences’. As a consequence service users witnessing other people in a similar situation may dwell on the fact that they do not observe people achieve recovery quickly, thus developing the vicarious experience to trigger self-doubt.

Figure 17. The Self-Fulfilling Prophecy Trajectory

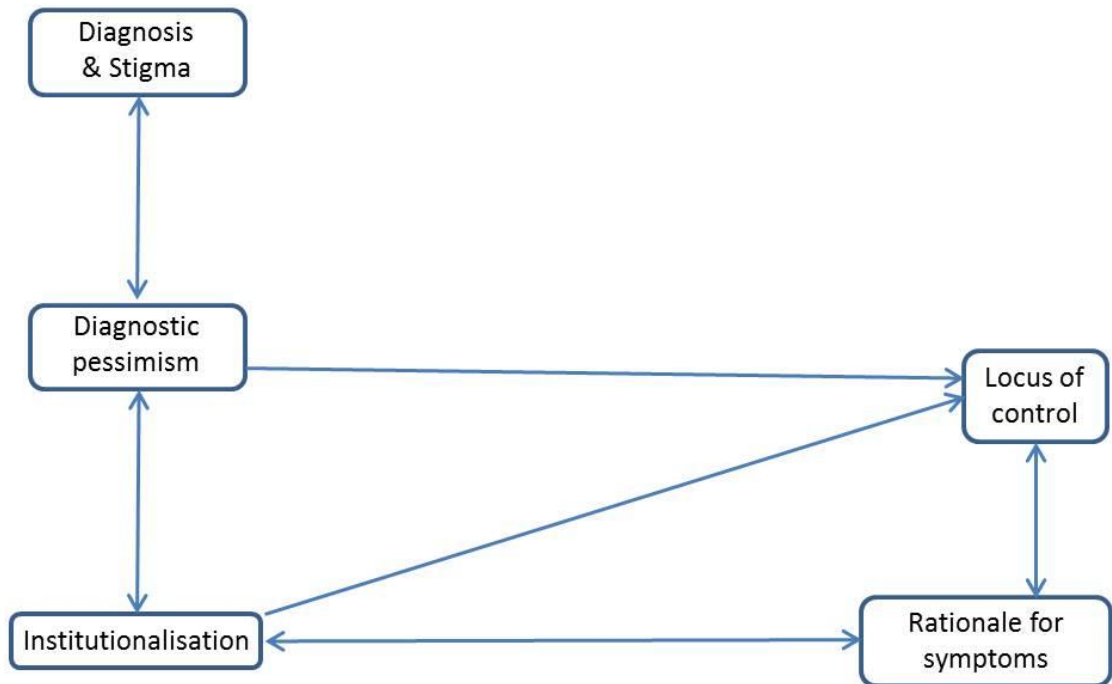


Figure 17 illustrates how this possible trajectory manifests, again utilising the themes in the conceptual map from Figure 15.

‘Institutionalisation’ – Despite receiving input from community-based services, service users of both teams (within this study) alluded to issues that were under the theme of institutionalisation. The sub-themes of ‘practitioner as a friend’, ‘completeness’ and ‘discharge anxiety’ were the areas highlighted. This may, initially, not appear to be in keeping with the more traditional nature of people residing within an institution, as a ‘social establishment’ (Goffman, 1961). Since de-institutionalisation and the advent of the Care Programme Approach (DoH, 1990) care management has been the technique for meeting the needs and developing care packages for people within secondary mental health services (Ryan *et al*, 1999). Given that inclusion into a Care Programme Approach is not open access, then Goffman may have to agree that by his comments people within community services may too be

considered to be institutionalised. Goffman (1961, p15) details that, “Every institution captures something of the time and interest of its members and provides something of a world for them”. Without the ‘world’ of secondary mental health services some service users may have concerns and anxieties of feeling lost, abandoned or neglected. Whilst it would be a role for practitioners to facilitate empowerment and hope assisting people to overcome this (Schrank & Slade, 2007), the feeling may be too omnipotent for some people.

‘Diagnostic pessimism’ – As the theme describes there can be pessimism associated with receiving and carrying a diagnosis of schizophrenia. In this possible trajectory the pessimism reinforces the sick role that people may adopt as described by Johnstone (2008, p13) “The common cultural understanding of being diagnosed as ill (‘schizophrenic’ or ‘psychotic’ etc.) is that you are not responsible for your condition and need to rely on expert help”. After receiving a diagnosis of chronic schizophrenia Deegan (1996, p92) stated it was like a “prognosis of doom”. Deegan then adopted ‘learned helplessness’ (Seligman, 1975), this was seen as a solution rather than a problem, as it protected her from wanting to do anything. This would presumably include recovering! This is not a unidirectional phenomenon as practitioners too can contribute to a pessimistic outlook for those with a diagnosis of schizophrenia. This could be influenced by many things including; the ‘clinician’s illusion’ (Cohen & Cohen, 1984) a bias in thinking due to clinician’s having more involvement with the more severe cases, also ‘high expressed emotion’ (Brown *et al*, 1972) which describes an emotional environment characterised by significant criticism, hostility and/or emotional over-involvement. Whilst this was originally significant among families, Keen & Barker (2009) add studies have demonstrated staff cultures also generate these feelings which create psychonoxious and non-therapeutic environments.

‘Diagnosis & Stigma’ – A respondent in a study by Thomas *et al* (2013, p136) reported, “The humiliation of being labelled schizophrenic threatened to become a self-fulfilling prophecy”. Thornicroft (2006, p156) states, “...Those who expect discrimination are more likely to accept it when it does occur: a self-fulfilling cycle”. A wide range of impacts were described for people since gaining the diagnosis of schizophrenia and this included experiencing stigma, because of the way people now saw them since the label was applied (Thomas *et al*, 2013). Internalising public stigma results in self-stigma and this is responsible for lowering self-esteem and self-efficacy (Rusch *et al*, 2009; Cavelti *et al*, 2012b). Unfortunately, many people experience themselves as only a patient or diagnosis (Langeland *et al*, 2007). Ahern & Fisher (2001)

recognise this as a barrier to recovery, perhaps given the impact this may have on a person it is an understatement. Rather than being a barrier to recovery, it may be seen as a contributor to relapse. White (1997) encourages people to perceive the diagnosis as a narrow description of reality. Given the impact of the diagnosis and associated stigma this may be easier said than done. This may contribute to the negative-cycle of consequences with this possible trajectory for service users; not forgetting that carers may also be stigmatised too, by association. Thornicroft (2006) identifies stigma by association as the knock-on effect of negative attitudes towards family members of the person diagnosed. Ultimately receiving a diagnosis of schizophrenia often compounds further the issues caused by the symptomatology and this can generate a negative view that recovery is unlikely.

'Locus of control' – The importance of adopting a feeling of control has previously been mentioned. By contrast, a self-perpetuating downward cycle can result from an untreated negative approach or outlook resulting in a more external locus of control (Harrow *et al*, 2009). Hopelessness is also highlighted as a factor that may contribute to chronicity (Hoffmann *et al*, 2000). People with a diagnosis of schizophrenia may abandon responsibility and/or hope if feelings are that things are beyond them. The themes contributing to this possible trajectory are all touching on similar elements, which indicate a loss of control and hope for the service user

'Rationale for symptoms' – As opposed to understanding and having some sense of control over symptoms, service users in this possible trajectory may be inclined to accept the symptoms as a consequence of the fact they have schizophrenia. Barham & Hayward (1998, p167) explain that if a persons' grasp is that they have "some kind of chemical reaction in the brain", this will place it in the domain of illness, as an 'I have' experience. Consequentially, people also become the thing they are labelled (Estroff, 1989). This experience, therefore, is seen to necessitate medical intervention and does not lend itself so well to methods of self-help. This may in turn affect the relationship between practitioners and service users. Practitioners do not hold the key to recovery (Anthony, 1993) and service users need to take an active part (Deegan, 1996). This may also be seen as the service user being unmotivated, or even further pathologised as negative symptoms of schizophrenia (Glynn, 1998), thus compounding issues regarding the rationale for symptoms.

This trajectory is fuelled by the self-perpetuating feeling of gloom and pity surrounding the diagnosis, the system and the manner in which interventions intended to facilitate hope are received, or not.

Possible Trajectory 3 – ‘Pessimistic Outlook’

This possible trajectory is somewhat similar to the ‘self-fulfilling prophecy’ in that it is not the ideal scenario for a recovery focused approach. Whereby the emphasis for the previous trajectory may have been predominantly generated from the thoughts and feelings of service users, this is more to do with negativity from practitioners and services, along with the influence from carers and family. Whilst this may not be vindictive or actually intended it nevertheless has the capability to arrest any movement towards recovery.

Figure 18. The Pessimistic Outlook Trajectory

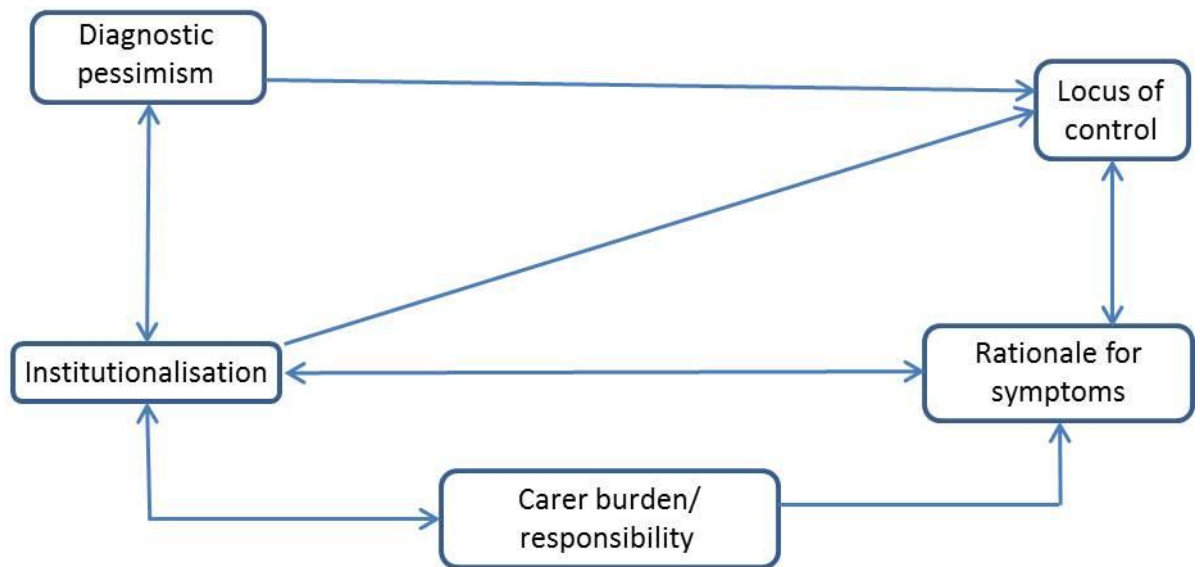


Figure 18 illustrates how this possible trajectory manifests, again utilising the themes in the conceptual map from Figure 15.

‘Diagnostic pessimism’ – Within this possible trajectory, service users may encounter practitioners who remain very traditional in their views and approaches for people with a diagnosis of schizophrenia. Practitioners adhering to measures of symptomatology as their only means to assess and work with service users may be demonstrating a restrictive and blinkered approach. Despite Kraepelin’s biological perspective being somewhat outdated,

Bardwell & Taylor (2014, p251) state, “His rather pessimistic outlook on the course of the disorder also remains valid for many individuals with schizophrenia”. If this remains the view of practitioners then a pessimistic view will continue to pervade and diminish any hope of a recovery focused approach.

‘Locus of control’ – Rather than the service user feeling helpless and not able to adopt the locus of control (as in trajectory 2, above), in this possible trajectory the practitioner may automatically assume control. This cuts across the grain of the sentiment asserted by Shepherd *et al* (2008) when they state that in order to facilitate independence the practitioners are there to be ‘on tap, not on top!’ Johnstone (2013) highlights a common source of irritation for clinical staff is the perceived passivity of the patients in relation to the sick role. If this is the overriding feeling for staff then they may feel it is better to ‘do it for them’ rather than allowing the service user to assume responsibility. It is a powerful position that mental health service providers occupy in relation to service user’s hope (Hobbs & Baker, 2012), and giving the impression that practitioners hold the locus of control will serve to diminish any hope that the service user was developing.

‘Rationale for symptoms’ – Irrespective of what the service user has gleaned as a rationale for their symptoms, if the practitioner emphasises that these are as a consequence of a medical or biological causation this perhaps indicates that medication may be the only answer. Boyle (2013) argues that even if there is acknowledgement of the symptoms, such as voices or beliefs being important, it still remains secondary to a supposed biological predisposition to illness. Leventhal *et al* (1989) suggest a self-regulatory model of illness behaviour, in which the person, when faced with a threat, will form a cognitive and emotional representation of that threat; coping will be attempted in relation to the representation made of this threat (Marks *et al*, 2011). The threat of losing hope may provoke many representations that would not be conducive to a therapeutic relationship. Also when distress gets treated as a medical illness, the personal meanings of people’s experiences are downplayed (Johnstone, 2013). Overall this is a pessimistic view of therapeutic opportunities.

‘Institutionalisation’ – Despite service users wishing to recover and work towards potential discharge the emphasis by the healthcare team in this possible trajectory is one of maintenance. This may be fuelled by the nihilistic view of the diagnosis and possibly the culture of the team resulting in a risk averse manner that maintains the service user within

services. This may foster an inclination to frame recovery more in medical terms of 'getting well' or 'not getting well' as described in a study by Ridge & Ziebland (2006). Although this study was addressing people with depression similarities can be drawn. This study also highlighted that some people found it easier to identify 'anti-recovery' examples (again, possibly a factor of the 'clinician's illusion' suggested by Cohen & Cohen, 1984), linked to long term use of medication and institutionalisation (Ridge & Ziebland, 2006). If mental health services are to over systematise recovery and risk losing sight of the individual person Deegan (1996) asserts than you have got it wrong. As an alternative 'personalisation' is suggested by Morgan (2014), this is the result of reformed services, as opposed to the process itself and is about giving people choice and control that has not previously been afforded within services. Perhaps this is a derivation of 'personhood' which was proposed by Tom Kitwood (1997) in his work with people with dementia. The sentiments of both personhood and personalisation would assist in overcoming the culture of institutionalisation.

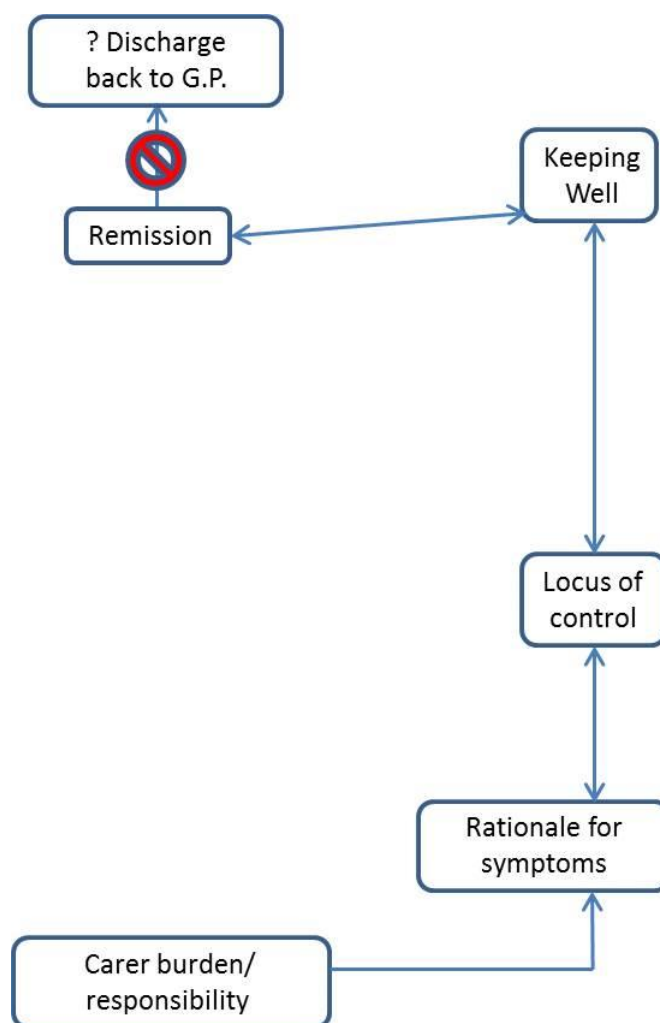
'Carer burden/responsibility' – Schizophrenia is often viewed as a long-term condition. This is not always made explicit but has been a long-standing point of view, as Smythies (1973, p281) adds, "If the patients do recover from the psychosis, their personalities may remain damaged with lessened capacity". The profound effects of mental health problems can impact upon family, friends and carers too (Repper, 2012). The responsibility that carers accept compounds the other issues and it has been recognised by Margereson (2010) that the contribution made to health and social care by carers is not fully recognised. There will be a lot of things which carers take on that is not visible and this will perhaps shape the way they feel in relation to the person they are carer for or towards mental health services. One particular difficulty that Repper (2012), highlights is the difficulty in navigating an array of different services and professionals who may not recognise or understand the concerns. These compounding issues may make the carers feel burdened and in need of support and assistance, therefore the prospect of the person they care for being discharged may induce fear and increased anxiety.

This possible trajectory may have a service user that is keen to progress and make attempts to recover their life, but they would be stifled by mental health services, practitioners and their carers'.

Possible Trajectory 4 – ‘Inhibitive; Glass Ceiling’

This possible trajectory resembles the ‘collaborative approach’ trajectory. However, the difference being that, despite good progress being made within secondary mental health services, discharge back to the primary care team and GP is thwarted. Figure 19 below demonstrates the point where this impasse may occur, between ‘remission’ and ‘? Discharge back to GP’.

Figure 19. The Inhibitive ‘Glass Ceiling’ Trajectory



The data generated from the participants highlight the difficulties encountered when the point of discharge is achieved for people who had been given a diagnosis of schizophrenia, despite being deemed well enough at that point. If practitioners are utilising the ‘Remission criteria’ as presented by Andreasen *et al*, (2005); then the person would be deemed to have symptoms below the threshold for a diagnosis of schizophrenia. Hopefully, this would reduce some of the

initial concerns of the primary care team. Despite this concern is, usually, due to the fact that the person is still requiring some form of antipsychotic medication. If the route by which this antipsychotic medication is to be administered is via intramuscular injection then the issues affecting discharge becomes much greater. This may appear to be a simplistic view, based purely on medication, and there may be much more embedded in the issues that concern staff in primary care; cost of physical healthcare, possibly 'payment by results', and overall monitoring. However, medication is the most common reason offered in terms of refusal of access back to primary care and the principle reason why this possible trajectory would be inhibitive. Some people may doubt whether people with a diagnosis of schizophrenia can recover; in fact one of the psychiatrists interviewed for this study stated that, if a person had recovered they would doubt the accuracy of the initial diagnosis. The issue is that the service user remains involved within mental health services and as a consequence 'full' or 'personal' recovery is compromised or at best limited. This would certainly not be in keeping with the rhetoric from mental health services who hopefully appreciate that, "Stagnation in mental health services can severely jeopardise an individual's recovery process" (Ford, 2010, p23). In addition to all of the components already mentioned, this possible trajectory would have the service user gaining full support, not in a dependent manner, by carers and family in their potential venture back to primary care and ultimately recovery.

This possible trajectory may have a service user that is keen to progress and make attempts to recover their life, supportive carers and the backing of the secondary mental health team. The problem is clearly in the transition and acceptance back to primary care from the team who would be receiving this person.

6.9 Chapter Summary:

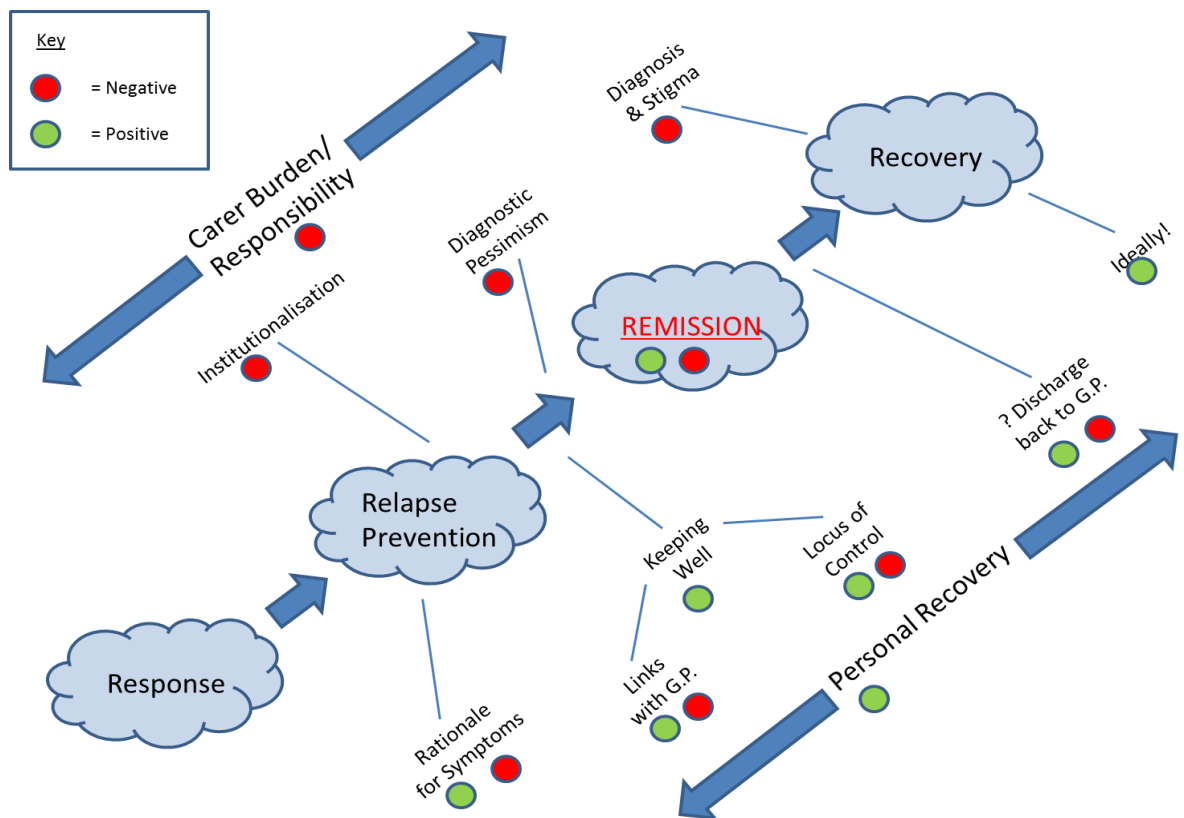
This chapter has introduced the themes from both phases and detailed the manner in which this data was generated. Visual representations have been utilised to demonstrate the relationship between the data and the concept of remission and the over-arching issue of recovery for this service user group. The analysis of this data resulted in the formulation of four possible trajectories:

- 1: Collaborative approach
- 2: Self-fulfilling prophecy
- 3: Pessimistic outlook
- 4: Inhibitive; Glass ceiling

As part of my commitment to producing outputs from this research study I have presented my findings with an emphasis on the trajectories at nursing research conferences in Edinburgh (Napier University, August 2014), Londonderry, Northern Ireland (Ulster University, October 2014) and at a pharmaceutical industry sponsored meeting for medical and nursing staff (mental health) in Gateshead (November 2014). Informal feedback from these presentations supported the notion that these trajectories actually exist and that practitioners could recognise the themes and issues from their own practice areas too.

To contextualise the themes a little more they were placed in a situational map (Figure 20 below) so called due to the locus of the analysis being the 'situation' (Clarke, 2005). In this study the situation is of remission in the context of people with a diagnosis of schizophrenia. This clearly places the themes within the context of the linear process advocated by Andreasen *et al*, (2005). The 'positive' and 'negative' aspects are highlighted as it is important to state that the themes may have been one or the other, or both. This was derived from the data and interpretation from the analysis in coding. Two themes are felt to represent a longer impact through this process (Carer burden/Responsibility and Personal Recovery). The remaining themes are situated at the point where they interject or have most impact in relation to what service users and carers reported. This indicates, by use of the situational map, a visual representation of points that may be flagged for attention in relation to 'pathways' or systems that may be introduced in a recovery focused approach.

Figure 20. Situational Map of Service User Transition with Themes Plotted



Remission has both negative and positive aspects, as reflected in the narratives gained from practitioners and service users and carers. The answer to the question, whether remission would be useful, continues to be held in abeyance presently and will be addressed within the conclusion of this thesis (Chapter 8). However, with due consideration to the themes around remission, it could potentially be incorporated with a degree of success for some people in some contexts and by addressing these themes it would certainly increase the applicability if required.

As some of the main issues cannot be dealt with in isolation by secondary mental health services alone the following chapter will address the complexities of the interface between secondary mental health services and primary care. This interface will be crucial if and when a person is at the stage of transition.

Chapter 7:
Primary Care and the Management of People with Psychosis: The
Complexity and Interface.

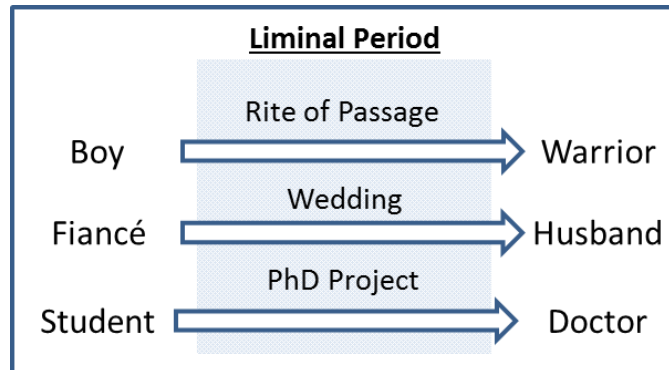
The relevance of this chapter is due specifically to the relationship between primary care services and people with psychosis. It was generated from the data and also supported by the literature relative to this subject area. Initial feelings may be polarised, that it is either a fraught relationship or a well-managed interface. This chapter highlights some of the issues which are apparent and illustrates how further clarity is required to reduce the complexity, also to understand what a person may be experiencing in relation to leaving secondary mental health services, which they may have been involved in for a considerable period of time.

Whilst the majority of lay people may be under the impression that all people with psychosis are contained and/or managed within secondary mental health services this is not the case. Despite numbers of people in the community experiencing some psychotic phenomenon not all will attempt to gain assistance from mental health services. Reilly *et al* (2012, p5) report that “on a per annum basis about a third of people with severe mental illness are not seen in secondary care ... and consult primary care for ongoing mental health reasons”. More specifically Kendrick *et al* (1998) report that of people with a diagnosis of schizophrenia 25% had no specialist contact and were solely looked after in general practice. People who have a diagnosis of schizophrenia have obviously been in mental health services at some point in order to be given this diagnosis. Despite deinstitutionalisation, hospital or clinic environments remain the principal sites where people are first diagnosed, receive initial treatment and encounter changes to their personal identity (Barrett, 1998). Following recovery, symptom remission or just an overall increase in well-being and ability to function a person may then find it difficult to progress. This progress, for those well enough at the time, should involve movement out of mental health services and back into the realms of primary care. However, this is not always easy for the service user or comfortable for practitioners. The ‘unease’ that is present when service users are ready to make this transition is due to many reasons from all parties concerned.

These issues raised fit with the notion that a diagnosis of schizophrenia is indeterminate, open ended with no point of closure (Barrett, 1998). This then places the person, who at one time was given the diagnosis, in a difficult position and needing to convince all others that they are

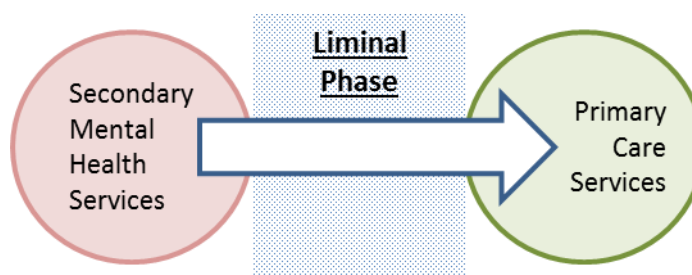
well. This also places pressure on the process of discharge as this transition may return to being subjective in nature. The process may be viewed, and experienced, as 'liminal'²⁰, as a rite of passage as seen in box 5.

Box 5. Rites of Passage (Woolley, 2012, p67)



This demonstrates the passages that people may take in life, the transition made in moving from a mental health service and returning into a less supported community may produce a similar liminal period. Warner and Gabe (2004) state that although liminality represents being 'in-between', or in transition, it also causes a merge of the two entities which creates something new. This 'something new' may not be recognised until the process has commenced. Cousin (2006) addresses liminal states in the context of threshold concepts for students within their learning. She goes on to describe that; "It is an unstable space in which the learner may oscillate between old and emerging understandings just as adolescents often move between adult-like and child-like responses in their transitional status" (Cousin, 2006, p4). The trouble with this phenomenon is therefore, within mental health services and under such scrutiny from staff any 'oscillation' in service users may be pathologised and over analysed as a potential relapse. Service users too are learning within this liminal period and therefore will experience similar phenomenon to that described.

Figure 21. Progression Through Liminal Phase

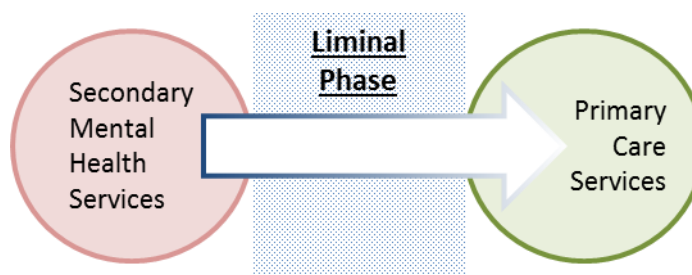


²⁰ Liminal is derived from the Latin word '*Limen*' meaning 'threshold' – the part of a doorway which is crossed between one room and another, can be used to infer movement between social positions too.

Figure 21 illustrates the direction and progression from Secondary mental health services to Primary care, passing through the liminal phase in the middle. Turner (1964²¹) identifies that during the liminal period the state of the ‘passenger’ is ambiguous whilst passing through a realm which possesses few or none of the characteristics of the past or coming state. The role of the practitioners in facilitating this transition appears to be straightforward, but this state of ambiguity needs to be acknowledged and the service user reassured that this may be a ‘normal’ experience in the given circumstance.

However, whilst there may be a variety of concerns, from all stakeholders, throughout this process there is one extremely relevant perspective which may often be disregarded in practise terms. Barrett (1998) highlights the ceremonial aspect of an admission to mental health services which includes diagnostic assessments, physical interventions, and consultations to gain a case history. This ‘induction’ then allows the service user to embark on an illness trajectory, albeit determined by the practitioners in the main. Working towards recovery establishes a pathway, a process and indeed a purpose for people but when this meets the juncture for discharge Barrett (1998, p479) identifies that there is “nothing to ceremonially mark the person’s transition back to health”. In contrast to the complex admission procedure the point of actualisation may fade into insignificance or not be afforded true significance (as seen in Figure 22), this could even be met with indifference from some practitioners who remark that there was probably a misdiagnosis rather than ‘true’ schizophrenia.

Figure 22. Progression Through Liminal Phase (Fading)



Barrett (1998) adds that this may provoke former service users to request an official written ‘statement of mental health’. This symbolic representation may be reassuring for former service users and add proof that the people qualified to incarcerate them and label them as

²¹ Taken from a reprint of original 1964 paper in ‘Magic, Witchcraft and Religion, Moro P. Myers J. & Lehman A. [Eds] (2008)’; both citations appear in reference list.

'insane' had the confidence that they were now well enough to regain a position in society outside of mental health services. Perhaps this may be one of the values of using the term remission in a discharge summary, that people may look back upon as 'proof' that they are well enough to resume life without mental health services. If this does not occur it leaves the person in a paradoxical position as they are both 'of' the community and requiring care (Bartlett and Sandland, 2000). Lewis *et al* (1989) had previously acknowledged people with mental health problems as being a new form of social construction because of this very issue. Perhaps we have become more familiar with this construction since Lewis *et al* (1989) made this statement but service users may still get a sense of being 'betwixt and between' as coined by Turner (1964). This could be applied more readily to people maintained in secondary mental health services rather than those being discharged. For those undergoing the process of discharge this theory highlights some of the rationale for altered behaviour and anxieties pre-discharge. It also raises concern that primary care services need to be aware of when receiving a person back into their domain following transition from secondary mental health services. As a cautionary note Barrett (1998) stresses the risk of implying that people with schizophrenia are 'liminal' people because this would add yet another attribute to people who are burdened by many other, negative, attributes.

There is no denying that the impact and expectations presently placed upon primary healthcare providers is high and demanding. This was recognised by the NHS Alliance (2014) who highlight that approximately 80% of all contact with health services in the UK involves primary care, between 1995 and 2009 appointments in general practice increased by more than 80 million and as a consequence of the growing number of complex cases the average appointment time is getting longer. Oud *et al* (2007) reveal that the personal characteristics of the GP and the quality of collaborative relations with mental health services are factors influencing current primary care for people with psychosis. Whilst this research from Oud *et al* (2007) is from the Netherlands it bears strong relation to the data generated from participants in this current study. The role of the GP in the management of people with schizophrenia has increased since the move to community-based services, with GP's potentially more involved either alone or in association with mental health services (Falloon and Fadden, 1993). In a study addressing attitudes of GPs and community mental health team staff towards people with chronic psychotic disorders Burns *et al* (2000) found that GPs had 'mixed feelings' about relapse monitoring, although agreed that these 'patients' are better off in the community. In a similar study from Australia (Carr *et al*, 2004) found that people ranked their close family as

more helpful than GP's or mental health staff. Carr *et al* (2004) concluded by stating that GP's fulfil a valuable role in the treatment of people with schizophrenia but this could be enhanced by further training.

Within a UK context, awareness has been growing of the need to bring a more cohesive partnership together between mental health services and primary care services. In 2001 Cohen and Singh produced a 'General Practitioner's Guide to managing severe mental illness'. This was aimed at informing GP's how to improve the care of people with a severe mental illness by utilising a four-stage plan, which was based on other 'chronic conditions' such as diabetes. The four stages were:

- 1) Create a register – identify the population
- 2) Develop a comprehensive needs assessment
- 3) Develop a care pathway
- 4) Provide care

(Cohen & Singh, 2001, p8)

This, quite simplistic, approach offers an idea where GP's may have been in relation to working with people with a severe mental illness, at that time. However, the weight in professional opinion and research results all supported a 'balanced care' approach. Thornicroft & Tansella (2003, & 2013) explain balanced care is essentially community-based with hospital beds providing backup only when necessary. Table 9 below illustrates the key principles for balanced care.

Table 9. Key Principles for Balanced Community-Based Mental Health Services

Autonomy	A patient's ability to make independent decisions and choices, despite the presence of symptoms or disabilities. Autonomy should be promoted by effective treatment and care.
Continuity	The ability of relevant services to offer interventions that are either coherent over the short term or both within and among teams (<i>cross-sectional continuity</i>), or are an uninterrupted series of contacts over the long term (<i>longitudinal continuity</i>).
Effectiveness	The ability to provide the proven, intended benefits of treatments and services in real-life situations.
Accessibility	Patient's ability to receive care where and when it is needed.
Comprehensiveness	A service characteristic with two dimensions. <i>Horizontal comprehensiveness</i> means the extent which a service user is provided across the entire range of mental illness severity, and the wide range of patient characteristics. <i>Vertical comprehensiveness</i> means the availability of the basic components of care, and their use by prioritized groups of patients.
Equity	The fair distribution of resources. Both the rationale used to prioritize competing needs and the methods used to allocate resources should be explicit.
Accountability	The answerability of a mental health service to patients, their families and the wider public, all of whom have legitimate expectations of how such a service should carry out its responsibilities.
Coordination	A service characteristic resulting in coherent treatment plans for individual patients. Each plan should have clear goals and necessary and effective interventions, no more and no less. <i>Cross-sectional coordination</i> means the interlinkages among staff members and agencies over a longer period of treatment.
Efficiency	Minimizing the inputs needed to achieve a given level of outcomes, or maximizing the outcomes for a given level of inputs.

Taken from Thornicroft & Tansella (2003, p18)

Whilst the contents of this table appear positive, this may only be the case for people requiring or experiencing long-term care. In some cases this approach may facilitate longer-term care rather than promoting true autonomy for service users. The elements of *Effectiveness*, *Accessibility*, *Comprehensiveness* and *Coordination* were also replicated in a paper by Caldas de Almeida and Killaspy (2011) addressing long-term health care for people with severe mental disorders. Therefore, overall this ‘balanced community-based’ approach may be viewed more as containment or maintenance rather than being truly balanced. That is not to say that there is a population requiring this input, but if service users are only offered this approach when they have potential to recover and/or achieve remission thus gaining discharge from services then this may be extremely inhibiting. The concern with approaches such as this is how they are interpreted and ultimately delivered in services and teams at a local level.

Practitioners need to embrace the concept of autonomy to assist in the promotion of independence for service users. Autonomy is associated with “allowing and enabling” service users to decide which, if any, health care interventions they receive (Entwistle *et al*, 2010, p471). The very use of the word ‘allow’ is a stark reminder of where the power sits in relation to this. Ultimately, and perhaps crudely, it can appear that service users could be encouraged to be autonomous if the practitioner permits. Obviously this may appear unjust, with the fear of non-compliance with medication or other interventions potentially driving this approach. It therefore sits in the realms of consequentialist orientation. It has been highlighted by Slowther *et al* (2004) that consequentialist theory is so concerned with ‘ends’ that it may overlook the ‘means’ which also hold moral importance, as the manner in which ends or goals are achieved. Service users are not traditionally steered into the position of making decisions about health care interventions they may or may not wish to receive, which appears to be borne from fear that there will be an abrupt discontinuation of medication or contact with services. This is echoed in responses by participants in this current study too, service users and practitioners alluded to the point that the message appears to be ‘keep taking the tablets’ with some participants adding, ‘or you will relapse’. Quite obviously, this can come across as a threat rather than a choice. This carries traits of the ‘illness like any other’ approach by which people are encouraged to continue taking medication and await improvement; this approach encourages passivity and therefore an impediment to recovery (Sidley, 2015). Tanner *et al* (2008, p757) suggest that people (practitioners in this instance) usually take a consequentialist perspective and “this implies a focus on outcomes only”. This could be due to service directives

to achieve outcomes, but this may inhibit a deontological approach which may appear to be a braver option, as practitioners may need to be more outspoken in asserting this approach by comparison. Deontology would state that, “What we do in our action, the nature of the action itself, determines its moral status” (Wheeler, 2012, p190). Therefore, if practitioners are unsure of their self-efficacy or lacking confidence this overall approach may not realistically be able to offer or enhance autonomy for the service user.

Conversely, autonomous service users may be regarded as rebellious or belligerent and are usually seen as non-conformist or non-compliant. Conforming and complying would be associated with being a ‘good patient’ to some, but could be more symbolic of a docile acceptance or passivity rather than striving for recovery. The importance of independence should be reinforced and service users should be encouraged to embrace and express their independence. Andresen *et al* (2003, p586) recommended ‘taking responsibility’ as an essential component of recovery, whilst Farkas (2007, p70) expressed importance of the service user ‘discovering a more active sense of self’.

Thornicroft and Tansella (2003, p18) state “Autonomy should be promoted by effective treatment and care”. This statement is unclear and will become rhetoric for some practitioners and not have any substance or true meaning to it. It is unclear what the ‘treatment and care’ is that the authors refer to. Efficacy for treatment is traditionally measured utilising positivist or quantitative approaches and these are also seen as the *gold standard*; “...the RCT [Randomised Control Trial] is seen as the hallmark of scientific enquiry” (Walker, 2005, p579). Yet, when treating a person with schizophrenia there is no universal treatment which is effective which may make this a therapeutic minefield to some extent. There may be a lot more value in talking to the person and utilising *their* priorities, and not necessarily by the use of a questionnaire. The value in connecting with a fellow human being will gain more disclosure and this can contribute to improve the collaborative planning of care. Accounts from the participants in this research study intimate that practitioners who listen and do not infantilise or patronise people are better thought of, also they are more appreciated by service users. Again, approaches such as this by Thornicroft & Tansella (2003) are regarded as service rhetoric and are not consistently applied, therefore reducing their overall effectiveness. Often processes are ‘shoe-horned’ into existing service provision that is laden with risk management and assessment priorities. The participants in this current study spoke of recovery pathways and processes being both generic and specific in the case of ‘Superflow’. Some were happy to

adopt these whilst others saw it as further administrative duties that keep them from face-to-face contact with service users.

It is acknowledged that mental illness touches everyone's lives and is a core activity in primary care risk (Lester *et al*, 2004). Badger and Nolan (1999) had warned of strides being made to strengthen collaborative approaches between staff in primary care teams and secondary services, in particular GP's and mental health nurses. Lester *et al* (2004) addressed integrated approaches in the light of the move towards a primary care-led National Health Services and they highlighted that this allows primary care to move beyond the gatekeeper role for secondary care services. Whilst this is very encouraging, and it certainly was at that time, it is primarily in respect of common mental health problems and not especially addressing people with schizophrenia. However, Helen Lester has been somewhat pioneering in her work, in so much that from her role as a GP she has advocated for people with serious mental illness and educated her peer group by raising awareness. Rather than adhering securely to a biological perspective Lester & Tritter (2005) advocated that utilising the social model of disability would provide a useful way of understanding and making sense of the experiences of people with serious mental illness.

The progress made has moved us towards a 'shared care' approach to healthcare. However, this policy imperative in England and Wales was unclear and its meaning, form and function remained open for debate (Lester, 2005). Again, language or terminology is criticised as Burns (2005, p140) states, "The very plasticity of the term frustrates our search for those changes in practice that improve collaborative working and are durable, feasible and not critically dependent on individual and local initiatives". Reilly *et al* (2012) suggest that primary care is centrally involved in caring for people with serious mental illness. This is despite research by Lester (2005) highlighting that previously, many GP's state that by comparison with other complex disorders such as diabetes or heart failure, the holistic care of people with psychosis is beyond their remit. Kendell (2009) postulates that the differences between mental and physical illnesses are quantitative, rather than qualitative with variances of emphasis as opposed to fundamental differences and no more profound than the differences between other physical systems. It could be hoped that we have progressed further in the decade since Lester and colleagues produced the findings from their study. However, this was the response found by some of the participants within this current study too, with a service user participant stating that the GP had openly admitted that this was an area outside his expertise. Another

response was one of reluctance from the GP as he did not want to interfere with an area managed by mental health services; so much so that the GP did not even acknowledge aspects of mental well-being by not asking how things were. Whilst Kendell (2009) offers a rationale for the possible difference between mental and physical illness the very debate continues to sustain an emphasis towards the continuation of a bio-medical approach. This 'dualism' expressed by the GP may be viewed as, at best, naïve. Perhaps these are anomalies and we may have progressed somewhat, but Lester (2005) had highlighted that the concept of shared care means different things depending on which side of the primary/secondary interface you are employed. This can account for a myriad of responses from professionals on either side but service users may also have different experiences as a consequence. Often people diagnosed with schizophrenia feel that they are not believed by professionals and their physical symptoms are underestimated (Gonzalez-Torres *et al*, 2007).

Barriers must be acknowledged and many GP's are reluctant to pursue forms of shared care due to the demands placed on them by people with mental health issues (Lester, 2005). The study by Reilly *et al* (2012) developed a profile of people who had a diagnosis of schizophrenia and their interactions with the GP practice. Of those using primary care only, over 70% of consultations were for physical health problems, 20% for mental health problems and 45.9% Quality and Outcomes Framework²² (QOF). This may be a little different to what people expect in terms of the difference between physical and mental health problems, these figures are for people only in contact with primary care. This would be the position that people in remission would progress towards if discharged from secondary services. Another point to note from this study is that the participants are on average almost 57 years of age; the average for men was 61 and women 34. The average duration of illness for people with schizophrenia and in contact with primary services only is 22 years. This highlights that the people on the records of the GP's are middle-age and beyond and have endured their diagnosis for a long-period of time. It would be hoped that since this research was conducted that we may see a shift towards younger people who receive a diagnosis of schizophrenia managing with support from primary care alone. The advent of Early Intervention in psychosis teams may help to facilitate this plus

²² Quality and Outcomes Framework (QOF) is a system for the performance management and payment of General Practitioners (GP's) in the National Health Service (NHS) in England, Wales, Scotland and Northern Ireland. The QOF is the annual reward and incentive programme detailing GP practice achievement results. QOF is a voluntary process for all surgeries in England and was introduced as part of the GP contract in 2004. For people with a diagnosis of schizophrenia GP's are expected to maintain a register, monitoring and recording of certain aspects in relation to health.

with the increase in awareness of schizophrenia the age group and numbers of years since diagnosis may be reduced. However, there is no clarity of the best route or pathway required, but early intervention services would advocate that the earlier the referral to them the better (Fearon, 2013), this may come through many routes such as primary care or the criminal justice system for example.

Medication is sometimes associated with being an issue in respect of people being discharged out of mental health services. Again this was raised by participants within this study, practitioners' expressed concern that medication was a big hurdle to overcome in relation to discharge. The study by Reilly *et al* (2012) highlighted that of the people with schizophrenia and accessing only primary care, fewer than 16% were not taking any medication. Of the people using medication a little over 45% were taking one medication and 24% taking two. The type of medication taken was recorded as newer (*atypical*) antipsychotics 34.2%, conventional (*typical*) antipsychotics 32.4% - it was not clear if people were taking a mix of both, which is not advocated but does occur - a further 17.8% were taking antidepressant medication. One aspect not made clear is whether the route of administration for the antipsychotic medication is oral, rather than intramuscular injection, as this can often be a barrier for primary care accepting people from secondary care; as expressed by participants of this current research. Despite the barrier associated with administering antipsychotic medication in some local practices, there have been studies demonstrating more positive results. Gray *et al* (1999) found in their study that 39% of practice nurses never gave intramuscular antipsychotic medication, yet 61% did this at least monthly, however the monitoring of side-effect was infrequent. The findings by Gray *et al* (1999) were reportedly due to poor education received by practice nurses in relation to mental health. The findings by Gray *et al* (1999) echoed the numbers seen in a smaller study by Kendrick *et al* (1998) who found that 68% of practice nurses were administering antipsychotic medication via intramuscular injection; they also concluded that education was negligible and no better than that of a lay person. Medication regimes may be interrupted or discontinued if people see different GP's, but in the study by Reilly *et al* (2012) a majority of over 55% had seen the same GP, which could be indicative of a good level of consistency in approach. Even though this may show some promise a couple of concerns persist from this study; practice nurses were not involved in care and health education was not regularly utilised in consultations, it was also reported that for people also in contact with secondary services the relational continuity in primary care and cross boundary continuity of care appeared to be poor (Reilly *et al*, 2012). If these findings are credible or

consistent with present practise then this may signify issues when attempting to discharge people from secondary mental health services. Practice nurses need to fulfil important roles in the provision of primary care for people moving on from mental health services with health education being a large part of their remit. Education of GP's with regard to mental health conditions may also be necessary as they will be expected to increasingly deal mental health, including psychosis. So stating that '*it is not my speciality*' will not suffice if they are to offer the best services. Or, 'in playing devil's advocate', are they safeguarding other areas where they have more expertise or have more interest or investment in?

It can be expected that a person leaving the support of mental health services will be initially regarded by practitioners as potentially vulnerable. Spiers (2000, p715) identifies, "Vulnerability is a fundamental aspect of how people experience health". The management of this situation is paramount, but may not actually require much, if any, input at all from any healthcare practitioners. However, there is almost a compulsion for involvement from primary care services to offer some input. The term 'vulnerability', within healthcare, is frequently used as an external judgement to an individual or group that may be susceptible to ill health (Heaslip, 2013). This is not exclusive to mental health issues at all; in fact NICE Guidance and National Service Frameworks suggest and almost demand this and they cover all long-term conditions. Risk is regularly associated with vulnerability with the elderly, children, the poor and people with chronic illness defined as groups prone to being vulnerable (Spiers, 2000). This may court controversy within primary care as the person discharged may not actually retain the diagnosis of schizophrenia, so technically is not 'chronically ill'. Given that the criteria for remission warrants the level of symptomatology to be below the threshold to gain a diagnosis of schizophrenia, then the diagnosis should have been discarded at the point of discharge. Despite the independence afforded by discharge from mental health services the person may still find that, due to the social construction of vulnerable groups (registers of people with long-term conditions held by GP practices) they are repeatedly 'invited' to attend for screening and immunisations. Failure to attend or accept these invitations may result in the person being labelled 'non-compliant' or 'refusing services' as GP practices attempt to gain the maximum uptake for the good of the public health agenda. This may undermine the freedom of choice with regard to personal health care and given that the person probably no longer has a diagnosis of schizophrenia then decisions made by the person should not be over pathologised. The NMC (2002) identify that people can experience feeling vulnerable whenever their health or usual function is compromised. If this is repeatedly being challenged

then the person may feel as though they are not getting better or coping since discharge. Vulnerability is due to a combination of medical, psychological, social, and cultural factors (Appleton, 1994). Therefore, it can be reasoned that vulnerability has to be considered holistically and contextually rather than just from a bio-medical perspective, which flies in the face of the idea of 'expert by experience'; again, this also covers many other conditions and is therefore not exclusive to mental health.

Social inclusion is a very important aspect of recovery for service users and practitioners have an important role to play (Clifton *et al*, 2013). Whilst working towards inclusion into mainstream society and recovery are accepted values within the field of mental health they are reported as being relatively new as explicit aims for primary care practitioners according to the Department of Health (2007). It has been suggested that recovery has a psychiatric rehabilitation slant to it and is led by practitioners (O'Hagan, 2008). Recognising the structures, both enabling and constraining, within which they work is a role for practitioners; structures which include the medical model, poverty, discrimination, stigma and prejudice along with the legal system that have constrained and marginalised people in mental health services for years (Clifton *et al*, 2013). Some professional groups of practitioners dislike the medical model as an approach, due to what it symbolises for them. However, the primary concern has got to be the impact that such an approach may have for the users of the service. Whilst also bearing in mind that service users may have different views and different rationales for their feelings. The inhibiting factors caused by a medical approach may impact significantly on the ability of a person to make a transition back into primary care. Language and terminology again are examples which may cause further confusion. Terms such as 'social inclusion', 'social exclusion' and 'social cohesion' are broad and mean different things to different people in different contexts (The Charity Commission, 2001). Sayce (2000) identifies that social exclusion can cause 'massive further damage' for people with a mental health problem and also add to health care costs. Reassuringly Clifton *et al* (2013) highlight that many people do overcome structural constraints, despite their mental health problems, during their recovery and this is a demonstration of their individual agency. This utilisation of control and resilience should be acknowledged positively and encouraged by all practitioners to enable service users make the transitions when ready and are not constrained by services or failing interfaces between services.

One point, very rarely raised, is whether the service user wishes to be 'socially included' into a society which is biased and prejudiced against people from mental health institutions. There is an overall assumption that society is beneficial in all aspects, yet the perception of the person may be of a potentially damaging environment. Care must be taken through all processes leading to this discharge that it is not only the physical environment which is assessed to be conducive but the psychological interpretation of the person too. There was certainly a degree of apprehension expressed by service user participants within this present study when discharge from mental health services was mentioned. A paper by Hannigan & Coffey (2011) illustrates how having once been seen as the solution to the issue of institutionalisation, community care has itself become 'the problem'. The explanation offered in respect of this by Hannigan & Coffey (2011) is due to a lack of rules and confusion around the progress of problem formulations, attempted solutions that are assessed in different ways and the way by which different stakeholders appraise the 'evidence' and their location within the system. Perkins (2012) asserts that recovery-focused services should consider 'the person in their life' as opposed to 'the patient in our services', which is unfortunately where some services begin in their mind-set towards recovery. Whether in primary care or secondary services in the field of mental health values and interests are often seen to collide (Woodbridge & Fulford, 2004). One of the primary pitfalls arises when clashes occur between the ideal of promoting recovery, wellbeing and community participation against the concerns involving public protection and the management of risk (Hannigan & Coffey, 2011). It had previously been reported by Morant (1995) that mental health professionals can exhibit ambivalence towards service users as they are expected to understand the problems of the service users' yet simultaneously they are not immune to lay representations conceptualising mental illness as dangerous and threatening. Despite the research by Morant (1995) being twenty years old it continues to resonate today. There is a powerful link between a person with schizophrenia and public danger and this deeply rooted cultural theme is often reproduced by the media (Barrett, 1998). This has often influenced debates and can be a deciding factor in clinical practice with the most risk averse practitioner(s), usually adopting a more subjective discourse to try and depose the idea of supporting the service user. This could, sadly, occur and two examples may be; if primary care teams are reluctant to accept a person from secondary services they may themselves feel pressured by the suggestions from secondary mental health services that a person is in remission or has indeed recovered and is ready to be discharged to them; secondly, if secondary services anticipate that a service user may be requesting discharge, they may be

fearful of risk factors, either actual or potential and overplay these in discussions to deny the service user any opportunities for discharge.

If the service user is to receive the best possible approach then services will be required to be a lot more cohesive than they have been previously, although some areas manage to work better than others. Hannigan & Coffey (2011) accentuate the issue that effective solutions to complex problems in one area are not guaranteed the same degree of effectiveness elsewhere, with this they cite the reduced efficacy of 'assertive outreach' or 'assertive community treatment' in the UK compared with the success it had in the USA. Regions within the UK may experience the same issues in relation to recovery, remission and discharge of people previously given a diagnosis of schizophrenia. Unfortunately, as highlighted by Morgan and Felton (2013), the opportunities for people using mental health services to make choices and take risks is governed by their relationships with services and their care team. It would therefore not be beneficial if primary care services fall foul of the same problems and issues once the person has left mental health services. This clearly points to issues around coordination and integration between services. When addressing the pressures of mental health services Gilburt (2015) states that a key message is the absence of robust data which renders it difficult to gain a definitive assessment of the state of mental health services. One of the newest initiatives from the NHS and other NHS bodies (2014) is the 'Five Year Forward View'. This suggests change and ambitions on quality by addressing required models of care for the future (Ham & Murray, 2015). It offers reassuring tones, looking to empower service users by offering support for people to manage their own health and for some to increase the direct control patients have with care provision. Whether this approach permeates through to people with a diagnosis of schizophrenia will need to be seen. Overall the 'new models of care' are proposed to offer care which is more integrated than they are presently; reassuringly this is a move away from the approach of 'one size fits all' (Ham & Murray, 2015). These new models will be applied by chosen 'Vanguard' sites, of which 29 were chosen in March 2015. It is proposed by the NHS (2015, p3) "Integrated primary and acute care systems will join up GP, hospital, community and mental health services, whilst multispeciality community providers will move specialist care out of hospitals into the community". If successful this may provide a better climate in terms of people with a diagnosis of schizophrenia making the transition back to primary care.

7.1 Chapter Summary:

This chapter has introduced the complexities of the interface between secondary mental health services and primary care. Whilst it is hoped that the progression back to primary care will be a seamless transition, there are some issues which need to be understood and addressed by practitioners on both sides of the secondary/primary care interface. The concept of liminality has been introduced; this demonstrated that there is a period of adjustment to be acknowledged in which the person may encounter sensations of oscillation between the known area of secondary mental health services and the, perhaps, lesser known area of primary care. This results in the person formulating a personal understanding of the occurrence with this sometimes being a make-shift combination of both. Confusion is not unusual at this juncture and therefore must not be interpreted as relapse by the practitioners involved. If remission is to be utilised for people given a diagnosis of schizophrenia then it may be incorporated within the liminal process, or 'rite of passage'. Concern regarding the role and attitudes which GP's may adopt in relation to accepting people previously in hospital and community services with a diagnosis of schizophrenia was expressed. This was raised due to hearing from participants that some GP's felt that mental health was outside of their remit of expertise. Overall the concerns and issues highlighted should be heeded with due consideration and planned for by mental health teams assisting a service user to navigate out of services if they are well enough.

The following chapter (conclusion) will develop some of the points highlighted in relation to understanding whether the concept of remission is viable for people previously with a diagnosis of schizophrenia. This will be addressed from different perspectives to offer a comprehensive view and fuller understanding.

Chapter 8:

Conclusions and Recommendations

8.1 Introduction:

Due to the complexity of the issues highlighted throughout this study a simple conclusion would not suffice. As a consequence there are a number of angles required to address the concluding aspects of this study. Perspectives of practitioners and service users are highlighted whilst the overall social construction and then the viability of remission are presented. In order to offer a flavour of how some of the findings have been accepted when presented up to this point a reflection upon this is offered too. It is important that the overall concluding points tie-in the overall sentiment of this study by asserting that power and control should not be the influencing factors in selecting remission as a concept to be employed.

The concept of remission is becoming more frequently employed as a term, originating in the area of physical disorders such as cancer, multiple sclerosis and rheumatoid arthritis; it has now permeated into mental health. Initially being used with depression and anxiety it has more recently been mooted and offered as a concept for people with schizophrenia. Primarily employed to address outcomes attached to the efficacy of antipsychotic medication remission is now being suggested to offer more, in terms of 'functional' and 'complete' remission. The impact upon practitioners who are working with people with schizophrenia and also, more importantly, the people diagnosed with schizophrenia and the carers should be of great consideration in areas adopting this concept of remission. How remission is interpreted, accepted and utilised, in relation to schizophrenia, could be the key to any viability of the concept; this has always been the issue driving the research question. As we are aware different and conflicting views can inhibit progress, with the diagnosis of schizophrenia and the concept of recovery being prime examples and if remission instigates the same level of debate with differing views and perceptions it could be untenable, unless we embrace it as a component of the recovery process to the benefit of the service user.

This chapter offers the conclusion to this thesis by revisiting and re-examining the research question:

“Is remission a useful concept to facilitate transition back to primary care for people with a diagnosis of schizophrenia?”

Simplistically the answer would be that ‘it could be’; remission may assist in the transition back to primary care for people with a diagnosis of schizophrenia. However, this would involve potential changes to service design and delivery in addition to a cultural change in organisations and for the practitioners working within; this would include practitioners from both secondary mental health services and primary care. Acknowledgement of remission and its value within the process of recovery would also be a requirement to facilitate the inclusion of remission. The multifarious nature of a persons’ passage through mental health services accompanied by their individualised personal journey of recovery can complicate and compound some issues, which may initially appear simplistic. The very nature of the ambiguity concerning diagnosis, definitions and identification of outcomes can result in a lack of consensus and cohesive practise and often this will have a negative impact for the service user. On the ‘flip-side’ if remission is not seen, or utilised, as a useful concept to aid the transition back to primary care then we need to re-think the relationship and value it holds in this context. Consequentially this may lead to the suggestion that remission be utilised primarily as a tool for monitoring symptomatic change in positivist research addressing medication efficacy, very much where it began in the context of its relationship with people with schizophrenia.

To assist in maintaining a focus for this conclusion the aims of the study shall be utilised as a guide (see below). However, they have informed the sub-headings rather than being an exact replication. This allows for deeper exploration rather than simply stating whether the aim was achieved, or not.

Aims of the study:

- To generate an understanding how practitioners, from different professional backgrounds, perceive remission in relation to people with a diagnosis of schizophrenia.
- To generate an understanding of how people with a diagnosis of schizophrenia and carers of people with schizophrenia perceive remission in relation to schizophrenia.

- To compare and contrast the perceptions of the stakeholder groups with the literature to inform and generate further theory.
- To gain a fuller understanding of how remission for people with a diagnosis of schizophrenia is socially constructed.
- To identify the potential viability of incorporating remission, or not, into the overall process of recovery.

8.2 The Impact of Remission from a Practitioner Perspective:

It is stated by Forrest (2014, p32) that a recovery approach within a multidisciplinary team can pose challenges as we are, "...still working in a hierarchical culture dominated by the medical model and by psychiatrists". Reilly (2015) adds that from his perspective, practitioners believe that medicine is a science, due to the nature that applying solutions to health related problems has got to be evidence-based and empirically tested so much so that questioning their efficacy would appear to be heresy. Shah & Mountain (2007) had suggested the medical model is the process of doctors advising, coordinating or delivering health-improving interventions informed by best evidence. Even among the practitioners who clearly intend to offer more fundamental challenges to the medical model the use of medical language remains widespread (Boyle, 2013). This has continued to be a cause for concern due to people being described and identified predominantly by their disability and symptoms. Foucault (1965, p46) states that, "Our philanthropy prefers to recognize the signs of a benevolence towards sickness where there is only condemnation of idleness". This suggests that there could be a possible benevolent rationale behind what initially may appear to be a patronising and quashing emphasis of the language used. Topor *et al* (2011) states that professionals do not have to show interest or pay attention to individual's point of view, thoughts or experience if we regard individual's as helpless victims. This is very much in-line with an approach akin to 'traditional psychiatry' rather than a more modern approach addressing 'mental wellbeing'. Whilst it may be wrong to assert these beliefs in present day practise, it may go some way to explaining why people are maintained within mental health services even when outcomes may be achieved providing evidence to the contrary.

This, more traditional, approach prevents the acknowledgement that recovery incorporates a social process (Topor, *et al*, 2011). It has been suggested by Double (2002) that a biological view needs to be tempered and complimented by psychological and social understandings to recognise the uncertainties of clinical practice, thus moving towards a biopsychosocial approach. This is certainly occurring in some teams since the advent of psychosocial interventions being employed to compliment the medical (biological) and traditional perspective. Double (2002) adds that this conforms to the new direction which had been termed as 'post-psychiatry'. Bracken & Thomas (2001) state that post-psychiatry has an emphasis on social and cultural contexts while placing ethics before technology as it seeks to minimise the control and coercive interventions of the medical model. Double (2002) states

that post-psychiatry is part of hermeneutics and this provoked several critical responses to his article. One respondent, favouring a more scientific approach, stated that hermeneutics is unsuited to solving real life problems such as mental illness, as this requires knowledge and understanding of how the world works (Abed, 2002). Smith (2002) adds that Double created a false distinction between everyday psychiatry and post-psychiatry, stating that psychiatry and psychiatrists become easy scapegoats and not all are to blame for worrying developments. In addition Smith (2002) also stated that he does not wish to be a 'biomedical scientist' as he takes a broader outlook into the complexity of people.

The introduction of the concept of remission for people with schizophrenia was very entrenched in an approach of positivism and practitioners, other than those in the medical field, may have paid little regard to it. Very few of the participants in this study had heard of remission used in connection with schizophrenia. As the main prescribers of medication the medical staff would obviously pay more attention to the research which utilised symptomatic remission to offer information regarding efficacy of antipsychotic medication. Informed by my clinical experience I have observed nurses, social workers, psychologists and occupational therapists with mixed responses regarding medication, but for some it may be viewed as the only answer or mode of treatment for a person distressed by psychosis, such as schizophrenia. This may be seen as a very blinkered or unidimensional approach and at a distance from the more desired recovery focused approach. The responses offered by practitioners within this study, when explored beyond the rhetoric did not always match with a recovery focused approach either. However, the advent of recovery approaches and in particular psychosocial interventions have allowed practitioners to appreciate other modalities of treatment as an alternative to, or to compliment the use of medication and this is also advocated in the NICE Clinical Guideline 178 (NICE, 2014b). Some participants within this current study also felt that the sentiment of remission was based in a medical model and this was off-putting for them and as a consequence they stated that they preferred what they had learned to be a more holistic approach, in that of recovery. However, this was not clearly demonstrated consistently in the data.

Reilly (2015), in agreement with Forrest (2014), states that the medical model in healthcare remains dominant and assumes a hierarchical structure in which decisions and opinions made by the doctor or consultant are seen as unquestionable. This goes very much against the grain of the '*New Ways of Working for Everyone*' (DoH, 2007) and with that the culture of a

multidisciplinary team approach to recovery for people with psychosis. The document states, "In essence, NWW [*New Ways of Working*] is about promoting a model where responsibility is distributed amongst team members rather than delegated by a single professional, such as the consultant" (DoH, 2007, p14). However, this contradicts a consultation/discussion document by the National Working Group on New Roles for Psychiatrists (NWGNRP, 2004, p7) which states, "They [consultant psychiatrists] are imbued with ultimate responsibility for both individual clients and the availability of resources". This extract was from the introduction to the document, and while addressing 'new roles for psychiatrists' is an example of the professional dominance and power that the medical profession has held. In describing the psychiatrist's role a traditional view is illustrated in the document which states that when other health workers undertake clinical work it is deemed to have been personally delegated by the consultant, implying ultimate responsibility (NWGNRP, 2004). This document then addresses 'emerging ways of working' and explores, albeit briefly, two possible approaches, described as 'models of leadership'; one of which would position the consultant psychiatrist as the person delegating tasks and ultimately shouldering responsibilities for the service and its shortcomings. In the, newer, alternative approach the consultant psychiatrist would be a member of the team and would be brought in when necessary, utilising a true sense of consultancy. The selling point for this, latter, approach is stated as, the responsibility for the service and its shortcomings will remain with the team. Both of the community mental health teams for psychosis employed within this current study utilise this approach and have a mental health nurse as the team manager and these teams contain a variety of disciplines each containing one consultant psychiatrist. The document concludes addressing suggestions for 'the way ahead'. Whilst advocating a team approach with people having different roles making up the value of the team, when it comes to the consultant psychiatrist the language used still speaks volumes in terms of power and control as they refer to themselves as 'specialist' and 'senior professionals' (NWGNRP, 2004, p13). In both scenarios there remains a sense of superiority with the role of the medic within the teams; after all it is the medic that holds the ability to place a diagnosis on a person. Boyle (2013) is critical of diagnoses as she feels they lack scientific support, but states that to some people that receive them, a diagnosis may serve important personal and social functions and they can also provide access to services. More recent than the NWW is a statement from the Academy of Medical Royal Colleges cited in a Department of Health (2010) document 'moving on from the new ways of working' which states; "Doctors alone among healthcare professionals must be capable of regularly taking ultimate responsibility for difficult decisions in situations of clinical complexity and uncertainty,

drawing on their scientific knowledge and well developed clinical judgement” (DoH, 2010, p14). Sidley (2015) states that this guidance typically has the in-patient setting in mind rather than community mental health teams where the primary challenge is to understand that no singular profession can claim to have ‘exclusive competencies’ from their professional training. As Rosenhan (*cited in Branaman 2001*²³) discovered, it is not so much the access to services (particularly in-patient services) that is the issue, it is the getting out once admitted. Once the ‘pseudopatients’, in this study by Rosenhan, had gained access by stating they had been hearing voices, they stopped simulating any abnormal responses. The report ‘*On being sane in insane places*’ by Rosenhan highlighted some interesting, if not alarming facts, such as fellow patients recognising ‘normality’ when the staff did not, and also the failure to overcome the tag of schizophrenia once they had been labelled. The same may be the issue in present day in terms of the transition back to primary care. Whether in remission or recovered with some residual symptoms the diagnosis of schizophrenia sticks once it has been bestowed. Rosenhan (*ibid*) states that if a diagnosis of cancer had been found in error it would give rise to celebration, whereas psychiatric diagnoses are a ‘mark of inadequacy forever’. In fact, Anthony (1993, p19) identifies that, “At times people who have successfully recovered from severe mental illness have been discounted as not ‘really’ mentally ill”. Sadly, this was the tone from a participant in the current study too. Anthony (1993) adds that sometimes this is viewed as an aberration or even worse as a fraud. Again, there are issues that may inhibit transition from secondary mental health services for those deemed to be in remission. If practitioners cannot agree that people can recover sufficiently from schizophrenia or if the ‘label’ of this diagnosis cannot be rightly cast-off then this may result in stagnation and “Stagnation in mental health services can severely jeopardise an individual’s recovery process” (Ford, 2010, p23).

Since the push to adopt the ‘New Ways of Working’ a study by Dale & Milner (2009) demonstrated shortcomings in its adoption in some areas. It was discovered by Dale & Milner (2009) that attitudes towards new ways of working by consultants and specialist registrars were generally negative with some being unclear as to whether or not the trust in question had adopted this approach or not. One reason for the confusion around the adoption was highlighted by Dale & Milner (2009) as possibly due to a clash with the rolling out of the multifaceted and overlapping proposals from the *National Service Framework for Mental Health* (DoH, 1999).

²³ Rosenhan – ‘On being sane in insane places’ was originally published in 1973 (Science, 179, p250-258) but the version cited from and contained in the reference list is a replication of the article within a chapter of a book edited by Ann Branaman (2001) – ‘Self and Society’.

The idea here is not to vilify our medical colleagues, but to be appreciative of some of the inherent issues that may be present in, some more than others, multidisciplinary teams. If remission is to be employed then we cannot apply this without the agreement of consultant psychiatrists and specialist registrars as their relationship with our primary care colleagues is imperative if a transition back to primary care is going to be a consideration for the service user. However, the issue of control and power is a long-standing component associated with this medical dominance. Illich (1995), whose interest was in the legitimacy of power in health systems asked, whether mental health professionals are necessary, as 'do it yourself' care was seen as preferable in his view.

Some medics have adopted the newer ways and are integral members within well-functioning teams, whereas others may offer resistance to these changes and feel unable to relinquish any control, albeit assumed in some instances. People can be determined and the meaning they attach to what they do is important to their individual identity (Pratt *et al*, 2005). Effective team working has got to be the answer although, despite consultation in preparation for the 'new ways of working' it was reported that some confusion remains in regard to extended roles and as such the 'distributed responsibility model' represents a challenge (DoH, 2007). It is not just medics that are expected to adjust their ways of working as all members of the multidisciplinary team have key roles to play. These key roles also include an issue not clearly addressed in the New Ways of Working document; the relinquishing of professional control in order that the service user may be more involved or responsible for decision-making. The idea that practitioners hold onto the power regarding decision making due to the service users lacking 'insight' may not be empirically justified (Schrank & Slade, 2007). McCabe *et al* (2007) state that 'insight' is a term widely employed by practitioners in a manner that describes the ability of a person to understand their illness. However, this 'understanding' would need to correspond with the understanding that the practitioner has, otherwise the person would be regarded as lacking in insight. Mosolov *et al* (2014) remind us that Andreasen *et al* (2005) insisted on including 'lack of judgement and insight' as one of the criteria within the remission criteria tool. This demonstrates the relationship between cognitive impairment and adequate self-judgement and self-control in the service user (Mosolov *et al*, 2014). Thornicroft (2006, p213) succinctly states, "Put crudely, insight refers to how far a person with mental illness agrees with the diagnosis made by the psychiatrist". This could perhaps be expanded in present service delivery to be any member of the mental health team. Good insight is reputedly the result of an appropriate developmental or restorative process that converts a

person who was perhaps, unaware and defensive previously into a person who has become more aware and compliant (Williams, 2008). Using the term and concept of insight forces us back into the dichotomous position of 'sane' and 'insane' and the point that people are either one or the other. If in remission a person would 'naturally' need to be insightful to fulfil the criteria stipulated to qualify as such. The polarised position then would be mental illness or madness as some may call it; it has certainly been referred to in many derogatory terms throughout the course of history.

Madness is very much owned by disciplines such as psychology, psychoanalysis and psychiatry with practitioners associated with them having the final word on madness (Danaher, *et al*, 2000). The point being, "Madness holds meaning and issues of power often lie at its heart" (Coles, 2013, p43). Danaher *et al* (2000) states that Foucault suggests power is first and foremost 'productive' and should never be thought of in purely negative terms. Fox (2000) states that Foucault's idea was that power and knowledge are unable to be detached from each other. Foucault also describes power as ever-present with an ever-changing flow that very much depends upon how different groups, institutions and discourses negotiate, relate and compete with one another (Danaher *et al*, 2000). In the context of mental health teams, knowledge may be primarily seen as being held by the practitioners and amongst them, again, potentially the medics. The distinction between 'power to' and 'power over' was made by Law (1991), and Fox (2000) describes how this places increased emphasis on the productive and generative aspect of power in relation to 'concrete practice'. Power and its effects within the mental health team may create instability as opposing views may be expressed in relation to diagnosis, the presentation of service users as seen by practitioners and treatment plans. Within the clinical environment there have certainly been episodes when I have witnessed heartfelt, well-intentioned and often heated debates within teams. Intuitive feelings, professional standing and team ethos all impact upon the decisions made and can be heavily weighted with issues related to power. For Foucault, power relations exist when all groups involved have degrees of both individual freedom and power over others, a 'state of domination' occurs when an individual loses his freedom in this power relation (Batters, 2011). This may be the case for service users and not always in the obvious sense as in when detained, but also when feeling restricted by mental health services. Newman (2005) observes that power runs through institutions such as the prison or the mental asylum.

The 'new ways of working' is not the only attempt at improving community team working practises as Onyett *et al* (1995) addressed this previously, but without the mass support of fellow organisations. Over time perhaps we have been able to contemplate the required developments and potential benefits of what has occurred since the explosion into community-based services. Certainly over this period we have heard more from service user groups in respect of what they expect from community mental health services. This represents a huge shift in community mental health practise, the emphasis from the Department of Health (2007) and the collaborating agencies is that everyone should benefit from this. Practitioners should have realistic workloads and clarity about team and service responsibilities whilst for service users the benefits may come from a team approach based on individual needs rather than clinical symptoms (DoH, 2007). In relation to the possible introduction of the concept of remission this may continue to provoke the on-going debate of it being embedded within a medical model. Due to remission primarily being utilised as an outcome measure addressing symptomatology this does not facilitate an easy fit into this approach. However, the aspects of functional remission could perhaps allow it to be viewed in a more holistic context. The argument then may arise regarding the similarity between functional remission and recovery, which is a favoured and more understood construct from all stakeholder viewpoints. Whether, we utilise remission or recovery there are common and shared issues that still require addressing. All practitioners need to make some shift in their values and attitudes as the concept of recovery proposes that they move "...from that of 'outside experts' for people's illness to that of companions and helpers on people's paths of life" (Schrank & Slade, 2007, p324). This would ultimately change the balance of power and would inevitably be challenging for staff and community mental health teams.

With respect to recovery, The Schizophrenia Commission (2012) also highlighted that there are barriers hindering change of both an attitudinal and structural nature. Within a new and flattened structure, as opposed to the historical hierarchical structure, it allows for other professional groups (other than medics) to be seen in more senior roles too. This is not without its own set of issues and Perkins (2012, p15) promulgates that, "Professionals of different hues may vie for supremacy – debate whose explanatory paradigm is 'correct', whose interventions are 'best'". This is why it is particularly relevant that, "Every interaction, by every member of staff, should confirm recovery principles and promote recovery values" (Boardman & Shepherd, 2012, p6). Topor *et al* (2011) highlight that a number of studies have described the person's role in the recovery process as being one of an 'actor', this is supported by

autobiographical narratives describing how people have taken control of their own lives. In 'the presentation of self in everyday life' Goffman (1959, p37) explains how, "When an actor takes on an established social role, usually he finds that a particular front has already been established for it". "What to do? How to act? Who to be? These are focal questions for everyone living in circumstances of late modernity – and ones which, on some level or another, all of us answer, either discursively or through day-to-day social behaviour" (Giddens, 1991, p70). The development of people taking control of their lives after being given a diagnosis of schizophrenia may be challenging to some practitioners and whilst the service user engages their 'front', a conflict may arise if the practitioner cannot identify the front they themselves may wish to employ in response, or it may clash with the front that the practitioner may have traditionally utilised. Goffman (1959) added that 'fronts' tend to be selected rather than created; therefore if the service user is not in the role of deferential patient then the practitioner may not be at ease in this situation. It is almost inevitable that after a long history of institutional care that recovery and associated concepts do provide challenges to some practitioners.

Empowerment of service users has got to be the way forward utilised by all practitioners, whilst this is mentioned a lot in the literature and in practice we need to ensure it is more than just research and/or service driven rhetoric. By empowering an individual, practitioners are ensuring control is given back to the person in order that they can learn to be independent or recapture the level of independence that was lost. The ultimate idea of recovery-orientated practices are those that recognise strengths of the service user and empower them within the mental health system, as opposed to stifling input because decisions are made by service providers (Atterbury, 2014). Forrest (2014) discusses human rights in relation to recovery and states that if a human rights interpretation of recovery can be adopted then other less measurable areas, such as 'hope', 'acceptance' and 'identity', are likely to follow. This may intimate that we have been placing 'the cart before the horse' when previously attempting to 'add' human rights to other, perhaps more tangible, aspects of recovery. If medics, or indeed practitioners from any professional background, construct and utilise measures such as remission criteria without service users having an understanding of this it could signal another subtle, or less obvious, way of disempowering service users. It had been suggested by the DoH (2009) that to assist recovery, tools and measures should be provided by services to allow the contribution by service users in relation to goals and outcomes around which their care is then

based²⁴. Tondora *et al* (2014) highlight concern that whilst practitioners strive to attend to people as individuals there are numerous strategies and tools that remain underutilised. The understanding of service users' being experts in their own experience is, and should be, embedded within the recovery orientation, and as a consequence the locus of control should remain with the service user to the greatest extent possible (Atterbury, 2014). This enforces a shift within the discourse in mental health services. Practitioners from all professional backgrounds must adopt a salutogenic approach for recovery focused interventions to be truly effective. This will facilitate the service user in accepting the notion of recovering a life, as opposed to suffering or enduring a disease as would be the case from a pathogenic approach. If discussions and dialogue were salutogenic rather than pathogenic this would also facilitate a transition beyond secondary services by use of goal(s) driven support, as opposed to only employing symptom criterion. The holistic and inclusive manner within an approach supportive of salutogenesis also redresses the balance of power (Antonovsky, 1985; Atterbury, 2014). Pathogenic approaches are controlling and power-based. Practitioners should be encouraged to facilitate freedom and reduce any issues of professional dominance as highlighted by Batters (2011).

As equally important as the management of the power dynamic, and perhaps an integral component too, is the use of language employed by practitioners. An important ethical consideration for practitioners is their use of language when interacting with fellow practitioners in the multidisciplinary team, the person using the service and, with the system (Forrest, 2014). "A more holistic view of mental health offers recovery as the hopeful protagonist in a narrative of health not illness" (Atterbury, 2014). Rather than utilising a 'deficit-based' language Tondora *et al* (2014) suggests employing 'strength-based' alternatives (See Appendix 16). This deficit-based language also includes negative terms which may be heard from practitioners from time to time such as, 'acting out', 'unrealistic' and 'unmotivated'; all of which are unhelpful and do not foster a recovery-focused approach. Practitioners may be offended at the idea that the care given is not recovery-orientated or person-centred, the objection to this is against the notion that they do not take the person into account (Tondora *et al*, 2014). Some participants in this current study did reveal that they felt individualised care was the way to care for and meet the needs of people with a diagnosis of schizophrenia. However, this does not reveal the language employed in the delivery of this approach. The fact that practitioners also discuss the use of processes and pathways which

²⁴ Examples of this would be the 'Recovery Star' tool (Mental Health Providers Forum, 2008) and the 'Wellness Recovery Action Plan' (Copeland, 1997).

may inhibit true individualised care, but at least offer all practitioners some direction despite possibly restricting the very thing they advocate as 'good practice'. Baker *et al* (2014, p19) postulates that "In theory, empowering clients to have a central role in the co-ordination of their own care should have clear benefits for MDT communication and cohesion". The degree to which service users are involved in ways other than tokenistic representation or occasional comments towards the direction of their care needs to be a consideration within community mental health teams. Tondora *et al* (2005) comment that no matter how person-centred practice is in theory, if it does not respect the individual's preferences and address existing capacities and resources of the person then it cannot be deemed to be person-centred any longer. In respect of remission being employed in mental health services, we would hope that a person-centred approach is, or would be, employed but the truth is probably that it is the practitioners making the majority, if not all, of the 'important' decisions regarding care. Despite the service user supplying the responses to the questions set to establish if remission is achieved or not, the practitioners may not prompt the service user to be more inclusive and collaborative in this venture. This needs to be the point where the 'collaborative trajectory', from this study, is viewed as an ideal route to progress in the journey of recovery for the service user. The observations made from the data that has informed this trajectory may be missed in regular healthcare delivery and as a consequence the opportunity for the service user to recover a life beyond mental health services is missed or ignored. Sadly, within clinical practice the other three trajectories '(self-fulfilling', pessimistic', 'glass-ceiling') would be more visible and recognisable than the collaborative trajectory. This therefore renders the collaborative trajectory as being aspirational and it would need to be brought to the attention of practitioners and services in order that better progress towards and through transition for the service user could be facilitated.

8.3 The Impact of Remission from a Service User Perspective:

It has been highlighted by Williams (2008) that literature has not paid sufficient attention to the social experiences related to receiving and endorsing a diagnosis of mental illness. The attempt to regain a feeling of social recognition and to feel part of a community again is paramount if recovery is to truly take place. Nobody will profess that recovery is easy and it is faced with many factors which, independently or combined, influence the ability of the person with on-going health problems to adjust (Margereson, 2010). This 'adjustment' is in keeping with the sentiments expressed by Anthony (1993) in relation to recovery. Once insight is established this involves taking on a new identity and alters the way people view themselves and the manner in which others view them (Williams, 2008). Illness perception has been established in the case of physical illness and Petrie *et al* (2008) addressed these in relation to mental health. The five illness perceptions identified were:

1) What caused the disorder?

This is often drawn from shared cultural understandings, in the case of schizophrenia this would be based on ignorance or a negative understanding.

2) The identity component;

Petrie *et al* (2008) report that within physical disorders patients attribute a wider range of symptoms to the condition than the staff, but add that this is not clear in mental health. From an experiential view in clinical practice it has been observed that practitioners may actually attribute some behaviours and presentations as being part of a condition or diagnosis which they are not usually ascribed to. This can be seen in some areas where there is a tendency to over pathologise issues which a service user may present with.

3) Perceptions about the illness;

Often there is difficulty for individuals to conceive that an illness will have a chronic course and in mental health this may be termed more as an acute or cyclical illness (Petrie *et al*, 2008). However, talk about remission and recovery may also impact upon the perceptions held with regard to the course and outcome of schizophrenia.

4) Cure control component;

This is divided into two perceptions that address how much treatment is likely and how their own behaviour can influence the course of an illness. Historically, service users

have not been encouraged to do much at all to influence a better outcome, as it was not thought to be very productive.

5) *Consequences;*

The perceived effect the illness will have on a person's life, including personal life, family, social and financial. Again, buying in to and believing recovery is a possibility changes the perceived consequence of schizophrenia.

The manner in which a person accepts a diagnosis can have differing impacts upon them, and Petrie *et al* (2008) suggest that the most interesting aspect of illness perception is the degree of variance between people with similar conditions. Williams (2008) highlights that the shift in identity may be more pronounced for people with a diagnosis of schizophrenia, as opposed to people diagnosed with any other mental illness. Quality of life and coping are linked to illness perceptions in schizophrenia (Lobban *et al*, 2004). Although service users and practitioners may hold different interpretations and this may result in practice which is not culturally sensitive or it may contribute to inappropriate behaviours and poor coping (Margereson, 2010). However, if practitioners have been informing people that schizophrenia is a long-term condition with a poor prognosis requiring life-long service input, then it may be confusing for some to hear about concepts such as recovery and remission. Perkins (2012, p15) identifies the issue as being due to the fact that, "Professionals think about 'the patient in our services' and start by defining a person's symptoms and problems then prescribe interventions and the services/supports the person is deemed to 'need' in order to achieve the goal of 'cure'". Despite all of the movement, and good work, towards a recovery orientated approach the comments by Perkins continue to resonate, therefore serving as a reminder that recovery is in many cases still in its infancy, and has a long way to go to fulfil the 'real' needs of a person rather than satisfying professional self-gratification. As Deegan (1996) reminds us that it is not the role of the mental health practitioners to judge who will or will not recover, but to establish strong relationships with people to enable them. Nelson & Prilleltensky (2010) highlight that there is sometimes an awkwardness, for helping professionals, associated with the roles of being both agents of 'compassionate care' and agents of 'social control'; this can sometimes result in a difficult decision for practitioners.

There are negative connotations associated with mental health diagnoses and it is not clear how this may influence the construction of the identity (Rose *et al*, 2007). "Illness perceptions may be best elicited in psychosis when the patient is in remission and better able to make

sense of the illness” (Petrie *et al*, 2008, p562). This comment does not make reference to the value of determining the perceptions the person may hold prior to being in remission and with this the potential benefit of the practitioner being able to acknowledge and appreciate what that person’s perception is. Johnstone (2013) observes that the perceived passivity of psychiatric patients can irritate clinical teams, but she adds that practitioners rarely appreciate that the ‘act of diagnosis’ has invited them into this position. The concept of ‘learned helplessness’ (Seligman, 1975) and the ‘sick role’ (Parsons, 1964) become dangerous traps that service users may fall into, or indeed be wrongly encouraged to adopt. There is a common cultural acceptance that people diagnosed with schizophrenia are not responsible for the condition and consequentially need to rely on expert help to get better. While this may be more the case with cancer or pneumonia, it is not generally seen as helpful for people with mental health issues to be encouraged to surrender responsibility to ‘professionals’ and wait for the medication to work (Johnstone, 2008). Creating dependence in service users goes very much against the overall ethos of recovery. Parsons (1964) describes the difficulties and fraught connections between the ‘patient’ and the ‘doctor’ and also the interplay between mind (psyche) and body (soma). In this current study participants reported differing relationships between themselves and all of the practitioners they had contact with from the mental health team. Some responses were positive but in some ways subservient to the person who was their respective care coordinator, however one was clearly upset by the patronising manner of his coordinator who took an infantilising approach towards him. This understandably caused resistance to any interventions and the ultimate breakdown of the therapeutic relationship.

In respect of Parson’s reference to mind and body, this is probably more relevant than ever due to the awareness raised with regard to physical conditions (Robson & Gray, 2007), poor mortality and morbidity rates (The Schizophrenia Commission, 2012). However, some participants still attend their GP surgeries for physical ailments, with the majority stating that the GP then either disregards or ignores the mental health aspect or openly admits to ‘not having sufficient expertise in this field’, so much so that they do not ask how things may be going. This would raise some clear concerns if the person had been discharged back to primary care and the GP was the principal contact regarding all aspects of health and wellbeing. The theory by Parsons (1964) details two possible reactions to diagnosis; the first being an emotional ‘shock’ followed by ‘anxiety’ in relation to the future. This anxiety leads to an over-estimation of the chance of quick recovery according to Parsons (1964). However, given both

the history and public interpretation of schizophrenia this could very well be the opposite with a diagnosis of schizophrenia. This may result in pessimism and a case of therapeutic defeatism and this may even be, unknowingly, supported by practitioners. Not all participants, who are service users within the present study, believed they could become well enough to leave mental health services one day. Being told you are 'in remission' may prove to be a frightening and anxiety provoking scenario for some service users. This is a sensitive issue which practitioners will have to acknowledge, understand and manage although, this may already be similar in the case of recovery. If some stability has been established within services then any change may appear to threaten that stability, unless properly prepared for. Taking charge of one's life means taking risks, and clutching at security can discourage interpersonal relationships and also impede self-growth (Rainwater, 1989). This is due to the fact that people who fear the future attempt to secure themselves and whilst Rainwater (1989) is referring to interpersonal relationships *per se* here, it resonates with the therapeutic relationship in the same manner.

The issue of preparation for recovery and beyond for service users may revolve around the understanding of self and social identities. If service users do not perceive themselves as possessing a positive social identity, or as one which is constrained within mental health services then this may inhibit recovery. Williams (2000, p21) states; "Both Hegel and Nietzsche make innovatory claims that the identity of persons is best understood not as a fact about the essential and universal features of their inner being but as response to, or an effect of, the activities of others". Therefore, the identity of the service user can be best understood by his/her response towards the activities of the care coordinator. Despite practitioners commonly stating that they operate using a humanistic approach, service users would benefit greatly from the emphasis from practitioners being on that of 'self-concept'. Carl Rogers (1959) identifies that self-concept has three components; i) Self Image (view of self); ii) Self Esteem or Self Worth (how much value you place on yourself); and iii) Ideal Self (what you wish you were really like). Establishing more understanding around these areas could provide an improved grounding in preparation for recovery. This would not mean being dismissive of the fact that schizophrenia will have impacted upon their life and previous desires. It may be easier for practitioners to consider responses from services user in light of what they already know about the clinical condition of the person; however it is important too that they understand how the service user perceives and interprets the meaning of the illness in relation to its impact on their life (Stein-Parbury, 2014).

One area which is growing in popularity is the use of the narrative or storytelling to enable service users to get across how they feel and the impact that schizophrenia has had on their lives. Mair (1988) states that we live in and through our stories, stories inform life. Stories infuse us with an awareness of our own individuality, while simultaneously connecting us to communal identities (Hall, 1996). Narrative or story structure offers an alternative method to conceptualise the self (Polkinghorne, 1991). This offers a refreshing approach to discovering what is important to the person, rather than the practitioners imposing their interpretation on this. An example of the impact of this comes from the narrative by Eleanor Longden:

“...The very first time I met him [the new consultant psychiatrist] he said to me, ‘Hi Eleanor, nice to meet you. Can you tell me a bit about yourself?’ So I just looked at him and said, ‘I’m Eleanor and I’m a schizophrenic’, and in his quiet Irish voice, he said something very powerful: ‘I don’t want to know what other people have told you about yourself, I want to know about you’. It was the first time that I had been given the chance to see myself ...” (Eleanor Longden, 2012, p143).

The substance and meaning contained within this narrative may have been lost if this was performed as a clinical assessment, rather than utilising the opportunity for Eleanor to tell *her* story. The point made here is also striking and should not be overlooked; practitioners need to hear the service user. It may be the case that service users who have had lengthy periods within mental health services become familiar with and also use language which either detracts from the meaning of their experience or contributes to their experiences being pathologised, thus reinforcing the need to be in mental health services. Bullimore (2011, p163) relates to his symptoms of psychosis by stating, “Hearing voices is a common human experience which needs to be normalised, not pathologised. If we pathologise it then we miss the person and start to treat the label rather than the individual. Labels are for bottles and cans, not people”. Some participants within this current study required encouragement to personalise their experience rather than it sounding ‘textbook’ like. Perhaps confidence may be a part of this or wishing to offer the practitioner what they think they should be hearing. In a similar vein some participants also demonstrated a defensive approach when asked about potential discharge from services, indeed one participant expressed initial suspicion that there may be a hidden agenda to close services which he was attending.

Perhaps the key to managing a way through mental health services and working towards and achieving remission and recovery is self-efficacy. The concept of self-efficacy, defined by Bandura (1994), is a person’s belief that they can achieve behavioural competence in particular situations. Such beliefs determine how people feel, think motivate themselves and behave

(Marks *et al*, 2011). This can be achieved through seeing others in similar situations achieving too, and mutual support groups can be useful adjuncts for service users having trouble with self-efficacy in managing their experiences (Arnold, 2011). This adds to the value of groups such as the 'Hearing Voices Network'; which was inspired by the work of Romme and Escher. A good proportion of the service user participants in this study attend and utilise the local hearing voices groups and offer positive feedback of its usefulness. Participants also talk of their ability to assist in problem-solving and sharing of coping skills and such with other members of the group. Indeed, one of the biggest advocates of the hearing voices network is Ron Coleman. Ron has set up a 'Working to Recovery' website and co-authored a series of books on the '*victim to victor*' series, all of which have been utilised in the groups that the participants of this study attend. The safety and security which these groups provide can sometimes be a contradiction for the development of independence for some of the service users. Practitioners need to be aware of when to allow development to take place and to encourage service users towards the larger, yet anxiety provoking, elements of recovery such as potential discharge back to primary care. Many participants in the study feared that if discharged from secondary services the thing they would miss would be the support provided from these networks. Clarity needs to be provided to avoid perceived fears and undue anxieties in relation to developing independence along the pathway *of* recovery. The emphasis has also got to be maintained that it is a pathway '*of*' recovery as opposed '*to*' recovery, as recovery is a lifestyle rather than a destination. Coleman (1999) makes a very poignant and important point that sometimes practitioners create or perceive service users, facing the difficulties and traumas of recovering and adjusting to having had schizophrenia, as '*Heroic*'. Coleman (1999, p52-53) describes the negative impact this had on a friend and warns of the dangers of falling "into the trap of the heroic self". As we are aware, the fall from 'hero' status can be devastating and will serve only negatively in the process of recovery. This provoked Coleman (1999) towards the 'bastardisation' (*sic*) of the famous phrase by the philosopher Descartes – "I think therefore, I am". Coleman's version reads: "I think therefore, I am, I think" and he explains that the additional ending completes the contradiction in understanding of the role of self within society.

It was hypothesised by Rutter (1985) that resilience develops from a belief in one's own self-efficacy and the ability to manage change and the development of a range of social problem-solving skills. It appears then that resilience has been the main characteristic of people such as Coleman and also many more who have moved beyond mental health services. Becoming

resilient does not mean that people will not experience difficulty or acute distress as this pathway to becoming resilient will involve considerable emotional, physical and practical challenges (Shackman, 2009). Opportunities are required for people to achieve recovery, remission, either or, or both. Opportunities which some participants in the study did not appreciate were there for them as they had not been informed by their respective care coordinators. Sayce (2000, p132) states the significance of this; “This process of recovery can only work if the external environment enables people to develop ‘their own unique possibilities’. Recovery is totally dependent on civil rights and opportunities for inclusion ... both based on valuing people who are different and not just those who ‘fit in’”. In the absence of practitioners advocating on behalf of service users, some service users have taken on this mantle themselves. However, this comes with a degree of risk as Goffman (1963) highlights that the person who takes on an advocate role may experience unrelenting social pressure to act as an ambassador for the community. This has been the case from clinical practice when the first service users joined NHS Trusts and were ‘wheeled out’ at every opportunity to meet the criteria of service user representation. Not to say that some may not thrive in this environment, but this should not be a position service users should be placed in without due consideration.

Service users and carers, in this study, expressed concern about being discharged from mental health services, as they would not feel sure that the GP would be able to deal with any relapse or reoccurrence of symptoms should it occur. There was a sense of anxiety in most and only a couple were happy to accept this, if well enough. In all honesty, and hindsight, perhaps the latter part of the question asked, during the interviews, was not fully understood; this was ‘if well enough’. The initial fear of transfer or discharge was the response offered. These responses allude to the fact that either people are not at the best stage to be discharged presently or it is missing from the agenda of the practitioners working with these people. There appears to continue to be a model of maintenance for service users who have had a diagnosis of schizophrenia. Further scrutiny may reveal whether this is as a result of practitioner’s beliefs, service user’s beliefs, service approach to recovery not facilitating or supporting movement out from secondary mental health services, or there could be the fact that the participants in the study were just not at the stage and ready to move on from secondary mental health services yet. However, it has to be mentioned as if not addressed practitioners and services may not be offering the best options for people.

8.4 The Overall Social Construction of Remission:

In terms of how the participants of this study viewed remission, it was very evident that it was a new phenomenon for them to consider in relation to people with schizophrenia. There were several varying views from the practitioners as to where remission 'fits', if at all, with the present method of working with people with schizophrenia. However, practitioners (other than the medics) feel that remission is something which the medics would be more familiar with. Despite using the word 'remission' from time-to-time on discharge summaries it was not used regularly. Recovery remains the favoured word or phrase and this highlights an issue if remission is to be also employed. The issue would relate to separating understanding between remission and recovery and being sure all concerned are working towards similar goals. This illustrates the significance of this research study; it is felt that imposing the term remission without due consideration may cause potential and possible uncertainty around the focus on recovery. Whilst this would also undermine service users further by utilising another term originating from a medical/pathological perspective. In this present study service users were not able to offer clear understanding regarding remission either, some had heard of it but related it to physical disorders only. It appears that no preceding research has either, addressed the awareness of service users in relation to remission for people with schizophrenia or how they may actually respond if remission was to be utilised as a concept. The big concern is that it reduces clarity in relation to a service user's understanding regarding their recovery process and importantly what assistance or input they can, or cannot, expect from service providers.

Figure 23. The Remission/Recovery Relationship

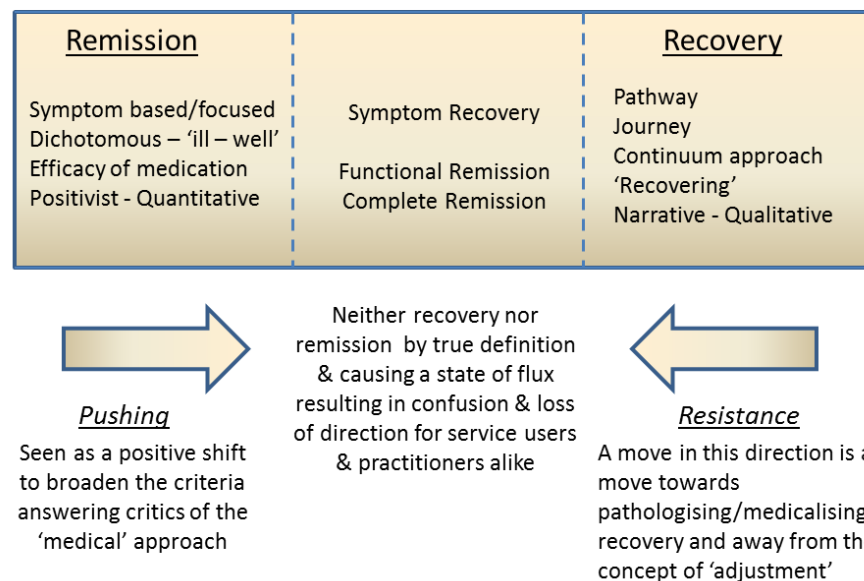


Figure 23 above represents where some of the confusion may lie, the figure attempts to identify and clarify this confusion. As remission is more readily considered symptom based and with its emphasis on medication efficacy it provides a positivist approach. People who are less than comfortable with this perspective push more towards a comprehensive view which encompasses 'functional' and 'complete' remission. Whereas, some people feel that recovery needs elements that can be monitored and measured, from a service user's movement perspective this is resisted against. The value of the narrative is embedded within the recovery approach and is qualitative in nature. This creates a stand-off and opposition for people adopting these polarised views. The alternative is the middle-ground and movement has been seen towards this; although this creates further confusion and dilemmas for service users and practitioners alike. The end result is something that is neither one thing nor the other in reality and working practice. The issue has often been in mental health that attempts are made to be all things to all people, in terms of models, frameworks approaches and even professional roles. This idealistic intent often causes more confusion than it solves across all areas of service delivery resulting in a reduction in consistency too.

The interface and communication between service user and service provider is of paramount importance, but this could be jeopardised if further confusion was to appear through the potential use of remission utilising a clumsy approach. Baker (2014, p20) makes the important point; "It appears that there is a disparity between what mental health professionals and service users regard as good communication". We do not need to be falling into the trap of making this worse or indeed more difficult for people to navigate through mental health services. The 'meanings' contained within explanations offered by practitioners may be misinterpreted or problematic at times. Deegan (1993, p7) explains that being given an illness explanation by practitioners effectively reduced her identity "...from being a person to being an illness". Kinderman *et al* (2006) identify that there may be important differences in the appraisal made by service users in relation to the use of illness labels in different contexts for instance socially, or by practitioners in therapeutic encounters. The central activity of therapy in psychosis is described as 'dialogical' by Dilkes *et al* (2013), their study addresses therapy by psychologists, but the same can be said of any practitioners when working with service users in respect of recovery. One emphasis practitioners reinforce in their practise is that of engaging the service user. Engagement in some instances can be the main activity for some time and can also involve assertive interventions. This approach strongly advocates compliance and concordance and can also foster a paternalistic and inclusive feeling. If practitioners do not

move on from this phase and assist in the development of independence with the service user it can result in the creation of dependence. Peplau (1952) in her developmental model of nursing recognised this issue and discusses the point where the 'patient' no longer requires a service and this would trigger the 'resolution phase'. The difficulty in either recognising or performing this phase when required raises concern that 'we' may be institutionalising people in the community setting. Almost as if the containment within secondary mental health services represents the walls of the 'old institution'. Research addressing remission in schizophrenia discusses treatment goals and potential reintegration into the community (Llorca *et al*, 2009). However, the assumption is that this is secondary mental health care and not regaining full citizenship or becoming un-tethered from mental health services. "...having emerged as a solution to the problems of institutions, community care has, in some assessments, itself become 'the problem'" (Hannigan & Coffey, 2011, p223). Whilst there may be a sense of positivity associated with remission, looking at it in more depth there may still be the remnants of Kraepelinian thinking that have not been amended. This may be further reinforced, perhaps unwittingly, if practitioners construct or utilise remission criteria without consultation or without imparting information to service users and their carer(s). It may be debated that the construct validity of the remission criteria cannot be guaranteed; one of the main reasons for this may be due to the fragility of the construct validity of the diagnosis it is addressing.

The benefits of social interaction and social networks are significant and assist in the recovery of people with schizophrenia and these elements must be preserved and enhanced. The person's recovery takes place in relation to social interaction with others within his or her surroundings and simply this is the social nature of recovery; however the longer a history of mental health issues continue the greater the probability that the social network will have changed (Topor *et al*, 2011). This will have a big impact upon a person's recovery, but hopefully due to the nature of community services the negative impact will be minimised as much as possible. This would be done by encouraging service users to maintain their social contacts and retaining their social roles. Whilst a lot of community teams encourage group activities with fellow service users, personal networks, possibly from a time prior to contact with mental health services need to be maintained. It was recognised by Fortune *et al* (2015) that teams within NHS trusts differed in their approach and recovery practices. It can only be hoped that this not one area overlooked by teams and consistency can be applied for the good of the service user.

Corrigan & Penn (1999) remind us that the recovery approach argues disability is only one aspect of the whole person and recovery does not require remission of symptoms or other deficits. This remains in the spirit of what Anthony (1993) highlights as adjustment to a disorder rather than a cure. This continues to be illuminating literature around recovery as Davidson (2003, p57) adds, "... we have been told that recovery from schizophrenia does not require remission of symptoms or of any other deficits brought about by the disorder". This may again raise elements of confusion between remission and recovery. There are some that may continue to ask, how may somebody profess to be recovered if remission has not been achieved? This is where the two ideologies clash, as illuminated in Figure 23, and this was also visible in responses from practitioners in this study as they attempted to state where in the overall process of recovery that remission would best fit. Of course, there is no right answer, and the reason for this is as individuals we cannot be overly specific and 'one size does not fit all'. Mental health, psychosis and recovery are not simplistic, there is complexity at every stage and this demands flexibility and creativity from practitioners adopting a collaborative and inclusive perspective with service users. At times a 'hands-off' or a more distant approach may be best, but service providers do not usually identify or facilitate this. The service perspectives can, at times, stifle people or 'shoe horn' them into the best approach that a service can offer and not necessarily the best service, or input, a person requires to attain their goal. There is logic in assuming that people can and are able to flourish even in the presence of distressing symptoms and suggest it is more helpful if practitioners consider wellbeing rather than the ill/well continuum; practitioners need to become familiar with this concept if they are to offer successful interventions over the next 10 years (Blakeman & Ford, 2012).

Overall, remission was initially utilised as a symptom outcome measure which, for some, has developed to signify and incorporate more than its original notion. Borrowed from physical disorders and after use with depression it was used for people with schizophrenia. With others adding broader contexts such as 'functional' remission and 'complete' remission this has served to further confuse issues relating to recovery. Practitioners, service users and carers are not familiar with remission in the context of schizophrenia, some appreciate it may be useful whilst others feel it reverts back to a purist medical approach. For service users and carers there is some confusion what it is and might signify.

Therefore the social construction of remission, in respect of people with schizophrenia, may be regarded as;

A concept imposed by a group of people that can utilise it, trying to convince others to adopt it on the merits of their research; but without the full consultation of all involved.

8.5 The Overall Viability of Remission for People with Schizophrenia:

There are many reasons why remission may be a cause of confusion for people, it may be difficult to appreciate where it may 'fit', or whether it would contribute to the recovery of people with a diagnosis of schizophrenia. However, there is perhaps one good reason how remission may prove to be a worthwhile contribution to a person's recovery. This would come about if a person is well enough to make the transition from secondary services back into primary care and remission may be used as a 'selling point' to the GP or utilised as a possible conduit through to primary care. The four trajectories that are possible, as presented in this study, demonstrate likely routes that a service user may take, dependent upon many the factors presented. These factors were extrapolated from the themes in the data generated. The most favourable, and ideal, of these trajectories would be the 'collaborative trajectory' which may see the service user making the move back to primary care with 'all concerned' being prepared for and accepting of this transition. There are however some debates to be had around this and some important points to consider.

Fear *et al* (2009, p111) state that the concept of remission has "obvious advantages for service users, carers and primary care clinicians". This all sounds very reassuring from a pro-remission perspective but the emphasis is on the use of the remission criteria tool and its potential applicability to practice areas. Gathering a 'snapshot' of the symptomatology at any given point may prove useful but as we have found out is only part of the overall issue. Fear *et al* (2009) add that the use of the tool may remove or reduce subjectivity from questions such as 'how are you feeling?' as highlighted earlier, the subjective nature of the narrative from the service user can provide so much more than a questionnaire or objective outcome tool and service users need the opportunity to relay to practitioners, whether in secondary mental health services or in primary care, how they feel and their interpretation of this. With this the danger again becomes apparent that practitioners in healthcare may pathologise and look to take control again. So, whilst this is a start, perhaps the true issue lays with the actual transition and integration for service users. Whilst remission and the remission criteria can help identify the absence, or significant reduction in symptoms for a service user it contradicts some of the philosophical notions associated with recovery.

Social exclusion has long-since been a real issue for people given a diagnosis of schizophrenia and plays an important part in the integration to full and independent community living.

People who lose out on opportunities may feel excluded, whether this is an exclusion from the opportunity for treatment options or opportunity to leave mental health services and further pursue recovery on the 'outside'. Labonte (2004) importantly raises the point that we should not focus on the people or conditions that are excluded; rather we should look to modify the socio-economic rules and political powers that benefit from the status quo. Slade *et al* (2014, p14) support this and state "Participation and inclusion do not involve changing people to fit in, but changing the world". The rhetoric and rationale offered may be to do with expertise being predominantly within secondary mental health services, lack of resources and/or expertise in primary care, or just the fact that a person requires antipsychotic medication to maintain a state of remission and this 'has' to be administered by mental health practitioners.

A paper by Williams (2008) addresses post-diagnosis identities for people with schizophrenia in relation to stigma and insight. There are four post diagnosis identities identified;

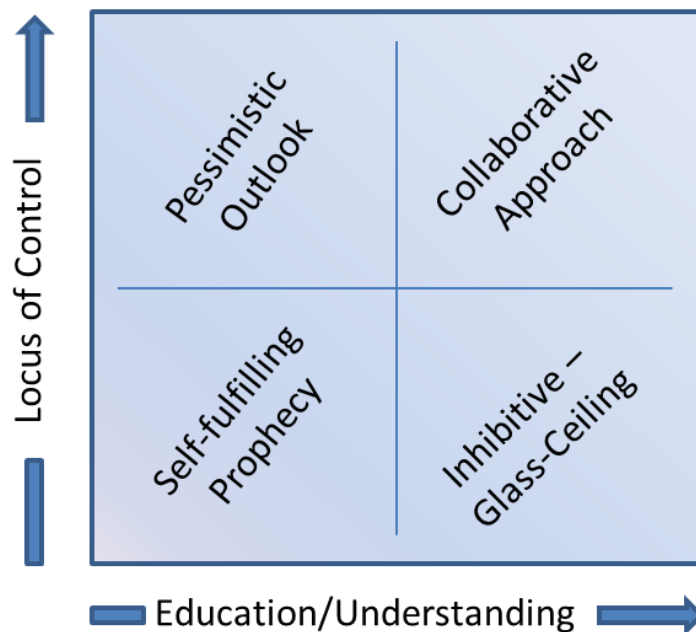
- Resistant
- Engulfed
- Empowered
- Detached

These post-diagnosis identities are ascribed in relation to the identification of people diagnosed with mental illness with varying degrees of internalised stigma. Williams (2008) asserts that no single post-diagnosis identity is desirable over the long-term and people will move around and not remain static in one identity. Initially, these were analysed with a notion of identifying similar properties to those found in the possible trajectories within this present study. However, the post-diagnostic identities are fluid and somewhat nebulous properties and do not map against the trajectories closely. It is important, however, to add that there is some interplay between these identities and the possible trajectory taken by a service user; especially in the case of the 'self-fulfilling prophecy approach' which would be greatly influenced if the service user adopted an 'engulfed' identity. Access to these identities is influenced by individual, social and illness related factors which change. These then, "contribute to unfixed relationships between insight, treatment compliance, and psychosocial outcomes" (Williams, 2008, p252). These influences and identities could perhaps determine a possible route or trajectory for a service user. One criticism of this model is with regard to the emphasis placed on being a 'good patient', by way of being compliant with treatment as opposed to an emphasis on becoming independent. The potential introduction of the concept of remission will pose additional challenges to practitioners, especially if they have already struggled with some of the concepts associated with recovery for people with a diagnosis of

schizophrenia. Services will also need to adapt and be confident that interfaces and systems will develop between secondary and primary care if remission is to be adopted and utilised. If adopted wholeheartedly remission will necessitate changes in services that will impact upon cost and resources. However, these issues may be secondary to the issues of the attitudes and acceptance of all practitioners and the much wider possible implications on society as a whole.

When addressing the viability of remission there is not a straight-forward answer. However, employing a matrix will assist in discerning whether it may be beneficial. The matrix devised is loosely based upon the 'power/interest' matrix (Gardner *et al*, 1986). Utilising the elements of 'Locus of control' [power] and 'Education/Understanding' [interest]; see Figure 24 below.

Figure 24. Matrix of Trajectories



The matrix highlights the two components which can heavily influence the possible trajectory taken when attempting to exit mental health services and return to primary care. The locus of control, which was a theme highlighted within this study is a principal factor, along with education and understanding in relation to the diagnosis, process and service components available.

Self-Fulfilling Prophecy:

If the locus of control perceived by the service user is low or reduced then there will naturally be a reluctance to make decisions or take responsibility in steering through mental health

services. This may be as a result of internalised stigma, as a consequence of an oppressive regime or practitioners and the manner in which 'care' is offered or services delivered. If this is accompanied by a low or negligible level of understanding or knowledge about the diagnosis and system then this contributes towards the self-fulfilling prophecy adopted by some service users. Feelings of 'poor me' and 'the practitioner knows best' may be a common feature in this component. This would also equate to the 'engulfed' identity as highlighted by Williams (2008). Remission may be employed by the practitioners within this scenario, but the value would be of little significance to the service user unless the situation and approach was altered.

Pessimistic Outlook:

In this trajectory the locus of control has been taken by, and increased in the service user. This may be due to strong will or resilience from the service user rather than collaborative practise by the practitioners. Whilst understanding and knowledge may still be negligible on the part of the service user, it may also be low on the part of practitioners and service too. The practitioners may fail to acknowledge the potential of the service user with an improved locus of control and this inevitably will create a pessimistic outlook. Opportunities are not created or offered by practitioners. This may develop from ignorance and naivety more than maliciousness on the part of practitioners or services. Ignorance or lack of understanding in relation to the recovery approach, individual needs of service users and the ability and courage to assist in the development of independence may be the downfall here. Comments regarding the dubious nature of diagnosis if recovery looks promising may contribute to therapeutic defeatism or even nihilism. Remission criteria would be of little significance if this was the trajectory taken as any positive outcome may be disregarded and not utilised fully therefore reducing any credibility. Bias may even form and influence the recording of any remission criteria utilised as a consequence of this outlook.

Inhibitive – Glass Ceiling:

Within this trajectory the understanding of the recovery approach is higher and recognition is afforded to the notion of people with a diagnosis of schizophrenia reaching their recovery. This can present from service users and practitioners alike and progress can be made towards recovery, utilising psychosocial interventions and working collaboratively towards the service user defined goals. However the sticking point comes at the stage of discharge from services. Everything may be in place from secondary mental health services, but the issue may, and

usually has, revolved around the willingness of primary care services to accept a person that has previously had a diagnosis of schizophrenia. The diagnosis may not be so much the issue as much as the medication prescribed, especially if this is to be administered in the form of intramuscular injection. Whilst Kendrick *et al* (1998) found 68%, and Gray (1999) 61% of practice nurses administering intramuscular antipsychotic medication in their studies, it is far less frequent in the local area within this present study. Although these statistics were not collected in this study there were comments by practitioners in both teams that intramuscular antipsychotic medications are a stumbling block to discharge. However, one team had more success than the other. Remission criteria could be utilised and incorporated well into this trajectory and it would be hoped that using remission as ‘proof’ of symptom reduction or absence may influence primary care teams to accept people back from secondary mental health services.

Collaborative Approach:

In the matrix this would be seen as being the ideal position as the locus of control is there for the service user to take. Also practitioners may feel that they can exercise some control in relation to advocating what, collaboratively, are agreed as being the best options. Practitioners will have a full appreciation of recovery from schizophrenia and assist where necessary in the facilitation of this. This will also allow the service user to develop and grow as they near discharge. When discharge nears all stakeholders, including those in primary care will be aware and allow the person to continue their recovery outside the remit of mental health services. Remission criteria would be ideally suited to this approach, where there may be a reassuring element for primary care that symptoms and any possible reoccurrence may be monitored. However, this should not be used as a threat of readmission or as a coercive way to force people to remain compliant with medication. Remission could be utilised to signify and represent the ‘rites of passage’ and become symbolic in manner. Hence, the use of remission in this trajectory may facilitate a smoother and perhaps more timely exit from mental health services for those who are well enough to make this transition. This approach may be summed up likewise;

“Recovery should be characterised through a positive goal of health and wellness as opposed to the avoidance of the negative aspects of pathology and illness. That positive goal is then connected to the agency of the individual, their own situation-specific self-management of the process to their identity” (Thornton & Lucas, 2011, p25).

8.6 Responses and Reflections from Presenting the Possible Trajectories:

The possible trajectories presented within this study have also been recently presented at three events at the end of 2014 (for full list of outputs and impacts from this study see Appendix 2). A presentation at Napier University (Edinburgh) to mental health nurses was received well and an understanding and appreciation was shown in respect of the difficulties in gaining access back to primary care. At Ulster University (Londonderry, NI) the audience was more diverse with service users, carers and different health care practitioners present. The response to my presentation was a little more appreciative of the concerns raised in the transition back to primary care. There was a general acknowledgement and agreement towards the possible trajectories for service users as they recognised the issues highlighted from the study. In November 2014, I presented at a workshop facilitated by a pharmaceutical company. The audience predominantly consisted of medics of different grades and a few community mental health nurses. As expected there was a degree more scrutiny following my presentation. I generally gained the impression however, that there was a general acceptance that people with a diagnosis of schizophrenia remain in secondary mental health services. The justification offered to support this was as a consequence of the 'relapsing and remitting nature of schizophrenia'. A debate ensued with no particular agreement when I asked if people have the right to recover within society and regain their rights as a citizen. There were comments from psychiatrists offering some specific cases. One psychiatrist commented that the team had some success with discharge back to primary care generally except for a few on 'depots' (antipsychotic medication administered by intramuscular injection), this included people who had a diagnosis of schizophrenia. There was a general consensus that the issue remains patchy as some GP's are receptive and some less so and this was to do with dealing with and discussing issues around mental health *per se*. Another angle was explored in discussion, with regard to whether it is about discharging service users to primary care or moving services in to primary care. This comment may be a reference to the increase of mental health resources in some primary care centres, but is not solely a provision for people with schizophrenia but linked to the much wider aspects of mental health. The community mental health nurses added that some people had been discharged back to primary care but contact with mental health services remained as they still administered the depot injection. However, work was on-going to facilitate 'full' discharge. Perhaps this partial arrangement is essential for some to facilitate the final aspects of the transitional phase.

8.7 Limitations of the Study:

The theoretical limitations of a grounded theory study have been addressed within the methodology. Therefore the limitations documented here are pertinent to the process of the study.

It was felt that in hindsight a couple of areas mentioned in the interviews by participants and which also became a little more apparent during data analysis could have been picked up and explored deeper. Some service user participants mentioned or intimated anxiety or resentment about the potential for being discharged back to the care of the GP. This was not in the majority of cases, but could have been explored at the initial stage during the interview. This would not have influenced the outcome of the study at all, but could have been an illuminating issue for potential future research and exploration.

The perspective and opinion from practitioners in Primary Care services was not proposed or included within this study. Literature did provide a perspective, but to gain an improved and realistic insight into this aspect a range of practitioners from primary care could provide data for any future study as this would prove to be a valuable enhancement.

The participants, representing practitioners, represented a wide range of professions. Whilst this offered a broad overview of professional groups with the ability to discuss mental health services, it did not allow for a concentration from specific professional groups and therefore they were not able to fully represent their professional group (for example psychologists, social workers and nurses). This was not in the control of the researcher as selection of participants was voluntary, although this could be a consideration in future.

Whilst emerging codes were discussed at supervision sessions for this study, in further research it may be better practice and in keeping with the approach to revisit the participants and discuss the codes and themes. This would ensure a higher degree of rigour in the research.

8.8 Concluding Points:

For those well enough to be discharged from secondary mental health services it appears that these services are not sufficiently efficient or responsive enough. Perhaps this is due to issues of concern around risk, fear of discharging a person, and removing the diagnosis and with it the attachment to mental health services. If we can overcome the inhibitive components and ensure a true collaborative approach then remission may well be a worthwhile concept to adopt. Unfortunately, the language and interpretation on all sides of the equation creates issues and stifles progression in equal measures. Remission itself cannot be considered a definition of recovery from schizophrenia (Lloyd *et al*, 2008) and what recovery involves will depend greatly on who you ask (Davidson, 2003). Whilst these debates continue, ambiguity will remain an indicator into the utility and future use of the term remission may be signified by any inclusion within policy and guidance. Whilst remission may be topical in some contexts within mental health it is not explained when included in documents such as NICE clinical guideline 155 [Psychosis and schizophrenia in children and young people: Recognition and management] (2013). The word 'remission' is present within the document but refers to a person with an absence of symptoms in the context of medication, treatment and in preparation for psychological therapies. Introducing remission in a fuller manner would raise understanding of how it may be employed more universally. The medical profession (psychiatrists) state "There needs to be clarity about which categories of patient should be seen in secondary mental health services" (NWGNRP, 2004, p14). This needs to be taken forward greatly to also analyse the category of people who are to be discharged from services too. It is all well and good having inclusion and exclusion criteria but the issue of throughput and how people can move on beyond mental health services needs to be addressed with a lot more clarity by all professionals. Cohesion within service delivery is often an issue and the clash of ideologies and approaches reverberates at many levels. Jobbins (2012, p171) identifies, "There is a general acceptance that you cannot successfully commission either health or social care in isolation of each other". Whilst this is another large argument for debate, it should be recognised that health and social care need to be cohesive when working towards recovery irrespective of whether remission is a component or not.

The arguments against the use of a heavily influenced medical approach by many people on both sides of the service user/service provider fence may signify that the use of remission may ultimately be rejected or not adopted. Remission carries with it the notion of medical practice

and a stronger history of use with physical disorders than within mental health. This notion makes it a difficult concept to appreciate or accept in relation to the wider concept of recovery. Within this study it has been noted that a truly collaborative approach is the way forward, thus accepting that individuality needs to be recognised and acknowledged to maximise the potential for recovery. Employing a concept which is perceived as potentially restrictive, such as remission, may jeopardise feelings of hope and progress for service users. Symptomatology is also an issue; remission signifies removal, albeit temporary in some cases, of symptoms and this has tended to be viewed as a hard and fast measure. However, the Remission in Schizophrenia Working Group (Andreasen *et al*, 2005) highlight that a reduction in symptoms below the threshold that would warrant an initial diagnosis of schizophrenia is required to signify the presence of remission. So total absence of symptoms is not required, but this adds confusion when other remission outcome measures utilise different tools and scales. Also the addition of the terms 'functional' and 'complete' remission contribute to and exacerbate further confusion. General Practitioners would be familiar with 'remission' in the context of physical disorders but may be confused in relation to a person who has received a diagnosis of schizophrenia. In some instances causing conflict with previous, possibly antiquated, learning that schizophrenia is a disorder for life. However, this is certainly an area for further exploration, especially in relation to seamless service provision promoting transition between the interfaces of primary and secondary care.

In contrast if remission was to be accepted as a concept for people with a diagnosis of schizophrenia this may facilitate easier progression back into primary care for those well enough at the time. All parties would need to have a shared comprehension of when remission could be employed and what it signifies. As General Practitioners are aware of the term in other contexts it may be a language that they could transfer to mental health. In this manner remission could be the conduit for transition back into primary care. The term itself could reduce the ambiguity and subjectivity in discharge documentation, so long as there was a standardised tool employed which could be understood and agreed by all stakeholders, including service users and their carers'.

Remission cannot, and must not, be used in relation to the practitioner assuming control or power to ascertain whether a person can be discharged or not, it needs to be a collaborative approach that has a place and function within the concept of recovery. As we know recovery needs to be defined by the person experiencing it and this should ultimately determine the use

of remission too. It is all too easy to overlook, disregard or abandon people due to any differences or diagnoses encountered. If discharge from secondary mental health services cannot be acknowledged as a realistic option for people with a diagnosis of schizophrenia, within their quest for recovery, then community based services are merely offering those people a peek over the wall.

This thesis began with a quotation from Sebastian Faulks:

“Psychosis, ladies and gentlemen, is the price we pay for being what we are.
And how unfair, how bitterly unfair it is that the price is not shared around
but paid by one man in a hundred for the other ninety-nine”
(Sebastian Faulks, 2006, p659)

We must be reminded of the sentiment behind this in relation to the study conducted and in keeping with this observe that respect must be paid to the one in a hundred, by the other ninety-nine; one hundred per cent of the time!

8.9 Recommendations:

The recommendations offered are suggestive of further research initiatives and ways in which understanding can be clarified and disseminated.

* Further research should be conducted utilising staff from the primary care setting to determine the understanding of remission and the transition of people from secondary mental health services their perspective.

* Further research and analysis should be performed in order to assess and understand whether components from this research study may be transferable and applied to Child and Adolescent Mental Health Services (CAMHS). This may prevent some people experiencing unnecessary extended periods within secondary mental health services, which may inhibit their recovery.

* Further scrutiny and analysis of the 'collaborative trajectory' will outline areas for best practice and this should be disseminated into practice areas to facilitate an improved transition for those ready to do so. This would include training and guidance to supplement recovery focused approaches.

* A clearer understanding of the transition between secondary mental health services and primary care should be disseminated to appropriate parties. This would include aspects of the liminal process and explanation of the relationships between remission and recovery in order to reduce any unnecessary pathologising of behaviours previously identified as relapse.

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Appendix 1: Remission Criteria & SIX

Symptoms	Assessment Date	Assessment Date
Delusions (P1)		
Unusual Thought Content (G9)		
Hallucinatory Behaviour (P3)		
Conceptual Disorganisation (P2)		
Mannerisms/Posturing (G5)		
Blunted Affect (N1)		
Social Withdrawal (N4)		
Lack of Spontaneity (N6)		
Remission Yes/No		

Tool for Implementation of the Remission Criteria

Modified PANSS Severity Rating

Level	Symptoms: e.g. Delusions (P1)
1 Absent	Absent
2 Minimal	Questionable pathology extreme normal limits
3 Mild	Symptoms are clearly present but vague and relatively unobtrusive. They do not interfere with thinking, social relations or behaviour
4 Moderate	Symptoms are several and unquestionable but shifting and only occasionally interfere with thinking, social relations and behaviour
5 Moderately Severe	Symptoms clearly manifest and preoccupy patient, occasionally interfere with thinking, social relations and behaviour
6 Severe	Symptoms extensive and manifest, preoccupy patient and clearly interfere with thinking, social relations and behaviour
7 Extreme	Symptoms are severe and extensive and dominate major facets of life, leading to frequently inappropriate, irresponsible actions

The above was drafted by prof. T. Burns in preparation for the Remission Consensus meeting 2008. Taken from original work by Andreasen *et al* (2005). Original PANSS developed by Kay *et al* (1987).

Social Inclusion Index [SIX] (Priebe *et al*, 2008)

Items	Score 0	Score 1	Score 2
Employment	None	Voluntary, protected, sheltered work	Regular employment
Accommodation	Homeless or 24 hour supervised	Sheltered or supported	Independent
Partnership/family	Living alone	Living with partner or friend	
Friendship	No meeting with friend in last week	Meeting with a friend in last week	
TOTAL (0-6)			

Appendix 2: List of Impacts and Outputs Associated with the Study

Impacts & Outputs from Research Study

2012

Leeds Metropolitan University – ‘Best practice in Psychosis Group’. Presented an overview of the research study.

2013

Northumbria University – Research Conference. Poster presentation.

Warwick University – September. RCN Conference 19th International Network for Psychiatric Nursing, Research Conference. Presented findings from phase one.

2014

Flintshire County Council – May & September. Two one day workshops on ‘Schizophrenia and Recovery’ for Local Authority staff. Transpired from networking at Warwick University in September 2013.

Meeting with ‘Recovery Lead’ (Alison Brabban) of Tees, Esk & Wear Valleys NHS Foundation Trust – May. Discussed research study and potential for dissemination to stakeholders in the trust.

Edinburgh, Napier University. – August. 3rd Mental Health Nursing research Conference. ‘Promoting Resilience’. Presented ‘Promoting the transition back to primary care for people with a diagnosis of schizophrenia’.

University of Ulster – October. 11th Annual Mental Health Conference. ‘Living with schizophrenia: Cry for hope and recovery’. Presented ‘Recovery from schizophrenia: The transition back to primary care’.

Angel Hotel, Gateshead. – November. Seminar meeting for psychiatrists. Presented ‘Care planning: How can patients with schizophrenia transition from secondary to primary care?’

2015

Durham University. – May. Mental Health Research Group R&D Second annual Conference. Poster presentation of full study.

Northumbria University. – May. Annual Research Conference. Poster presentation of full study.

Appendix 3: Comparison Between Two Studies

First Rank Symptoms (Saddichha *et al*, 2010, p263-4)

- **Made feelings, made impulses, made action, somatic passivity.**
 - i) **Narrow** – the subject experiences these sensations as not being his own but as arising from an outside source.
 - ii) **Wide** – the subject experiences them as his own, but as being controlled from outside.

- **Thought insertion**
 - i) **Narrow** – the subject experiences thoughts as not being his own and being inserted into his mind.
 - ii) **Wide** – the subject experiences them as being controlled from outside.

- **Thought withdrawal**
 - i) **Narrow** – the thoughts cease in the subject’s mind owing to the direct influence of an outside agency.
 - ii) **Wide** – thought block is accepted in the absence of an experience or thoughts being interfered with by an outside agency.

- **Thought broadcast**
 - Narrow** – the subject not only experiences thoughts leaving the confines of his own mind, but also experience them being shared with others.
 - Wide** – either thought leave the confines of the subject’s mind but are not shared or they are so loud that others can hear them.

- **Voices in discussion, voice commentary, audible thoughts**
 - i) **Narrow** – the voices are heard outside the subject’s head (true hallucination).
 - ii) **Wide** – the voices are heard only inside the subject’s head/mind.

- **Delusional perception**
 - i) **Narrow** – the delusional idea and the perception are directly linked to one another such that the delusional idea cannot be separated from the perception and occurs in very close temporal relationship to it.
 - ii) **Wide** – there is a relatively loose link between a perception and a delusional idea and the delusional idea is often linked, with other phenomena.

First Rank Symptoms according to Mellor (1970) in Idrees *et al*, (2010)

- | | |
|----|-----------------------|
| 1 | Audible thoughts |
| 2 | Voices arguing |
| 3 | Voices commenting |
| 4 | Somatic passivity |
| 5 | Thought withdrawal |
| 6 | Thought insertion |
| 7 | Thought broadcast |
| 8 | Made affect |
| 9 | Made impulse |
| 10 | Made volition |
| 11 | Delusional perception |

Appendix 4: List of Principles of Recovery

The Principles of Recovery

- Recovery is about building a meaningful and satisfying life, as defined by the person themselves, whether or not there are ongoing or recurring symptoms or problems.
- Recovery represents a movement away from pathology, illness and symptoms to health, strengths and wellness.
- Hope is central to recovery and can be enhanced by each person seeing how they can have more active control over their lives ('agency') and by seeing how others have found a way forward.
- Self-management is encouraged and facilitated. The processes of self-management are similar, but what works may be very different for each individual. No 'one size fits all'.
- The helping relationship between clinicians and patients moves away from being expert/patient to being 'coaches' or 'partners' on a journey of discovery. Clinicians are there to be "on tap, not on top".
- People do not recover in isolation. Recovery is closely associated with social inclusion and being able to take on meaningful and satisfying social roles within local communities, rather than in segregated services.
- Recovery is about discovering – or re-discovering – a sense of personal identity, separate from illness or disability.
- The language used and the stories and meanings that are constructed have great significance as mediators of the recovery process. These shared meanings either support a sense of hope and possibility, or invite pessimism or chronicity.
- The development of recovery-based services emphasises the personal qualities of staff as much as their formal qualifications. It seeks to cultivate their capacity of hope, creativity, care, compassion, realism and resilience.
- Family and other supporters are often crucial to recovery and they should be included as partners wherever possible. However, peer support is central for many people in recovery.

Taken From:

Shepherd *et al*, (2008) adapted from Davidson (2008).

Appendix 5: NICE QS14 – 15 Statements

QS14; List of statements:

- 1) People using mental health services, and their families or carers, feel optimistic that care will be effective.
- 2) People using mental health services, and their families and carers, feel they are treated with empathy, dignity and respect.
- 3) People using mental health services are actively involved in shared decision-making and supported self-management.
- 4) People using community mental health services are normally supported by staff from a single, multidisciplinary community team, familiar to them and with whom they have continuous relationship.
- 5) People using mental health services feel confident that the views of service users are used to monitor and improve the performance of services.
- 6) People can access mental health services when they need them.
- 7) People using mental health services understand the assessment process, their diagnosis and treatment options, and receive emotional support for any sensitive issues.
- 8) People using mental health services jointly develop a care plan with mental health and social care professionals, and are given a copy with an agreed date to review it.
- 9) People using mental health services who may be at risk of crisis are offered a crisis plan.
- 10) People accessing crisis support have a comprehensive assessment, undertaken by a professional competent in crisis working.
- 11) People in hospital for mental health care, including service users formally detained under the Mental Health Act, are routinely involved in shared decision-making.
- 12) People in hospital for mental health care have daily one-to-one contact with mental healthcare professionals known to the service user and regularly see other members of the multidisciplinary mental healthcare team.
- 13) People in hospital for mental health care can access meaningful and culturally appropriate activities 7 days a week, not restricted to 9am to 5pm.
- 14) People in hospital for mental health care are confident that control and restraint, and compulsory treatment including rapid tranquillisation, will be used competently, safely and only as a last resort with minimum force.
- 15) People using mental health services feel less stigmatised in the community and NHS, including with mental health services.

Appendix 6: Service User Good Practice Checklist

Checklist of Good Practice for Professionals

(Gould, 2012)

Are you:

- 1) Drawing on service users' personal descriptions of recovery?
- 2) Taking special account, too, of recovery concepts that service users from particularly disadvantaged groups and communities find meaningful and valid?
- 3) Helping service users to find the ways of understanding mental distress that make most sense to them, rather than offering medical explanations alone?
- 4) Putting as much emphasis on the warm, human qualities that service users want from professionals as on skills and knowledge that service users find support their recovery?
- 5) Recognising in practice that medical treatment is useful only insofar as it assists service users with leading lives that they find meaningful and offering treatment accordingly?
- 6) Employing the full range of holistic approaches that are important to a particular service user?
- 7) Allowing for drawbacks that set recovery tools can have and varying tools to meet differing service user wishes?
- 8) Having adequate discussion with service users when medication is prescribed, acknowledging service users' concerns about distressing side effects and working actively with service users to keep these to a level that service users find acceptable?
- 9) Tackling any staff discrimination towards people with mental health problems, including the additional discrimination which may be experienced by service users from marginalised groups and communities?
- 10) Helping service users to feel safe, whilst avoiding a focus on risk that service users say is counterproductive to recovery?
- 11) Making active use of positive risk-taking?
- 12) Addressing the tension highlighted by a number of service users: between the use of compulsion under the Mental Health Act 2007 and the exercise of choice, control and citizen rights that is fundamental to most service users' concepts of recovery?

- 13) Making sure that service users have involvement, influence and control in relation to their individual care plans?
- 14) Acknowledging peer support in practice when service users find that this helps?
- 15) Providing opportunities for service users to influence the Care Programme Approach at a strategic level?
- 16) Employing resources as effectively as possible by listening to service users' expertise about useful recovery services, not to professionals alone, and by providing consistent and reliable support?

Taken from:

Gould D. (2012) *Service users' experiences of recovery under the 2008 Care Programme Approach*. Mental Health Foundation, National Survivor User Network. London.

Appendix 7: Team Leader Invitation Letter



NHS Foundation Trust



Project Title: A two-phase qualitative study to explore and conceptualise the introduction of remission into the process of recovery for people with schizophrenia.

Researcher: Keith Ford

My name is Keith Ford and I am a senior lecturer in mental health nursing at Northumbria University. I am presently commencing the above research and I am looking to recruit people to be participants in this study. Initially I am looking to recruit a selection of four qualified/trained practitioners. Thereafter, and later in the study I hope to recruit four service users, four carers. If participants consent I will conduct an interview and this will be expected to take approximately one hour each.

I would appreciate it if you could discuss this matter with your team. If your team is agreeable I would appreciate the opportunity to come and talk to your staff about this study, perhaps at a team meeting or similar gathering. I would also appreciate the opportunity to contact you again to ascertain your response to this request. The enclosed information sheet gives extra information in regard to this study. I would appreciate it if you could distribute the information sheet to any members of your team that you feel may be eligible to participate in this study.

Many thanks

Keith Ford
Senior Lecturer
Room G215, Coach Lane Campus
Northumbria University
Benton, Newcastle upon Tyne.
NE7 7XA

Tel: 0191 2156229 Email: keith.ford@northumbria.ac.uk

Appendix 8: Practitioner Information Sheet



Practitioner Information sheet

A two-phase qualitative study to explore and conceptualise the introduction of remission into the process of recovery for people with schizophrenia.

Keith Ford

Senior Lecturer Mental Health Nursing, Northumbria University

My name is Keith Ford and I am a senior lecturer in the School of Health, Community and Education at Northumbria University. I am seeking to recruit potential participants for a proposed PhD research study.

This invitation has been sent to you on my behalf by your Team Leader because they think you may be interested in taking part in my research. I have no knowledge at all about who they have contacted and no information about you, nor have any of your contact details been given or shown to me. If you choose to contact me about taking part in my research I will not reveal that to anybody and so your decision about taking part or not is in private. If you choose to take part you would be part of a small sample of four people drawn from the team you work in and so while your names will not be published it would seem likely that people may well know (or at least speculate) about who took part and who said what.

What is the purpose of this study? The purpose of this study is to gather information on issues around remission for people with a diagnosis of schizophrenia. It is hoped that this information may be useful to assist services to accurately address issues of recovery for people with a diagnosis of schizophrenia. I would appreciate the opportunity to further discuss this study at a team meeting or a similar gathering.

Do I have to take part? Taking part is entirely voluntary. If you agree to take part in the study you will be asked to sign a consent form before being interviewed. You would be free to change your mind at any point without having to give a reason. If you do wish to take part please complete and return the reply slip to me at the address given at the end of page 2.

What will happen to me if I agree to take part? You will be interviewed by myself (Keith Ford) at a time and place convenient to you. These interviews should take about an hour. You will only be interviewed once. With your permission the interview will be recorded so that I can get the detail in what you are saying in the interview. The interview questions will be around your experience of care for people with a diagnosis of schizophrenia.

Will my taking part in the research be confidential? Yes. The information that you provide will normally be treated confidentially. If you inform me that you or someone else is at any risk of harm I may be obliged to pass this information on to someone in authority, but I will discuss this with you first.

Any information collected would be made anonymous with the aim that others would not be able to identify you. Information will be allocated a code number so that the researcher will

have a record of who said what in the interviews (this will be the number from the top of the information sheet). The information that you offer will be looked at by myself and my research supervisor at Northumbria University. Information will be stored carefully on a password protected computer and all the information will be destroyed once the study is completed in accordance with the Data Protection Act (1998).

What are the advantages and disadvantages of taking part? I do not consider that there will be any disadvantages in taking part except that you will be giving up your time. The advantages are that your views will be recorded and may contribute towards improving services locally and perhaps nationally.

What will happen if I do not wish to carry on with the study? Your data will be link-anonymised – this means that your data does not carry any personal information about you but is linked to you by a unique code number which is on the top of this information sheet. This is so that if you changed your mind about taking part before August 31st 2014 and told me your unique code number I would be able to identify and withdraw your data. After August 31st 2014 the link code will be confidentially destroyed, your data will then be anonymous and so you would no longer be able to withdraw it. No further contact will be attempted and this will not affect your employment in any way.

What if I have any questions? If you have a question about any aspect of the research please contact me at the number below and I will do my best to answer them.

What will happen to the results of this research study? It is intended that the results will be written up and published in healthcare related journals to inform other healthcare staff. It is also an intention to make a presentation from the results and deliver this at conferences to healthcare staff, service users and carers. Whilst direct quotes from participants may appear in written work or presentations no names will be attached and whilst you may recognise your own words nobody else will.

Who is organising and funding this research? This research is part of my personal PhD study and is being supported by Northumbria University. No outside or additional funding has been sought.

Has the research been ethically approved? The research received a favourable opinion from the Health, Community, Education School Research Ethics Sub Committee at Northumbria University and also permission gained from the Research & Development department within the NHS Foundation Trust. This study has been reviewed and received a favourable opinion from the NRES Committee North East – County Durham & Tees Valley.

Who do I contact if I have any concerns? If you have any concerns about the research that you do not wish to discuss with me you can contact:

Research Supervisor: Dr Toby Brandon, Coach Lane Campus, Northumbria University, Benton, Newcastle, NE7 7XA. Tel: 0191 2156672.

Further information and contact details: If there is anything that is not clear or that you would like to discuss, please ask me for more information. You can contact me at:

Keith Ford,
Room G215, Coach Lane Campus (East), Northumbria University, Benton,
Newcastle upon Tyne, NE7 7XA.
Tel: 0191 2156229

Email: keith.ford@northumbria.ac.uk Thank you for taking the time to read this information.

Appendix 9: Practitioner Consent Form



NHS Foundation Trust



Practitioner Consent form

Project Title: A two-phase qualitative study to explore and conceptualise the introduction of remission into the process of recovery for people with schizophrenia.

Please initial
all boxes if in
agreement.

I have been given and read the information sheet (Version 2 Sept. 2012)
Explaining this research study

I am willing to be interviewed for the purpose of this research, on one occasion
lasting approximately one hour

I am willing to allow quotes be used from my interview when the research
is presented, although I understand that my real name will not be attached
to any of these quotes

I am willing for the interview to be audio recorded

I understand that my participation is voluntary and that I can withdraw
at anytime if I change my mind without any adverse consequences to myself
or my employment

I know my name and details will be kept confidential and will not appear in
any printed documents

I have answered the questions above and agree to take part in this research

Participants signature

Participants Name Date

Researchers signature

Researchers Name Date

**Keith Ford, Senior Lecturer, Room G215, Coach Lane Campus, Northumbria University
Newcastle upon Tyne NE7 7XA Tel: (0191) 2156229**

Appendix 10: Service User Information Sheet



Service User Information sheet

A two-phase qualitative study to explore and conceptualise the introduction of remission into the process of recovery for people with schizophrenia.

Keith Ford

Senior Lecturer Mental Health Nursing, Northumbria University

My name is Keith Ford and I am a senior lecturer in the School of Health, Community and Education at Northumbria University. I am seeking people to help with a proposed research study.

This invitation has been sent to you because *[name of Team Leader or care coordinator]* thinks that you may be interested in taking part in this research. I have no knowledge at all about who they have contacted and no information about you, nor have any of your contact details been given or shown to me. If you choose to contact me about taking part in my research I will not reveal that to anybody and so your decision about taking part or not is in private. If you choose to take part you would be part of a small sample of four people drawn from the team you work in and so while your names will not be published it would seem likely that people may well know (or at least speculate) about who took part and who said what.

What is the purpose of this study? This study is about people's experience of staying well. To do this I would like to talk to people who have a diagnosis of schizophrenia. It is hoped that the information I get may help mental health services consider how best to look at recovery for people with a diagnosis of schizophrenia.

Do I have to take part? Taking part is entirely voluntary. If you agree to take part in the study you will be asked to sign a consent form before being interviewed. You would be free to change your mind at any point without having to give a reason. If you decide that you do not want to take part it will not affect the services you receive in any way. If you do wish to take part please complete and return the reply slip to me at the address given on page 2.

What will happen to me if I agree to take part? You will be interviewed by myself (Keith Ford) at a time and place convenient to you. These interviews should take about an hour. You will only be interviewed once and with your permission the interview will be recorded so that I can get the detail in what you are saying. The interview questions will be around your experience of care received and what you do to feel well.

Will my taking part in the research be confidential? Yes. The information that you provide will normally be treated confidentially. If you inform me that you or someone else is at any risk of harm I may be obliged to pass this information on to someone in authority, but I will discuss this with you first.

Any information collected would be made anonymous with the aim that others would not be able to identify you. Information will be allocated a code number so that the researcher will

have a record of who said what in the interviews (this will be the number from the top of the information sheet). The information that you offer will be looked at by myself and my research supervisor at Northumbria University. Information will be stored carefully on a password protected computer and all the information will be destroyed once the study is completed in accordance with the Data Protection Act (1998).

Who else might you wish to talk to? If you agree to be interviewed for this study, I will ask if you agree to a family member or friend being contacted to also take part in the study. However, if you do not wish me to contact them you are still able to take part in this study without any change to your rights.

What are the advantages and disadvantages of taking part? I do not consider that there will be any disadvantages in taking part except that you will be giving up your time. The advantages are that your views will be recorded and may contribute towards improving services locally and perhaps nationally for similar people.

What will happen if I do not wish to carry on with the study? Your data will be link-anonymised – this means that your data does not carry any personal information about you but is linked to you by a unique code number which is on the top of this information sheet. This is so that if you changed your mind about taking part before August 31st 2014 and told me your unique code number I would be able to identify and withdraw your data. After August 31st 2014 the link code will be confidentially destroyed, your data will then be anonymous and so you would no longer be able to withdraw it. No further contact will be attempted and this will not affect your care at all.

What if I have any questions? If you have a question about any aspect of the research please contact me at the number below and I will do my best to answer them.

What will happen to the results of this research study? It is intended that the results will be written up and published in healthcare related journals to inform other healthcare staff. It is also an intention to make a presentation from the results and deliver this at conferences to healthcare staff, service users and carers. Whilst direct quotes from participants may appear in written work or presentations no names will be attached and whilst you may recognise your own words nobody else will.

Who is organising and funding this research? This research is part of my personal PhD study and is being supported by Northumbria University. No outside or additional funding has been sought.

Has the research been ethically approved? The research has received a favourable opinion from the Health, Community, Education School Research Ethics Sub Committee at Northumbria University and also permission gained from the Research & Development department within the NHS Foundation Trust. This study has been reviewed and received a favourable opinion from the NRES Committee North East – County Durham & Tees Valley.

Who do I contact if I have any concerns? If you have any concerns about the research that you do not wish to discuss with me you can contact:

Research Supervisor: Dr Toby Brandon, Coach Lane Campus, Northumbria University, Benton, Newcastle, NE7 7XA. Tel: 0191 2156672.

Further information and contact details: If there is anything that is not clear or that you would like to discuss, please ask me for more information. You can contact me at:

Keith Ford,
Room G215, Coach Lane Campus (East), Northumbria University, Benton, Newcastle upon
Tyne, NE7 7XA. Tel: 0191 2156229 Email: keith.ford@northumbria.ac.uk

**For independent advice you can contact Patient Advice & Liaison Services
(PALS) at:**

Tel: 0800 052 0219 (free phone) Mobile: 07775 518 086

Web: www.pals@nhs.net

Post: PALS

Appendix 11: Service User Invitation Letter



Project Title: The concept of remission for people with a diagnosis of schizophrenia.

Researcher: Keith Ford

I would like to invite you to take part in a research study about peoples experiences of staying well. I am inviting you as a person who has been given a diagnosis of schizophrenia. I would be very interested to hear your views and experiences about this subject. This research may be able to help mental health services deliver better care in the future. This letter has been sent to you on my behalf by [*name of care co-ordinator to be added*] who obtained your contact details from records held by [*team and Trust name to be added*]. They sent you this as they think you may be interetsed in taking part in my research. I have no knowledge at all about who they have contacted and no information about you, nor any of your contact details have been given or shown to me. If you do choose to contact me about taking part in my research I will not reveal that to anyone so that your decision about taking part or not is private.

I would also be interested to hear the views of a family member or friend (carer). If you are interested in taking part in this study please read the information sheet. Before we discuss your views at the interview I will answer any questions you may have and ask you to sign a consent form. If you are interested in taking part please complete the reply slip attached to this form and give it back to the person who handed you this letter. I would greatly appreciate it if you could respond within 10 days of receiving this letter.

Many thanks

Keith Ford
Senior Lecturer
Room G215, Coach Lane Campus
Northumbria University
Benton, Newcastle upon Tyne.
NE7 7XA
Tel: 0191 2156229
Email: keith.ford@northumbria.ac.uk

Appendix 12: Service User Reply Slip



NHS Foundation Trust



Project Title: "A two- phase qualitative study to explore and conceptualise the introduction of remission into the process of recovery for people with schizophrenia".

Researcher: Keith Ford

Service User Research Reply Slip

My Name

.....

I have read the information sheet concerning the research study:
"A two- phase qualitative study to explore and conceptualise the introduction of remission into the process of recovery for people with schizophrenia".

I am willing to be interviewed by Keith Ford as part of this study.

I would like to be contacted with further details by:

My care coordinator

Directly by Telephone by Keith Ford (researcher)
(please give number below)

.....

Directly by Email from Keith Ford (researcher) (please give address below)

.....

Directly by Post from Keith Ford (researcher) (please give address below)

.....

Appendix 13: Service User Consent Form



NHS Foundation Trust



Project Title: The concept of remission for people with a diagnosis of schizophrenia.

Please initial
all boxes if in
agreement.

I have been given and read the information sheet (Version 2 Sept. 2012)
Explaining this research study

I am willing to be interviewed for the purpose of this research, on one occasion
Lasting approximately one hour

I am willing for the interview to be audio recorded

I am willing to allow quotes to be used from my interview when the research
is presented, although I understand that my real name will not be attached
to any of these quotes

I understand that my participation is voluntary and that I can withdraw at
any time if I change my mind and this will not affect my treatment and/or care

I know my name and details will be kept confidential and will not appear in
any printed documents.

I have answered the questions above and agree to take part in this research

I consent to my carer to be invited to take part and for
him/her to take part if they so wish

Participants signature

Participants Name Date

Researchers signature

Researchers Name Date

**Keith Ford, Senior Lecturer, Room G215, Coach Lane Campus, Northumbria University
Newcastle upon Tyne NE7 7XA Tel: (0191) 2156229**

Appendix 14: Flipchart Sheet Example

88107

DEFINITION OF REMISSION

107 - PHASE OF REMISSION IN CONNECTION WITH DISEASE (OUTSIDE - NURSING & MEDICINES (9))

107 - REMISSIONAL - THAT PHASE WHERE THE SYMPTOMS ARE LESS (8)

107 - THINGS ARE THE IDEA THAT THINGS ARE BETTER BECAUSE OF THE PHASE (6)

107 - THERE ARE NO LONGER USING DISEASE (MILITARY) OF THE KIND OF CHANGE HAS COME FROM A THREATENED & AN A WELL (10)

107 - THINGS START TO LOOK BETTER FOR PEOPLE - PEOPLE CAN THINK ABOUT THINGS BEHIND THEM IN LIFE (12)

107 - I THINK IT'S A PHASE - THINGS ARE THE PHASE (13)

107 - FROM A PROFESSIONAL PERSPECTIVE THE MORE SOME REMISSION IS TO STRAIGHTFORWARD IN TERMS OF REMISSION (14)

107 - THINKING OF THE PHASE WITH A VERY IMAGE OF WHAT REMISSION IS LIKE & THAT IS A KIND OF STATE OF MIND THAT THINGS ARE GOING TO GET BETTER (15) & THEN GOING TO TRY TO GET THE PHASE & NOT BEE FIRST AND OF THE TIME (17)

107 - FROM A PROFESSIONAL PERSPECTIVE IT'S DIFFICULT FOR PEOPLE TO GET TO THAT - YOU LIVE IN STATE OF SOMETHING COMING BACK AGAIN (18)

107 - I THINK SO (REMISSION) USED IN LIFE (19)

107 - I HAVE NEVER THOUGHT ABOUT USING THE WORD 'REMISSION' - ONLY BECAUSE I AM A PSYCHOLOGIST (20)

107 - I HAVE NEVER SEEN REMISSION REVISION TO IN TERMS OF MEDICAL HEALTH (21)

107 - I WOULD THINK IT ONLY GOES TO THE PHASE (22)

107 - IS A CLINICAL TERM (23)

107 - IF A PERSON IS ENJOYING THEM I WOULD SAY THAT THEY ARE IN REMISSION (24)

107 - REMISSION HAS TO DO WITH FEELING (25)

107 - NOT THE LANGUAGE (26)

107 - BUT IT'S A STATE OF MIND (27)

107 - YOU NO LONGER (28)

107 - BUT YOU CAN NEVER COMPLETELY GET RID OF IT (29)

RECOVER

107 - I GUESS YOU THINK RECOVERIES ARE MORE THAN THEY ARE IN YOUR MIND, BUT A FEELING (30)

107 - IF PEOPLE RECOVERED IT WAS BETTER THAT CALLED RECOVERY (31)

107 - DIFFERENT FOR PEOPLE TO SEE THE LIGHT & THE WAY FORWARD (32)

107 - IT'S RECOVERING FOR PEOPLE WHO HAVE USED RECOVERY BEFORE BUT NOT BEEN SUCCESSFUL TO MOVE FORWARD (33)

107 - I THINK 'RECOVERY' CAN BE AN UMBRELLA WORD FOR PEOPLE BECAUSE I THINK PEOPLE FIND IT VERY DIFFICULT TO IMAGINE WHAT RECOVERY MEANS (34)

107 - AND A RECOVERY IS TO GO WITH WHAT THE PERSON DOES A RECOVERY (35)

107 - I USE RECOVERY FROM THEIR PERSPECTIVE THEY OFTEN THINK OF 'SHORT' & 'LONG TERM' RECOVERY (36)

107 - SHORT TERM - 'CUP OF TEA' - LONG TERM - WORK, RECOVERY (37)

107 - I WOULD NOT BE CHANGING TO MUCH OF WHAT I THINK RECOVERY IS BECAUSE FOR ME RECOVERY IS 'MY LIFE' AND I TRY NOT TO APPLY MY OWN LIFE TO THEM (38)

107 - WE SAY WE ARE A RECOVERY FROM SOMETHING - I STILL THINK PEOPLE WITH RECOVERY FEEL VERY DIFFICULT TO THINK ABOUT THAT - THEY NEVER COME BACK TO THE POINT THAT SOME OF THEM WANT THEIR SYMPTOMS BACK (39)

107 - WE CAN'T SAY ALL OF THEM - SOME TIMES IT'S ABOUT DEALING & MANAGING THEM (40)

107 - THE LANGUAGE OF SOMETHING RECOVERING IS ABOUT DEALING & MANAGING THEM (41)

107 - I THINK IT'S ABOUT RECOVERING FROM SOMETHING (42)

107 - PEOPLE DON'T SEE IT AS A RECOVERY (43)

107 - PEOPLE DON'T SEE IT AS A RECOVERY (44)

107 - IF THE WORD COMES FROM RECOVERY RECOVERY, IT MEANS THAT IF JUST PROFESSIONALS USE IT (45)

107 - A RECOVERY - RECOVERING FROM SOMETHING (46)

107 - PEOPLE USE IT IN A WAY WHEN I WOULD LIKE RECOVERY (47)

107 - PEOPLE BECAUSE I THINK NOT ALL PEOPLE WHO DON'T LIKE WORDS (48)

107 - THEY DON'T LIKE MEDICALISED TERMS - THEY USE THE WORD & HAVE ALWAYS MADE THEM OWN LANGUAGE FOR IT, WHICH I FIND QUITE INTERESTING (49)

107 - THAT IS WHY I SEE THE LINK BETWEEN RECOVERY & REVISION (50)

107 - THEY USE IT IN A WAY WHICH I WOULD LIKE THEM TO USE (51)

107 - I WOULD LIKE PEOPLE WHO RECOVER TO SAY THE TERM HAS CHANGED TO RECOVERY (52)

107 - THE WORD YOU CAN MANAGE, BUT IT'S ABOUT THE STATE OF MIND (53)

107 - I THINK I WOULD LIKE TO SEE THE WORD RECOVERY (54)

107 - SOME MIGHT BE CONFUSED RE RECOVERY & REVISION (55)

107 - I WOULD LIKE TO SEE IT (56)

RELAISE

107 - WE CAN NEVER COMPLETELY GET RID OF IT (57)

107 - BUT YOU CAN NEVER COMPLETELY GET RID OF IT (58)

USE OF REMISSION

107 - QUOTE LIKE THE IDEA OF SOMEBODY WITH RECOVERY (59)

107 - I THINK IT'S A MORE HEALTHY WAY TO THINK ABOUT IT (60)

107 - IT WOULD HAVE TO BE CONSISTENT (IF ADAPTED) (61)

107 - IT WOULD NEED TO HAVE A CONSISTENT MESSAGE ACROSS THE BOARD (62)

107 - IT IS POSSIBLE BECAUSE 20 YEARS AGO I DON'T THINK RECOVERY WAS RELEVANT FOR PEOPLE WITH SCHIZOPHRENIA (63)

107 - I DON'T KNOW HOW ONLY IT WOULD BE (64)

107 - IT WOULD HAVE TO BE GIVEN TO THEM IN A POSITIVE PSYCHOLOGY KIND OF WAY THAT IS PART OF RECOVERY, PART OF THE WAY FORWARD & ONE IDEA OF THINKING (65)

107 - NORMALISING MAY BE A WAY OF INCREASING ADOPTION OF THE TERM (66)

107 - WE HAVE NEED TO DRAW OUT THEIR (ANXIETY) RECOGNITION OF IT & WHAT THEIR UNDERSTANDING OF REVISION WOULD BE (67) & WHETHER IT IS A CLINICAL TERM (68)

107 - TO MAKE IT WORK WE NEED TO GET THE CASE - LOOKING NATURAL ON BOARD TO EXPLAIN IT (69)

107 - (DUE TO LANGUAGE & WORDS) I WOULD THINK YOU WERE TALKING ABOUT HOW YOU WOULD CHANGE SERVICES SOMETHING (70)

107 - IT MIGHT BE ABOUT FOCUSING ON NEW PEOPLE COMING THROUGH THEM - ABOUT THINKING HOW YOU FEEL IN THE EXTENSIVE PHASES - THEY ARE NOT GOING TO USE THOSE TERMS (71)

107 - GIVE INFORMATION ABOUT THE PHASE (72)

LANGUAGE

107 - I THINK LANGUAGE IS IMPORTANT (73)

107 - I THINK THE LANGUAGE THAT YOU USE - I DON'T FIND THAT THE LANGUAGE THAT YOU USE - I DON'T UNDERSTAND ABOUT RECOVERY AS I DO (74)

107 - LANGUAGE CAN BE A WAY OF RECOVERY AS I DO (75)

107 - WE ARE NOT USED TO HEARING THE WORD 'RECOVERY' (76)

107 - IN A CLINICAL SENSE OF THE WORD 'RECOVERY' (77)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (78)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (79)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (80)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (81)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (82)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (83)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (84)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (85)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (86)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (87)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (88)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (89)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (90)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (91)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (92)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (93)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (94)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (95)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (96)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (97)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (98)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (99)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (100)

SERVICE USE UNDERSTANDING

107 - IT WOULD BE INTERESTING TO SEE WITH THE PERSPECTIVE OF (101)

107 - WOULD THEY SEE IT AS 'RECOVERY' (102)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (103)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (104)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (105)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (106)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (107)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (108)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (109)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (110)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (111)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (112)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (113)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (114)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (115)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (116)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (117)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (118)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (119)

107 - I WOULD LIKE TO SEE THE WORD 'RECOVERY' (120)

PROFESSIONAL ROLE

107 - GIVE INFORMATION ABOUT THE PHASE (121)

107 - GIVE INFORMATION ABOUT THE PHASE (122)

107 - GIVE INFORMATION ABOUT THE PHASE (123)

107 - GIVE INFORMATION ABOUT THE PHASE (124)

107 - GIVE INFORMATION ABOUT THE PHASE (125)

107 - GIVE INFORMATION ABOUT THE PHASE (126)

107 - GIVE INFORMATION ABOUT THE PHASE (127)

107 - GIVE INFORMATION ABOUT THE PHASE (128)

107 - GIVE INFORMATION ABOUT THE PHASE (129)

107 - GIVE INFORMATION ABOUT THE PHASE (130)

107 - GIVE INFORMATION ABOUT THE PHASE (131)

107 - GIVE INFORMATION ABOUT THE PHASE (132)

107 - GIVE INFORMATION ABOUT THE PHASE (133)

107 - GIVE INFORMATION ABOUT THE PHASE (134)

107 - GIVE INFORMATION ABOUT THE PHASE (135)

107 - GIVE INFORMATION ABOUT THE PHASE (136)

107 - GIVE INFORMATION ABOUT THE PHASE (137)

107 - GIVE INFORMATION ABOUT THE PHASE (138)

107 - GIVE INFORMATION ABOUT THE PHASE (139)

107 - GIVE INFORMATION ABOUT THE PHASE (140)

107 - GIVE INFORMATION ABOUT THE PHASE (141)

107 - GIVE INFORMATION ABOUT THE PHASE (142)

107 - GIVE INFORMATION ABOUT THE PHASE (143)

107 - GIVE INFORMATION ABOUT THE PHASE (144)

107 - GIVE INFORMATION ABOUT THE PHASE (145)

107 - GIVE INFORMATION ABOUT THE PHASE (146)

107 - GIVE INFORMATION ABOUT THE PHASE (147)

107 - GIVE INFORMATION ABOUT THE PHASE (148)

107 - GIVE INFORMATION ABOUT THE PHASE (149)

107 - GIVE INFORMATION ABOUT THE PHASE (150)

STIGMA

107 - I THINK IT'S ABOUT STIGMA (151)

107 - I THINK IT'S ABOUT STIGMA (152)

107 - I THINK IT'S ABOUT STIGMA (153)

107 - I THINK IT'S ABOUT STIGMA (154)

107 - I THINK IT'S ABOUT STIGMA (155)

107 - I THINK IT'S ABOUT STIGMA (156)

107 - I THINK IT'S ABOUT STIGMA (157)

107 - I THINK IT'S ABOUT STIGMA (158)

107 - I THINK IT'S ABOUT STIGMA (159)

107 - I THINK IT'S ABOUT STIGMA (160)

107 - I THINK IT'S ABOUT STIGMA (161)

107 - I THINK IT'S ABOUT STIGMA (162)

107 - I THINK IT'S ABOUT STIGMA (163)

107 - I THINK IT'S ABOUT STIGMA (164)

107 - I THINK IT'S ABOUT STIGMA (165)

107 - I THINK IT'S ABOUT STIGMA (166)

107 - I THINK IT'S ABOUT STIGMA (167)

107 - I THINK IT'S ABOUT STIGMA (168)

107 - I THINK IT'S ABOUT STIGMA (169)

107 - I THINK IT'S ABOUT STIGMA (170)

107 - I THINK IT'S ABOUT STIGMA (171)

107 - I THINK IT'S ABOUT STIGMA (172)

107 - I THINK IT'S ABOUT STIGMA (173)

107 - I THINK IT'S ABOUT STIGMA (174)

107 - I THINK IT'S ABOUT STIGMA (175)

107 - I THINK IT'S ABOUT STIGMA (176)

107 - I THINK IT'S ABOUT STIGMA (177)

107 - I THINK IT'S ABOUT STIGMA (178)

107 - I THINK IT'S ABOUT STIGMA (179)

107 - I THINK IT'S ABOUT STIGMA (180)

MEDICALISATION

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (181)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (182)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (183)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (184)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (185)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (186)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (187)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (188)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (189)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (190)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (191)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (192)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (193)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (194)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (195)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (196)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (197)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (198)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (199)

107 - ONE OF THE MAIN PROBLEMS IS THAT THE PHASE (200)

PROCESS/PATHWAY

107 - I THINK IT'S PROBABLY PART OF THE PATHWAY (201)

107 - IT'S A LONG PROCESS WITH A TON OF IT (202)

107 - THERE IS A LONG PROCESS BEHIND IT TO GET TO THAT POINT (203)

107 - THE WAY THAT PEOPLE ARE NOT RECOVERING FROM RECOVERY (204)

107 - I THINK PEOPLE DON'T RECOVER AS MUCH AS THEY DO INTO RECOVERY (205)

107 - IT DOESN'T HAVE TO BE A FULL RECOVERY (206)

107 - RECOVERY IS ABOUT THE PHASE (207)

107 - RECOVERY IS ABOUT THE PHASE (208)

107 - RECOVERY IS ABOUT THE PHASE (209)

107 - RECOVERY IS ABOUT THE PHASE (210)

107 - RECOVERY IS ABOUT THE PHASE (211)

107 - RECOVERY IS ABOUT THE PHASE (212)

107 - RECOVERY IS ABOUT THE PHASE (213)

107 - RECOVERY IS ABOUT THE PHASE (214)

107 - RECOVERY IS ABOUT THE PHASE (215)

107 - RECOVERY IS ABOUT THE PHASE (216)

107 - RECOVERY IS ABOUT THE PHASE (217)






107 - RECOVERY IS ABOUT THE PHASE (218)

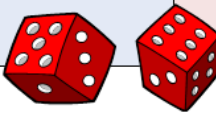
107 - RECOVERY IS ABOUT THE PHASE (219)

107 - RECOVERY IS ABOUT THE PHASE (220)

Appendix 15: 'Snakes & Ladders' From a Poster Developed to Discuss the Research Project at Northumbria University Research Conference 2013

Navigating through the mental health system may resemble 'Snakes & Ladders' for some people with a diagnosis of schizophrenia

 36 <u>Recovery</u> Personal recovery & independence		 34 Access to Primary Care		32 Not sure if I am recovering or not?	
25	26	27	28	29	30
<u>Remission</u> Move to Primary Care from secondary MH services	23	22	21	20	19
13	14	15	16	17	18
	Losing Hope !		Starting to feel better		<u>Relapse Prevention</u> starting to understand how to manage
12	11	10	9	8	7
 1 <u>Diagnosis</u> Historically a diagnosis of schizophrenia did not offer 'hope'	2	3	4	5	6
				<u>Response</u> The initial goal of treatment	



Appendix 16: Strengths-Based Alternatives

Deficit-based Vs Strength-Based Alternative Language

(Tondora *et al*, 2014)

	Deficit-Based Language	Strength-Based Language
1	A schizophrenic, a borderline	A person diagnosed with schizophrenia who experiences the following ...
2	An addict/substance abuser	A person diagnosed with an addiction who experiences the following ...
3	Clinical Case Manager	Recovery Coach/Recovery Guide (I'm not a case, and you're not my manager!)
4	Frontline staff/in the trenches	Direct care/support staff providing compassionate care
5	Suffering from	Working to recover from; experiencing; living with
6	High-Functioning versus Low-Functioning	Person's symptoms interfere with their relationship (work habits, etc.) in the following way
7	Acting out	Person disagrees with recovery team and prefers to use alternative coping strategies
8	Unrealistic	Person has high expectations for self and recovery, ambitious
9	Denial, unable to accept illness, lack of insight	Person disagrees with diagnosis; does not agree that he/she has a mental illness precontemplative stage of recovery
10	Resistant/noncompliant	Not open to ... Chooses not to ... Has own ideas ...
11	Unmotivated	Person is not interested in what the system has to offer; Interests and motivating incentives unclear; preferred options not available
12	Decompensation, relapse	Person is re-experiencing symptoms of illness/addiction; an opportunity to develop and/or apply coping skills and to draw meaning from managing an adverse event; Reoccurrence
13	Maintaining clinical stability	Promoting and sustaining recovery
14	Manipulative	Resourceful; really trying to get help
15	Baseline	What a person looks like when he/she is doing well
16	Helpless	Unaware of capabilities
17	Hopeless	Unaware of opportunities
18	Grandiose	Has high hopes and expectations of self
19	User of system	Resourceful; good self advocate

Abridged version taken from: Tondora J. Miller R. Slade M. Davidson L. (2014) *Partnering for Recovery in Mental Health: A practical guide to person-centred planning*. Wiley Blackwell. Chichester. UK. (page 46-47).