

**RECEIVING A MENTAL HEALTH DIAGNOSIS: AN EXPLORATION OF  
SERVICE USERS' EXPERIENCES AND STAFF RESPONSES TO  
EMERGENT THEMES**

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## **ABSTRACT**

In recent years, the personal and financial cost of mental illness has gained attention in the UK. Research indicates mental illness will affect one in four of the population at some point in their lives. This statistic is recognised in the increasing pressure on mental health services, which have historically been underfunded. Rhetoric surrounding the lack of investment, has led to a drive to ensure parity of esteem between physical and mental health services. To achieve full parity, it is essential this translates into the field of research. Although literature on mental illness is vast, the specific experience of receiving a mental health diagnosis has received little attention. This is an area of importance as it is an experience that can change people's lives and impact on their identity.

The current research, based in South Wales, gave voice to both service users and staff. Therefore it contributes to the knowledge base on the experience of receiving a diagnosis from two perspectives. This is achieved through the implementation of a novel concurrent multi-method design that incorporates a Research Advisory Panel of people with lived experience of mental illness. In-depth interviews and Interpretative Phenomenological Analysis were used to capture the experience of the service user (Study 1). Emergent themes from this analysis were taken to staff focus groups and Thematic Analysis was conducted (Study 2). Study 1 findings evidenced the 'bitter sweet' nature of receiving a diagnosis, where support could be accessed but diagnosis did not mean cure and was accompanied by stigma. Study 2 indicated staff were aware of the service users' journey, however they highlight the problems in the healthcare system that led to difficulties in fulfilling their roles and supporting recovery. Synthesising these two sets of findings resulted in 'Recommendations for practice' which emphasised: the importance of the relationship between the service user and staff, the opportunity at diagnosis to positively 'frame' new knowledge and the need for a community approach to mental illness.

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## ABBREVIATIONS

<b>AHPs</b>	<b>Allied Healthcare Professionals</b>
<b>APA</b>	<b>American Psychological Association</b>
<b>BBC</b>	<b>British Broadcasting Corporation</b>
<b>CPN</b>	<b>Community Psychiatric Nurse</b>
<b>GIG Cymru</b>	<b>Gwansanaeth Iechyd Gwladol Cymru</b>
<b>GP</b>	<b>General Practitioner</b>
<b>ICD</b>	<b>International Classification of Diseases</b>
<b>IPA</b>	<b>Interpretative Phenomenological Analysis</b>
<b>NHS</b>	<b>National Health Service</b>
<b>MS</b>	<b>Medical Staff</b>
<b>PhD</b>	<b>Doctor of Philosophy</b>
<b>PIS</b>	<b>Participant Information Sheet</b>
<b>OT</b>	<b>Occupational Therapist</b>
<b>RAP</b>	<b>Research Advisory Panel</b>
<b>RCT</b>	<b>Randomised Control Trial</b>
<b>R</b>	<b>Researcher</b>
<b>TA</b>	<b>Thematic Analysis</b>
<b>TS</b>	<b>Third Sector staff</b>
<b>UK</b>	<b>United Kingdom</b>

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# Chapter 1: Introduction

This thesis is a qualitative study which explores the experience of receiving a mental health diagnosis, taking into the views of both service users and staff. This Introduction begins by offering an overview of current policy to provide a context for the research. It will then moves on in section two, to introducing the researcher in order to position myself in the research. This is an essential component to qualitative research and not only makes transparent the influences on the choices made during the research process, but also allows for a deeper understanding of the perspective taken by the researcher. The third section presents the aim and objectives and is followed by an outline of the chapters of which the thesis comprises.

## Mental health: The policy context

This section offers a picture of the mental health service provision as well as the prevalence and cost of mental illness. Beginning with a global focus on mental illness, the lens is then brought closer to home in the United Kingdom (UK) and Wales more specifically. Mental health services in the UK are influenced by the constantly fluctuating focus of government legislation and policy. Therefore relevant state guidance will highlight the changing rhetoric and campaigns surrounding mental health.

‘Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity’ (World Health Organisation, 2016). This statement by the World Health Organisation (WHO) highlights that achieving health is more than simply avoidance of illness. They suggest health is also linked to the ability to cope, to contribute to the community and to have enough control to fulfill personal abilities. Taking a global view, the WHO sees individuals’ poor health or mental illness as detrimental to entire communities and countries. WHO (2011) research indicates huge discrepancies between countries worldwide, with 23% not having separate policies for mental health. Using WHO statistics Prince *et al.* (2007:861) estimate neuropsychiatric disorders contribute 14% of the global cost of disease in ‘disability adjusted life years’. However, Prince *et al.* (2007) note the

difficulty in coming to a figure at all due to the complex issues linked with mental health. They conclude the global cost of mental illness is likely to be underestimated due other conditions often leading to mental illnesses and comorbidity complicating the picture.

In order to assess the impact of mental illness on countries worldwide, the WHO launched the *Mental Health Atlas* in 2001. Collecting data from 171 countries indicated a gap between the demand for and supply of services and the most recent 2014 Atlas highlighted the need for investment and improvement (WHO, 2015). Data collected show that although there is a trend towards treatment outside of the traditional institutional care, many resources remain focused on service provision in hospitals. Access to these services is also limited in low-income countries (compared with high-income countries) where supporting legislation and policy is equally lacking (WHO, 2015). The infrastructure to support individuals with mental illness outside of hospitals is deficient in much of the world and conclusions drawn from the Mental Health Atlas indicate a global picture of inconsistencies in service provision.

To help address these worldwide inconsistencies the WHO (2013) published a *Mental Health Action Plan 2013-2020*. The plan advocates developing governance for mental health, integrated services, preventative measures and strengthening research. Collaborating with the WHO, European member states have developed a mental health action plan for Europe (WHO Europe, 2015). This resonates with the global action plan to address issues within the means of each European country and promote equal opportunities for mental wellbeing, as well as rights for those with mental illnesses. It also highlights the need to provide accessible integrated services that offer evidence based, safe treatment. Inconsistencies in access to treatment found globally by the WHO, are also transparent closer to home in the UK. These are, in part, as a consequence of decades of a discrepancy in funding and resource allocation between physical and mental health.

Suggestions made by the European division of the WHO (2015) resonate with the trends in legislation and policy provided by UK governments. These draw from the *1959 Mental Health Act*, which gave those with mental illnesses the same protection and legal status as those with physical illnesses (Ministry of Health, 1959). Revision

of this Act took place in 1983 when Compulsory Treatment Orders (CTO) were introduced in response to the deinstitutionalisation of services (see Chapter 2) and the need to strengthen medical professionals' powers in treating service users in the community (Department of Health, 1983). The shift from institutionalised care was brought in under the leadership of Prime Minister Margaret Thatcher (1979-1990), who recognised the substantial and unsustainable cost of inpatient care and treatment. It also came at a time of changing societal discourse regarding service users' agency and their rights in having their voice heard in relation to their care. The Conservative Government bolstered care in the community with the *1990 National Health Service and Community Care Act* highlighting the involvement of service users in their care (Department of Health, 1990). Although this legislation was promoted as liberating for service users, one prime agenda of the Government was to make savings in the significant costs of healthcare.

Housing those with mental illnesses in community settings was a significant shift in healthcare provision. This prompted the need for further guidelines to facilitate consistency and quality care. Consequently the introduction of a *National Service Framework (NSF) for mental health 1999*, refocused the vision for mental health services (Department of Health, 1999). Providing a ten-year plan for improving service provision in the UK, the framework defined the direction of services through guidance on how care should be provided and highlighted the importance of measuring outcomes (thus indicating the move towards a market economy model of healthcare provision). It also maintained a focus on a preventative approach as well as incorporating the need to provide integrated services. Many developments in mental health provision have built on this framework and it has been used as a minimum standard for further care models (The Kings Fund, 2017). These 'minimum standards' in more recent times incorporate challenging discrimination, providing equal access to effective and integrated services, recognition of carers' needs and a focus on suicide reduction. This, together with changes to the *Mental Health Act*, highlight the inherent complexities in balancing service users' rights and state responsibility to protect from risk or harm. This complexity remains and can be evidenced in the more recent revisions to the Act: the 2007 amendments not only reinforced involuntary treatment and broadened powers to other healthcare professionals (to provide treatment without consent), but also introduced

independent advocates to support the service user (Department of Health, 2007). This highlights the tension surrounding who holds the expertise to comment on service users' treatment and care, those with the lived experience or those with clinical training. This is an important aspect as clinicians have held a position of power in relation to service users since the inception of healthcare provision and although legislation attempts to redress this, the system is well established.

Nuances in healthcare provision can be found across the UK, therefore for the purposes of this thesis it is important to draw attention to the legislation affecting the country in which the current research has taken place. Provision of healthcare services was devolved to the Welsh Government from the UK Government, in 1999. The Welsh Cabinet Secretary for Health and Social Services holds responsibility for the provision of health services for the nation, namely the National Health Service (NHS) or Gwansanaeth Iechyd Gwladol Cymru (GIG Cymru). Therefore the following focuses on relevant legislation and policy in the recent past within Wales, to highlight the present trends within the country. An influential piece of legislation, *The Mental Health (Wales) Measure 2010*, was introduced by Welsh Government to provide a legal framework for delivery of mental health services (Welsh Government, 2010). Although the powers set out in the 1983 and 2007 Mental Health Acts remain, the Measure focused on support for those experiencing mental illness in Wales. It also reinforced the involvement of service users and carers in decisions concerning care as well as promoting person-centred treatment plans, integrated care, recognising diversity and increasing access to information. These not only extend the scope of primary care but also make it a legal requirement for all subject to the *Mental Health Act 1983*, to have access to an independent advocate should they request it. The extension of the right to independent support once again strengthens the voice of the service user and indicates the Welsh Government's commitment to this by placing it in law.

Building on the changes made in the *Mental Health Measure*, the Welsh Government implemented *Together for Mental Health 2012*. This replaced the NSFs and prompted service provision based on need, rather than previous age boundaries (Welsh Government, 2012). This strategy for health and wellbeing in Wales is supported by delivery plans and echoes the sentiment and direction of the Welsh Government. The

vision of the government is to improve the wellbeing of the entire nation through community education and cohesion, addressing poverty and integrating services. As part of improving services for those with mental illnesses, the Welsh Government in 2012 introduced a 28 day waiting time for assessment and, significantly, treatment 2015 (NHS Direct Wales, 2017a). To aid the cohesion of health and social care in achieving this aim, both the *Social Services and Well-Being Act 2014* and the *Well-Being Future Generations (Wales) Act 2015*, make it a legal requirement of public bodies to work in partnership (Welsh Government, 2014a; 2015). By encouraging partnership working, the Government's intention is to create a more streamlined, effective and efficient service. Therefore, although integrating services is proving difficult (as indicated by the National Audit Office, 2017), it is maintained as an essential goal in improving the experience of the service user in receiving appropriate and timely care.

The main provision of mental health services in the UK is through the National Health Service (NHS), set up in 1948. The aim of the NHS was, through central planning, to provide services for the population that were free at the point of access. Since this time some, such as Wallace and Taylor-Gooby (2010), argue the system has gone from being paternalistic, top down, to an autonomous one driven by a market philosophy and the decisions of managers. This shift towards a market economy was introduced and supported by successive governments in an attempt to address the increasing and overwhelming pressures on the system. It also reflected the rhetoric at the time by incorporating 'consumer opinion' to help drive up the quality of services. The development of this trend is evidenced in the policy context of Service User Involvement below and is explored in more detail in Chapter 2. This provides an understanding of the continued influence over current healthcare provision and its impact on the design of the current research.

Current service provision in UK healthcare is made up of primary, secondary and tertiary care. Subsequently those in primary care, namely General Practitioners (GPs), are often the first point of contact for an individual experiencing difficulties in their mental health. The system allows that these healthcare professionals act as gatekeepers, often via diagnosis, referring onto secondary or tertiary services that provide inpatient and outpatient specialised care. Although service provision is

nuanced across the country, Molodynski and Burns (2008) note that one constant element that informs all mental health services, is the promotion of multidisciplinary team working. This way of working is now common practice in mental health treatment and today there are many more healthcare professionals (and other staff such as those working in the third sector) involved in service users' care, aside from the traditional medical practitioner. Subsequently delivering the current model of service provision is a costly venture, a matter Governments have been attempting to address over the decades and an area explored in the following section.

### **The cost of mental illness**

1.7 million adults were in contact with the NHS in the UK for severe and enduring mental illnesses during 2013-14 and nearly 950 thousand were referred for psychological therapies (NHS digital, 2017). Consequently the infrastructure needed to support those with mental illness becomes a costly endeavour for governments. Calculating an exact figure on the financial burden that mental illness places on the UK is challenging. However it is estimated mental illness represents up to a third of all illnesses and consequently costs tens of billions in treatment, sick leave and benefit claims (NHS Direct Wales, 2017b). This cost has been highlighted as a major current, and future, burden on the country and one which the Chief Medical Officer, Professor Dame Sally Davies (2013:1), believes 'is a topic we simply cannot afford to ignore'. In saying this Professor Davies indicates that there is more than one cost of mental illness: the personal and the economic.

The personal and the economic cost are interrelated. Lelliott *et al.* (2008:1) point out that mental illnesses 'have a greater impact on people's ability to work than any other group of disorders', indeed in 2016 nearly 16 million days were lost in sickness absence due to mental illnesses (Office for National Statistics, 2017). As well as working days lost, Knapp and Lemmi (2017) suggest other influences that often occur with mental illnesses that contribute to poor health outcomes. These include smoking, unemployment, poverty, erratic education, involvement with the criminal justice system and obesity, all of which add to the burden carried by the healthcare system and the quality of life of the individual. Appropriate and timely access to support not only reduces the long-term burden on the health system but also lessens

distress for those with mental illnesses. Timely interventions facilitate valued contributions to society through engagement in work and are essential for the UK economy. In her report to the government in 2008, Dame Carol Black focused on the benefits of employment for those with mental illnesses and went on to propose changes to the sick note, with the 'fit note' focusing on the strengths of the individual and the contributions they could make, regardless of their health condition. This indicated a vast shift in the perception of the ability and agency of those with health conditions. However the roll out of this initiative has caused much controversy, with many service users appealing the outcome of 'Fit for Work' assessments and questioning whether it is fit for purpose.

Provision of financial support to healthcare services in the UK has traditionally focused on the physical health of the population. However in response to the ever increasing demand, and subsequent pressure on the UK caused by mental illness, there has been a recent change in focus of the national government. In her vision to tackle the 'burning injustice of mental health and inadequate treatment', Prime Minister Theresa May (2017) promoted a different way of working with a 'shared society' taking responsibility and building resilience in the population. This indicates the government's drive to save money by encouraging the public to take responsibility for their health and their communities. The move away from the traditional paternalistic view of state provision, is not only an attempt to lessen the pressures on the NHS, it also echoes the wish from some groups to empower service users (explored further in Chapter 2). The current Conservative Government aims to support mental health by providing additional funding for crisis care, online therapies and ensuring parity of esteem with physical health provision (May, 2017). This is evidenced by the recent pledge by the Secretary of State for Health and Social Care to 'embark on one of the biggest expansions of mental health services in Europe' through investing £1.3 billion to train new staff and provide a 7 day, 24 hour service (Hunt, 2017). Thus indicating the demand for services and widespread pressure on the UK Government to take steps to address this.

The Welsh Government has also taken steps towards addressing the unsustainable nature of service provision in the country. The Bevan Commission was set up in 2008 to scrutinise healthcare and provide advice for the (as was) Minister for Health and



Social Care in Wales. *Prudent Healthcare* is an approach launched by the commission to work towards a sustainable future for healthcare provision across the nation. The Bevan commission (2015:2) defines prudent healthcare as that which is:

...conceived, managed and delivered in a cautious and wise way characterised by forethought, vigilance and careful budgeting which achieves tangible benefits and quality outcomes for patients.

The six principles of Prudent Healthcare centre on equity between professional and patient, encouraging co-production, doing no harm and using the minimum, most prudent evidence-based interventions. There has since been launch of a website; *Making Prudent Healthcare Happen* to encourage the activation of these principles in the system as well as across the nation, healthcare staff and service users alike (Welsh Government, 2017). These principles highlight the vision of the Welsh Government in changing a culture of both from inside and outside of health services. Redressing the historic power imbalance between service user and professional, alongside inclusion of service user involvement as core principles, echo the current zeitgeist promoting the voice and expertise of service users. However, there is often a discrepancy between promotion of a principle and its implementation in practice (explored in Chapter 2).

As mentioned the Welsh Government has devolved powers in healthcare provision. Therefore it is important to focus more specifically on the statistics and rhetoric arising within the country. With a focus on the discrepancies between areas across Wales, the 2015-2016 annual report of the Chief Medical Officer for Wales (Dr. Frank Atherton), noted the link between poor health and the clear 'social gradient' across the nation (Welsh Government, 2016a). This document highlighted the correlation between being born in poorer areas and the likelihood of experiencing poor health and therefore promoted ensuring a good start in life for all. As a way for the NHS to contribute towards leveling these inequalities, Public Health Wales (2016) in *Making a Difference*, promoted the provision of training, building resilience, ensuring parity of income, local regeneration and independent living. However when it comes to mental health services there remains a 'postcode lottery' for access to psychiatric consultants across the UK, with the media reporting Wales having the fewest psychiatrists per head of population (BBC news, 2017). The above indicates the

inconsistencies that remain at both local and national levels and in urban and rural settings in within Wales. It also evidences the need for continued focus, improvement and investment in mental health services to address these inconsistencies and meet demand.

Welsh Government statistics show 9,570<sup>(b)</sup> admissions to mental health facilities in 2015-16 with a total of 1,430<sup>(c)</sup> inpatients across Wales in 2017 (Welsh Government, 2016b,c). It is estimated that the annual cost of mental illness in Wales (2007/8) is £7.2 billion (Friedli & Parsonage, 2009). This is coupled with the NHS being Wales' largest employer and consequently the main focus of spending for the Welsh Government (Welsh Government, 2014b). There is an annual investment in mental health services of £600 million and the Welsh Government believe that this, together with the additional £16 million invested in 2016-17, will address the disparity in service provision between this and physical health. The Cabinet Secretary for Health and Social Services, Vaughan Gething (2016) on launching the *Together for Mental Health ten year delivery plan: 2016-2019* stated, 'we want to ensure that all people of all ages that need to access high quality, mental health services can do so and that they are treated with dignity and respect'. This is an ambitious aim given the gradual increase of people reporting treatment for mental illness in Wales over the past decade (Welsh Government, 2016d).

As indicated, as well as the financial, there is also the personal cost of mental illness to consider. Mental illness will affect one in four of the UK population at some point in their lives (McManus *et al.*, 2009). Although questions have been raised about the legitimacy and usefulness of this statistic (see Horder, 2010), it remains in widespread use. There has also been a suggestion that the statistic is underestimated and the problem of mental illness is in fact far more prevalent. Indeed the latest official statistics show an increase from 23% to 26% (McManus *et al.*, 2015). This trend is mirrored in Wales where an increase, not found in the preceding years, has been noted in the 2008 data collected in self-reported treatment for mental illness (Welsh Government, 2016c). For the mental health charity Mind (2017a) these rises are a worrying trend; coupled with changing pressures on employment and the UK populations' finances in recent years, they question the resilience and ability of the population to cope. The trend also increases concern of the ability and resilience of

services to cope with growth in demand, a sentiment echoed in much of the rhetoric surrounding the sustainability and future of the NHS.

In recent years a spotlight has been placed on the cost of mental illness to the individual. For some mental illnesses can have fatal consequences and personal accounts of the impact are prevalent across many different platforms including social media (see SANE, 2017; Hafal *et al.*, 2018a) and the national press (see Stokes, 2017; Gander, 2017). Recent campaigns highlighted the personal cost of mental illness and empower the service user through providing a platform for their voice. These stories include those given by celebrities and have contributed to challenging the stigma surrounding mental illness (see Mind, 2017b), however stigma remains prevalent in society. As noted there has been a recent significant investment allocated for mental health service provision, a goal of which is to address stigma through parity of esteem between physical and mental health services. Policy and legislation have supported this and there has been a spotlight on promoting the general health of the public across the UK and in Wales (see Welsh Government: *The Wellbeing of Future Generations Act 2015*; *Together for Mental Health*, 2012). The changes in policy, campaigns and investment are an attempt to encourage the population to talk about mental illness in the hope more people will access services in a timely way. Consequently this would lessen their distress and the chance that they will need more costly intervention later, should their condition deteriorate.

It is in this context that the current research has been carried out. The above highlighted relevant legislation and policy has both influenced, and been influenced by, the changing rhetoric and discourse on mental illness. The growth of the voice of the service user, demand for services and criticism of service provision has forced both the UK and Welsh Government to respond. Both investment and legislation have been targeted at addressing the problems in mental health service provision. However the current rising prevalence of mental illness maintains the increase in pressure on the NHS and other services. Although services are responding, there remains a deficit in timely and appropriate access to clinicians leading many service users to gain support from the third sector. The picture presented also indicates the need for further research in this area with trends suggesting continued increases in mental illnesses and subsequent demand for services. Understanding the experience

of service users is an important aspect for the future progression of services. This can also be said of those working in services who are able to bring a different experience and thereby provide insight to the system in which they practice. Although previous studies have given voice to both service users and staff working in mental health, the specific experience of receiving a mental health diagnosis has received little attention.

## **Service User Involvement (SUI): The policy context**

Service User Involvement (SUI) emerged from a social movement that facilitated significant changes in service provision. It is a mechanism that positions the service user at the centre of their care and treatment, giving their voice and opinion weight to change services for the benefit of those that use them. This has been endorsed by recent governments who have encouraged clinicians and researchers to incorporate it into their practice and therefore supports the incorporation of SUI in the current research.

There have been major changes in mental health service provision.

Deinstitutionalisation from the mid 1950s and the shift towards a community-based model of healthcare, interrupted decades of status quo. These changes were in response to a variety of complex interlinked factors, however a significant focus for the UK Government was the question of the sustainability of hospitalised care. As institutions began to close and concurrently the service user voice became stronger, the Conservative Government of the late 1970s and early 1980s began to introduce the concept of 'citizens as consumers'. The 'consumer' of healthcare services consequently had a voice and power to question the quality of services received. This approach and ideology was complemented with a legislated focus on target driven service improvement in healthcare. This also advanced the idea of active, social participation to create change.

The market economy approach continued with the 1997 Labour Government who further conceptualised the idea of citizenship and consumerism. In doing so they indicated their recognition of the need to harness and use the power held by the public. Consequently there was a new focus on the rights of the consumer and empowerment of individuals and communities: identification of a previously

untapped 'core economy' of third sector, family, friends and communities providing unpaid support and care. These were seen as a resource by New Labour to ease the pressure on state systems and subsequently partnership working was embraced and the voice of the service user began to be incorporated into service development and provision. This resulted in the healthcare system, and those working within it, having to adapt and increase transparency in their practice to create an environment that was open to challenge: an uncomfortable adjustment for many. What follows is an overview of some of the legislative framework that facilitated the adoption of SUI in healthcare and research.

Government legislation has strengthened involvement of people with lived experience of physical and/or mental illnesses. In the recent past there has been a move towards patients and public, carers and healthcare professional's influencing the development and delivery of services. An influential piece of legislation that introduced the concept of equality in society for those with disabilities was the *Chronically Sick and Disabled Persons Act 1970* (Department of Health, 1970). Among other ways of levelling the playing field, it included accessibility rights and the need for representation of someone with experience of disability on public bodies. This was at a time when the disability rights movement was gaining pace after a decade of campaigning, and paved the way for the *Disability Discrimination Act 1995* and more recently the *2010 Equality Act* (Department of Health, 1995 & 2010a). This has seen the rise of people with impairments entering the workplace and using the law to call for reasonable adjustments at work to support their continued employment.

Focusing on healthcare specifically, there has been more recent legislation encouraging SUI. The *NHS and Community Care Act 1990*, encouraged competition created by an 'internal market' in the NHS, to drive up the quality of services (Department of Health, 1990). Subsequently it incorporated the empowerment of those using services in choosing and demanding the services of highest quality and best outcomes. This was supported by the *1991 Citizen's Charter* which put in place a structure to support hearing and implementing the service users' priorities as well as making evident their rights within the NHS (Department of Health, 1991). In 1997 the Labour Government set out their vision for the public healthcare provision in *The New NHS. modern. dependable* (Department of Health, 1997). The focus on 'rebuilding

public confidence' in the NHS through involvement of public and service users, extended to partnership working of NHS staff and local communities in the hope that 'openness and public involvement will be key features of all parts of the new NHS' (Department of Health, 1997:4.09 & 2.23). These statements indicate the deteriorating view of the healthcare system held by the public, alongside an understanding of the need to embrace their opinion to improve this and create a 'new' NHS.

*A First Class Service. Quality in the New NHS 1998*, built on this approach with a proposed healthcare model that situates service user and public involvement. Thus increasing transparency and influencing 'professional self-regulation, clinical governance and lifelong learning' (Department of Health, 1998: fig1). Involvement of staff and service users in a collaborative decision making process was justified by recognising the value of the knowledge and experience that is held by both groups. The *1999 NSF for Mental Health* supported the Care Programme Approach (CPA), in which service users have input, 'where appropriate', to decisions made about their care (Department of Health, 1999). To reinforce this, the *NHS Plan 2000*, invited service users and the public to take part in 'redesigning the health service from the patient's point of view' (Department of Health, 2000a). Chapter 10, Changes for Patients, asserts that the empowerment of service users through increasing transparency and choice is paramount:

NHS care has to be shaped around the convenience and concerns of patients. To bring this about, patients must have more say in their own treatment and more influence over the way the NHS works (Department of Health, 2000:88).

This theme extended beyond the individual level to include participation in planning services from industry, as well as the third and private sectors. The recognition of the benefits of, and need to support public services through collaboration with other agencies, continued gaining ground.

The consultation document *Quality Strategy for Social Care 2001*, carried a strong message promoting independence and resilience in the public (Department of Health, 2001a). Driving up standards, addressing inequalities and social exclusion complement the proposals set out in the paper. Accountability, sustainability through staff development and 'active involvement' of service users is promoted to increase equality and the philosophy of services centred around the service user. Section 11 of

the *2001 Health and Social Care Act* was more direct in responding to the need to make services more 'user-led'. Explicit in this section was the 'duty' of those developing and delivering health services to involve and consult throughout the process, those that the services are provided for (Department of Health, 2001b). This highlighted the direction of travel, integrating health and social care, and also the role of the service user in influencing this.

Concurrent to this Act was the discussion document *Involving Patients and the Public in Healthcare* (Department of Health, 2001c). This was aimed at developing 'systematic involvement' and culture that empowers service users and the public at all levels in the NHS. *Shifting the Balance of Power 2001*, focused not only on the service users themselves, but also the empowerment of frontline staff who are often the conduit through which their voice gets heard (Department of Health, 2001d). To help facilitate this reform, *The NHS Reform and Health Care Profession Act 2002*, introduced the Commission for Patient and Public Involvement in Healthcare (CPPIH) to manage Patient and Public Involvement Forums (PPIFs) (Department of Health, 2002). These bodies facilitated the voice of the service user on boards and at a strategic level. Legislating for a 'shift in the balance of power' in the healthcare system, not only challenged the status quo but also demanded huge cultural change: a difficult, uncomfortable and slow process in any environment.

This change was reinforced by the then Prime Minister, David Cameron, his Deputy Prime Minister and Secretary for Health, who shared their vision for the future direction of the NHS in the 2010 white paper *Equality and Excellence*. They announced service users would have more choice and control over decisions and healthcare professionals would be empowered, resulting in this partnerships becoming a set standard in research (Department of Health, 2010b). Chapter 7 of the *Health and Social Care Act 2012*, extends the 2001 act of the same name, making it a duty of NHS Commissioning Board to involve service users, as well as make provision for public consultation, in service planning and decision making (Department of Health, 2012). More recently in Wales *Prudent Healthcare* (see above) has been introduced incorporating co-production as one its core principles (Welsh Government, 2017) and Prime Minister Theresa May set out England's *2016 Five year forward view for mental health* (Mental Health Taskforce, 2016). This plan placed an

independent taskforce to oversee its implementation, the chair of which was Paul Farmer, the Chief Executive of the mental health charity Mind.

SUI has been encouraged and supported by the recent past and current governments in the UK. Much legislation has been passed to enable the voice of those receiving care to be heard and have influence. This support has also been extended to research and evaluation. This is notable in the *Research and Development for a First Class Service 2000*, where requests for identification of SUI in NHS research and development departments, must be in place before funding is agreed (Department of Health, 2000b). A strong advocate for SUI is The Chief Medical Officer, Professor Dame Sally Davies, who believes 'patients and public always offer unique, invaluable insight' (National Institute for Health Research, 2013:2). In her foreword to the *Research Governance Framework for Health and Social Care* (2005), she notes that the 'participants come first' and the document goes on to encourage SUI in the 'development, undertaking and use of research' (Department of Health, 2005:ii&16).

## **Comment**

SUI has been incorporated into legislation concerning the provision of healthcare services over recent decades. This was in response to the empowerment of service users as they began to voice their opinion on their own care and that of services more generally. This social movement called for influence over matters that directly affected its members and I doing so demanded the right to access consistent, quality care. Although this legislation supports such rights, the continued creation of this guidance since the 1970s, is indicative of resistance to the cultural change needed to facilitate incorporate of SUI. This resistance extends to the area of research and evaluation which has historically practiced with a power imbalance between researcher and researched. Some adjustments in this field have been made to address this power difference and the voice of the service user has gained some prominence especially in qualitative research. However many believe current systems are not conducive to SUI and argue it is far from being systematically embedded in healthcare and research (see Chapter 2). This is also evidenced in the lack of empirical research that indicate SUI is taking place widely. Those papers that do illustrate user-led research and SUI, are far outweighed by those emphasising the



lack of it in traditional healthcare and research environments. The design of the current research attempts to redress this balance through the incorporation of a Research Advisory Panel (RAP) (see Chapters 2 and 3).

## **Summary**

This first part of this chapter set the context for this thesis. Mental health legislation, the prevalence of mental illness and the systems of healthcare provision have been explored. These indicate the current burden of support and treatment of mental illness in the UK and Wales. Over the decades, and as a result of pressure by service user groups, legislation has promoted inclusion of SUI in design and delivery of services, not least of all in mental health where those experiencing mental illness are considered a marginalised group. This, combined with the research focus, indicate the importance in hearing the voice of the service user in the current research. Therefore adopting a qualitative approach, with its focus on capturing the participant story and the meaning placed on phenomena, lends itself to exploring the experience of receiving a mental health diagnosis. This approach also emphasises the importance of role the researcher in the process to aid transparency, therefore what follows is a brief introduction to myself.

## **Introducing the researcher**

Qualitative research acknowledges the vital role played by the researcher in exploring phenomenon and co-creating meaning. This highlights the influence and impact of the approach of the researcher on all aspects of the research process. As Finlay and Gough (2003) argue, inclusion of personal motivations (as well as academic rationales), not only helps clarify the research question but also further contextualises the research. Therefore within this thesis, reflexivity is used to make transparent my position, motivation and approach to the research (see Chapter 3 for the concept of reflexivity). The following offers explanation of my motivation for the research and influence on design choices.

My name is Nicole Burchett, I am White, British and 45 years old. I graduated from two Universities in South Wales with degrees in Behavioural Science and

Occupational Therapy. I have been registered with the Health and Care Professions Council (HCPC) since 2001 and remain so (OT40257).

I have always been, and remain, fascinated by people. On returning to college to take my 'A' levels, psychology sparked an interest in mental illness, which remained and has influenced and guided my training and career. This interest became more defined as I developed an identity as a clinician on graduating as an Occupational Therapist (OT). This led me to enter the world of public services and the National Health Service (NHS), where I stayed for 6 years. As promoting equality and empowering people is important to me, I began to question the power imbalance between service users and healthcare professionals. Although public services advocated involvement of service users, it by no means embraced it. Nonetheless working in a forensic unit I was able to co-facilitate an art group with an ex-patient and when working in the community I wrote an article with a service user for my profession's magazine (Burchett, 2009). Involvement of service users felt a natural extension to my role, but looking back it was minimal and comfortable.

Never career driven, my work has been guided by my interest and so it was no surprise when I moved from the NHS into the third sector. Taking a role working in a project focused on suicide reduction and prevention, was a leap of faith. However it was not only the role that provided a huge learning curve, but the philosophy and environment adopted by the organisation. I have always approached working with people with mental illness without judgement, however this was tested when joining a team where many of the staff had experience of mental illness and at least half were volunteers currently managing mental illnesses. This gave me an insight into how the third sector operates very differently to the NHS, as well as providing a 'gold standard' example of SUI. This way of working planted a seed and led me to incorporate SUI in the current research design as a 'non-negotiable' component.

The experience of working in mental health in the NHS and third sector also allowed me to appreciate the variety of responses to receiving a diagnosis. Some service users actively sought a diagnosis, some put their life on hold until they received one, others did not place much credence to having one, whilst others used it to evidence their expertise in a condition. This prompted me to consider the reasons for the

different responses and question the influence of the interaction at diagnosis. The idiographic experience of receiving a mental health diagnosis, led to consideration of Interpretative Phenomenological Analysis (IPA) as an approach to capture this. For Smith *et al.* (2009:29) IPA is 'committed to understanding how particular phenomena (an event, process or relationship) have been understood from the perspective of particular people, in a particular context' (brackets the authors own). However working as a clinician, it is apparent service users do not experience receiving a diagnosis, or indeed most forms of support from healthcare services, in isolation. This signifies a need for not only the voice of the service users, but also the staff voice to be heard in research. These formative experiences of employment led to feel strongly about adopting three interrelated areas I felt non-negotiable in the current research, combining the story of the service user, the opinion of staff and the integration of SUI. These I considered essential aspects for exploring the experience of receiving a mental health diagnosis and therefore were incorporated into the research design (see Chapter 3).

This researcher profile provides transparency and rationale for the choices made in the current research. Further attention is given in this thesis, to the researcher role and influence on interpretation of findings and reflections of the PhD process as a whole. Intrinsically linked with the above motivation and interest are the research aim and objectives. These are introduced below before concluding this chapter with a structure of the thesis, through a brief overview of its chapters and a clarification of the terminology used.

## **Aim and objectives**

### **Aim**

The aim of this research is to gain an understanding of the experience of receiving a mental health diagnosis and to explore this with staff delivering services in mental health in relation to their everyday practice and wider service provision.

## **Objectives**

- 1) To review the background literature related to diagnosis and mental health service provision in the United Kingdom.
- 2) To investigate the ideological and practical literature on Service User Involvement and form a Research Advisory Panel for guidance over the lifetime of the research.
- 3) To conduct interviews with people on the experience of receiving a mental health diagnosis and analyse data using Interpretative Phenomenological Analysis (Study 1).
- 4) To run focus groups with staff delivering services to discuss emergent themes from Study 1 in the context of service provision (Study 2) and analyse data using Thematic Analysis.
- 5) Draw together analyses from Study 1 and Study 2 to identify recommendations for practice in mental health service provision.

## **Structure of thesis**

This thesis consists of 6 chapters. Having introduced this thesis in Chapter 1, the purpose of Chapter 2 is to provide a literature review. The historical development of diagnosing mental illness and the provision of services are explored using empirical literature (objective 1). The design of the research also necessitates attention be given to SUI, therefore this chapter also presents the literature on service user movement that provided the foundations of SUI (objective 2).

Chapter 3 focuses on the methodology employed. This sees a shift in the tone of the thesis through combining not only the theory, but also its application in the current research. The chapter details the novel and concurrent research design, before moving onto the methods chosen to achieve the research aim. The chapter concludes with literature on achieving validity in qualitative research and a reflexive section that includes profiles of the participants and the influence of my approach on the analysis.

Chapter 4 provides the findings from Study 1: interviews with participants on the experience of receiving a mental health diagnosis. This uses the processes and steps of analysis in Interpretative Phenomenological Analysis suggested by Smith *et al.* (2009) (objective 3).

Chapter 5 presents the findings from Study 2: the analysis of focus groups conducted with staff working in mental health services (objective 4). The overarching and subthemes developed using Thematic Analysis are explored.

Chapter 6 brings together Study 1 and Study 2 in the current research (objective 5). The interview and the focus group findings are synthesised and the resulting discussion develops understanding of receiving a mental health diagnosis. From this synthesis, emerge recommendations for practice in mental health service provision. The limitations of the current research are offered and private reflections of my PhD experience bring this thesis to a close.

### **A note on terminology**

There are a variety of terms in use in the field of mental health. Therefore it may be of help to make clear my reasons for choosing two particular terms (mental illness and service user) within the thesis.

#### **Mental illness**

As Leach (2009a) notes, the term mental health is actually often used to mean the opposite, i.e. mental illness. To clarify for the purposes of this thesis, the term mental illness is used to represent individuals that have been diagnosed by a GP or consultant psychiatrist with a mental illness, as defined by the Diagnostic and Statistical Manual for Mental Disorders (DSM) or International Classification of Diseases (ICD). There are other terms such as 'mental disorder' and 'mental health problem' used in literature, however the choice of mental illness was chosen after communication with service users in the conducting of this research and on communication with Mind. In email correspondence with the mental health charity, it was suggested it was most appropriate to use either 'mental health problems' or

‘mental illness’. The latter of the two indicates the physical framework in which mental health diagnoses are given (Leach, 2009b) and was used by some participants interviewed for this research. To show respect to the service users involved in this research, who felt more legitimacy was given to the distress they experienced through classing it as an ‘illness’, the term ‘mental illness’ is adopted throughout.

## Service user

There is much literature on SUI as explored in the following chapter. This includes discussion of the changing terminology for this group: patients, consumers, citizens, experts, survivors and service users. The terms adopted are influenced by the environment in which services are accessed i.e. patient is often associated with clinical settings and survivors with the service user movement. However although these terms are used in these different contexts to represent certain agendas, Russo (2016) points out that many people with lived experience do not identify with them. Roberts & Boardman (2013:403) clarify the term service user from a user’s perspective: ‘I am a person who uses services/I am a person who uses services who has a mental health problem’. To clarify this further Beresford (2005:7) states service users are ‘people who are on the receiving end or eligible to receive health and social care service’. The term service user is in frequent use among academic researchers with lived experience of mental illnesses and in itself is a self-explanatory term (with limited judgment) therefore it is used in this thesis.

## **Chapter 2: Mental health diagnosis and SUI**

### **Introduction**

This literature review looks at two key areas; mental health diagnosis and SUI. Introduced in Chapter 1 with the legislative backdrop, here they are more deeply considered using relevant empirical literature. The research title concerns ‘the experience of receiving a mental health diagnosis’, and so attention is given to ‘diagnosis’ and ‘experience’. With its long history, the development of diagnosing brings understanding to the structure and practice in healthcare services today. This history of service provision gives context to the development of the nosology of mental illness through a burgeoning profession of psychiatry. It also charts the dramatic changes in the provision of mental health services. In exploring this, two sides emerge from the literature: diagnosis as a helpful way of explaining experience and diagnosis as a labelling, limiting process. Therefore, the following focuses on the development of diagnosis before exploring the challenges to it.

The latter part of this chapter explores the development of SUI in healthcare and research. SUI was a non-negotiable component in the current research and is integral to its design. Therefore it is important to consider the history of SUI and the ideas and influences that created the social movement from which it arose. The literature indicates two main approaches to SUI which are presented, as well as exploration of the numerous forms it takes and different ways of implementation.

It is worth noting there are numerous histories on the development of psychiatry and medicine and the position taken by each author will have influenced their representation (Berks, 2005). This point not only relates to developments in healthcare, but also the development of SUI. It also echoes the need for transparency in the position adopted by the researcher. Offering an introduction to myself as a researcher in Chapter 1 (together with the reflexive sections in Chapters 3 and 6) aid this, however it is important to further clarify my position in relation to the empirical literature. Taking an emancipatory position, I advocate for the empowerment of the service user and challenge the traditional power imbalance that exists in healthcare and research. As a consequence I am drawn to arguments that support this view,

however I am also aware of this preference. Berks (2005) advocates combining both social and traditional focuses in literature in psychiatry (negative and positive perspectives) to provide a balanced picture. Therefore I have presented the different viewpoints of healthcare provision and SUI to present a balanced picture, as well as making transparent my own perspective.

## **Mental health diagnosis**

*Diagnosis is an example of where knowledge alone  
can profoundly change people's lives (Hayne, 2002:181).*

The experience of receiving a mental health diagnosis is the central focus of the current research. The roots of the development of diagnosing behaviour as mental illnesses lies within mental health service provision, which have developed over centuries to the services accessed today. Care of those with mental illnesses was initially provided privately in residential institutions, which led the way for larger asylums (Shorter, 1997). These provided the environment for the development of the profession of psychiatry and, subsequently, a systematic diagnostic procedure. These aspects are explored before attending more specifically to the manuals of diagnosis in use today and the challenges made to the concept and process of diagnosing. This evolution is an important picture to explore as it provides the foundations of the medical model approach of current service provision and the basis of care.

## **Care of those with mental illnesses**

The dawn of widespread mental health institutions came about in the 18th century. Prior to this, there was an expectation that family would provide care for those with mental illnesses. The focus of institutional care came about through the development of private providers offering support to 'feeble' people who came from prosperous families (Fakhoury & Priebe, 2007:113, quote marks authors own). Those that were unable to cope with daily life were protected from the stresses and strains for their rehabilitation and recovery. Subsequently institutionalised residential care became the accepted and recommended course of providing services for those with mental illness. A consequence of this was an increase in demand for admittance to these institutions, in part driven by the emerging recognition that many accommodated in



workhouses and prisons would be more appropriately placed in these institutions (Murphy, 2003). This demand acknowledged the need to accommodate the lower classes with mental illnesses (not only those with wealth) in more appropriate institutions. Organising service provision in this way drew attention to the classlessness nature of mental illness. The increase in people admitted to the institutions also allowed a broadening of the medical professions' observations beyond those considered 'feeble'.

The demand for care of those with mental illnesses was met with the construction of large asylums. Rogers and Pilgrim (2010:189) note these were located away from the town centres resulting in the 'segregation of lunatics' and reinforcing the binary view of sane and insane. This indicated the medical model approach to mental illness adopted from the view of physical illnesses of 'dis-ease' in the body to be identified and treated. Segregating those with mental illnesses, Hooper and Lincoln (2009) point out, enabled society to forget this section of the population by literally removing them from view. The state of mental health system in this period was 'sprawling, unplanned, ill coordinated' (Hooper & Lincoln, 2009:76). Stories of inhumane and brutal treatment grew alongside these flourishing private institutions, where the voices of those experiencing these practices were not heard. These questionable practices (such as chaining patients to beds) were characterised by the documented stories that emerged from the Bethlem asylum (or Bedlam as it infamously became known) where the public paid a small fee to view the patients (Jones, 1993). Segregation and separation reinforced this sense of 'them and us' and the lack of understanding of those with mental illnesses strengthened societies distrust towards them.

Over time documentation of life within these institutions became public, this included the seminal essays by Goffman. In *Asylums* (1961:7,306) Goffman gave an insight into the 'social world of the hospital inmate' where he observed 'a uniform professional courtesy shown to patients is matched with a uniform applicability of psychiatric doctrine'. In observing this Goffman suggested that the hospital regime was as much about patient control, as treatment and cure. This was a sentiment later echoed by another sociologist, Scull (1979:265) who believed control was maintained by the medical doctors who 'negotiate reality on behalf of the rest of society'. The principle

that underpinned this approach justified medicine as the authority (Bentall, 2004). The medical model approach and biological lens used by medical experts, viewed people as functioning or dysfunctional entities: a body made up of parts. This approach Kendell (2009) argues, led to the loss of seeing and treating the individual with a mental illness as a whole person, a human being, and subsequently reinforced poor treatment in asylums.

The 1845 *Lunatics Act* helped put in place measures for quality assurance in the asylums and workhouses, which Jones (2013) highlighted as signifying the humanitarian nature of society. However it was not until early 19<sup>th</sup> century that governments were forced to take interest as the regulation of asylums was accompanied by the growth of the human rights movement in the late 18<sup>th</sup> century. This was fuelled by an increase in the number of media exposés highlighting conditions and treatment within the asylums. The state interest however, as Dowbiggin (2011) points out, was not purely altruistic: people equated to productivity and this linked to the country's prosperity. This interest initiated the link between government involvement in the care of the public and subsequently the beginning of the 'therapeutic state' in the 20<sup>th</sup> century (Dowbiggin, 2011:37). This setting provided the catalyst for a different approach to healthcare provision, from private to public, today recognised in the UK as the National Health Service (NHS). Notwithstanding these changes, the medical practitioners overseeing the care in these institutions remained a central thread throughout and later formed what was to become an elite group that held the knowledge and therefore, power.

### **Psychiatry and the categorisation of mental illnesses**

Entry into institutions that provided care for those with mental illnesses came about via the signature of a medical practitioner. Indeed Wright (1998) points out in the majority of cases little more was needed for admission. This placed the medical profession, above other healthcare professionals in these environments, in a position of power and authority. The expertise of the medical professionals developed as the demand for services grew and the opportunity for mass observation of those with mental illnesses presented itself within institutions. This saw the dawning in the 18<sup>th</sup> century of the new profession of psychiatry. This specialism within medical practice

subsequently became an authority; through scientific investigation they developed theory from their research and subsequently were seen as the experts in their field (Scull, 2015).

Given time, these medical professionals began to organise the knowledge they produced. During the mid to late 1800s, there were developments across Europe and beyond in this distinct profession. Some credit Philippe Pinel (1745-1826) as a key founder of modern psychiatry through his advocating more moral and humane practice for those with mental illnesses (Andreasen, 2007). However, Bentall (2004) notes that the progression made in Germany, due to education and research, had great influence on the development of the profession and nosology. This was in part due to the German born doctor Johann Reil coining the term 'psychiatry' in 1808, from the Greek 'soul' and 'doctor' (Scull, 2015). This addition to the language supported visiting professors teaching a new specialty and subsequently the establishment of a separate division at Berlin University that combined clinical research and education (Bentall, 2004). Wilhelm Griesinger (1817-1868) oversaw this department and his approach towards empiricism and methodology (away from the romanticism and philosophy prevalent at the time) had much influence on the direction of the department (Hoff, 2009). This approach not only prompted many discoveries through use of a more scientific approach, it also set the foundations for the concept of disease classification within the biological medical model. Alongside this is a neurobiological scientific approach, Hoff (2009) points out the additional influence of Griesinger on current practice of psychiatry through advocating community-based care. He argues this laid the foundations of modern social psychiatry, promoting a person-centred approach to care and seeing the person holistically.

A highly significant development within the burgeoning field of psychiatry, was that of the nosology of mental illness. It is widely acknowledged that Emil Kraepelin (1856-1926) fundamentally influenced the understanding of mental illness through introducing the concept of categorisation (Hoff, 2009). Kraepelin gathered vast amounts of information on the symptoms of patients in his care and it was this data that led him to publish a *Compendium of Psychiatry* in 1883 (Bentall, 2004). Over the next decade through contact with patients, Kraepelin continued to gather evidence to

further define mental illness for prognosis. These observations resulted in two categories that he considered broadly held all conditions; manic-depression and dementia praecox, a final category of paranoia was added in a later Compendium (Bentall, 2004). This document, and its categorisation of behaviour, became the foundations of understanding and medical practice in mental health. Over the following decades the medical profession agreed, disagreed, adapted and sought to enhance the suggestions Kraepelin put forward. Consequently the Compendium became the starting point for the current classification of mental illness used across the world. Historical summations of the development of psychiatric nosology by Hoff (2009), Bentall (2004) and Shorter (1997) highlight key figures in this process. The following offers a brief overview of these figures in order to indicate the philosophical, psychological and sociological influences on the development of the categorisation of mental illness.

Eugen Bleuler (1857-1939) revised the concept of dementia praecox and in doing so coined the term 'schizophrenia'. He introduced a psychological approach to the scientific route taken by Kraepelin and upheld the idea of a continuum of mental health to mental illness. This approach was supported by Ernst Kretschmer (1888-1964) who supplemented it with a suggestion that mental illness was linked with physical build; also on a continuum. The psychiatrist and philosopher Karl Jaspers (1883-1969) however proposed a re-focus of practice where the psychiatrist focused on the *form* of the symptom rather than its *content*. In doing this he gave more weight to how the service user interprets their belief and therefore introduced the importance of integrating the subjective world of the service user, alongside the psychiatric view, to form an opinion.

Kurt Schneider (1887-1967) furthered this approach in his work, and in doing so, defined the differences between schizophrenia and psychosis. His proposal of a set of 'first-rank symptoms' of psychosis that characterised schizophrenia, influenced the criteria used for diagnosis. He also advocated for the inclusion of environmental and psychological influences alongside a neurobiological basis for mental illness. This influenced a move to a more social approach within psychiatry, which was promoted by Adolf Meyer (1866-1950) who also had great influence on psychiatry in the early 1900s. Meyer emphasised the need to take patient histories and question *why* the

patient was experiencing symptoms, as well as maintaining a focus on diagnosing (Pilgrim, 2007). Karl Kliest (1879-1960) and his student Karl Leonhard (1904-1988) continued to refine Kraepelin's classifications focusing on the similarities between definitions of schizophrenia and manic depression. Leonhard later published on the mental illness of 'bipolar depression', which separated this condition from schizophrenia.

These iterations of Kraepelin's initial Compendium are noteworthy for their influence on how we define mental illness today. Although there were many adjustments, the categorisation of mental illness sparked the beginning of a system of classification of psychiatric disorders used across the world. There are two widely used manuals for disease classification published by the World Health Organisation (WHO) and the American Psychiatric Association (APA). The starting points of these have influenced the focus and purpose of the two manuals; international focus of the WHO and the national focus of the APA. There are periodic revisions of each manual and although progress has been made to align the two, it has been complicated by rigid controls, divergences in financial support and incompatible timings (Kendell, 1991). There remains a concerted effort to harmonise the two for the purpose of sharing scientific knowledge in order to support international regulatory organisations (APA, 2013). However the current versions of DSM and ICD (V and 11 respectively) remain distinct from each other and as Tyrer (2014) notes, it is these differences that are often the reason for preferences in use. This further complicates the process of harmonisation of the two manuals.

Of the two manuals the American diagnostic manual for mental disorders was first published by the APA in 1844. The initial intention of the manual was to classify the mental illnesses of institutionalised patients. This goal developed in subsequent editions to offering guidelines for diagnosis with the aim of informing the management and treatment of mental illnesses (APA, 2013). The expanding and refocusing of the manual was driven by the recognition of the incongruent ways of diagnosing mental health across the nation, post-second World War. In an attempt to rectify this, the Diagnostic and Statistical Manual of Mental Disorders (DSM) was established in 1952. Over the decades major changes have been made to the manual due to the influence of the thinking at the time and the preferences of the overseeing

task force (see Blashfield *et al.*, 2014). These provide an indication of trends and societal attitudes towards mental illness and behaviour deemed to be 'deviant' over time and form some of the challenges made towards the manual discussed below.

The second manual widely used across the world is The International Statistical Classification of Diseases and Related Health Problems (ICD). This was validated by the WHO and its member states in 1990. The 1893 first edition was entitled International List of Causes and Death (or Bertillion Classification) which gives an indication to the role it played in gathering statistics on death and disease (WHO, 2009). Over the decades of the manuals' development, it maintained its purpose in monitoring the prevalence of disease and deaths in 194 countries. However, it was not until 1938 that the ICD incorporated mental illness alongside its initial focus on physical illnesses. This indicates the changes over time in the understanding, development and interest in mental illnesses. The aim of the manual was to promote ease of use and international communication, thereby assisting analysis of data and comparisons across time and various locations (WHO, 2017). This ambition also drives the desire to synchronise the DSM and ICD and produce a manual that is standardised for world-wide data collection.

The developments made over the decades have not gone unchallenged and many question the use and effectiveness of diagnosing. These challenges from the antipsychiatry and social disability movements played a significant role in changing the way service is provided today and are therefore explored below.

## **Challenges to service provision**

As hinted above, there were dissenting voices in the provision of mental health services. These voices were supported and driven by an international movement that demanded human rights for those viewed as disempowered in society. In the following narrative challenges to service provision begin with the antipsychiatry movement that sparked the move to community-based care. The social model of disability is then introduced, with exploration of the concept of mental illness from a sociological perspective. This includes criticisms of the nosology of mental illness and leads onto the aspects of treatment and recovery prompted by this discourse.

The stigma associated with diagnosis and accompanying labelling theory are explored, leading the way to conclude this chapter with literature on the experience of receiving a mental health diagnosis. Viewing this as a unique and personal experience provides the link and introduction to part two of this chapter; concentrating on the voice of the service user in influencing service provision.

### **Antipsychiatry and deinstitutionalisation**

Due to the segregated nature of institutionalised care, practice within them went unchallenged for many decades. This changed in the 1960's with a movement that questioned the benefit of the concept of mental illness and of labelling behaviour. Labelling behaviour was seen as the problem as it resulted in medicalisation for the purpose of diagnosis, rather than to aid those experiencing the symptoms (Shorter, 1997). At a time of anti-authoritarianism and the civil rights movement, there were other outspoken voices that joined Goffman (1961) in challenging the dominance of psychiatric thinking. Although not all agreed with the membership of this group, the antipsychiatry movement highlighted the unhelpful nature of institutional care and of categorising behaviour. There are key figures that Shorter (1997) notes influenced psychiatry through their writings during this decade: Thomas Szasz's (1960) *The Myth of Mental Illness*, Ronald David Laing's (1960) *The Divided Self* and Michel Foucault's (1961) *Madness and Civilisation*. The perspectives these thinkers held are briefly introduced below to indicate the nature of their challenges.

Szasz (2009:48) questioned the concept of disease by highlighting the influence of the medical profession's interpretation and judgement, stating that there are no 'value free medical considerations'. Although the title of his 1960 book suggests differently, he did not dismiss the existence of mental illness, rather he argued behaviour should be 'regarded as expressions of man's struggle with the problem of *how we should live*' (Szasz, 2009:49, italics authors own). Laing, who was a prominent figure in the antipsychiatry movement, challenged the medical model of disease promoting a similar line of argument. He believed the approach taken by the medical profession did little to capture the complexities of the individual and dismissed the, often explanatory, meaning attached to symptoms. In the case studies presented he argues that mental illness develops through sustained use of coping strategies originally

developed by the individual 'in order to keep safe from the persistent threat and danger from the world' (Laing, 1973:237). Therefore behaviour deemed as stemming from a mental illness, is in fact a rational response to life events.

Both Szasz and Laing advocated focus on the pressures faced by the individual in allowing deeper understanding of responses to them. The medical model was seen as dehumanising the individual through approaching the mental illness in isolation (not as an intrinsic part of a complex human being). This was echoed by the work of Foucault and his attention on the influence of social constructs and what he saw as the implicit power imbalance within society. He believed the 'strange practices woven around madness...which glorify and at the same time discipline it' (Foucault, 1961:82). This perspective led him to view the diagnosis of mental illness, and its treatment within asylums, as a social construct, the aim of which was to oppress and socially exclude. In this statement Foucault suggested institutional care simultaneously promoted the need for psychiatrists and reduced the human qualities of the service user, therefore allowing domination.

The antipsychiatry movement highlighted the damaging nature of the prevailing view of mental illness held for centuries. The impact of treating mental illness as a disease that needed treatment and cure, resulted in service users being seen as lacking in agency, capacity and rational thinking. The arguments and philosophical thinking proposed by those aligned with the antipsychiatry movement, led to a revolution in care. What had been considered best practice was questioned and the rights of those residing in the institutions was championed by the healthcare staff working within them. This led to a shift in the care provided in the institutions such as the St Lukes, London (founded in 1751) and The Retreat, York (founded 1792). Here visits by external medical staff were introduced and encouraged, this was a significant move away from standard practice and created a space for challenges to practice, leading to accountability and humane treatment (Jones, 1993). Although England was seen as a role model for service provision in mental health, many US states and European countries began developing services that promoted moral treatment of the patients in care (Dowbiggin, 2011).



Over the decades as the buildings that housed the mentally ill deteriorated, the criticisms of institutionalisations grew. The beginning of a different approach to provision of care led to what became known as a 'deinstitutionalisation'. The latter part of the 20<sup>th</sup> century saw asylums close and community mental health teams develop, as service users were housed and supported in local communities. This growth and decline of institutions is charted by Turner (2004), however Novella (2008) argues that causes of deinstitutionalisation provide a far more complicated picture than at first glance. The developing discipline of psychology alongside the antipsychiatry and human rights movements, as well as legislative and pharmacological change, all suggest an influence towards the adoption of treatment in the community (Rogers & Pilgrim, 2010; Novella, 2008). This was advocated as best practice and promoted the rights of service users to live among the general population with the same rights and agency.

The move to community care prompted interest in monitoring the success, or otherwise, of this new approach (see Leff & Trieman, 2000; McInerney *et al.*, 2010; Thornicroft *et al.*, 2005). There are many who questioned the beneficial impact of community care for those with mental illness and links have been made to a rise in homelessness (see Craig & Timms, 1992). Others argue deinstitutionalisation has simply resulted in a different form of institutionalisation, evidencing an increase in admissions to psychiatric hospitals (see Rogers & Pilgrim, 2010; Fakhoury & Priebe, 2007). There is widespread agreement however, that poor implementation and a lack of funding compounded the difficulties faced when transitioning to care in the community. Different conclusions have been drawn from the processes and results of moving to community care and the benefits, or otherwise, for those with mental illnesses. This remains a complex picture with stigma and discrimination playing a vital role in sense of community, empowerment and integration felt by service users (see Bromley *et al.*, 2013, for example). Leff (2001:382) suggests this negative view of the care in the community initiative driven by the mass media, results in the Government 'pandering to public misconceptions' of mental illness when developing legislation. It was hoped this process of deinstitutionalisation to care in the community would not only save the state money, but also prompt a shift in the negative perception of disability. This is explored below and provides a further link the literature presented on SUI later in this chapter.

## Changing perceptions of disability

Coinciding with the widespread move of service users out of institutions was a social narrative that viewed disability in a different light. Post-enlightenment the explanations of disability shifted from ideas highlighting the moral failure of the individual and reinforced the need to seek their biological basis (Shakespeare, 2006). The narrative drew inspiration from the Fundamental Principles of Disability (developed by Union of the Physically Impaired Against Segregation, UPIAS, 1975) and Social Role Valorisation (developed by Wolfensburger, 1972). These principles and ideas laid the foundations for the empowerment of people with impairments to be seen as valued members of society. Society was seen as the cause of 'disability' through devaluing those with impairments and consequently excluding them: impairments themselves may limit the individuals functioning, however the cause of a lack of opportunity to engage equally (as non-disabled) lay in social barriers.

This perspective developed into a movement that advocated equal rights and a model of disability that held society responsible. The social disability model, according to Shakespeare (2006), introduced a different view of disability. The premise of which was to accept the impairment rather than try and change it, see disability as a social creation rather than a deficit of the individual and view society as an oppressor of disabled people (as opposed to non-disabled). Oliver (2013), who promoted the social disability model among healthcare professionals, recognised its role in strengthening the disability rights movement. In the 1990s this movement took up the slogan 'nothing about us without us', calling for society to listen to service users and provide structures that allowed their influence to permeate all aspects affecting them. In the UK promoting the rights of those with disabilities was at the forefront of the model and placed the cause for disability with capitalism and oppression (Owens, 2015). The model aided the move towards a fairer society through highlighting the rights of disabled people resulting in changes in UK legislation such as *the Disability Discrimination Act 1995* (Department of Health, 1995). This act, replaced by the *2010 Equality Act*, promoted equal rights regardless of personal characteristics and made discrimination unlawful (Department of Health, 2010a). Indeed many have used this

legislation to better the lives of those with disabilities, however whether this has changed the public perception of them, remains questionable.

Although progress has been made since coining the term 'social model of disability' in 1983, Oliver (2013) has called for more action and less talk; reiterating its principle purpose of promoting social change. His frustration is shared by others such as Beresford (2002a), who noted that the social model was developed as a progressive tool, promoting independent living through removing societal barriers such as discrimination. The premise that society creates dependency in disabled people, making them victims, also allows that without these barriers disability would not occur. Over the decades there have been other criticisms of the social model such as Beckett's (2006:735) assertion that it reinforces a Cartesian view of disability as 'disembodied'; where impairment is distinct from the individual. However she also recognises its benefit as a foundation for hearing the voice of the service user and promoting inclusion and equal rights for disabled people. This indicates the complex nature of the promotion of service user rights and voice, within existing structures in society.

The roots of the social movement and the model lie in physical disability. This has led some to question whether there should be a separate social model of disability for mental health. Beresford (2002a:583) sees some benefit in developing a 'social model of madness and distress', and subsequently separating it from physical disability. In his research with service users, who had varied views of the social model of disability, he found that there was a need to move on from the traditional medical model of illness, which incorporated the concept of impairment. Many service users did not feel they had an impairment, but nevertheless recognised societal barriers to engagement and felt a social approach may help highlight these (Beresford *et al.*, 2010). The model proposed by Beresford *et al.* (2010) incorporates autonomy for service users to choose appropriate support; flexibility in state benefits to take into account the non-linear process of recovery and a shift in focus from medicalised service provision. However he highlights a danger of accepting a social model as it would simultaneously move focus away from challenging the underlying value system on which healthcare is based. This, he believes, is the fundamental cause of the disempowerment of service users.

Some believe that empowering service users goes beyond calling for changes within the healthcare system and argue attitudes in wider society must also change. The concept of social justice aligns with the social model of disability and dates back to early philosophers who promoted free will in a free society and the rights of the individual. For Bankston (2010) social justice is based on power and incorporates two principles; redistribution of resources to aid the lives of the disadvantaged and recognising their human rights. Braveman and Suarez-Balcazar (2009:13) elaborate on this description combining various concepts: fairness, equal opportunities and access to resources, empowerment and equality between people and government. They promote the view that empowering marginalised groups is the joint responsibility of the state, organisations and the individual. However, some such as Roe *et al.*, (2004:35) highlight society's 'narrow focus on symptoms and pathology' reduces the chance of empowering service users by dismissing the 'possibility that individuals may possess both strengths and weaknesses, competence and dysfunction, simultaneously'. This echoes Beresford *et al.*'s (2010) concern that the narrow focus of the healthcare system and society, limits the potential of those with disabilities. Once diagnosed, the individual is seen in this light and the qualities they possess are overshadowed by it.

The 'narrow view on symptoms and pathology', many argue, is driven by the medical model prevalent in healthcare. Rosenberg (2002) recognises that the sustained prominence of the medical model in society justifies the standing of the profession of psychiatry. This is also evidenced by the focus of considerable funding to find a biological basis of mental illness, echoing the original Krapelin attention on causal genetic imperfections for mental illnesses. Rogers and Pilgrim (2010:2) also highlight psychiatry as the 'dominant discourse' that has shaped concepts of mental health. There have been challenges to this discourse from many different paradigms since the antipsychiatry movement of the 1960s (for an overview see Rogers & Pilgrim, 2010) and criticism remains widespread. Some such as Bentall (2009) and Beresford (2009a) call for rethinking of the entire mental health system and question the medical model as an appropriate framework with which to view it. Pilgrim (2007) however, suggests why this venture is unlikely to succeed due to numerous parties both inside and outside of the medical profession: the pharmaceutical industry, bio-

medical clinicians, psychiatrists, politicians planning services, the media and law courts as well as relatives of those with a mental illness. Therefore there are many invested parties who wish to maintain the status quo due to their dependence on, and the benefits from, the 'dominant discourse' in healthcare.

There are many that view the cause of mental illness as not an either/or case; rather it is likely to be a combination of biological *and* social causes. Indeed for Pilgrim *et al.*, (2009) the biopsychosocial model of health (combining biological, psychological and social factors and viewing the individual holistically), would address this complex interplay. They fear this has not yet become the standard approach in psychiatry, which is of interest given the sentiment of the founders of the profession that advocated for adopting a holistic view of the service user. Brown (1995), suggests the dichotomy within the social construct of illness may affect adopting the biopsychosocial approach: the individual understanding of mental illness as opposed to that held through medical knowledge i.e. diagnosis. These two approaches to mental illness offer very different conceptual frameworks for creating understanding. The former is constructed according to the symbolic interactionism of Mead (1934) and the experience of illness, the latter constructed within the biomedical framework. This framework focuses on logical definitions and natural categorisation that are '*revealed* by the methods of science', which differs from the abstract, '*negotiated*' meaning developed by individuals, culture and social constructs (Maddux, 2016:23, italics authors own). However Shorter (1997) argues opportunity lies in this conflict, where diagnosis plays the beneficial role of linking both the emotional and the bureaucratic need, thereby acting as a connection between the individual and the system. An exchange that further reinforces the status quo in service provision where diagnosis remains central.

Taking a broader view, Henn (2001) highlights a fundamental dichotomy in the classification of mental illness: psychiatry deals with individuals, however the profession practices within a nomothetic paradigm. Information is continually collected in an attempt to find patterns and predict the course of diseases to inform diagnosis and subsequent treatment. This process has had a fundamental influence on the various iterations of the DSM and ICD and has led many to question their purpose and validity. Indeed Jablensky (1991:323) notes flaws in research and gaps

in knowledge 'nourish skepticism' on the processes of classification. In a review of the literature he sets out a number of issues that impact on the legitimacy of the DSM and ICD, including comorbidity, cultural diversity, limitations in categorisation and Atypical disorders (Jablensky, 1999). He concludes that the development of a more appropriate process of diagnosis was likely to combine both the aetiological and behavioural, which would correlate with clinical practice. Although nearly 20 years on, notwithstanding the promotion of the biopsychosocial model in healthcare, First and Westen (2007) found this viewpoint continued to have support from clinicians. The argument for the incorporation of social and psychological factors in finding explanations for mental illness is still present, and is indicative of the strength of the biological focus found in healthcare and the difficulties in challenging this.

Wakefield (1992) proposed approaching the definition of mental illness from evolutionary theory and suggested combining scientific and social components. This perspective highlights the individual's ability to 'fit' into their environment. However Bolton (2004) argues this does not take into account the environment not being a 'fit' for the individual, or indeed the influence of the individual's coping strategies. This view is supported by Guerin (2017:xii) who believes mental illnesses are 'sincere attempts by ordinary people to adapt to difficult situations not of their making'. This contemporary view resonates with the antipsychiatry movement of the 1960s and indicates there remains a need for a wider approach to viewing behaviour, incorporating its context. Indeed Bentall (2009:19) points out what psychiatrists see as 'symptoms' could be interpreted as 'psychological mechanisms'. Although there is much investment in finding biological makers to mental illnesses to aid diagnosis, the fact they are not yet well-defined, Alarcón (2009) argues, further adds to this confusion. However not all agree that biological focus could provide the answer and Bentall (2004:492) suggests this is unachievable as humans are a 'complex chain of interacting processes can rarely be reduced to simple causal laws'. Together these perspectives provide an indication of the complex nature of mental illness and the attempts to define and understand its cause.

Attempting to define mental illness has in recent years moved away from the binary roots of diagnosis as sane versus insane. However the move towards more 'elastic scales' of abnormal to normal, has fuelled disapproval of the process of diagnosis

(Sweet & Decoteau, 2017:16). Whitley (2012:1041) condemns the 'expansionist tendencies' of the psychiatric profession in continually broadening definitions of mental illness and consequently pathologising behaviour. Some argue that the ever-expanding list of disorders and symptoms now produce a catchall for the majority of the populace, subsequently diminishing the usefulness of diagnostic manuals (Kirk & Kutchins, 1994). Indeed Kendell (1991:300) highlighted current coexisting systems for diagnosis (DSM and ICD), reminding us that 'all our diagnostic terms are simply concepts and all our definitions more or less arbitrary'. This view is supported by Rosenhan's (1974:389) experiment testing the reliability of diagnosis and from which he controversially concluded 'we cannot distinguish the sane from the insane'. In response to the challenges and changes in the profession of psychiatry, Craddock *et al.* (2008:6) called for a strengthening of its core due to the resulting 'exaggerated and unrealistic expectations' on the profession that a continuum of mental health and illness creates. They suggest their profession avoid 'medicalising' where possible in order to combat this, this highlights an awareness within the profession of the difficulties surrounding diagnosis and the increasing pressures on them.

Many voices remain discontent with the use of diagnostic manuals for defining behaviour as mental illnesses. Merten *et al.* (2017) in their literature review focusing on child services, raise concern about *misdiagnosis*. They noted the cause of misdiagnosis included the use of heuristics in the diagnostic process, individual interpretations of criteria and constraints of the system that link treatment with diagnosis. Indeed Porter (2002) notes a correlation between developments in psychiatry and services and a steady increase in demand for them. Dowbiggin (2011) suggests this relationship is associated with the development in treatment options and points out the corresponding prevalence of specific mental illnesses in society. This creates a complicated web of influences on diagnosis, often used as evidence to challenge its objectivity and rigour.

Some, including psychiatrists, continue to oppose diagnostic manuals and go so far as to call for their abolition. Timimi (2014:209) argues that although progress has been made in the recognition of mental illnesses, evidence suggests that the foundations of the 'diagnostic-based medical model' remain unsuitable. He highlights deficiencies in establishing the aetiology, diagnostic validity, reliability, treatment and prognosis,

alongside an imposition of Western values and a lack of cultural sensitivity, in support of this view. This fact in part, drives the wish for more objective ways of categorising and diagnosing. Therefore although there have been a great many thinkers who advocate for a holistic approach to viewing mental illness, contemporary thinking maintains an interest in finding a biological cause for symptoms. Despite the 'serious misgivings' in the current system of diagnosing mental illness noted above, Raskin and Gayle (2016:453) point out the DSM remains a well-used diagnostic tool. Bolton (2004) suggests this is due to its usefulness in specifying criteria for diagnosing and in creating a common language for healthcare professionals and service users alike, thereby facilitating explanation and links to treatment. Even without this support from healthcare professionals and services users, as mentioned earlier, there are other powerful parties invested in keeping diagnosis central in healthcare.

The above narrative highlights the challenges and changes that have impacted service provision. To bring this up-to-date is of use to highlight the recent trend in mental health service provision that has resulted from them: the recovery approach to treatment in which the service user voice provides a link to the second part of this chapter.

### **Treatment and recovery**

Brown (1995:47) notes that 'in construction of illness comes construction of ways to treat it': treatment becomes a 'logical sequence' on from diagnosis. Treatment of mental illness is a multifaceted complex area, impacted by a variety of influences not least of all resources and focus of research. Treatment options have developed to include the concept of the 'recovery approach' which has recently gained momentum. The recovery approach was given impetus through the survivor movement in the 1980s, where people with mental illnesses demanded influence on services (although Roberts and Boardman, 2013, point out its roots lie with the philosophers and humanists that influenced the development of psychiatry). The introduction to the discussion of service user experiences shifted the rhetoric and balance in power in treatment regimes. Subsequently the spotlight was on the therapeutic relationship between healthcare professional and service user, promoting a more collaborative



approach to treatment (Osborn, 2017). However some in the service user movement question, with some cynicism, the concept of recovery. Turner-Crowson and Wallcraft (2002) argue the concept of recovery must be understood and developed with services users and consequently she begs the question of 'recovery from what, to what and for who?' This indicates the different perspectives of the service user movement and the medical profession: the former accepting and working with the condition, the latter focusing on cure.

There are numerous definitions of recovery: personal, clinical, as an approach and as a movement (Roberts & Boardman, 2013). Indeed Roe *et al.* (2004:37) believe recovery 'involves much more than recovering from the illness itself' and highlight the wider and influential social context. They believe the additional focus is needed on challenging stigma (discussed below) to address the resulting diminished opportunities, agency and hope that some experience. Defining a recovery approach in service delivery incorporates many different but overlapping ideas and the APA (2004) suggest ten recovery principles: self-direction; person-centred care; empowerment; holistic; nonlinear; strengths-based; peer support; respect; responsibility and hope. Similarly a position statement by consultant psychiatrists sets out the view that recovery is a process defined by hope (which is central), agency (choice of the service user) and opportunity (for social inclusion) (Boardman *et al.*, 2010).

Jacobson and Greenley (2001) clarify this further by developing a model that incorporates both the internal and external aspects of recovery, which they see as inextricably linked. They argue that for the process of recovery to occur key aspects must be in place; (internal) hope, healing, empowerment and connection, alongside (external) human rights, positive culture of healing and recovery orientated services. Therefore, as the recovery approach promotes, the concept of 'recovering' from a mental illness involves the combined effort of both the service user and services, as well as wider community. Echoing the social justice perspective of Braveman and Suarez-Balcazar (2009) where responsibility of health lies with the state, organisations and the individual. However, as Harrison *et al.* (2002) point out, adopting a collaborative approach is not without its complications. They highlight the dichotomy that arises with SUI within an evidenced based medical model of

healthcare: what the service user requests for their treatment, may not actually be what the evidence suggests will be beneficial to them. Attention therefore must be paid to the ethical and moral standpoints of the healthcare system and those that work within it, of 'do no harm'. Difficulty consequently arises in the empowerment of service users and the question of who holds the expertise.

This creates a complex picture that affects the implementation of the recovery approach. As mentioned, this includes not only the individual and the staff they are working with, but also the state. Taking a sociological approach to this Pilgrim *et al.* (2009), argue that social policy developers are in a prime position to promote an environment that supports recovery. They believe services can help facilitate the 'chances of respectful supportive relationships in the life worlds of people with mental health problems' (Pilgrim *et al.*, 2009:249). This would have an additional benefit for those experiencing mental illness through the building of social capital in the form of benign networks. Indeed, addressing the stigma surrounding mental illness would inevitably lead to further engagement in life opportunities, including employment which has been proven to support mental health (see Black, 2008). The narrative now turns to the stigma surrounding mental illness to highlight the wider societal influence on the service user.

### **The stigma of mental illness**

Further criticisms surrounding the defining of behaviour as mental illnesses concern the impact of being diagnosed; namely the accompanying stigma. Goffman (1963:15,25) described stigma as 'an undesired differentness to what we anticipated' where the individual experiences shame and has to be 'self-conscious and calculating about the impression he is making'. This self-consciousness links with disclosure and as Limandri (1989) points out stigmatised conditions are often accompanied with concealment. The anticipated response from others acts as a limitation to disclosure, as stigma 'diminishes self-esteem and robs people of social opportunities' (Corrigan, 2004:614). It is no surprise that many conceal their mental illness with research evidencing the negative consequences that disclosure can elicit. As Thornicroft *et al.* (2007) note in their research, when an individual has a condition that society stigmatises, prejudice, more so than stereotyping, not only results in negative

thinking, but can also extend to hostile behaviour (discrimination) towards those with mental illnesses. This raises the point that those with mental illnesses can also become the victims of crime, although they are often portrayed as the perpetrators. Indeed Weinstein (2012b:122) argues those with mental illnesses are 'doubly jeopardised', firstly through their mental illness and latterly through stigma in society.

The Time to Change *Stigma Shout* research showed stigma and discrimination curtailed people's lives. Two-thirds of those surveyed stated they had ceased everyday activities due to stigma or the fear of it (Mind *et al.*, 2008). The survey also showed an increase in discrimination among those with more severe mental illnesses, as compared with depression and anxiety. This finding is supported by the WHO global survey of psychiatrists and psychologists; the former identifying schizophrenia as the most stigmatising diagnosis and the latter clinicians identifying personality disorder (Robles *et al.*, 2014). The impact of stigma and resulting discrimination, affects many areas of service users' lives not least of all accessing services. Rickwood *et al.*, (2005) found fear of mental health stigma an inhibiting factor in help-seeking behaviour among young people. Not only did they not want their peers to know they were experiencing difficulties, they also had concern of professional confidentiality. The impact of inhibiting behaviour Sickel *et al.*, (2016) found, not only influences mental health outcomes, it can also have detrimental effects on physical health and therefore the lack of engagement with services, caused by the lack of disclosure, is of concern. This is reinforced by findings that indicate disclosure is accompanied by positive treatment experiences, especially for those with severe or 'milder problems' (Reavely *et al.*, 2017:275).

A 2009 survey showed 87% of mental health service users had experienced discrimination in England (Henderson *et al.*, 2012). The survey showed discrimination was reported in the work place as well as among the healthcare professionals service users regularly came into contact with. In recent years there has been a focus on healthcare professionals attitude towards those with mental illnesses, as well as that held by the public (for example see Cleary *et al.*, 2002). Schulze (2007) highlights the 'intricate relationship' that results in professionals' opportunity to both compound and alleviate stigma. Another side to this, she points

out, is the stigma and discrimination psychiatrists often receive, commonly precipitated by the media who she believes have much power over public perception. This is supported by Walsh (2009:135) who believes media misrepresentation of mental illnesses subsequently reaffirms stigma. However it is not only the external world of the service user that impacts on their behaviour, but an internal one also: service users' view of themselves.

### Labelling theory and mental illness

There is a body of literature that has built up over the decades exploring stigma and responses to it. One concept proposed within this corpus is labelling theory, which drew from the writings on the conception of the self by, among others, George Mead and Erving Goffman. In *Mind, self and society*, Mead (1934) explored the ability of humans to become an object of themselves, through the possession of the self, i.e. the self allows an individual to perceive and communicate with itself. This self for Mead was not static structure but rather a dynamic process based in context, which can judge, reflect and plan consequently influencing an individual's interactions with others. Although critical of his work, Blumer (1966:535) points out he made 'brilliant contributions' that stood apart from much of the thinking at the time that saw society as a structure or functioning organism; giving little agency to the individuals that formed it. Mead (1934), in his concept of symbolic interactionism, proposed that an individual's interaction was formed of both involuntarily responses to stimuli in the environment, as well as employing interpretation and description to guide these responses. Therefore behaviour is elicited through the context of an individual's social world and influenced by cultural. This theory highlights the influence of Western concepts of mental illness and diagnosis, which, through the use of DSM and ICD, some criticise as having undue influence across the world (see Timimi, 2014; Crowe, 2000).

Another influential thinker contributing to the development of the labelling theory was Erving Goffman. The premise of *The presentation of self in everyday life*, was that individuals are continually seeking information about each other to aid their interactions (Goffman, 1959). He proposed this information influenced the 'performance' an individual chooses to give when with others: certain behaviour

allowed a certain impression. An individual's performance involved adopting predicted roles that guide and shape behaviour, subsequently maintain consistency and understanding in interactions and between groups. Becker (1973) drew on the concept of the self and development of group identity in his research, which resulted in the book *Outsiders*. In studying marginalised groups he wrote on the deviant culture of musicians and drug users and proposed labelling their behaviour reinforced the view of them as deviant and consequently reinforced this behaviour. This further aided the development of the labelling theory for mental illness proposed by Scheff (2009).

Drawing on these earlier writings, Scheff is credited with introducing the labelling theory to mental illness in 1966. He suggested stereotypes held by society become internalised by the individual experiencing the mental illness. As with Becker's musicians, this becomes a self-fulfilling prophecy and results in prolonging the mental illness. To help evidence the labelling theory of mental illness, Scheff (1974) reviewed research in mental health and concluded 13 of the 18 studies (including work by Goffman and Rosenhan) supported his theory. Scheff's labelling theory of mental illness was further developed by Link (1987) through his *modified* labelling theory, which suggested a five-stage process centering on psychological integration of information (i.e. diagnosis) that result in negative feelings. This process occurs on two levels; in the individual themselves where the cultural concepts of mental illness are absorbed with the self being seen in a negative light, and the expectations (held by those labelled) of negative responses from others. He believed this process affects the self-esteem of the individual and the "imaginative rehearsal" that occurs when expecting negative interactions, which subsequently restricts their life choices (Link 1987:97, quote marks the authors own). More recently, this theory has been supported by Kroska and Harkness (2008). They argue that the negative views engendered by society assume personal significance, which triggers defensive responses resulting in a breakdown in social engagement. This highlights the impact of stigma on the lives of those with mental illnesses, whose quality of life may change as a result of the *perceived* negative attitudes of others (see Mind *et al.*, 2008).

There has however, been criticism of the labelling theory of mental illness and challenge to the premise that stigma associated with mental illness leads to low self-

image and a change in behaviour. Warner *et al.* (1989), in their study with individuals with psychosis, concluded that internal (or external) locus of control and acceptance (or not) of mental illness, were more influential than the labelling theory allowed. Others have rejected the theory considering it too simplistic, suggesting many other factors that influence the behaviour and responses of those with mental illnesses (see Lehman *et al.*, 1986 for example). This indicates the deeply complex, multi-layered responses of those with mental illnesses their diagnosis and to stigma. These complexities also extend to the experience of receiving a mental health diagnosis, an experience that has received some attention in research. Although limited, this research is important in developing an understanding of this experience and is introduced below.

### **The experience of receiving a mental health diagnosis**

Complex responses to diagnosis and stigma are intrinsically linked to individual experience; the second strand in the current research. Experience is simultaneously unique to the individual and integrated into the context in which it happens. Smith *et al.* (2009:29) express this as experience being 'in-relation-to', not only contained solely in the individual, rather it is 'immersed and embedded in a world of things and relationships'. Smith *et al.* (2009) go on to explain a 'hierarchy of experience' that relates to the consciousness of the individual. Without consciousness the experience is simply in flow, consciousness brings the experience in relation to something else (such as other people or life events) and consequently meaning is attributed. Experience is seen in context, reflected on and made sense of, through the use of these life events and the individuals prior understanding. It is this meaning and reflection, researchers attempt to capture in order to convey events as experienced by the individual (see Chapter 3 for further information on the use of Interpretative Phenomenological Analysis to facilitate this).

As a service user researcher Russo (2016:215) notes 'first-person accounts of people labelled mad have become an object of increasing interest for non-survivor scholars with backgrounds in psychology and psychiatry'. Although her main argument is the need to increase the input of those with lived experience in the development and conducting of research, she highlights a research trend. Notwithstanding this trend,

there is limited research on the experience of receiving a mental health diagnosis from service users' perspective (Rose & Thornicroft, 2010). Hayne (2003:728) points out 'little is reflected in health-care literature to substantiate diagnosis as a phenomenon of consequence at all'. She notes literature focuses on the impact of stigma, rather than on changes in self-perception brought about by diagnosis. The effect of this is much of the literature on mental health centres on the experience of living with and managing particular mental illnesses, rather than receiving a diagnosis itself. Research has however attended to the experience of receiving cancer diagnoses, therefore parallels with this and receiving other types of health diagnoses can be drawn. Subsequently findings from research on receiving a cancer diagnosis will accompany those of receiving a mental health diagnosis where similarities and differences are relevant, to aid providing a deeper depiction of receiving a health diagnosis.

Indeed Stegenga and Ward-Smith (2009) found adolescents receiving a cancer diagnosis experienced an initial state of shock and a sense of not feeling normal. Service users responded to this by gathering additional information, gaining support and beginning a process of acceptance, some also reported wanting to help others going through similar experiences. There are parallels with this in research on receiving a mental health diagnosis, however there are also major departures. A sense of relief felt rather than shock, has been reported as well as recognising the stigma automatically accompanying mental illnesses. A sense of 'relief and elation' on receiving a diagnosis of attention deficit hyperactivity disorder in adulthood was found by Young *et al.* (2008:496). However this positive response was by no means the entire picture that emerged from the research. Receiving the diagnosis in later life led participants to reframe previous experiences, with some regret, in light of this new information. Participants also sensed the stigma surrounding this diagnosis and felt others would see it as an excuse for their behaviour. This was also evidenced by Horn *et al.* (2007) who looked at the experience of receiving a borderline personality disorder. The specificity of this diagnosis was noted as influencing participant responses; they felt it signified 'not fitting' into the diagnostic categories and resulted in a rejection of them by services (Horn *et al.*, 2007:262).

Hayne (2003:725) also noted the 'duplicity in the force of diagnosis'. In her research on experiencing receiving psychiatric diagnoses, she found it could both make the individual feel unique and valued and at the same time delegitimise them, leading them to question their identity. She noted this indicated the authority that diagnoses hold by those receiving them, who see it as a fact. For participants the benefit of receiving a diagnosis was the clarity it brought to their understanding and affirmation of their experiences. The double-edge to diagnosis was noted by Hayne and Yonge (1997:319) who found some participants felt diagnosis was 'condemnatory' and the accompanying label led them to experience a 'diagnostic identity' and to lose their sense of themselves. Young *et al.* (2008:499), identified a six-stage process of acceptance that participants expressed on receiving a mental health diagnosis: relief and elation; confusion and emotional turmoil; anger; sadness and grief; anxiety; accommodation and acceptance. The experience of mixed emotions associated with the grieving process is echoed in the experiences of receiving a cancer diagnoses (see Wanat *et al.*, 2016).

As indicated, findings of research concentrating specifically on the experience of receiving a mental health diagnosis, summarise it as simultaneously helpful and unhelpful. In service user led research conducted by Pitt *et al.* (2009), on the experience of receiving a diagnosis of psychosis, they conclude that diagnosis is contradictory in nature: empowering through access to services and disempowering as a cause of social exclusion. They also suggest a power differential that accompanies the label that is weighted against the service user. Pitt *et al.* (2009:723), argue language used in clinical settings often reinforces this without conscious intention and diagnosis is held in 'reverence' (as found by Hayne, 2003). In research on delivering a cancer diagnosis, preparing the patient, delivering an honest and clear diagnosis, discussion of planning and treatment, consideration of the psychological well-being and exploring the feelings, were aspects appreciated by the individual receiving the diagnosis (Schofield *et al.*, 2003). Indeed guidelines are available for practitioners to help communicate diagnosis of cancer to a patient (National Breast Cancer Centre & National Cancer Control Initiative, 2003). This area of guidance and support for clinicians is not given equal support in mental health and as Fallowfield and Jenkins (2004:317) point out: if diagnoses are communicated poorly it may result



in 'confusion, distress and resentment', when done well however, it can facilitate 'understanding, acceptance and adjustment'.

This above picture indicates the complex nature of receiving a mental health diagnosis. Indeed Hayne and Yonge (1997:314) state the 'unique and particular' experiences of those with mental illness, are not open to 'empirical generalisations or law-like statements that can give such an understanding'. Therefore, they argue the need for in-depth qualitative research that allows for understanding of the lived experience of having a mental illness, of which receiving a diagnosis is part of for many. Kirkpatrick (2008) adds to this picture, reinforcing the findings of Fallowfield and Jenkins (2004), by highlighting the importance of the role played by those delivering services as well as those using them. Joint decision-making in the therapeutic relationship paves the way to recovery, consequently she highlights the importance of the stories of service users in improving healthcare professionals' ability to understand.

## **Summary**

The overview of the literature presented, helps position the current research. The context to receiving a mental health diagnosis incorporates the history of the development of mental health services, in which diagnosis is based. Care of those considered mentally ill in asylums, provided medical officers the opportunity to observe behaviour and begin to categorise symptoms. This led to the development of a nosology in mental illness, which formed the roots of the diagnostic manuals used today. However the provision of healthcare that stemmed from a medical model of illness, did not avoid criticism and social movements offered an alternative view to the concept of mental illness. Consequently service provision changed, the voice of the service user was heard and their experiences began to be the focus of researchers. Although the current provision of mental health services has changed dramatically, with introduction of the biopsychosocial and recovery approaches, the medical model remains dominant (evidenced by the use of diagnosis to access services). Subsequently diagnosis remains central to the experience of individuals attempting to understand and manage distressing symptoms, as are the staff providing the services and interventions. The current research design has therefore incorporated both the

experience of the service user and the perspective of staff, to create an opportunity for deeper understanding on the experience of receiving a mental health diagnosis. Central to the current research is the experience of the service user and to aid their voice a Research Advisory Panel (RAP) has been incorporated. Service User Involvement (SUI) also has a rich history which combines with some of the narrative offered above and in Chapter 1. What follows is a deeper exploration of SUI.

## **Service User Involvement (SUI)**

*...research being carried out **'with'** or **'by'** members of the public rather than **'to'**, **'about'** or **'for'** them. (INVOLVE, 2018a, quotation marks and bold used by author).*

The second part of this literature review is focused on the Service User Involvement (SUI) and the service user movement. The development of SUI was drawn out of a movement that links with disability rights and social justice mentioned above. Within this history lies a diverse language and the varied attempts to conceptualise SUI indicate its multifaceted nature. These concepts and approaches are explored below and descriptions are offered to provide clarity. There is also discussion within the literature of the difficulties in applying SUI in the healthcare environment and subsequent calls for the system to change (a sentiment that offers a link to criticism of the medical model of service provision explored earlier). This chapter concludes by offering the literature surrounding the current use of SUI in research and development, and introduces the argument that its implementation is considered 'good practice'. This both indicates a shift to addresses the criticisms made by those championing SUI and also provides a rationale for its incorporation in the current research.

### **The development of SUI from a social movement**

SUI is placed within the development of a social movement. The antipsychiatry movement (see above) laid the groundwork for the sporadic and organic development of a wider movement, which has been supported over the decades by legislation and policy (provided in Chapter 1). The roots of the service user movement are found in the challenges to a status quo that held limited expectation of service users' recovery or ability, thus supporting their apathy. Although there was

little scope for a service user-led, organised approach to challenging the system in place, the establishment of the welfare system in the UK increased access to healthcare for all. In doing so, it highlighted the civil rights and issues of equality for disadvantaged groups, including those with mental illnesses (Campbell, 1996).

This challenged societal beliefs about disempowered groups. However it did little to advance a social movement that challenged inequalities and stigma surrounding those with mental illnesses. Barnes and Bowl (2000) believe this lack of action was in part due to the difficulty in creating a 'unitary identity' to capture the diversity in experiences of those with mental illnesses. Subsequently the absence of a cohesive identity and 'one voice', limited power to challenge discrepancies in healthcare provision (or inhumane practices within institutions), and voices of service users remained unheard. It was not until over a decade later that this slowly began to change. Although the *1959 Mental Health Act* initiated compulsory orders for treatment and detention of those with mental illnesses, the 1960s also saw an increase in concern for the civil rights and freedom of the individual (Ministry of Heath, 1959). The changing zeitgeist in Europe and the United States prompted a challenge by healthcare staff, to the provision of healthcare for those with mental illnesses and drew attention to the oppressive regimes. Indeed Barnes and Bowl (2000) note those working within the system argued that professionals defining mental illnesses (rather than those with lived experience of it), was indicative of this oppression. This suggests the disquiet of many healthcare professionals of the power imbalance inherent services based on the medical model.

It was not until the 1970s and 1980s that service users began to establish themselves into numerous, but disparate, organisations (see Barnes & Bowl, 2000, for an overview of these). This 'movement' grew spontaneously across the UK, with little cohesion between organisations. On this point Campbell (1996) argues it important to acknowledge the seeds of the movement begun well before the documented 1985 international conference hosted by Mind. This conference saw service users co-present with professionals and staff; a move considered groundbreaking at the time. It was this public platform that prompted a surge in the development of many independent organisations, promoting the service user voice. However these organisations remained independent of each other, which Minogue *et al.* (2009),

argue was due to a lack of guidance and inconsistent language that consequently led to misunderstanding. They also note that creation of a movement was hindered by societal structures that were 'underpinned by issues of power, culture and politicisation' (Minogue *et al.*, 2009:215). Therefore the structures in place not only did not support a service user movement, they actively discouraged it; an argument that remains a criticism for many in the service user movement.

Given this environment and perceived restrictions, the service user movement was gradual in its progression. Even with support from professionals and academics, Campbell (1996:221) believes the legacy of the antipsychiatry movement in the history SUI, was more 'emotional and spiritual rather than pragmatic and practical.' This point is fundamental to the development of the movement and its, at times, latent motivation, i.e. the empowerment of the service user. Adopting this approach changed the power dynamic in services and as Kemp (2012) notes, began to introduce a different approach to care and treatment. Integration of the values of the service user movement, such as the social model of disability, empowerment, social justice and the recovery approach, influenced the provision of care in the community introduced in 1990 (see part one of this chapter). This resulted in a dramatic shift in not only the presence of service users in society, but also in providing a platform for their voice which was supported by legislation (see Chapter 1).

### **Language and terminology in SUI**

As well as the developments in policy, Beresford (2002b) points out that SUI was accompanied by the emergence of a new language, terminology and rhetoric. The language adopted was far from consistent and therefore became unclear for those inside and outside of SUI. Some suggest these inconsistencies further diminished the opportunity for a unified voice in the service user movement (Harrison *et al.*, 2002). If language posed a challenge for those who are designing and implementing SUI, it followed that it would also confuse the public and service users themselves. This remains a criticism and some suggest may result in a misunderstanding on the meaning of involvement, subsequently leading to uninformed decision-making on the part of the service user (Campbell, 2009). To confuse matters further, the language used changes as service users' roles change: by becoming involved, service users

become service *providers* through giving their time and some become *user-researchers*. These labels are suggestive of the different positions service users can adopt and the potential power they have to challenge the system from within.

In their literature review of SUI in mental health, Minogue *et al.*, (2009) found different groups adopting different terminology. Those providing guidance and producing policy preferred 'public and patient involvement or engagement', whereas within service provision and delivery 'service user and carer involvement' was adopted (Minogue *et al.*, 2009:212). The language used in different settings often indicate the approach, position and agenda of the individual or group. As Harrison *et al.* (2002), point out through the use of the terms 'citizen' (used in policy) and 'patient' (used in clinical settings). One may be a citizen *and* a patient, however this does not equate to them having the same interests and citizens may not have questions about their health at the forefront. In addition to this confusion Campbell (2009) notes language is often modified with changing experience and environment: once in the healthcare system, service users often adopt the language of those delivering services to aid communication. This morphing of language extends to service users working in research or policy, where diverse interpretations and understandings of language have the propensity to lead to diverse implementation and action. These facts lead to a complicated and often confused picture that makes it difficult to capture a representation of SUI in healthcare.

As well as the settings and levels of SUI that impact on language, there is also the incorporation of the diverse range of terms for those who may become involved. Indeed Wallcraft and Nettle (2009) draw attention to the lack of consistency in language used to describe mental illness by, and between, service users and providers. This adds another layer of complexity and thereby indicates the limited possibility for agreement and adoption of universal terminology within SUI in mental health. Stickley (2006) goes further arguing that those with mental illnesses cannot be seen as homogenous and trying to represent them in a systematically integrated way, is flawed. Notwithstanding this, Hubbard *et al.* (2004) call for clarity in defining terms with the goal of aiding the implementation of SUI. They argue the fact there are numerous levels and various ways in which service users can be involved in their care, as well as the diversity of services to become involved in, evidences a need for

consistency. This is reinforced by Damodaran (1996) who suggests the provision of clear information from the start and throughout any process, as vital in preventing confusion and the disempowerment of service users. This is an aspect advocated by many promoting SUI and therefore to aid clarity, the terms commonly found in SUI literature are provided in Table 1, accompanied by brief explanations.

### **Approaches to SUI**

The diverse language offered in SUI is accompanied by many different concepts that attempt to explain it. This begins by attending to the literature that influenced the focus of service user movement, and subsequent involvement. Harrison *et al.* (2002) argue this corpus falls into three different and interrelated areas and begins with the drive to build societal structures on the market economy of supply and demand. This approach brought consumerism to the forefront and with this emphasised the service users to have access to information and choice in treatment options. Secondly the influence of literature concerning democracy and citizenship, which encompassed the notion of the 'British constitution' working alongside service users and the public for development of the communities in which they lived. Finally, the third group of literature concentrated on the development of proactive social and political pressure groups, found to span both political and sociological arenas.

These three bodies of literature, and the ideological thinking within them, naturally elevated the voice of the service user. Subsequently SUI became a way of addressing the lack of influence service users had previously had. Literature on the development of SUI often defines its conceptual basis as stemming from two ideologies: consumerism and democratisation (Rowe & Shepard, 2002). The consumerist/managerialist approach is based on the foundations of market economy drivers, improving and ensuring service quality and efficiency through feedback via consumer/ customer consultation. The democratic approach however, comes from the backdrop of service-user, disability and civil-rights movements and is motivated by emancipation, autonomy, independence and inclusion of marginalised groups (Beresford, 2003). These two offer approaches from very different standpoints, which influence processes (often without transparency in motivation).

<b>Term</b>	<b>Description</b>	<b>Author</b>
<i>Service user</i>	People to be involved in a project are using, or have used, services.	Faulkner (2004:2)
<i>Citizen</i>	A legally recognised subject or national of a state or commonwealth.	Concise Oxford English Dictionary (2011:261)
<i>Consumer</i>	A person who buys goods and services for personal use.	Concise Oxford English Dictionary (2011:307)
<i>Survivor</i>	Those who have lived experience but who have not accessed services for support.	Faulkner (2004:2)
<i>Participation</i>	A method of decision-making in which those who are directly affected by the action make the choice.	Hooper & Lincoln (2009:77)
<i>Lay people</i>	People who are neither health care professionals nor health services researchers, but who may have specialised knowledge related to health.	Entwistle <i>et al.</i> (1998:463)
<i>Service user involvement</i>	Participating in the decision-making process.	Hickey & Kipping (1998:84)
<i>Service user-researchers</i>	People who have both research skills and first-hand experience of mental health services and treatments.	King's College London (2015a)
<i>Partnership working</i>	Researchers actively work with users as collaborative partners, equitably sharing all final decision-making and control.	Trivedi & Wykes (2002:468)
<i>Participatory Action Research</i>	A participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes.	Reason & Bradbury (2002:1)
<i>User-controlled/led</i>	Research that is actively controlled, directed and managed by service users and their service user organisations.	INVOLVE (2015b)
<i>Co-production</i>	Developing more equal partners between people who use services, carers and professionals.	Social Care Institute for Excellence (2015)

Table 1: Definitions of terms found in SUI literature.

The democratic approach has at its heart improving the experience of the service user, whereas efficiency and financial savings drive the consumerist approach. Although these two concepts approach service development from different ideologies, they converge in their combined goal of improving the quality of services. However Beresford (2003) highlights the convergences and divergences of the consumerist (provider-led) and democratic (user-led) approach to SUI. Although

connections can be made between the two, he points out that they are not necessarily happy companions and deviate in their focus on power distribution and redistribution (social justice). He strongly supports the view that the essential inspiration of service user movement (and subsequently SUI) is the improvement of the quality of the lives of people with conditions and impairments, both collectively and individually (Beresford, 2002b). Hickey and Kipping (1998) suggest that the rationale for incorporating SUI defines the choice of approach: responsive (consumerist) versus rights based (democratic). Therefore being accountable and bringing transparency to the motivation for incorporating SUI allows awareness for all involved, and subsequently supports informed consent. Service users who come without awareness of the agendas others may hold, reinforce the ethical need for transparency.

There has been criticism of the consumerist approach as it lends itself to maintaining the current structure in service provision. Some believe this reinforces ultimate responsibility with management and providers who mediate decisions and thereby diminishing service user influence (Stickley, 2006; Rowe & Shepard, 2002). Beresford (2003) also draws attention to the limited value this approach places on the democratic agenda. Consequently he argues the emancipatory philosophy and principles that formed the development of the service user movement, are often dismissed. However Hickey and Kipping (1998) note that organisations adopting the consumerist approach, not only responded to pressure from external sources but also developed their own internal checks (for example through quality audits). Audits are undertaken with the clear purpose of helping increase responsiveness and through transparency of results, strengthen the position of the service within the market economy (Hickey & Kipping, 1998). Although not motivated by a democratic, emancipatory position, this approach has changed the culture within services and consequently aided service users' goal for transparency and quality service provision. The motivation for SUI, driven by the agendas originating in the consumerist or democratic approach, has influenced the conceptualisation of SUI and the subsequent theoretical models produced.



## Conceptualising SUI

Over the decades, due to the service user movement and supporting policy, SUI has become a mainstream concept. As well as the development of new language and terminology, there has been focus on conceptualising SUI. Due to the organic and sporadic development of the movement (and SUI), as well as the differences in implementation, creating a theoretical framework has proved challenging (Minogue *et al.*, 2009). Through observing the power imbalance in America at the time, Arnstein in 1969 suggested a model to capture SUI. This influential interpretation was named the *Ladder of Participation* and became a focal point of discussion and critique. The model was developed at a time of division in society: those with and the marginalised without. Therefore one of the main focuses of the model was the argument that SUI, generally, served only to legitimise the status quo due to its ‘tokenistic’ nature. The eight rungs on the ladder move from ‘manipulation’ through ‘consultation’ to ‘citizen control’ with an adjoining narrative of increasing power to the service users as the ladder climbs (see Figure 1).

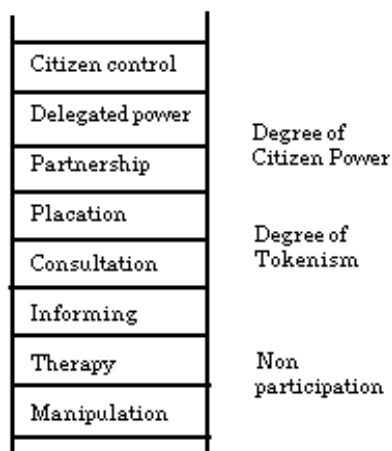


Figure 1: Arnstein’s Ladder of Participation (1969)

For nearly 50 years the model has been accepted, referenced, criticised and developed by a number of authors. Hickey and Kipping (1998) offer a different model to capture SUI and rather than partitioning sections, as with the ladder of participation, they suggest a continuum. Also based on power distribution, it is influenced by the theoretical standpoint organisations and individuals take (consumerist or democratic). The continuum moves from a position of limited power

with 'information/ explanation' and 'consultation' at one end, to an increased power and choice with 'partnership' and 'user control' at the other. This is model echoed by Minogue (2009) in her own continuum, however she highlights that although consultation may be an important stage in research, there remains a risk of tokenism. Here she indicates incorporating SUI has the propensity to be used to tick a box, rather than have any great influence on outcomes (a fact explored later).

Service user and academic researcher Syrett (2011) also views SUI on a continuum. He suggests it encompasses three levels: consultation; collaboration and service user-controlled research. Using his own positive experience, he gives examples and highlights that each level can be beneficial. In concluding he notes an important 'by-product' of SUI is increasing service users' capability in moving towards their own recovery. This is an aspect that another service user researcher Campbell (1996:220) has advocated, suggesting that 'self-help principles lie close to the heart of more user/survivor enterprises.' This indicates the emancipatory approach that provides the link with the recovery model, promoting involvement of service users in decisions about their care and future.

Tritter and McCallum (2006) find value in Arnstein's model in clearly showing inequalities between those holding the power and those who do not. However they note the ladder is linear, has 'missing rungs' and is so hierarchical in nature that it fails to capture the nuances found in current practice of SUI. Although they recognise its influence in forming the basis of wide implementation of SUI, they also suggest (like Beresford, 2002b) it serves to maintain rather than challenge imbalances in power distribution. They offer a different way to capture the nuances and complexities of involvement and suggest a mosaic formation, rather than linear. Complexity and dynamism are intrinsic to this analogy, which lends itself to incorporating different theoretical bases and approaches. Moving away from Arnstein's model and focus on the 'conceptualisation of activism', the mosaic allows both service users and non-services users to enter the debate and subsequently incorporate a variety of ideas (Tritter & McCallum, 2006:157).

Finally to capture further the complexity of SUI, Russo and Stastny (2012) draw attention to the roles adopted when engaging in it. This is from the perspective of the

service user and based on Russo's own experience as an 'expert by experience'. The proposed concept is accompanied by a critical eye as she suggests four roles are adopted in SUI, each with accompanying risks. *The first role* is an invitation to collaborate in which the service user may feel they are not an equal partner (she advocates the importance at this stage to ensure the service user has a role). *The ideal role* concerns instigating change in a collaborative working relationship, however here she warns of the scientific nature of much research can cause barriers to hearing the agenda of the services user. Thirdly *The common role* promotes research and interviews using the peer-to-peer model, where researchers with lived experiences are paired up with participants with the same diagnosis. She also notes here lies a risk of researcher with lived experience not being 'let in' or used as an unpaid worker. *The final role* is of the individual's 'expert by experience' forming their identity as a researcher, which she argues has inherent dangers preventing the formation of other identities.

Both the consumerist and democratic approach share the goal of service improvement, however the former is focused on *outcome* and the latter on *process*. These approaches have influenced some of the models developed to capture SUI and highlight its multifaceted nature: numerous settings, approaches, motivations and experiences. As indicated above there is criticism of the motivation for incorporating SUI and the systems and structures in society that inhibit the widespread adoption of SUI. Indeed Weinstein (2012a) argues there is an inherent social structure that disempowers and marginalises those with mental illnesses in society: instead of concerning ourselves with the person, the mental illness becomes the focus. Others criticise the healthcare system for also adopting, and thereby reinforcing, this view. These arguments are explored in the following narrative in relation to the application of SUI and provide a link with challenges to the medical model presented earlier in this chapter.

### **Structures in healthcare**

It is important to draw attention to the healthcare system in which SUI exists, due to its influence. Some argue that although SUI is supported by legislation, the healthcare system itself presents barriers to service users' influence in the development and

delivery of services. Those advocating this perspective believe the medical model of service provision in healthcare holds an implicit power dynamic, which subsequently creates difficulties for embracing the emancipatory philosophy of SUI. Indeed Stickley (2006:570) suggests 'psychiatry is an archetypal arena in terms of power and control' and believes service users are often situated at the bottom of this hierarchy. Supporting this view, Beresford and Wallcraft (1997:79) see the psychiatric system as an 'unpromising ground for reform', without flexibility to change. Supporting this view Johnstone (2009:37), a clinical psychologist with 25 years of clinical experience, notes 'the more things change, the more they remain the same'.

Even given the guidance and governance enforcement, some argue, intention does not automatically equate to action. McKinley and Yiannoullou (2012) point out systems in the public health sector do not easily lend themselves to encouraging SUI. In the past within healthcare provision, service users were perceived as unable, physically and cognitively, to make a meaningful contribution to their own care. Due to the established patriarchal medical model, they argue a shift that supports the needs of the individual rather than the organisation (as has historically been the case) is vital, and advocate more creative thinking to enable viable SUI within the current restrictive environment. This suggestion links with the current promotion of the recovery approach to service provision, embracing joint responsibility for health: the state, the organisation and the individual.

However, Russo and Stastny (2012) believe the system limits its own ability to allow for any suggested change. They suggest a latent denial of the inequality in the system results in pretence that it doesn't exist, therefore meaningful change would require redesigning the entire system to incorporate service users as 'change agents' throughout, to promote true collaboration. Stickley (2006) suggests standing back and viewing the system objectively, as a start to challenging the accepted organisation of traditional services. This would allow full examination of the fundamental structures and would, as Russo and Stastny (2012) note, create space for the development of new systems for real and meaningful partnerships in health and social care: from participatory to emancipatory involvement. However Kemp (2012:17) continues to question the impact that service users have within the given healthcare structure due to its 'central control and dispersal of power.' Campbell

(2001) takes this argument to the wider society and argues people with a diagnosis of mental illnesses start in a disadvantaged position. This is due to 'an accumulation of messages, attitudes and disempowering practices that have emanated from the health and social care professionals over a long period' (Campbell, 2001:100).

The power dynamic in service provision and research is an area that is prevalent in the literature surrounding the service user movement and SUI. Faulkner and Thomas (2002:2) argue SUI cannot take place 'without a consideration of the power differentials involved' due to fundamental differences in status. The traditional structures of healthcare providers, workers and users have often been considered as reinforcing this power imbalance. Indeed Crossley (1999) notes healthcare workers themselves have little agency to change the system in which they work although they are the ones holding a position of power in relation to the service user.

Notwithstanding this, authors such as Farr (2012), Stickley (2006) and Faulkner and Thomas (2002) urge psychiatrists and healthcare professionals to reflect on the beliefs and values underpinning their daily decision-making and clinical reasoning. The recognition of care for the service user as central to clinical practice would aid working in true partnership and lead to new systems integrating user-led initiatives in design and development. This, he argues, is the only way to facilitate services that do not discriminate or disempower. However Hubbard *et al.* (2004) note that since the early 1990s the power imbalance in healthcare has seen little change and therefore, it follows, there is little influence of service users in the development and planning of services. Writing as a person with lived experience of mental illness, Campbell (2009:115) highlights the scientific basis of the medical model as 'a social construct: partial, colluded and inscribed with power, bias and stereotype' that reinforces this. Although she argues that the past 30 years have progressively seen change to balance this dynamic, the simple fact of working within a structure that focuses on disease rather than 'recovery vision' can mean that the voice of the service user remains unheard.

Highlighting a dichotomy in healthcare practices, Faulkner and Thomas (2002) note the validity given to the voice of the service user when relating symptoms for diagnosis. It is widely accepted that the account given by the service user is of value to healthcare professionals to aid diagnosis, which is central to the healthcare system.

Here lies incongruity; service users' validity diminishes immediately on entering the medical system and receiving diagnoses. Bentall (2009:19) takes a historical view of this and notes the voice of the service user commenting on their care and treatment, has traditionally been dismissed by psychiatrists due to the 'diseased brain' from which it comes. Indeed Rose (2013:314) points out, the involvement of 'lay' people in more general health research, will not experience the same barriers as those considered 'inherently irrational' due to their mental illnesses. Stickley (2006:571) also recognises this point and queries the effectiveness of SUI, he questions how those considered 'mad' and 'therefore irrational', can truly work in partnership within existing healthcare structures. This is further reinforced, not only by the attitude of those working within healthcare services but also its culture, represented in the systems and processes as well as the language used.

As well as the differing approaches of service users and providers, the language used by the healthcare profession may create a barrier. Healthcare professionals choice of language and terms, may be inaccessible to those not similarly educated. In evidence of this Stickley (2006) points out that illness and wellness concepts are created and bestowed by those in power rather than developed by service users, subsequently maintaining inequity. A widespread lack of remuneration for service users' time, also reinforces this power imbalance and suggests a devalued view of SUI (see Stickley, 2006; Faulkner & Thomas, 2002; Trivedi & Wykes, 2002). The benefits of payment to service users specifically for their involvement, is two-fold according to Syrett (2011); it validates the sharing of their experiences and increases the value placed on the information gathered. However often funding, resources and budgets do not take service user payment into account, leaving a lack of ability to provide for this even if the intention is present. Oliver (2002) widens this point by highlighting SUI is positioned within a political realm (as well as at the individual or system and societal level) and therefore demands a much broader approach to address inequalities. This point emphasises the many different levels of influence over the widespread adoption of SUI in healthcare and research. The complexities that lie within these levels provide evidence for the discrepancy between the promotion of SUI and its practical implementation.

These levels of influence lead some to question the validity of decision-making, even when SUI is an integral part. Involvement of the third sector as a key stakeholder in decisions made by government is something that Martin (2012) challenges. Developing a close relationship with the governing body can be seen as a strategic move in influencing the direction of travel, however he fosters caution asking whether they can be truly critical and autonomous. Beresford and Wallcraft (1997:71) reinforce this view stating that organisations often use ‘conventional fudges’ and in fact little changes intellectually or politically when incorporating SUI. There are others however who disagree with this view believing that some SUI, in relation specifically to Action and Participatory Research, has been developed with the overt goal of empowering service users (Boote *et al.*, 2002). Indeed Davidson *et al.* (2009:89), state ‘service-user guided research has changed as an explicit goal in and of itself’ thus moving towards an emancipatory approach to SUI advocated by others such as Beresford (2003). Notwithstanding these disparities, SUI is supported by policy and advocated as ‘good practice’. Therefore in concluding this chapter, the following explores SUI in health research, before bringing attention to the area of mental health and providing examples of SUI in this area. Advocating SUI as good practice, provides the rationale for the incorporation of the RAP in the current research (see Chapter 3 for further detail on the implementation of this).

### **The application of SUI in health research**

There are a number of different areas that SUI, in the most generic sense, can be employed. Minogue *et al.* (2009) suggest the research arena has two agendas into which it can be incorporated; the actual research level and the strategic development level (not necessarily separate and distinct areas). However when considering research and development, Wallcraft and Nettle (2009), warn of barriers to SUI within organisational systems due to a hierarchical division and the split between ‘pure, lab-based’ and ‘applied, social’ research; the former not being so open to SUI as the latter. Beresford (2009b) warns these positivistic ideologies may result in service user views becoming an ‘add-on’. There may also be a lack of experience in being challenged at management level as well as creating an opportunity for service users to gain status and influence, which may lead some to resist (Stickley, 2006). Wallcraft and Nettle (2009) reinforce this point by highlighting the familiar relationship that

has developed between government and commerce: a structure that does nothing to diminish the power imbalance or promote a democratic approach to research.

Within the field of research, knowledge and skills have traditionally remained with researchers. Goodare and Lockwood (1999) in their editorial *Involving patients in clinical research improves the quality of research*, indicates a shift in the traditional thinking of service users as 'subjects' or 'objects'. However further progress is needed to apply SUI to the research environment and they argue, specific knowledge and skills have to be shared with service users. Sharing these skills allows those with subjective experience and 'expert' knowledge to be placed in the unique position of becoming both service users *and* researchers. Beresford (2002b) points out this position is distinct from generic involvement, as it often requires training and support to be considered a colleague in the truest sense of the word. However he argues, there remain philosophical and ideological disparities in service user researchers' involvement that need to be considered. These stem from a service-led wish to discover new areas for academic attention, as opposed to the service user-led agenda of developing their own knowledge and dialogue to affect change. To break down these barriers to wide-scale reform, education of both professionals and service users is advocated by Tritter and McCallum (2006).

However, many argue for a different attention and approach to SUI to elevate it to its true *raison d'être*. Hubbard *et al.* (2004:55) argue little is likely to change where the focus is placed on training alone; there needs to be a deeper understanding of the 'epistemological significance of patient perspectives and experiences.' Faulkner (2009), Minogue (2009) and Tritter and McCallum (2006), believe the focus should move away from the outcome and be on the *process* of involvement. Here resides the space for empowerment and potential for subsequent cultural and organisational change. Questioning this context brings attention to the assumptions made by 'paternalistic' healthcare professionals and researchers on areas for enquiry or fields for further development (Boote *et al.*, 2002). This approach is advocated by Park (2002) who suggests a focus on the concepts of *how* we acquire knowledge rather than solely focus on the outcome. Indeed, Thornicroft *et al.* (2002) found that the top priority for mental health service users was not so much the research itself, but the want for their voice to be heard at all stages of the research process. This echoes the



democratic (rather than consumerist) approach to SUI adopted by the service user movement. Lindow (2001) suggests these two approaches can be aligned through partnership working where the 'rights-based' agenda of the service user movement is recognised and incorporated. Working from this platform initiates changes in the existing power inequalities, where service users collaboratively set agendas and conduct research. She advocates this as the correct way to measure mental health service interventions and outcomes.

To help incorporate all views, Hickey and Kipping (1998) urge those in research and development to take into account the various influences that can constrain the ambition to take apply SUI in practice. They split these influences into four groups: issues the service user may have; organisational culture; professional culture and trends in wider society. These philosophies and value systems can be extremely divergent when considering the scope of potential involvement from private, public and third sector organisations. Boote *et al.* (2002) support the need for consideration and reflections of the ideologies and paradigms influencing the choices made when involving service users. These influences that impact on SUI design, its motivation and success, they argue has too long been ignored. To facilitate change, Wallcraft and Michaelson (2001) promote 'self-advocacy discourse' to challenge the historical assumptions present in the medical model of mental health. They point out that assumptions remain in explanations and solutions offered favour biomedical explanations, as opposed to social ones. Giving voice to service users in research would expose the unique sense of what it means to have a mental illness, subsequently allowing more appropriate understanding and education in this area. Indeed Tritter and McCallum (2006) suggest sharing these personal experiences adds another important layer to the dynamic: acting as a catalyst by simultaneously breaking down barriers and building up understanding as both sides share their complementary knowledge.

### **A shift in the scientific research approach**

The 'gold standard' of randomised control trials (RCTs) within research in the health service has long influenced the design and delivery of services. However there are numerous dissenting voices in employing these methods when attempting to capture

human experience (see Wallcraft & Nettle, 2009). Faulkner and Thomas (2002) argue RCTs are given high status within the methodological research realm but argue they are unable to capture the complexities of human existence. This view is supported by Campbell (2009) who notes that the theoretical framework of this domain can lead researchers to attempt to separate the experience from the person in order to rigorously examine it. She maintains that the approach of 'scientific inquiry' reinforces the biomedical model and the perspective that people are passive objects to observe and make sense of. This is in opposition to the approach adopted by SUI and consequently diminishes the validity and value of the experience of the service user.

For Beresford (2013:141) 'what distinguishes user involvement in research from traditional approaches is the emphasis it places on experiential knowledge'. The perspective service users bring to research has a depth that is grounded in lived experience. Traditional approaches are questioned in the rapidly changing world of science where the use of qualitative methods in research are becoming an accepted approach. As Lindow, (2001:141) puts it 'the scientific method developed to study stones and atoms is too simplistic for a holistic view of individual humans.' Although adopting qualitative research methods and theoretical standpoints to influence the field of mental health, Beresford (2003) warns of discounting quantitative methods in complementing research and building the knowledge base of SUI. As Rose (2013) notes, the validity and use of quantitative enquiry is linked to how grounded the data is in service user experience. Therefore it is the relevance to the service user that is of most importance, rather than the approach employed in the research.

Oliver (2002) recognises the difficult position researchers find themselves in, given the restrictions placed on them by the rules of the system and funding constraints. This view is supported by others who note the preference of funding agendas where research is often secured by larger organisations with the resources and skills to apply, which smaller user-led organisations lack (Beresford & Wallcraft, 1997). This then drives the research agenda which becomes dominated by these larger and more established systems, which in turn reinforces the status quo. On this point Minogue (2009) warns of SUI being incorporated to legitimise research and the decisions that follow. Not only does the power remain with those who drive the agenda, there is

also a risk of fatigue in service users who recognise their limited influence (even when involved). Indeed Campbell, as early as 1996, noted that groups had already begun to turn down invitations for SUI due to this. The doubt in its effectiveness is supported more recently by Rose *et al.* (2010) who, in user-led research with ‘activists and non-activists’, found although both groups agreed on the importance of SUI, they also questioned its ability to effect and impact service development. To address this there needs to be a shift in the design focus that allows attention on questions critical to service users’ (Faulkner & Thomas, 2002). Concentrating on ‘symptom relief’ may miss the individual story and focus on areas assumed to be relevant to service users, but which are in fact considered irrelevant by them. This reinforces the argument for promotion of user-led and co-produced research in facilitating a focus on areas truly meaningful to those with lived experience.

Although symptom relief is likely to be an important need for the service user, it may be given undue attention to the detriment of other issues. In an attempt to synthesise these two Boote *et al.* (2002) suggest recognising the separation between the condition itself and how it is experienced. This, they believe, provides a route to further understanding the condition via the voice of those living with it, thereby validating the experience of the service user and further facilitating their influence. Indeed Oliver (2002) suggests adopting this approach would create a very different world and involve the development of a new epistemology and context for research promoting full SUI. He suggests challenging the methodological tradition by shifting the focus in research from *investigating* the world to *producing* it: ‘we engage in the world, not distance ourselves from it’ (Oliver, 2002:14). This view ties in with philosophy of social practice, the goal of which is engaging people locally to create real change in their communities (such as in Participatory Action Research) as opposed to the research being the main focus (see Park, 2002).

The above focused on the barriers to the application of SUI in healthcare. Various strong advocates for the emancipation of service users, such as Beresford (2002b), have suggested the current medical model of healthcare provision in the UK, sustains their disempowerment. This power imbalance is reinforced in the research structure which restricts co-production and user-led initiatives through lack of opportunities

for funding and dissemination. However there remains a body of evidence that suggests, despite these challenges, SUI is developing in mental health.

### **SUI in mental health**

There is evidence SUI and user-led research is taking place. Organisations such as the Service User Research Enterprise (SURE) established in 2001 at King's College London, maintain SUI as an integral part of the process in mental health research. SURE provide training and opportunities for service users to learn research skills and boast the largest unit employing people with 'first-hand' experience in a University across the world (King's College London, 2015b). Rose (2013:314) a service user researcher within SURE, argues SUI should not be suggested as a replacement for traditional research in mental health, rather it should be considered as 'a critical part of the jigsaw'. Other organisations such as INVOLVE (2018b) of the NHS National Institute for Health Research (2013), are driven by a similar philosophy and provide opportunities for SUI in research.

There are some such as Syrett (2011) who originate from an academic background and on experiencing mental illnesses, combine knowledge and experience of the two and become 'service user-researchers'. Involvement of service user-researchers, Thornicroft *et al.* (2002) believe helps skew the focus of research to areas that are fundamentally important to those with experience of the condition being explored. This model empowers service users in research and evaluation, however their influence does not necessarily extend to the dissemination of the research undertaken in the partnership. This highlights the discrepancy between the value placed on SUI and the perspective taken by more academic journals and publishers, on the write up of findings (Lindow, 2001). Consequently, service users are only able to publish in limited places where the use of academic language is not given importance. Although this tide is turning with publications from service users such as Professor Beresford and Professor Rose, the latter suggests additional attention to the epistemological bases of SUI, may provide the vital link with academia (Rose, 2017).

There have been a number of initiatives that have involved service users in research in mental health over the decades. User-led research and Advisory Panels in research continue to gain ground in mental health and for organisations in the third sector, such as Rethink, the voice of the service user is integral to their philosophy. This naturally leads to empowering service users to become user-researchers and those with lived experience to interview participants (see Ajayi *et al.*, 2009). Within more traditional arenas the concept of user-led research can be found in the literature, where service users 'rather than being the objects of the research, become active agents in decisions about the process' (Pitt *et al.*, 2007:55). In the main, the focus for the research is service users' experiences of services and treatment (see Taylor *et al.*, 2012; Middleton *et al.*, 2011), however others have implemented Participatory Action Research to effect change at a service level (see Boniface *et al.*, 2015). In all these studies, service users made the transition to become user-researchers through training and access to the support of research teams. This requires additional resources and funding, as well as capacity within the workforce and the motivation to facilitate such an approach, all of which can form a barrier to implementation.

Although limited by comparison, some researchers have published on the experiences of incorporating SUI and the processes involved, from both a researcher and service user perspective (see Atkins *et al.*, 2013; Cowburn & Lavis, 2013; Staley, K., 2013; Fothergill *et al.*, 2012). The use of Advisory Panels in mental health research is also evident in the literature. Those with lived experience, carers and advocates as well as stakeholders such as those working in affiliated organisations, join Advisory Panels (see Nestsiarovich *et al.*, 2017; Galante *et al.*, 2016; Rose *et al.*, 2015, 2010; Sin *et al.*, 2013). The role of panel members in these studies ranges from giving advice and commenting on findings, to active involvement in the research (see Edwards *et al.*, 2015; Irvine *et al.*, 2015; Cowburn & Lavis, 2013). However there is limited indication that Advisory Panels are being integrated into mental health research at PhD level (see Garbutt, 2003 for example of an emancipatory approach). SUI in both healthcare and academia is seen as 'good practice' and, through supporting legislation and guidance, is an expected aspect in these areas. However it still remains far from an integral part of mainstream practice.

## SUI as good practice in healthcare

SUI provides an essential opportunity for services users to become ‘moral architects of their own destinies’ (Campbell, 2009:132). This suggests the empowerment that many authors note is the essence of ‘good practice’ and therefore should be a goal of SUI. Indeed two decades ago Hickey and Kipping (1998) found SUI at a decision making level had begun to be seen as good practice. Approaching from the service users’ perspective, Minogue *et al.* (2009) found those involved actively seek to be empowered through the process of research and many develop additional skills and confidence due to this experience. The literature on the benefits to service users draw similar themes related to personal development and gaining control. Boote *et al.* (2002) create a summary of these benefits and note that identifying and prioritising areas of importance to service users, limits wasted time researching irrelevant areas. They also suggest it facilitates inclusion of marginalised groups and provides wider opportunities for dissemination of research. Indeed, other research highlights the benefit of co-production suggesting it facilitates the public in taking responsibility, forming an essential and inevitable part of a sustainable future (Parks *et al.*, 1981). As an additional layer to this, Wallcraft (2008) points out that improved quality of life, increased learning and self-esteem, can only come through being involved in something that is of personal concern to the service user. Again this reinforces the argument for the research agenda to be set by the service user in creating a successful experience of SUI, for all.

However there is another side to SUI that is given limited attention in the literature. Highlighting the lack of literature on the *effectiveness* of SUI, Beresford (2002b) and Harrison *et al.* (2002) argue this is vital in creating a comprehensive picture of SUI. This concept is explored by Staniszewska *et al.* (2012), who to draw attention to the negative aspects of service user and public involvement experiences. They question the motivation for implementing the Government’s ‘top down initiatives’ and suggest there are a variety of factors that impact on its success or otherwise. This view is supported by Minogue *et al.*, (2009) who again highlights the lack of evidence of SUI actually impacts on altering the power balance to make it sustainable. The effectiveness and experience of SUI are the deciding factors of its success, regardless

of whether 'good practice' is seen to have been done: how it is done, rather than the outcome, is of importance (echoing the point made by Park, 2002).

For Davidson *et al.* (2009), SUI must not only improve the quality, relevance and utility of the research, but also act as a conduit for the inclusion of previously marginalised groups. To help facilitate the success and sustainability of SUI, diversity must be present at all levels in a system according to Tritter and McCallum (2006). This would provide an open door to service users and allow their influence to create meaningful involvement that provides the structures to reinforce good practice. In helping create these 'true' research partnerships, Russo and Stastny (2012) advocate certain areas of focus that echo Tritter and McCallum, 2006. They suggest acknowledging that inequality exists as a fundamental starting point, facilitated by practicing true equality and diversity in recruitment, as well as making sure service users are able to access strategic positions. To complete this focus they promote challenging the nature of the structures used to provide evidence, achieved via service user-led research. Although time and resources are needed to create such an environment, Damordaran (1996) argues that the rewards often warrant such investment.

In attempting to facilitate this approach, Farr (2012) suggests the involvement of staff is vital. Although acknowledging the pressure on frontline staff, she believes they are often overlooked when implementing SUI and argues they are essential in attempting to equalise hierarchies. Adopting this approach would not only allow staff to directly hear the voices of service users and gain an understanding of their perspective, but also encourage reflexivity in personal practice and the sharing of power. The need for comprehensive and systematised reflection in traditional practice in healthcare provision have been called for and Farr (2012) advocates SUI in aiding these practices. Reflection on what worked, what made it work, what did not work and what could be done differently, is essential to clinicians' development and learning. This is something Barnes and Cotterell (2012) agree would naturally extend to practice incorporating SUI and the purpose of assuring a shared goal of good practice.

## **SUI in the current research**

The latter part of this chapter gave an overview of the growth of SUI as part of a social movement. Government has supported this with the development of guidance and legislation to promote equity and encourage the use of public and patient involvement in healthcare (see Chapters 1 & 3). Although the movement, and consequently SUI, began in an ad hoc and sporadic manner, with legislative support it has gained significance within healthcare and became accepted as 'good practice'. This is also the case in the research and development arena, where service users become co-producers and research colleagues. There are many different levels on which SUI can be implemented and for the voice of those with lived experience to add transparency to the research process. However literature highlights a lack of involvement as an integral part of healthcare developments, as well as a dearth in its evaluation and dissemination of this practice from the service user perspective.

Thornicroft and Slade (2014) argue that hearing the voice and opinion of the service user is a vital component of research through the value it adds. Service users and 'experts by experience' as well as staff, are best placed to contribute to dialogue on services due to their perspective of using and providing them. Therefore many argue to improve services, their views and comments should be integrated into the dialogue on the reform of healthcare. Indeed Beresford (2005:7) notes there are in fact two 'key sources of evidence that have historically tended to be marginalised in health and social care and indeed in public policy more generally'; practitioners and service users. He argues in doing this we risk underrepresenting important perspectives on health and social care from the perspective of those who are best placed to comment on them. Although there have been studies that have incorporated the views of both groups, such as Stalker *et al.* (2005), there remains a scarcity in the literature. This further positions the current research and offers reasons for its novel design, which is explained in the following chapter.

The current research design adopts qualitative methods to hear the voice of the service user (Study 1) and staff (Study 2) with the aim of developing understanding of the experience of receiving a mental health diagnosis. However the design goes further to address some of the inequalities noted in the literature, that those with



mental illnesses face, by incorporating a Research Advisory Panel (RAP). The RAP, made up of people with lived experience of mental illness, was involved for the duration of the research (see Chapter 3 for detail on its implementation). Study at PhD level requires the research to be conducted by the student and consequently the RAP's involvement in the current research was in a 'consultation' capacity. Giving their opinions from a service user perspective, they acted as a sounding board for the design and development of the research, as well as commenting on the findings. This enabled the development of a richer understanding of the experience of receiving a mental health diagnosis. The RAP was invited to aid in the dissemination of research findings and, to address the lack of literature on the experience service users have of involvement, to co-produce papers focusing on this.

## **Summary**

This chapter considered the development of diagnosis, the concept of mental health and illness, as well as the challenges made to them and the healthcare system in which they sit. It introduced the idea of SUI as a way of elevating the voice and opinions of those using services. The literature highlights the gap between the legislative encouragement to incorporate SUI and its actual implementation in healthcare and research practice. Current service provision was presented to position the current research and exploration of SUI provided the landscape for incorporation of a RAP. Further to this, the literature review begins to suggest a questioning of whether diagnosis is a help or a hindrance for those receiving it and those working with them. The stigma attached to mental illness is accompanied by the acknowledgment of the link between diagnosis and support. This complex picture highlights the need to hear the voices of those involved in healthcare services (those that use and those that provide) to further understand this experience. The following Methodology chapter explains how the voice of the service user and staff were incorporated to achieve the aim of this research.

## **Chapter 3: Methodology**

### **Introduction**

This chapter is divided into two parts. Part one begins by setting out my conceptual framework, comprising of interpretative and theoretical paradigms. This includes making explicit ontological, epistemological and axiological assumptions that have guided my choices in research methodology, design and processes. In helping build this context, the field of qualitative research is briefly introduced, the research aims and objectives are given and the research design, being novel, is given additional focus. The philosophical underpinnings of the chosen methods are then explored and the section concludes by making overt the links between the methodological choices and the conceptual framework.

Part two of this chapter moves on to the practical application, of the methods presented in Part one, in the current research. This includes participant selection, data collection procedures and processes of analysis, which are accompanied by examples from the research. The chapter concludes with the theory of reflexivity incorporating discussion of quality and validity in research (which is revisited in Chapter 6 in relation to the current research).

### **Part one: Conceptual framework**

Silverman (2015) recognises the complexities within competing paradigms, positions and approaches by likening the ensuing debate to a war. However he is keen to point out that rather than adopt this attitude, researchers should see this as a call to action to be clear about their own approach. Indeed Madill *et al.* (2000) argue researchers have a responsibility to make clear their own position in relation to their research to ensure that they remain transparent and faithful to the chosen theoretical position. For the purposes of making my own approach explicit, I shall draw on the writings of Creswell (2013), King and Horrocks (2012) and Lincoln *et al.* (2011). Creswell (2013) suggests the researcher must ensure transparency within four philosophical assumptions: ontology, epistemology, axiology and methodology. These assumptions form the basis of the researcher's interpretative framework and are influenced by

them. The framework set out by Creswell, alongside discussion by King and Horrocks and debate by Lincoln *et al.*, create a structure for discussion that follows (see Figure 2).

## **Ontology**

Ontology concerns itself with the nature of reality. Researchers hold a multitude of differing opinions on what constitutes reality and how it is accessed. This can be conceptualised as a continuum from realist objectivity (positivist) to relativist subjectivity (constructivism). The positivist approach values scientific objectivity and consequently 'truth' is seen as concrete, measurable and accessible via observation. At the other end of the scale are those who believe 'reality' is more subjective, grounded in interaction and incorporating multiple realities. The constructivist, or interpretative, approach accepts and integrates the complexities of the dynamic interplay between people and the world in which they live (King & Horrocks, 2012). I approach the current research from this constructivist ontological position, driven by my wish to explore the meaning an individual places on a specific life experience.

## **Epistemology**

Recognition and explanation of the ontological position creates a transparency that highlights researchers' epistemological beliefs. Epistemology is the philosophical debate concerning how knowledge is formed and how we access it. Again here lies the positivist approach to knowledge, where objective laws can be created, and the subjectivist epistemology, where the assumption held is that we cannot be separated from what we know. The latter conveys the constructivist approach through adopting a 'transactional' epistemology and, consequently, the researcher is seen to play an important part in the development of knowledge (King & Horrocks, 2012). The social constructivist position is an area incorporated into this approach and holds that subjective meaning is constructed by individuals in the context of their society: this directs researchers to capture the participants' view. In the case of this research a social constructivist approach lends itself to relativist ontology and enforces the need for the researcher to

## The process of research inquiry: the influence of the conceptual framework through to thesis

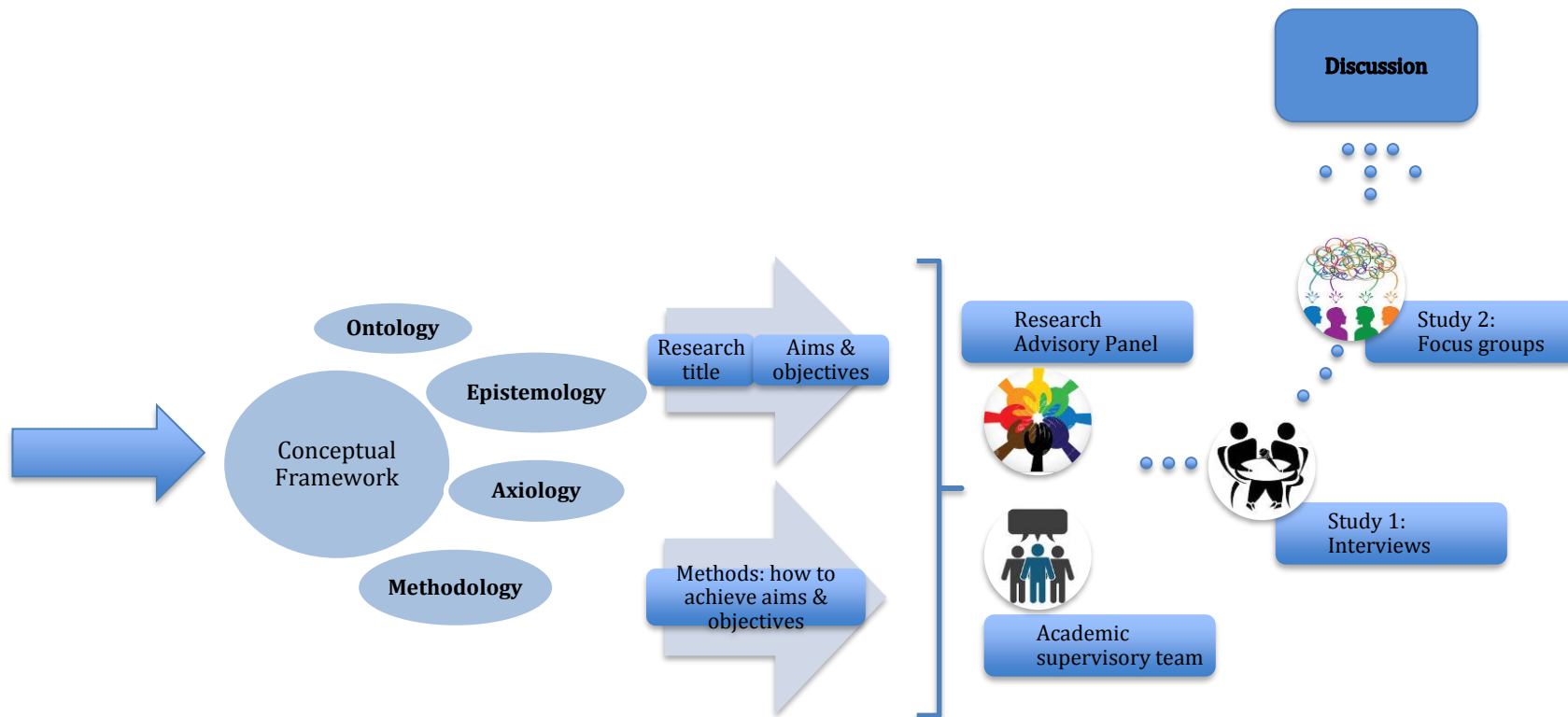


Figure 2: Process of research

approach the subject inductively and make overt the impact of their own influence in the research (Creswell, 2013).

### **Axiology**

Axiology is the field of philosophy concerning ethics and spirituality. Lincoln *et al.* (2011) have revisited and further incorporated, this aspect of influence in their later writings. They highlight this as a 'major point of departure' from positivist approaches to inquiry to interpretative positions (Lincoln *et al.*, 2011:116). This also echoes the need for researchers to make their values known within the context of inquiry and carefully consider ethical issues throughout. For this purpose, the design of the current research is approached from a participatory position, which holds the ideology of inclusion, participation and empowerment of minority groups.

### **Methodology**

The approach to research design and development is captured by the methodology adopted by the researcher. Whether the approach is positivist or constructivist, or lies somewhere on this continuum, influences methodological choices. The positivist position calls for theory driven and deductive quantitative research, the latter more inductive, qualitative research. There are degrees of variation such as using mixed method approach and pluralist approaches; combining different paradigms to gain further understanding of a research area.

The two studies conducted in this research are rooted in the qualitative paradigm and the belief that knowledge is co-constructed. However, the analytical focus differs between these two studies. Study 1 maintains the relativist position using Interpretative Phenomenological Analysis, whereas the use of Thematic Analysis in Study 2, has been argued to be 'independent of theory and epistemology' (Braun & Clarke, 2006:78). Therefore I have chosen to use it in a way that combines relativist position (holding the belief participants are co-creators of knowledge through discussion in the focus group) with realist leanings (reality can be accessed through language without focusing on latent meanings or group dynamics). The belief that

knowledge is co-constructed and can be accessed through direct contact with participants drives my choice of qualitative methodology. Alongside this, the current research incorporates a Research Advisory Panel as well as an Academic Supervisory Team, both of which informed and influenced the research process. Guidance from these two groups resonates with the position that knowledge is co-constructed.

The start of this chapter provided a theoretical frame for the choices made in the design of the research. Building on this, the narrative now turns to the novel design for the current research and accompanying theoretical underpinnings of each design element. Qualitative research is introduced before leading onto a detailed explanation of the research design. This is followed by the theoretical foundations of the chosen research methods; use of semi-structured interviews and Interpretative Phenomenological Analysis (IPA) Study 1, and use of focus groups and Thematic Analysis (TA), Study 2.

## **Qualitative research**

The wish to understand human behaviour drives research in the field of psychology. Research processes, design and procedures have developed and changed throughout the lifetime of the discipline and continue to do so. The traditional, observational, scientific approach to research was challenged, highlighting its accompanying ontological and epistemological assumptions (Shaw & Frost, 2015). This led to a 'scientific revolution' in psychology and more attention was placed on hearing the voice of the participant in an attempt to address the power imbalance between researcher and researched (Creswell, 2013).

Qualitative research affords a variety of choices for the researcher. Theoretical approach, design and methods all have to be given careful consideration due to this freedom. Creswell (2013) notes there are many different definitions of qualitative research however he highlights common characteristics. He suggests eight features: use of a natural setting, the central role of the researcher, use of multiple methods, use of inductive and deductive logic, focus on participant experience, dynamism of design, reflexivity and an holistic approach (Creswell, 2013:45-47).

In relation to these features, the current design incorporates all but the use of a natural setting and deductive logic. Unusually the design also incorporates the additional feature of a Research Advisory Panel (RAP) of people with lived experience of mental health. This is further explained in the research design below and practically when exploring its application in the current research (see Chapter 2 for its theoretical basis).

### **Qualitative research design**

As noted there is a call for researchers to make transparent the design, process and underlying assumptions that influence their research decisions. Therefore it is important at this stage to introduce the theory related to the current research design to frame the narrative that follows. The researcher is required to make choices about how, and whether, to combine multi-method (within the same approach) or mixed method (combining approaches) design. Hesse-Biber and Leavy (2011) suggest taking an overview of the entire research project before deciding on the sequence of the methods involved. Viewing the method as a 'phase' of the complete plan, aids the researcher understanding the best approach to achieve the research question or aim.

There is huge scope in combining qualitative methods and gathering data from focus groups and interviews is the 'most typical and straightforward pairing' and one that comes with abundant benefits (Hesse-Biber & Leavy, 2011:176). Some such as Frost *et al.* (2011), support the use of combining qualitative methods for the purpose of triangulation and they highlight research projects that involve concurrent use of different methods. This practice may be used for numerous reasons (e.g. time constraints) however consideration of the impact intended or otherwise, of this on data collection and analysis is important due to its potential influence on findings.

The choices made in the design of the current research rest on the theoretical points highlighted above. However, the combination of these and the research aims and objectives (see Chapter 1), result in an innovative and novel research design. Smith *et al.* (2009:52) encourage researchers to be 'more adventurous' when using IPA and to consider creating a 'bolder design'. They suggest re-interviewing participants or incorporating multiple perspectives as examples of this. Being granted 'permission'

to be creative in how I utilised IPA to achieve my research aim, resulted in a very different design. Therefore this design deserves additional time and description due to its 'bold' nature and processes, which are explained below (see Figure 3).

## Concurrent multi-method design

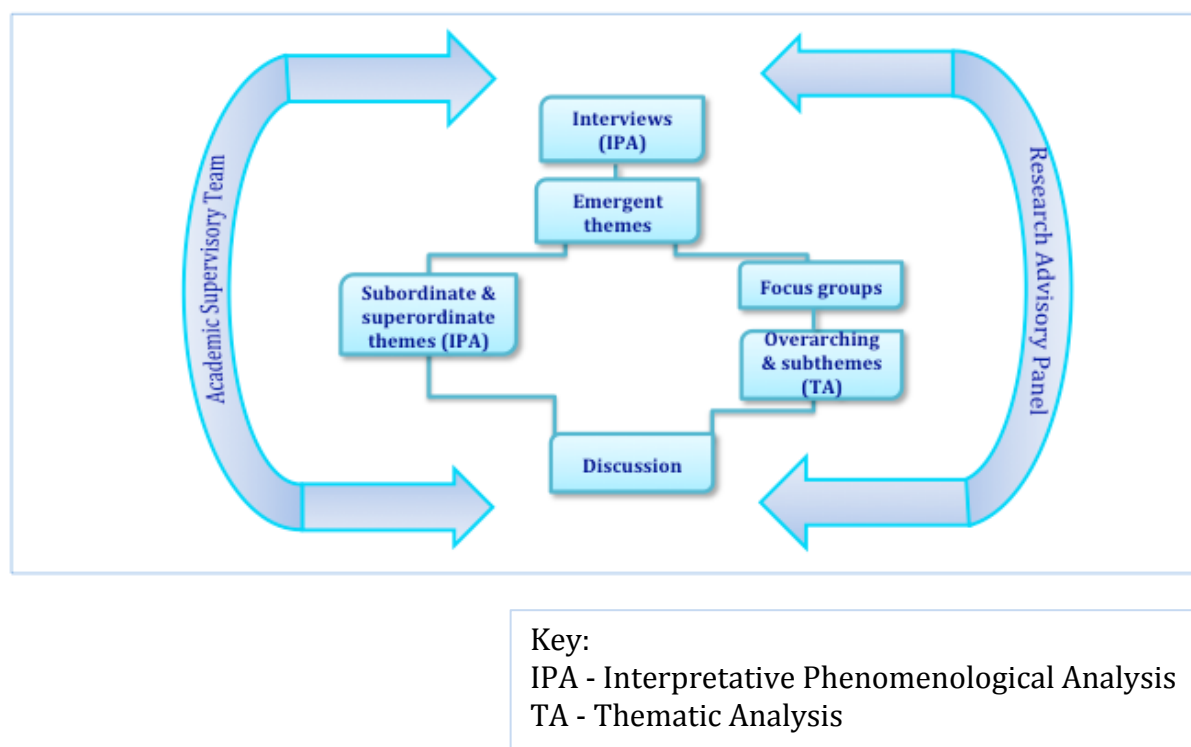


Figure 3: Concurrent multi-method design of current research.

Figure 3 introduces the 'concurrent multi-method' design of the current research. The design is unusual due to the need to incorporate all aspects of the research aims and objectives. These research priorities are achieved in two ways: through 'concurrent' data collection and themes development, in addition to use of a 'multi-method' approach. The design is also novel in use of one of the methods (IPA), driven by a specific intention to reduce researcher influence in the second part of the research (Study 2) and is explained below.



## **Concurrent guidance**

The design is concurrent in two ways. Firstly as well as the Academic Supervisory Team (AST), additional support and guidance were accessed throughout through a Research Advisory Panel (RAP). The use of a RAP as an integral part of PhD research is uncommon. The RAP was accessed for consultation and provided an independent sounding board, therefore enhancing credibility. They were involved at all stages of the research making the design 'concurrent', allowing for looped feedback from 'experts by experience' of mental illnesses. Although the panel were not accessed to *validate* findings (due to the choice of method and access to the AST justifying this), they were vital in developing a deeper understanding of mental illness and service provision from the users' perspective.

The structures in place in academia promote the use of a supervisory team. Supervisory teams approach the progress of the research from a different perspective and agenda to the RAP. In the current research their input was also concurrent, dynamic and allowed for looped feedback to enhance the progress of the research. In this way the AST and the RAP complemented each other highlighting different aspects of the research; the RAP coming with the expertise of lived experience and the AST with expertise of the academic context. Therefore combining the RAP and AST enriched the research through the challenges these contrasting approaches brought.

## **Concurrent themes development**

The aim of finding out how individuals make sense of their world and their perspective on it, is key in qualitative research. The aim of the current research was to capture the specific experience of receiving a mental health diagnosis and following this, explore staff responses to initial findings and their views on service provision. Therefore the design incorporates two studies: interviews with people about the experience of receiving a mental health diagnosis (Study 1) and focus groups to capture responses of staff working in mental health services (Study 2). The research design was directed by the decision that initial findings (IPA emergent themes) from Study 1, provided the basis of discussion in Study 2. Therefore

although pairings of interviews and focus groups can take on a variety of formulations (Hesse-Biber & Leavy, 2011), in this research the interviews preceded the focus groups.

Importantly the themes explored by staff at the focus groups had been developed to an 'emergent' stage. The rationale for using themes at this stage, as opposed to more refined superordinate and subordinate themes, was related to the method of analysis chosen for Study 1. IPA is recognised for its in-depth interpretative nature, this being the case the continued development of themes from the initial emergent ones, requires the researcher to make sense of the participant making sense of an experience, and is consequently subjective (Smith *et al.*, 2009). The emergent themes were closest to the raw data and therefore used to reduce the imposition of subjectivity and the influence of researcher interpretation in the focus groups (see Appendix 1 for emergent themes used in focus group).

The intended focus within the groups was the service user experience of receiving a mental health diagnosis. To ensure the emergent themes resonated with those with lived experience prior to their use in the focus groups, they were taken to the RAP. This resulted in the 11 emergent themes used Study 2. The development of these themes through further analysis, continued concurrent to the recruitment and running of the (Study 2) focus groups (see Figure 3). As this was the case there was likely to be some influence between the two, however this was a side effect rather than an intrinsic, chosen path. Notwithstanding this, listening to the discussion as I concurrently developed the themes, heightened my understanding of the experience of receiving a mental health diagnosis.

### **Multi-method**

As mentioned when introducing the current research design earlier, two different methods were employed. Choices for these were driven by the aim of the research and related to different focuses of Studies 1 and 2. The purpose of Study 1 was to capture the experience of receiving a mental health diagnosis. IPA's phenomenological and idiographic focus expressed through in-depth analysis and interpretation, lend itself to this end. However Study 2 was designed to capture staff

responses to the emergent themes of Study 1 (in relation to everyday practice) and move the focus onto wider issues around service provision, making views from a staff perspective vital in Study 2. Thematic Analysis (TA) was chosen to make overt the themes within these discussions (both methods are explored below). The use of both TA and IPA fall under the umbrella of qualitative research therefore the research becomes 'multi-method' in design. Although IPA implicitly incorporates an inductive approach to data analysis, I chose this inductive approach for use with TA.

The chosen research methods for Study 1 and Study 2 have been indicated above. To further add some detail to these methods their theoretical underpinnings are explored. Starting with IPA and the use of semi-structured interviews, TA and focus groups, follow. The first part of this chapter closes with a figure presenting the links between the conceptual framework and methods chosen (see Figure 4).

## **Study 1: Interviews and Interpretative Phenomenological Analysis**

### **Semi-structured interviews**

Approaching Study 1 from a relativist constructivist position, supports the choice of qualitative methods to capture an individual's experience. Using semi-structured interviews aligns with taking an interpretative approach and use of qualitative methodology (Creswell, 2013). Smith *et al.* (2009:57) notes interviews are a 'conversation with a purpose' and in this context the role of the researcher is of active listener, helping facilitate the participant tell their story. This being the case interviews vary on a continuum of how structured they are and the level of control held by researcher and participant (Hesse-Biber & Leavy, 2011). The use of semi-structured interviews allows for guidance as well as covering topics introduced by the participant, therefore both parties are actively involved in the research process (Smith *et al.*, 2009).

There are close links between the choice of method of data collection and analysis. The current research uses Interpretative Phenomenological Analysis (IPA) for the purpose of analysis and although other methods of data collection are used in IPA, verbatim transcripts of semi-structured interviews remain the 'gold standard'

(Mercer, 2012). During interviews attention is given to specific personal events in an individual's life with the aim of developing an understanding of the phenomena studied. Aligning with a phenomenological epistemology of IPA, semi-structured interviews allow for the researcher's influence and interpretation in this process and, rather than deny this, it is made overt through reflexive practice (Smith *et al.*, 2009); evidenced in this thesis in Chapters 1, 3 and 6.

### **Interpretative Phenomenological Analysis (IPA)**

IPA adopts the premise that human beings often go about their lives without detailed examination or consideration of their experience in and of it. The analytical method brings this into sharp focus via detailed inquiry of particular aspects of an individual's life: 'when everyday flow of lived experience takes on particular significance' (Smith *et al.*, 2009:1). In their systematic review of literature in health psychology, Brocki and Wearden (2006) noted a trend towards understanding the meaning an individual places on their life experiences. This is especially poignant when considering changes in health. Indeed Biggerstaff and Thompson (2008) believe through the use of qualitative methods, such as IPA, clinicians are best placed to engage with their patients and capture their viewpoint.

Smith (2004) noted two overarching themes within the corpus of research: a focus on life changing events and the construct of identity (for examples see Crowe *et al.* 2016; Patterson *et al.*, 2014; Arroll & Senior, 2008; Borkoles *et al.*, 2008). It can be argued that receiving a mental health diagnosis is a major life experience for some which may impact on identity (see Rogers & Pilgrim, 2010, for a sociological context to this argument). The growing use of IPA in health and social sciences in an attempt to get 'experience close' indicates its usefulness in this intention. Concurrently the underpinning philosophical foundations of the methodology resonate with qualitative researcher's attempts to understand life experiences. IPA brings together the three concepts of phenomenology, hermeneutics and the idiographic, which will be introduced.

## Phenomenology

To understand phenomenology as a concept it may be helpful to consider the origins of the word; 'phenomena'; that which appears and 'logos'; to study. The essence of phenomenology is the study of things as they appear; as we become aware of them and are no longer immersed in them. The scientist and philosopher Husserl (1859-1938) is accepted as the founder of the phenomenological approach. He wished to develop a scientific approach to the study of 'things' (Ihde, 1998). He argued we need to 'go back to the things themselves' to discover the true nature of them, focusing on *describing* qualities rather than *explaining* them (Smith *et al.*, 2009:12).

Husserl introduced the concept of the lifeworld and in this he highlighted 'intentionality' (Smith *et al.*, 2009). Intentionality stemmed from the belief that we are conscious beings and therefore it follows we are always conscious or aware *of* something and in relationship *with* it (Larkin *et al.*, 2011). He connected the meaning we place on our lifeworld and our intentionality in it. The influence of this meaning-making was referred to as 'epoché' by Husserl and he suggested in order to see the phenomena 'as they appear' one should 'bracket' any preconceptions, beliefs and experiences held (King *et al.*, 2008). Bringing awareness to the preconceived ideas, through personal reflection, 'bracketing' is intended to limit its influence on the description of the phenomena.

The phenomenological approach was further developed by Husserl's student Heidegger. Heidegger challenged the notion of 'bracketing' as an approach to the study of phenomena, arguing we are constantly a 'person-in-context' (Larkin *et al.*, 2006). He opposed Husserl's transcendental phenomenology, believing that we are 'thrown' into a pre-existing world at birth that we are unable to move beyond. Therefore our choices are influenced and bound by what is meaningful to the individual (intersubjectively grounded) and what is possible given the nature of the world (physically grounded) (Larkin *et al.* 2011). In his critically acclaimed work, *Time and Being* (1927) Heidegger talked of *Dasein* (literal translation 'there-being'), in IPA this is the recognition researchers can only attempt to understand another's world and get 'experience-close', from a third person perspective (Larkin *et al.*, 2006).

Adding to the idea of being-in-the-world was the phenomenological philosopher Merleau-Ponty who was influenced by both Husserl and Heidegger. Merleau-Ponty emphasized the importance of the role the body plays in our experience of the lifeworld which we are *embodied* in it (Larkin *et al.*, 2011). Our bodies provide the vehicle through which we develop knowledge of the world and therefore we were first and foremost 'body-subjects' as experience the world through our senses (Larkin *et al.*, 2011). Associated with this view was the philosophical thinking of Satre whose thoughts extended to include the notion of the importance of the absence of things, as much as their presence: we are continually 'becoming' and defining ourselves through the choices we make (Smith *et al.*, 2009).

## Hermeneutics

A second important contribution to IPA is made by the field of hermeneutics: the interpretation of text. The development of hermeneutic thinking grew alongside an increasing interest in scientifically making sense of biblical and historical texts occurring in the late 19<sup>th</sup> Century (Ihde, 1998). In hermeneutics texts are studied in relation to their context and therefore parts are seen in relation to the whole and the whole in relation to its parts: the hermeneutic circle. Smith *et al.* (2009) highlight the influence of key figures on the development of IPA and therefore these individuals maintain the present focus.

Heidegger engaged with the development of hermeneutics. As noted earlier he believed 'fore-understandings' enable individuals and communities to process information and develop meaning in their lifeworld (Finlay, 2008). Therefore the interpreter of the text needs to take a deeper look at the data, to fully understand and make overt the 'filter' through which an individual makes sense of their world (Smith *et al.*, 2009). A second key influence in IPA was Schleiermacher who suggested the structures and rules to text interpretation should incorporate an understanding of the writer as well as the text (Smith *et al.*, 2009). Finally for Smith *et al.* (2009) Gadamer further developed Heidegger's hermeneutical phenomenological standpoint by highlighting language as the means to which 'being' is captured: linguistics is fundamental to our reality and understanding (Palmer, 1969). Gadamer built on Heidegger's hermeneutic circle to involve the researcher as part of the interpretative

process; the researcher's fore-structures respond *to* the analysis and they are subsequently changed *by* it.

### Idiographic

The third aspect of IPA is the incorporation of the idiographic: small sample sizes facilitate an in-depth examination of experiences. The nature and philosophy of IPA processes encourage a leaning towards the detail and commitment to understanding the particular (Smith *et al.*, 2009). The 'particular' refers to the unique nature, experience and context of the individual (Heidegger's Dasein) and to do justice in understanding phenomena from participants' perspective an idiographic approach is vital. The focus in IPA is to capture the unique experience of each individual *before* looking for divergences and convergences across cases and subsequently adding to the wider corpus of knowledge (Smith *et al.*, 2009).

The focus of the idiographic in IPA is in direct opposition to the traditional nomothetic model use in psychology (Smith, 2011). Smith (1996) argues that this approach has led to neglecting research in certain areas due to the difficulties attempting to capture them quantitatively. He believes IPA can bring balance and add value to the development of knowledge, as 'delving deeper into the particular also takes us closer to the universal' (Smith, 2011:42).

### Summary

IPA is underpinned by a set of ideological traditions; its roots in phenomenology, hermeneutics and incorporating the concept of the idiographic. Philosophical ideas from Husserl, Heidegger, Merleau-Ponty and Satre form the foundations of IPA. The method seeks to capture the experience of a particular event in an individual's life and most often interviews are the natural choice to collect data. The collaborative nature of the method highlights the role of the individual *and* researcher in making sense of the phenomenon; it therefore becomes the combined effort of both parties and leads onto the hermeneutic aspect of the method. During analysis the researcher takes a holistic, questioning approach to text interpretation, capturing the idiographic context of the data collected.

Part two of this chapter provides detailed explanation of the use of IPA in the current research. However before addressing this, the theoretical foundations of the second qualitative method shall be introduced; the Thematic Analysis used in focus groups (Study 2).

## **Study 2: Focus groups and Thematic Analysis**

### **Focus groups**

The objective of Study 2 was to illicit staff responses to themes found in Study 1 and discuss wider service provision. Focus groups were chosen as a way of capturing this discussion; a method that has been used in research since the 1920s (Kitzinger, 1994). Moving on from its beginnings in consumer research, focus groups have been utilised throughout a wide range of areas (e.g. education, criminal justice, health and media studies) and are often adopted when research is of an exploratory nature (Hesse-Biber & Leavy, 2011). The fundamental difference between focus groups and in-depth interviews is group interaction. This interaction, Kitzinger (1995) argues, is key to participants considering and clarifying their own views by exploring it from different perspectives. This uniquely created 'group effect' is indeed what Hesse-Biber and Leavy (2011:167) believe to be an important data source: 'focus groups are not equivalent to the sum of individual interviews'.

King and Horrocks (2012) recognise focus groups are only one of a number of techniques available in the genre of group interviews. These range in their structure as well as the role of the facilitator. This continuum from formal to informal is influenced by the aims and design of the research, taking into account the anticipated response of participants (King & Horrocks, 2012). Hesse-Biber and Leavy (2011) highlight that focus groups are often used to elicit viewpoints from hard to reach groups, therefore there should be consideration of cultural variables. Interaction is the focus groups' strength, therefore good facilitation is fundamental to their success and although discussion may be unpredictable, it is not without structure and therefore differs from natural conversation (Hesse-Biber & Leavy, 2011).



## **Thematic Analysis (TA)**

Although TA has no philosophical foundations comparable to IPA, it nevertheless calls for consideration of the approach to be taken by the researcher (Clarke *et al.*, 2015). To aid this, Braun and Clarke (2006) set out structure in the use of TA, exploring the researcher's approach. The method allows the researcher to adopt a realist approach where a 'simple, largely unidirectional relationship is assumed between meaning, experience and language' (Braun & Clarke, 2006:85). This is opposed to a constructivist approach, which focuses on the dynamics and interactions within the group. The fact that TA 'can be used to address most types of research questions and analyse most types of qualitative data', gives it its flexibility and reach (Clarke *et al.*, 2015:225). This flexibility includes the theoretical approach taken by the researcher, which Braun and Clarke (2006) believe to be a strength, stating the responsibility lays with the researcher to make their choices and theoretical position clear.

Braun and Clarke (2006) promote TA as an essential learning need for all early researchers. The core skills learned through the use of TA, extend and filter through a variety of other research methods. However as noted above, with the addition of transparency of researcher approach, it becomes more than just a 'tool' that some have and becomes a 'method in its own right' (Braun & Clarke, 2006:78). A method that purely because of its flexibility has potential to offer the complex and detailed analysis researchers often strives for.

## **Summary**

Focus groups have been a staple method of data collection for nearly a century. Their endurance highlights their usefulness in capturing opinions on a multitude of topics. Kitzinger (1994:112), who advocates their use, points out that 'people do not operate in a social vacuum', therefore capturing naturally occurring conversations for research purposes is the ideal. TA is often chosen in qualitative research to analyse the data collected (Grbich, 2013). Without theoretical foundations it is an approach that is implicitly flexible, something Braun and Clarke (2006) consider a strength. However the authors also add a caveat to use of TA purely due to this flexibility: a duty rests on the shoulders of researchers to make their position and choices

implementing TA explicit. Use of focus groups and TA, enables the researcher to gain an understanding of the views of a particular group on a particular topic.

### To conclude Part one

Part one of this Methodology chapter introduced the theory that supports the current research. This made overt the conceptual framework influencing the approach to the research being of a constructivist, participatory position. This, alongside the research aim, influenced its design and progress: seeking to understand the meaning an individual places on an event and the innovative incorporation a RAP. Figure 4 demonstrates how the concepts, theory and methods combine and aids the conclusion of Part one of this chapter whilst introducing Part two. Part two builds on the theory provided above by moving onto the application of this theory and explanations of how these processes were used in the current research. This being the case the tone will also shift to a first person narrative.

### Methodological links to the conceptual framework

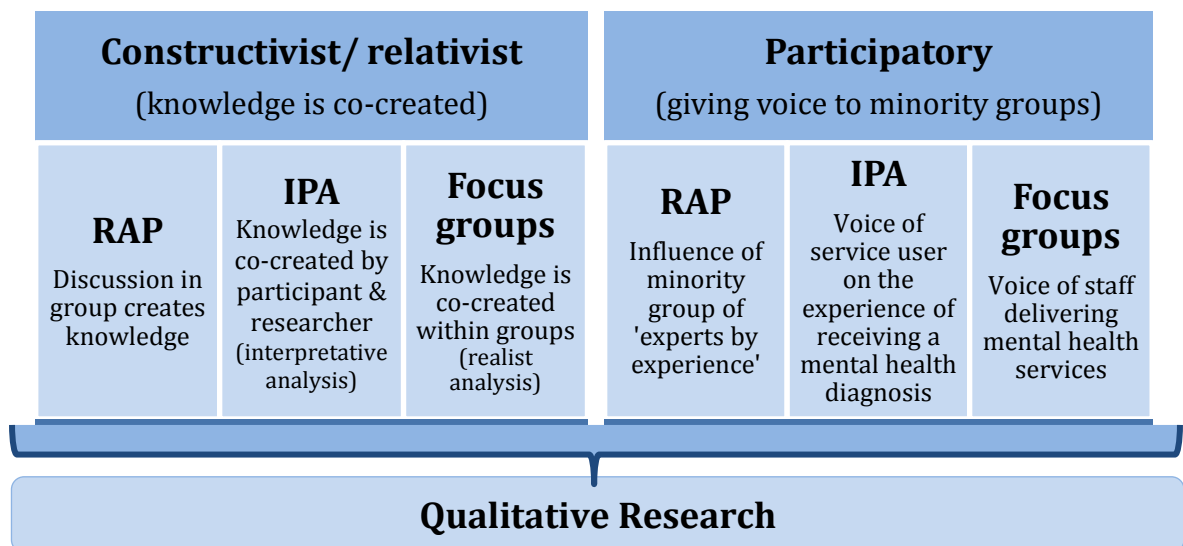


Figure 4: Links between the conceptual framework and methods applied.

## **Part two: Practical application of methods**

### **Introduction**

Part one set out the conceptual framework and theoretical underpinnings for the current research. The focus of the latter part of this chapter is the practical application of these concepts and ideas: the connection between theory and practice. The narrative will begin with the implementation of the Research Advisory Panel (RAP) including the considerations necessary for setting up such a group. This will be followed by Study 1 (interviews and Interpretative Phenomenological Analysis) that explored the experience of receiving a mental health diagnosis. The narrative will then turn to Study 2 (focus groups and Thematic Analysis), which captured staff views on emergent themes and service provision. Part two of this chapter will conclude by presenting the theoretical basis of reflexivity, which in turn provides context to introducing the participant profiles alongside reflections on my role as a researcher in the current research.

### **SUI: Implementation of RAP**

#### **Research Advisory Panel (RAP)**

On discussion in supervision at an early stage, I introduced and justified the use of a RAP to help guide the research: not only was it good practice and ethical, it would enable me to test my ideas with ‘experts’. It was decided this was to be at the level of ‘consultation’ rather than ‘co-creation’ (see Minogue, 2009), as it was my intention to carry out the research. Notwithstanding this, the RAP would offer guidance and act as a sounding board at each stage the research. Importantly they also would play an independent role, adding credibility through transparency of the research through discussion with people with lived experience of the research topic.

As mentioned there are many resources to support researchers to introduce participation in their research. The guidelines set out by Faulkner (2004) in *The ethics of survivor research*, have an applied focus and following these guidelines, I

considered recruitment and ethics, as well as the practical running of the group. These considerations and the process of setting up the RAP are now explained.

### **Ethics and recruitment**

Whilst developing ideas for the structure of the group, the Directors of the South Wales branches of a national mental health charity were contacted. Request to access their network for recruitment to a RAP and ethical considerations were discussed. The distinction was made between volunteers and service users currently accessing support from the charity for their mental health. There was recognition that volunteers were potentially more stable in their mental health than those currently accessing support, therefore the former were chosen for recruitment to the RAP. The Directors acted as gatekeepers and three of the four local organisations contacted agreed to advertise and inform their volunteers of the opportunity. I developed a poster in collaboration with a service user, making clear the reasons and expectations of joining the RAP (see Appendix 2).

For ethical purposes, support offered to the members was considered. As volunteers, the members were already aware how to access mental health services. However for best practice, I provided them with a resource sheet of support organisations. Building on this I took the opportunity to reinforce they could withdraw at any time, enabling them to practice self-care to take into consideration any fluctuation in their mental health. I also requested that a service user-researcher deliver training on the research process at the inaugural meeting. As mentioned, remuneration is another aspect that reinforces the value of members' contribution and evidences their value in research (Syrett, 2011). Although remuneration was not available at the commencement of the RAP, I was able to provide gift vouchers to those who had remained the duration.

### **Setting up and running the group**

Faulkner (2009) recommends ensuring clarity and transparency for service users throughout their involvement. To aid this she suggests developing 'Terms of Reference' for the group, which I drew up prior to the first meeting and subsequently

clarified with the group members (see Appendix 3). I developed provisional agenda ideas for the first three meetings, which were discussed at supervision and sent out to those interested. Initially the RAP consisted of eight members (one of whom preferred not to attend the group and therefore was contacted via email), this number dropped over the first 18 months to a constant four members by the end of the research due to changes in members' circumstances.

Each meeting took place at a venue chosen by democratic vote. In the inaugural meeting I presented a summary of the research idea, design and explained my role as a researcher (including clarification of boundaries and confidentiality). This enabled me to manage expectations and although the discussion was often challenging in nature, the members understood the context in which the research was progressing. Empowering the members is of importance and can be facilitated through rotating the chair and minute taker (however this opportunity was declined in the current research). Subsequent agendas related to the need at the time e.g. the development of the interview schedule, ethical considerations and discussion of the findings. This also influenced the frequency of the meetings, moving from three in the first three months, to three over the course of a year. The RAP is a thread that runs through the research and references to its explicit influence are made where relevant. Although it is common practice when undertaking a PhD, it is also important to note the presence of the Academic Supervisory Team (AST). Both the RAP and the AST guided, influenced and advised throughout the current research.

What follows is an exploration of the application of the methodological aspects of the research. This begins with Study 1; implementation of interviews and application of IPA, and moves onto Study 2; implementation of focus groups and application of TA.

## **Study 1: Implementation of interviews**

The following section will consider the application of the methods used in Study 1. Attention is given to the choice of sample (including size), process of recruitment to the research, development of the interview schedule, ethical considerations and concludes with the steps of analysis with examples given from the current research.

## **Sampling**

When using IPA the aim is to access a homogeneous sample of participants. This is to facilitate capturing an understanding and representation of a particular experience and Gray (2014) suggests purposive sampling is used to achieve this. In the current research the particular experience being researched was that of receiving a mental health diagnosis. The intention in sampling here, is to not to achieve a wholly representative sample as even within a common experience, individuals develop uniquely different meanings of them (Flowers *et al.*, 2006). Therefore the aim is to allow exploration of convergences and divergences between participants via the detailed process of analysis (Smith *et al.*, 2009).

Although there is no 'right' sample size when using IPA, its idiographic nature lends itself to the smaller end of the spectrum. Smith and Osborn (2008:56) suggest six is a reasonable size for a sample for IPA research; therefore 'one is sacrificing breadth for depth'. In order to further protect participant anonymity, and allow flexibility in recruitment, a sample size of six to ten was chosen during discussion in supervision.

Criteria for participant inclusion was discussed at the RAP. It was proposed that participants had to meet the following criteria: their mental health diagnosis was given by a GP or consultant psychiatrist (i.e. not self-diagnosed); the diagnosis had to have been received a minimum of 12 months previously (to allow time for processing the information and accessing support) and their current mental health was stable (to address ethical and mental capacity issues around gaining informed consent). The RAP added evidence to my choice not to focus on a single diagnosis, highlighting the idiographic nature the experience and highlighting the fact diagnoses can change over time.

## **Recruitment**

I approached a mental health charity to support recruitment to the research. In order to do this effectively, and in line with the geographical boundaries agreed at the proposal stages, the Directors of the organisation (based in the South Wales area) were contacted and I gained permission to proceed to recruit interview participants.

Liaison persons aided recruitment, which took place over a number of weeks. To facilitate this process I provided a research outline and what participant involvement would entail. I was also invited to give a talk at one of the organisations about the research and the outline was placed on social media, both of which resulted in further recruitment.

As the numbers interested steadily increased I found the need to develop a spreadsheet for monitoring purposes. This allowed a 'first come, first served' process to limit bias that could have occurred (often the individuals shared their story in the initial contact). An initial telephone conversation gave an opportunity to build rapport, check suitability, hear an outline of their experiences and answer any questions. Once participants had the Participant Information Sheet (PIS, see Appendix 4), a week was given for their consideration and in the majority of cases the individual was happy to be further involved in the research. It was made clear that a consent form (see Appendix 5) would be signed at the time of interview although they maintained their right to withdraw at any point. It was also reiterated that the interviews would be digitally recorded, data would be stored in line with the Data Protection Act and all information would be anonymised.

### **Ethical considerations**

Ethical approval to conduct the interviews was granted by Cardiff Metropolitan University, 8<sup>th</sup> January 2015. Reference: 0048-SREC-2014(2).

When involving people in research, ethical consideration of the welfare of all concerned is imperative and this was of particular importance in this research due to the nature of the subject being discussed. Therefore key points were contemplated in this process (guided by King & Horracks, 2012) and these are explored below in relation to the current research.

Firstly, the right to withdraw was considered due to the emotive nature of the subject of the interview. I felt it important to empower the participants and was clear about the boundaries relating to withdrawing from the research process. The research process was made transparent throughout and ample opportunity was given for

questions or reassurance. Secondly, managing emotional responses to ensure the safety of the participants was considered. As a registered healthcare clinician with experience working in mental health, I felt competent to suggest appropriate action should emotional distress occur (indeed two participants became emotional for a few seconds from which they recovered under their own volition and the interview continued directed by them). A resource sheet of local support was given to all participants at the start of the interview to help manage any emotional response that may occur post-interview. Thirdly, the location of the interview was discussed with the participant. The gatekeepers offered interview rooms in addition to those at the university and it was hoped that the choice would allow the participant to feel comfortable, alongside reducing the risks associated with lone working. Only two interviews took place at venues outside of those initially offered, one due to the constraints of the participant's mental illness and one due to their work commitments.

### **Development of interview schedule**

Guidance given by King and Horrocks (2012) and Smith *et al.* (2009) aided the development of the interview schedule. The former suggest beginning with ideas of topics the researcher would like to cover before moving attention to the questions. As these topics were developed it became apparent they flowed logically from experiences pre, during and post-diagnosis and sequenced to naturally move from broader issues to more sensitive. When developing the questions themselves, Patton (2015) proposes consideration of six types of questions; background, experience, opinion, feeling, knowledge and sensory (see Appendix 6 for examples of how questions map onto Patten's question types). Ideas were also gathered from previous published interview schedules (such as Patterson *et al.*, 2014) and questions were refined in light of discussion in supervision. This process concluded in six open-ended lead questions and accompanying prompts and probes (see Appendix 7 for interview schedule).

When developing the topics with the RAP, they suggested inclusion of 'behaviour change' as this was felt to be significant in the experience of receiving a diagnosis. I took the opportunity to review the interview schedule with the panel once the



questions were in their final stages. This resulted in minor adjustments such as using the plural of the term diagnosis and replacing 'why' with 'how'. As suggested by King and Horrocks (2012), I piloted the questions with a randomly selected volunteer from the RAP (it was conducted in the knowledge that the data would not be used). Feedback consisted of allowing the participant freedom to take their story in whichever direction they chose and therefore to use the schedule flexibly.

### **Transcription and verification**

I transcribed each interview verbatim in the order in which they were conducted. Due to the method of analysis chosen, I recognised the benefit of transcribing to begin to 'immerse' myself in the data. Participants were then sent their transcripts for verification with a three-week deadline and given the opportunity to add, amend and delete the text. All but two of the transcripts were agreed without requests for amendments: one participant amended grammar and spelling and another had replaced all anonymised detail and deleted a short extract I felt had no bearing on the research aim. Once I had received the transcripts back, and all participants had verified them, I moved onto analysing them using IPA, the process of which I shall now explain.

### **Application of IPA**

As Smith *et al.* (2009:26) note analysis consists of a 'dialogue between what we [the researcher] bring to the text, and what the text brings to us'. Smith (2011) suggests the process of this in IPA is a 'double hermeneutic'; the individual participant is making sense of the event and the researcher is making sense of their making sense. IPA is by nature a detailed and time consuming process where the researcher returns and re-returns to the data with different intentions. The iterative process facilitates the aim of making sense of participants' experiences and in order to stay true to the story given, Smith (2004) suggests approaching the analysis of the text maintaining a balance of 'empathy' with the more critical stance of 'questioning'.

Smith and Osborne (2008:54) argue there is 'no single, definitive way to do IPA', however I followed the framework provided by Smith *et al.* (2009), for the process of

analysis. These six steps are used to guide the following narrative and include examples from the current research. Although not part of the six steps, it is important to mention the process of 'bracketing' before, during and after this process in an attempt to recognise my influence on the entire process. To this end I began by taking time to reflect on my experiences and consider what influences these may have. I also noted any opinions I formed during and immediately after the interviews in an attempt to put these to one side when analysing.

- Step one: Reading and re-reading

This first step is to enable the researcher to take time to set the pace for the process of analysis. Reading and re-reading not only facilitates the beginning of getting to know the transcript fully, it also begins the process of immersion. During these first stages of reading and listening I noted down my understanding of the issues that arose to 'bracket' them to only work with the data that was there. At this time I also developed an overview 'timeline' for each participant; something not overtly suggested within the six steps, however it enabled me to make sense of the interview content and structure.

- Step two: Initial noting

The process of analysis deepens at this stage through making careful notes on the content of the transcript. Smith *et al.* (2009) guide this line-by-line commenting by suggesting a focus on the descriptive, linguistic and conceptual aspects. During listening and reading the transcripts I noted the descriptive and linguistic comments in the margins of the document, almost simultaneously, using different coloured pens. The final noting concerns the conceptual comments, a task that requires concentration and is at a more interpretative level. This builds on the former two tasks of noting and is influenced by the personal knowledge of the researcher and moves onto making sense of the participant making sense of their experiences: the double hermeneutic (Smith *et al.*, 2009). Table 2 shows an extract from an interview alongside my initial notes made during analysis (the quote is in a section in which the participant discusses recovery).

Extract from interview	Descriptive notes	Linguistic notes	Conceptual notes
<i>(long pause) well, recovery to me would like t' like to you know er, I'd like to feel sort of er, probably a lot happier in myself, be able to you know function daily without the constant nagging of my cleaning and the ritual I have to do every day, you know the hovering and the dusting erm, that's what I would like to call a recovery then, to get up and do we'll say normal things that normal people do, which I can't do.</i>	<p>Recovery would mean being happier in himself</p> <p>Able to function without cleaning ritual</p> <p>Ritual constantly there</p> <p>Behaviour related to condition</p> <p>Consideration of normality</p>	<p>Long pause, hesitant sentence formation: difficulty answering question</p> <p>Use of clinical language: 'function'</p> <p>'constant', 'have to', 'every day' 'can't': absolutes, suggest no choice</p> <p>Repetition of normal: significance of difference of own life</p> <p>Change in 'I' to 'we', bringing in wider society perceptions on behaviour</p>	<p>Like to feel 'happier' hints at current sadness/ being unhappy?</p> <p>'Constant nagging' unable to get away from a belligerent wife??</p> <p>Constancy of condition/ no respite</p> <p>Limited agency in changing situation</p> <p>'Normal things, normal people': sees self as separate/ different from others due to mental illness/ behaviour</p>

Table 2. Example of descriptive, linguistic and conceptual notes made during analysis.

- Step 3: Developing emergent themes

Building on the knowledge developed during the process so far, shorter excerpts of text then become the focus. Understanding these excerpts in relation to the entire transcript, enables the development of themes that are meaningful to the participant through questioning what the participant was trying to relay in the quotation. The emergent themes were noted in the left margin without initial concern for making connections between them, in order to diminish the influence between the developing themes.

- Step 4: Searching for connections across emergent themes

Continuing to work on one interview, this step enables the emergent themes to be brought together in a more comprehensive manner. The aim of this is to capture the most meaningful and important aspects of the participant's experience and involves finding similarities and connections. Although this can be a very creative process, I started with the linear development of tables of quotes under headings capturing areas discussed by the participant. I then paused and revisited all notes, data and coding completed during analysis. Reviewing in this way checked that emergent themes were congruent with the meaning the participant made of their experiences. This process is also aided by the suggestion of Smith *et al.* (2009) to use the hermeneutic circle to gain clarity: viewing the word in the sentence, the sentence in the paragraph and this in the entire transcript and back again (see Figure 5 for example of steps 3 and 4).

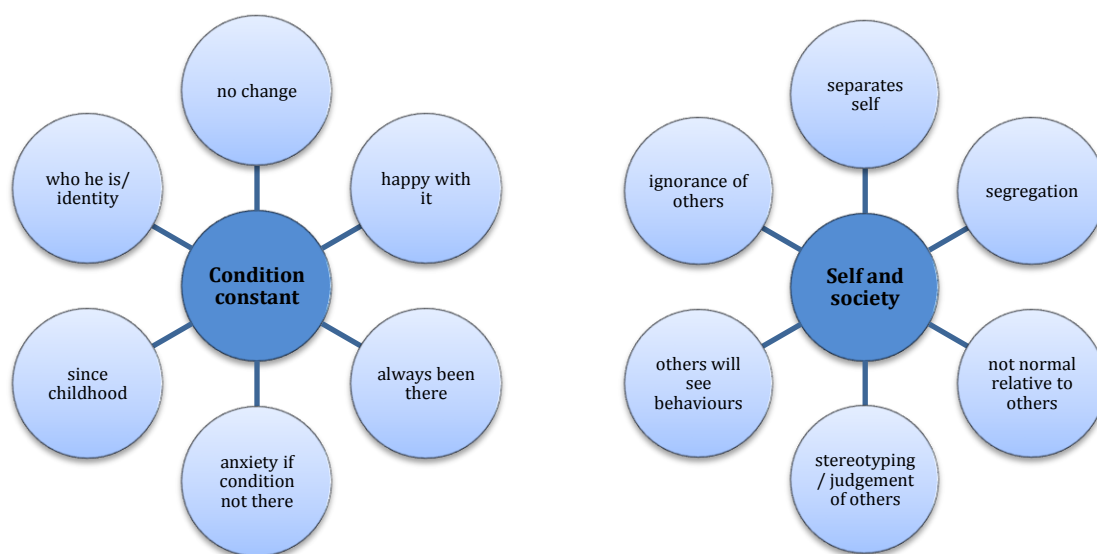


Figure 5: Example of how two emergent themes were constructed from one interview.

- Step 5: Moving to the next case

Using IPA to make meaning of more than one interview involves an 'idiographic commitment' (Smith *et al.*, 2009:100). I maintained this need to remain true to each participant's experience and working through the process described above, I focused

on each transcript before moving onto the next. However I recognised the need to 'bracket' emergent themes from previous interviews, which became increasingly difficult towards the end of analysing the entire data set.

- Step 6: Looking for patterns across cases

Bringing the themes together across all analysed cases, completes the final stage. This process captures divergences and convergences amongst participant experiences. The entire process set out by Smith *et al.* (2009), allows each case or interview equal time and care during analysis. To move onto developing superordinate and subordinate themes for all interviews, I wrote all themes from each interview and proceeded to group them (see Figure 6 for example). These groupings were then placed into a table of frequency, which Smith *et al.* (2009) suggests helps clarify whether a theme is representative across all cases and subsequently whether it should be included (see Appendix 8 for table).

Moving onto creating superordinate and subordinate themes involved grouping and regrouping the emergent themes in different ways: continuing to make sense of them in the context of each other. Some emergent themes held their own such as 'connection to others', 'stigma' and 'validation via diagnosis' and easily fell into place leading to a superordinate theme. Others required clarification; 'owning mental ill-health' became the superordinate theme 'integration and reframing' and the two emergent themes related to control became the subordinate themes 'turning point' and 'impact on life'. On further reflection and discussion in supervision, I realised some emergent themes were more of a by-product of the conversations in the interviews and unrelated to the research aim (e.g variations in service provision). Once the superordinate and subordinate themes were collated I revisited the transcripts to further verify the choices made. In doing this I brought together selected quotes across all interviews that evidenced the convergences and divergences within the subordinate themes (see Appendix 9 for example).

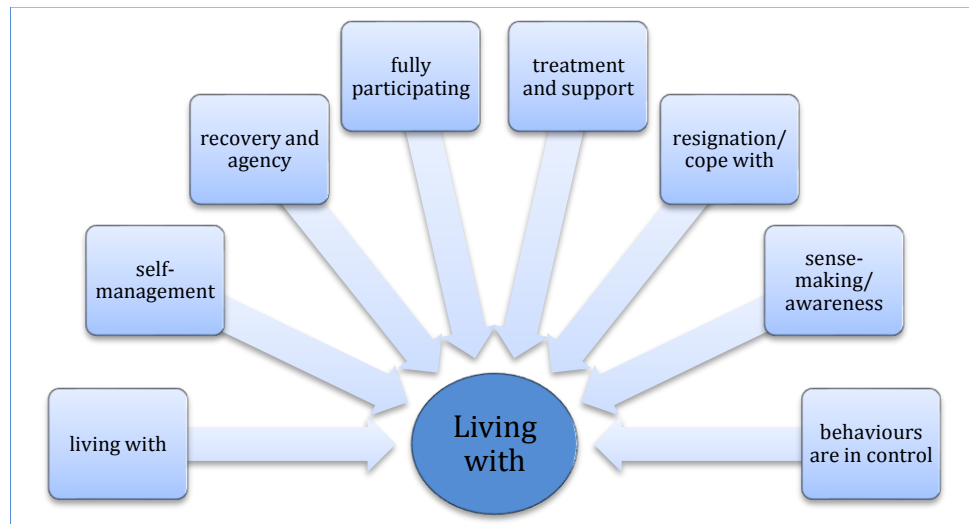


Figure 6: Example of collated emergent themes across all cases to form subordinate theme.

Having explained the implementation and application of Study 1 methods, the same is explored below for Study 2.

## Study 2: Implementation of focus groups

In planning Study 2, I took guidance from numerous authors (Krueger & Casey, 2015; King & Horrocks, 2012; Hesse-Biber & Leavy, 2011; Kitzinger, 1995). The process of setting up focus groups incorporated a number of different decisions that supported the aim and objectives of this research and complied with the time and resources available. Initially attention was given to the homogeneous or heterogeneous nature of the groups, including how many groups to hold and criteria for attendance. The decision on the process of recruitment, development of the discussion guide, ethical and logistical considerations are discussed below.

## Sample

### Statutory and non-statutory services

As the research aim was to capture staff views in different settings, I chose to invite staff members from separate and defined areas within health services: third

(voluntary) and statutory (National Health Service, NHS) sectors. Having worked in both sectors I was aware of the provision of services to those with mental illnesses and differences in approach. On reflection of these differences I decided upon running three focus groups capturing the views of third sector staff, medical staff and Allied Healthcare Professions (AHPs).

The well-structured process of receiving a mental health diagnosis in the UK influenced the staff groups chosen for Study 2. Certain professionals are qualified to give a diagnosis: General Practitioners (GPs) and consultant psychiatrists. Due to this the views of these two groups of professionals were of interest and naturally led to their inclusion. The group of AHPs encompasses a huge range of professions including nursing, physiotherapy, psychology, midwifery etc., however the constraints of this research led me to involve one: Occupational Therapy (OT). The justification for this was in part due to having established contacts within the profession, however it goes beyond this to an interest in challenging my perception of service users' experiences and service provision as an AHP. Having practiced for a number of years as an OT, I was interested in hearing the responses of my 'colleagues'. This was to further clarify the influence of my profession on my personal views and consider the insider/ outsider aspects of my role as a researcher (see Chapter 6 for personal reflections relating to this).

The criteria for attending the focus groups differed slightly between the third sector staff and those working in the NHS. It was necessary that the latter group were qualified as healthcare professionals and, due to NHS ethical approval process, were employed by the named health board. Participants were to have at least three years' experience in working in mental health services (to allow for a level of knowledge and self-care), were able to give informed consent, happy to contribute to group discussion and able to follow conversation in English.

### Homogeneity

Researchers often choose a homogeneous group for the obvious advantage of capturing a shared viewpoint (Kitzinger, 1995). However this choice requires reflection and justification. The decision to use participants from specific staff

groups, aligned with my wish to capture the particular view of these groups. It was important that those invited worked directly with people with mental illnesses but in different settings. Although homogenous in nature, the focus group design incorporated 'segmentation': using homogeneous groups for comparisons *between* groups (Hesse-Biber & Leavy 2011:179). Therefore standardisation of the approach to each group was important; each would be set up and run the same, creating a platform for robust comparison between groups (rather than adapting as the research progresses as with grounded theory).

## **Recruitment**

As mentioned there are advantages and disadvantages to homogeneous and heterogeneous groups. Although Krueger and Casey (2015) warn of capitulation within groups, Kitzinger (1995:300) suggests that bringing together 'naturally occurring' groups would likely lead to a 'naturally occurring data'. To support this natural discussion, each of the focus groups was recruited from teams with experience of working together. This also aided the logistics of bringing them together through naturally occurring team meetings. Recruitment varied for each of the three groups and was a combination of contacting previously known managers alongside making new contacts. Gatekeepers for each of these groups were identified and approached during the process of applying for ethical approval and contact was maintained to help expedite the process once approval was granted. Different methods were used to recruit: one team was given little choice in attending through their manager imposing this decision on them; one manager requested I gave a presentation and the final manager invited his staff to attend. See Appendix 10 for the Participant Information Sheet (PIS) and Appendix 12 for the consent forms that accompanied recruitment to the focus groups.

## **Sample size**

Kitzinger (1995) proposes the ideal number of participants for a focus group is between four and eight. This is echoed by Hesse-Biber and Leavy (2011) and similar to Krueger and Casey (2015), who advise no more than ten. Too few as well as too many participants may lead to discomfort in engaging with the topic. I therefore,



through discussion in supervision, settled on a minimum of four and a maximum of ten for each of the focus groups. Final group numbers were as follows; third sector staff, six; OT, seven and medical staff, four.

### **Development of discussion guide**

An integral part of the novel design of the current research was the use of emergent themes from Study 1, in Study 2. Consequently questions relating to the themes (see Appendix 1) were used to start the group discussion. The introduction of the emergent themes at this point played a vital role in setting the tone for the remaining conversation in each of the focus groups. Although literature was accessed to inform the development of the discussion guide, the decision to use the emergent themes in this way impacted on the questions chosen.

Authors propose different ways of developing a discussion guide for use in focus groups, nevertheless there is a theme of using a funnel down approach. I adopted this approach and started with broad areas and further refined these in relation to the chosen research topic. Krueger and Casey (2015) suggest beginning with easy to answer questions to help promote discussion before moving onto the more important ones. Fact-based 'Opening questions' are followed by 'Introductory questions' and 'Transition questions' (core to the researchers interest) before concluding with 'Ending questions' (Krueger & Casey, 2015, see Appendix 11 for examples of questions mapping onto this structure). This process of developing a discussion guide was followed and led to six questions with related prompts and probes: an initial question for introductory purposes, followed by two on emergent themes, one regarding service provision and closing with two for summary and reflections (see Appendix 13 for discussion guide).

### **Logistics**

All options of times and days for the focus groups were given to each of the gatekeepers. The most suitable time suggested by the gatekeepers was during working hours, therefore consideration was given to the appropriate length of time for the focus groups and time constraints on staff taking part. Although Kitzinger

(1995) hints towards the flexibility needed in the duration of a focus group, one hour maximum was decided upon to fit in with the scheduled meetings and cause least disruption to clinical/ contact time. I facilitated the groups with this in mind and two of the three groups finished within this time. For ease and least disruption the focus groups took place at the organisations in which the participants worked and consent (see Appendix 12) was given at the start for video and audio recording of the groups.

### **Ethical considerations**

Ethical approval to conduct the focus group with third sector staff was granted by Cardiff Metropolitan University, 22<sup>nd</sup> October 2015. Reference: 7143-SREC-2015. Ethical approval to conduct two focus groups with NHS staff was granted by Cardiff and Vale Research and Development, 21<sup>st</sup> April 2016. R&D reference: 15/MEH/6305 IRAS reference: 191499.

At each stage of recruitment the right to withdraw was explained and reiterated. Due to the nature of focus group discussion, withdrawing comments was not feasible as it would disrupt the flow and subsequently other comments would therefore be made out of context. The right to withdraw during the group was given as an option, with the knowledge that what was said up to that point would be incorporated into the analysis. Notwithstanding this approach, each participant received a copy of the particular focus group they attended (i.e. for reference only). Due to the topic being emotive for some, I asked an AHP researcher to accompany each focus group to help support any participant should the need arise. This additional support was not necessary and the resource sheet given at the start sufficed, the additional role taken on by the accompanying AHP was therefore of note taking and videoing.

### **Application of TA**

Clarke *et al.* (2015) argue that themes do not passively 'emerge' from the data. They result from the researcher creating them from the entire data set by using their previous knowledge, theoretical position and experience. Although this by its very nature is a unique process, Clarke *et al.* (2015) aid the researcher in doing this by setting out six phases to use of TA. I followed this guidance and the phases, and

examples of how I employed them are given below. As the process of analysis offers some similarities with IPA, the narrative shows brevity in explanation.

- Phase one: Familiarisation

To begin the process of analysis, familiarisation of the entire data set is essential. Clarke *et al.* (2015:231) suggest this reading and rereading is undertaken at least twice approaching the data in a 'curious and questioning' manner. They propose questions to consider whilst conducting this phase and note-taking to help capture observations made about the data. I began this process by transcribing each of the focus groups using both audio and video recordings for accuracy. Clarke *et al.* (2015) warn that the process of transcription, although helpful, does not replace the need to read and re-read the transcripts. I made notes immediately after each of the groups to capture anything I felt stood out, such as group dynamics which were of interest to me, but not relevant to the research aim (and therefore should not be attended to in the analysis).

- Phase two: Coding

Clarke *et al.* (2015) emphasise the importance of this phase in forming the basis for the development of themes. They warn against the urge to formulate themes directly, as coding is an activity that allows the researcher to identify items of importance in relation to the research area. The coding and, therefore resultant labelling, should be focused on two levels: 'semantic and latent': the former focusing on description and the latter on the hidden aspects of the discussion (Clarke *et al.*, 2015:235). This phase can be supported by the use of software programmes and as labels can be altered and added to during this phase: Clarke *et al.* (2015) advise it is more beneficial to over rather than under-code in this phase. They suggest two rounds of coding at the semantic level before moving onto latent coding. This second level of coding builds on the semantic coding and 'moves beyond what is explicitly stated to consider the frameworks the participant uses to explain their world' (Clarke *et al.* 2015: 235).

Following this advice on coding I worked through all three transcripts. Coding became quicker as I worked through to the final focus group, this was in part as

similar codes were found but also due to focusing on the research aim (which I had omitted to do at the start). To help clarify the coding I used two different colour pens and noted the short phrases in the left margin. I also engaged with NVivo software, transposing sections of the transcripts into the management programme (QSR, 2014). Table 3 shows an example of the coding of one extract where participants discuss stigma.

- Phase three: 'Searching' for themes

The purpose of this next phase is to connect the codes to develop something that does not exist already. In creating something new Clarke *et al.* (2015:236) believe a theme has a dual purpose: it '*both* identifies a coherent aspect of the data *and* tells you something about it' (italics used by authors). Clarke *et al.* (2015) the essential themes have a central idea that aids in organising the codes and suggest a maximum of three levels of themes. One way of helping this process is through the use of thematic mapping, which Clarke *et al.* (2015) suggest help the researcher reject, retain and refine themes through gaining an overall perspective.

To begin 'searching' for themes I re-read the codes and noted phrases to group the codes using the right margin and a different coloured pen. As I progressed through the three transcripts I became aware of similarities occurring through the data set. I then turned my attention to NVivo again, to help formulate a figurative representation of these themes (see Figure 7).

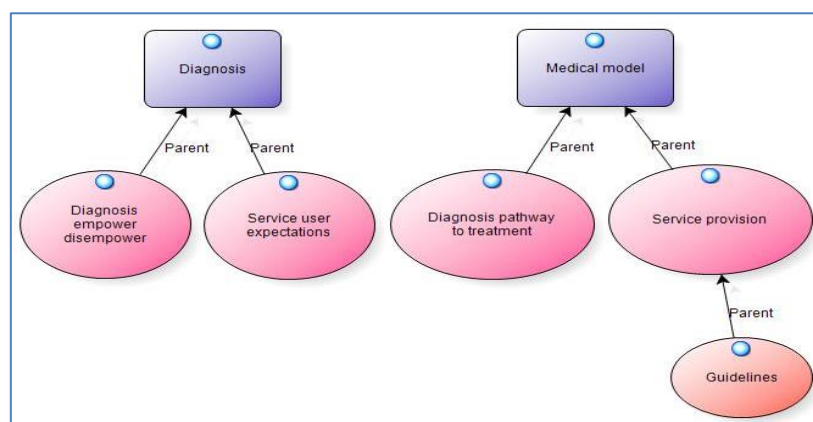


Figure 7: Thematic map of two emerging themes from entire data set (NVivo).

Quotes from focus group with medical staff	Initial semantic and latent coding
<p>M1: <i>...but I don't think stigmas are necessarily negative, the definition of stigma I suppose is, but I, I think that a label, I don't think is necessarily negative and I think it can be helpful</i></p> <p>M2: <i>hmmm, it's important for some people</i></p> <p>M1: <i>yeah</i></p> <p>R: <i>and that's the difference is it, if you use the word label rather than</i></p> <p>M1: <i>possibly yeah</i></p> <p>R: <i>so it's an understanding</i></p> <p>M1: <i>yeah</i></p> <p>R: <i>of what's going on</i></p> <p>M4: <i>but some people, they don't like the word label</i></p> <p>M1: <i>yeah I see</i></p> <p>M4: <i>label (laughs)</i></p> <p>M1: <i>(laughs) coat hook, I don't know</i></p> <p>R: <i>'cause it's too, too linked with stigma?</i></p> <p>M4: <i>yes, label</i></p> <p>M3: <i>I think that it's, it's difficult isn't it 'cause often people say I don't want a label but what they want is a, what they want is validation</i></p> <p>M1: <i>yeah</i></p> <p>M3: <i>they want someone to say yes, there is something wrong that's not going right and this is what we call it, you know</i></p>	<p>Challenging assumption that stigma is negative</p> <p>Semantics used to separate stigma from label. Suggesting one is negative (stigma) and one is neutral (label). Label helpful, stigma not so – can the two be separated? Good from bad?</p> <p>Important to <i>some</i> but not to others? Perhaps to those seeking an explanation and understanding as opposed to those just seeking symptom relief? Why is it important to some but not others? Can they predict how helpful a diagnosis is to the patient? Does this change their approach?</p> <p>Uncertain whether in agreement. Was this difference not considered before?</p> <p>Recognise the importance of gaining an understanding for some patients.</p> <p>Is 'label' seen as the same as stigma for some? Branded? Staff trying to separate the helpful from the unhelpful aspects of receiving a diagnosis.</p> <p>Shared understanding of difficulty of the language used (label).</p> <p>Laughter indicates language available is not fit for purpose. Uncertain appropriate language exists to suit the need.</p> <p>Label still too close to stigma - historical roots?</p> <p>Recognition of difficulty separating stigma from diagnosis. Clarification given showing the underlying motivation for patients seeking a diagnosis. Validation links with findings of Study 1 and what participants felt they gained, i.e. recognition from staff</p> <p>In agreement</p> <p>Patient seeking recognition, explanation and understanding of problem. Medic has role of 'expert'; able to provide validation during consultation and subsequent diagnosis. Providing comfort and control to patient</p>

Table 3. Extract from focus group with medical staff showing initial coding. (M= medical staff & R = researcher.)

- Phase four: Reviewing themes

This phase encourages researchers to check the development of the themes on two levels: in relation to the coded data and the complete data set. Once the researcher has reread and coded the data and is content with the themes, they move on to review these in relation to the entire data set. This may result in disparity between the data set and developed themes and the researcher may need to return to the raw data and re-code to resolve this. Although not suggested within this phase, due to the time that had elapsed, I found it of help to revisit the raw data in order to refresh it in my mind before moving on to focus on the coding and themes. I adapted the thematic map, adding the codes for each transcript and representing their relationship with the themes through connecting arrows. Although this resulted in a complex diagram, it allowed me to gain confidence that the raw data, coding and themes were representative. As a final way of clarifying what had become a complicated and untidy thematic map, I created a further map in NVivo (see Appendix 14). This acted as a reference point for checking across the entire data set and at this stage I felt confident to move onto the following phase.

- Phase five: Defining and naming themes

This final phase in the analysis focuses on the transition from themes to writing up. Previous phases will have helped in the development of a robust thematic map that the researcher will be '(reasonably) confident' in (Clarke *et al.*, 2015: 240, brackets authors own). One helpful step to take the researcher from the map towards writing up is to produce a short summary of the definition of each theme. This I did and, as suggested, it encouraged development of the interpretative narrative that surrounds and supports the quotes used from the data. This phase, as the title indicates, involves the important decisive stage of naming the themes: the essential aim of this is to capture the essence of it, allowing the reader some insight into its content. This began by listing the themes found and grouping, reminding myself of the relationships between them (see Figure 8 for example). These themes allowed me to recognise what was drawing them together and concentrate on finding a phrase that

would represent this. At this point I realised one theme I considered to stand-alone (patient lost in system) was implicit in another (pressures on practice).

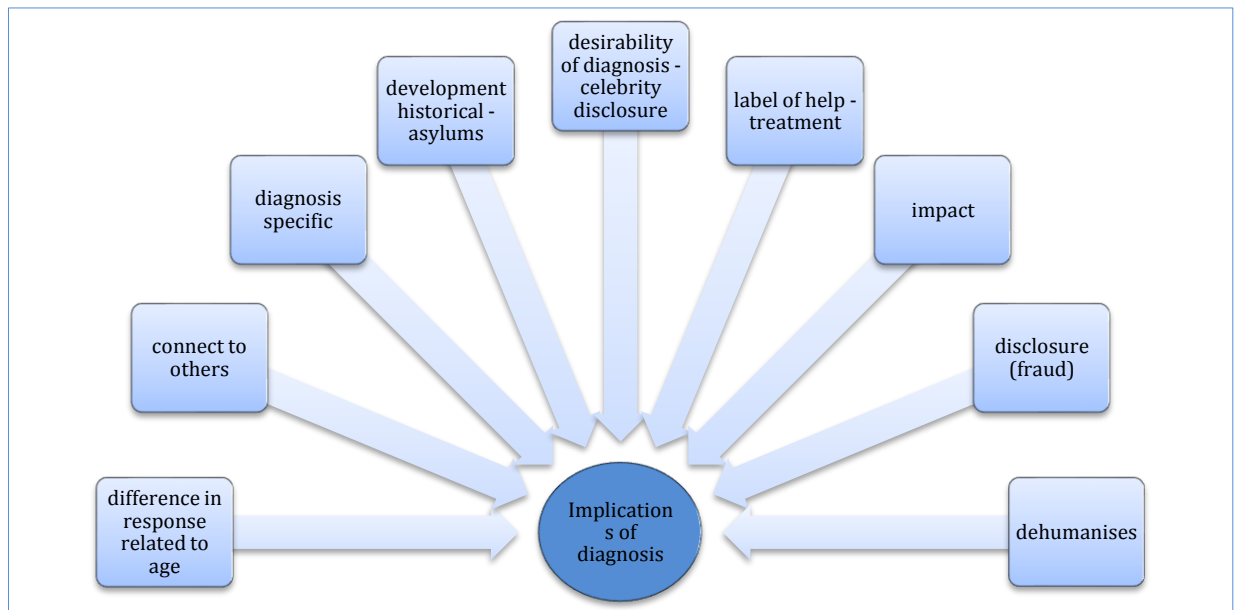


Figure 8: Development of sub theme across entire data set of focus groups.

#### - Phase six: Writing up

As Clarke *et al.* (2015:241) point out 'there is no clear separation between analysis and writing in TA'. In stating this they show their belief that writing up is threaded through the entire process of analysis and suggest a maximum of six themes for a report. The process of writing up is also intrinsic to the development of the analysis and it is at this stage that researchers need to make choices about the weighting given to the quotes and narrative in the write up. The authors also point out the need to consider whether the associated literature is incorporated into the write up of the results or represented separately. My choice of representing the literature separately, rather than threaded through the results, was due to the overall design of the PhD research; Study 2 is intrinsically linked to Study 1 and consideration of appropriate literature would take place once overall findings were concluded (in Chapter 6).

Above I have explored the applied use of the methods set out in part one of this chapter. To conclude Part two, the use of reflexivity in research will be explored,

which includes a framework to ensure validity (used in relation to the current research in Chapter 6).

## **Validity in research**

There are numerous guidelines available to support researchers in producing quality research. Willig (2013) points out that most of these include reflexivity, credibility and transferability as a way of ensuring 'good' qualitative research. In her paper *Dilemmas in qualitative health research*, Yardley (2000) explores the need to assess the value of qualitative research. As she notes quantitative research has a 'well-established and widely acknowledged' basis for scientifically checking validity (Yardley, 2000:216). However differences between the two approaches, notwithstanding their complementary nature, do not allow an ease of transposing quantitative approaches to validity onto qualitative research as Creswell (2013) notes. To address this, Yardley (2000) proposes characteristics to benchmark good qualitative research: sensitivity to context; commitment and rigour; transparency and coherence; impact and importance. These provide the framework for exploring the quality of the current research (see Chapter 6). The practice of reflexivity is a suggested way of evidencing and achieving the characteristics that represent good qualitative research, therefore it is briefly introduced below.

## **Reflexivity in research**

Shaw (2010:233) argues 'reflexivity is integral to experiential qualitative research'. It is the process by which the researcher acknowledges their role and influence in the research conducted. Reflexivity encourages a 'critical attitude' towards research processes; from design, through to fieldwork and analysis (Gough, 2003:22). Acceptance that both researcher and participant have a history of experiences, allows opportunity for explicit representation of this. However although seen as good practice, Nicolson (2003) argues, there remains a lack of consistency amongst researchers to evidence the relationship with their research. The need for reflexive practice is two-fold; not only does it help the researcher manage the impact of their presuppositions on their research, in doing this it also facilitates a measure of objectivity that aids validity (Finlay & Gough, 2003). For Smith *et al.* (2009), the



incorporation of reflection is intrinsic to the use of IPA and helps incorporate the unconscious as well as the conscious and deliberate. Indeed Shaw (2003:340) argues that through the use of reflexive practice, the research becomes ‘even more successful and enlightening’.

### **Definitions of reflexivity**

The terms reflection and reflexivity are used widely within qualitative research literature. Some argue that reflection occurs *after* an event whereas reflexivity takes place *during* an event. Others place more focus on the level of awareness gained through the practice. Shaw (2003:236) argues that reflexivity provides greater insight and to facilitate this understanding ‘involves reflecting your thinking back to yourself’. For the purposes of this current research the view that reflective practice facilitates the development of reflexivity is adopted (Alvesson & Sköldberg, 2009). There are also numerous definitions of, and guidance for, reflexivity. Willig (2013) highlights the different levels of reflexivity that can be adopted by the researcher: personal and epistemological. The former focuses at an individual level and the latter has a much broader approach assessing the influences over the design of the research. Capturing both of these levels Finlay (2003:4) defines reflexivity as the ‘*project of examining how the researcher and intersubjective elements impact on and transform research*’ (authors own italics).

### **Reflexive practice**

Gough (2003) explains there are a number of different approaches to applying reflexivity. In his writing he reiterates the importance of the influence of the researcher’s theoretical approach in their choices on how to implement this, as well as the method chosen. Reflexivity is indeed an integral part of IPA due to its philosophical underpinnings and is a way of ‘bracketing’ before, during and after engaging with the data. Therefore within the current research reflection and reflexivity are apparent in the process and evidenced in Chapters 1 and 6 as well as below. Early on I reflected on my experiences of being a healthcare professional using the ‘strands of reflection’ model (Fish & Twinn, 1997). This enabled me to

connect my personal view of the world to my choice of research aim and design, including my 'non-negotiables' (see Chapter 1).

I began the reflexive process by following the suggestion by Gough (2003), to question the research title. This (alongside the 'strands of reflection') enabled recognition of the theoretical framework, my motivation, my choice in method and subsequently the ontological and epistemological beliefs, which I have made transparent in this chapter. During the data collection process I also took time to reflect on each interview and focus group conducted. These reflections captured my feelings and judgements with the intention of distancing myself from them (for purposes of analysis) and the incorporation of them (for reflexive purposes). This was aided by a journal kept throughout the duration of the research, in which I noted my responses to the processes of research in more general terms.

Reflexivity is an integral part of the research methods chosen, therefore this thesis has represented this practice at different stages. To aid transparency and rigour further, below I provide brief profiles of the participants involved to frame the following findings chapters. To continue to evidence this practice, I also offer personal reflections on my fore-structure as a therapist in relation to the findings chapters (4 and 5) before presenting them.

### **Participant profiles**

The following interview participant profiles give a brief overview of each participant without disclosing their diagnosis. The focus groups' participant profiles follow, in a more generic sense, attending to the setting and make up of the team, rather than each individual. Although information on their specific diagnoses was freely given by all participants during the interviews, I am choosing to omit this to reduce the chance of it becoming the focus rather than the research aim: to explore the experience of receiving a mental health diagnosis (i.e. any). The reason for not specifying a diagnosis in research design and aim, relate to my strongly held view of the idiographic nature of experience: regardless of shared diagnoses, experience will be unique. This choice is also supported by the fact that diagnoses can change over time, therefore the specificity of the condition becomes secondary, as well as the fact

different medical staff may give different diagnoses to the same service user. These reasons were all evidenced by the lived experience of the RAP, who were consulted on my choice against specificity.

#### Interview participants

*Zoe* (41) is a single mother working in a mental health charity. Over the period of a decade, she was diagnosed with different mental illnesses by different practitioners. Zoe has lived both independently and with her parents during this time and has a supportive family and social network. She has become very open about her mental illness and has used her lived experience to support others.

*Tony* (50) viewed his experience of receiving a diagnosis as an iterative one. Reflecting back after receiving it he recognised the difficulties he experienced as a young man, could have been attributed to the condition. Although he was cautious about disclosure in his career environment, he volunteered in a mental health charity using his business expertise.

*Steph* (20) is a bright and insightful lady, who was simultaneously open and cautious about disclosing her condition. She recognised the deeply complex process of acceptance of having a mental health diagnosis but felt it an integral part of her. She volunteered at a mental health charity and highlighted the need to reduce the stigma attached to mental illnesses.

*John* (60), although unable to recall the experience of receiving an initial mental health diagnosis, he was coherent about the impact it had had on his life. Being diagnosed as a child, he had lived a life dominated by the condition and had developed a coping mechanism which had led to an addiction. For John, his condition was all he knew and he felt little was likely to change with respect to this.

*Rupert* (43) was diagnosed with a mental illness, which acted as a gateway to support. The quality of his life had deteriorated over many months and, although cautious in disclosure, his contact with others with lived experience has had some beneficial

impact. He holds some regret over the changes that have taken place and was resigned to having a mental illness and the life he lived.

*Lisa* (26) had been in a violent relationship in her later teenage years, which had affected her mental health. This led her to receive a diagnosis for a mental illness that was explained as a consequence of this experience. For Lisa the maintenance of her mental health was of constant concern, although she indicated some hope for a return to her confidence and energetic past self.

*Keith* (48) whose mental illness had caused him to leave work and prompted a career change, now used his lived experience working in a mental health charity. Over the years, with support from his partner, friends and services, Keith regained his sense of volition and had developed a more balanced view of his experiences. He subsequently regained his fulfillment in life and was encouraging others to do so.

*Joseph* (26) despite some disruption caused by his mental illness, had graduated from university and was in full-time employment. He had suspected accessing services would result in a diagnosis and although in agreement with it, he maintained that an additional diagnosis would help him (and others) make sense of the way he currently experienced the world.

*Katherine* (22) is a very driven and passionate lady who completed a Masters in a subject related to her lived experience. Having survived a violent relationship, she accepted the link between her experiences and her mental illness and now worked for a charity supporting others. Disclosure was not an issue for Katherine and she maintained that being open would help address the stigma surrounding mental illness.

*Simone* (45) had found support from services of great help before and after receiving a mental health diagnosis. Having endured a violent relationship and abuse as a child, she had come to a place of acceptance of herself and recognised the benefit of self-care. Discovering a latent creative talent, Simone hoped to channel this into helping others see their own worth.

## Focus group participants

*Mental health charity workers.* The group was formed of six staff members ranging in age from approximately 20 to 45. A tight team that worked together supporting tenants with mental illnesses in the community, each had their own opinion and communicated well, offering their insights respectfully. Their views converged on the rights and needs of the service user over and above, those of the mental health system.

*Medical staff.* These four staff members, three of which worked in the same practice, brought both community and statutory experience. The group, all approximately in their 40s, and made up of one GP and three consultant psychiatrists, culminating in decades of experience working in mental health. Through the discussion they indicated a person-centred approach, however they highlighted the lack of resources that interrupted this.

*Occupational Therapy staff.* Seven members of the Occupational Therapy mental health department took part in the focus group, aged approximately 25 to 55. They brought with them knowledge of in-patient and community work across many different settings. Although coming with a variety of experiences, they all converged with a healthcare professional group identity and advocated the philosophy of the profession.

## **Therapist as researcher**

Bringing reflexive practice into qualitative research enabled me to develop a deeper awareness to the influence of my approach to the current research. The profile given in Chapter 1 introduced the motivation and interest in the subject, here however an overview of the process of 'bracketing' noted earlier is given attention. As a healthcare professional I had to *consciously* adopt a researcher approach to the data collection and analysis. This was prompted both in discussion with my funding body and my supervisor and was an aspect I had not previously been mindful of. Bringing awareness to this allowed me attempt to set aside my urges to act as a therapist and

instead focus on the goal of the research. This came to the forefront with the greatest effect when participants were sharing suicide ideology. Another clinician-researcher, suggested in such instances there would be opportunity to offer information or pick up and review risk, post-interview. I found this advice invaluable as it enabled me to stay in researcher role throughout the interviews and follow-up the risk once they had finished.

To facilitate 'bracketing', I employed the technique of mind-mapping pre and post contact with participants, as well as reflections pre and post the entire data collection period. This brought the influence of my background and interest to the forefront and enabled me to recognise my role as a researcher in the current research. This is an aspect encouraged to Finlay and Gough (2003) to create a complete picture a piece of research. Of interest to me was the influence of this on my focus when running the focus groups and the subsequent analysis. I found it natural to judge the position taken by each staff group, not least the charity staff and OTs, in relation to the medical staff. Having worked in both setting it was natural for me to 'side' with these groups and share opinions and equally approach the medical staff with more cynicism. Being aware of this, I was able to recognise the impact this would have in skewing the research focus and I was able to hear and acknowledge, the person-centred practice of the medical staff. This enabled me to draw a more balanced view of the data due to the reflexive practice.

Another area that deserves a note of reflection due to its influence, was the impact of the interview participants personally. To my surprise I became emotionally drawn in to participant stories and on a few occasions I found the writing 'debrief' of help in letting these stories (and therapy tendencies to 'rescue') go. Nevertheless it remained an uncomfortable (and humbling) aspect, that I would not again see the participants yet they had given so much of themselves for my gain.

The above reflections give an indication to some areas of influence of the role of the researcher in the current research. They evidence the need for reflexivity to provide transparency and create rigour in research and go some way to create context for the following findings in Chapters 4 and 5.

## Chapter 4: Study 1 findings

### Introduction

The interview schedule used in Study 1 was designed to focus on the experience of receiving a mental health diagnosis. Therefore questions encouraged participants to share experiences that led to, and resulted from, receiving the diagnosis. As explained in the Methodology (Chapter 3), IPA was used to analyse the transcripts and the introduction to this chapter gives an overview of superordinate and subordinate themes that resulted from this (see Table 4).

Superordinate and subordinate interview themes			
Superordinate theme	Subordinate theme	Subordinate theme	Subordinate theme
<i>Pre-diagnosis</i> <b>Sense-making: the need to understand and be understood</b>	Impact on life	Turning point	Validation via diagnosis
<i>Post-diagnosis</i> <b>Discernment of ‘them and us’; self-perception and society</b>	Stigma	Selective disclosure	Connection to others
<i>Post-diagnosis</i> <b>Assimilation of mental illness into everyday life</b>	‘Living with’ as opposed to recovery from	Integration and reframing	

Table 4: Superordinate and subordinate interview themes.

Receiving a mental health diagnosis was by no means a simplistic process for participants. The process of receiving a diagnosis started prior to the point of being diagnosed, subsequently the first superordinate theme captures experiences pre-diagnosis. The remaining two superordinate themes encapsulate the complex, multi-faceted post-diagnosis participant experience.

There is a notable difference in how each of the subordinate themes relate to each other within the given superordinate themes. The first superordinate theme *Sense-making: the need to understand and be understood*, incorporates three subordinate themes which follow a clear linear path (see Figure 9). The *Impact on life* the symptoms had, led to a *Turning point*, where action was taken to access support and subsequently receive *Validation via diagnosis*. This consecutive link between these first subordinate themes was not repeated in the remaining subordinate themes. Post-diagnosis subordinate themes were interwoven and inseparable in their influence over each other.

The second of the three superordinate themes is *Discernment of 'them and us'; self-perception and society*. It contains three subordinate themes: *Stigma*, *Selective disclosure* and *Connection to others*. This part of the participant story highlights the start of adjustments that occur post-diagnosis where new information is being incorporated and support is being accessed (see Figure 10). The final superordinate theme, *Assimilation of mental illness into everyday life*, refers to a longer-term response to receiving a diagnosis. The two subordinate themes '*Living with*' as *opposed to recovery from* and *Integration and reframing* represent changes in response to living with mental illness (see Figure 11).

What follows is a detailed explanation of each of the subordinate themes found, with quotes used as supporting evidence. The first set of subordinate themes echo the linear process noted above and the remaining are presented to represent the interwoven journey of post-diagnosis that participants experienced.

### **Superordinate theme 1: Sense-making: the need to understand and be understood**

This first superordinate theme incorporates the time up to and including the experience of receiving a diagnosis. Experiencing symptoms of a mental illness came without a framework to make sense of what was happening and during this time participants often felt overwhelmed and lacked agency to action change. Differences were noted in the self, in relationships, their sense of control and ability to function or be productive. Either with the help of others or alone, recognition developed of the



need to initiate change and interlaced through this was a need to make sense of what was happening.

This process involved awareness and acceptance of an inability to cope. Accompanying this admission was the realisation that a mental health diagnosis was likely. Any initial informal contact for support led to more formal routes being accessed and the process of diagnosis began. Although participants took different paths to gaining a diagnosis, all accessed support from other services alongside receiving medication. Importantly for the majority of participants diagnosis came with a framework to make sense of their symptoms as well as justification for changes that had occurred over the preceding months and, in some cases, years.

The following narrative explores the three subordinate themes in the superordinate theme of 'Sense-making': *Impact on life*; *Turning point*; *Validation via diagnosis* (see Figure 9). It begins with *Impact on life* and considers the first stages of participants acknowledging that things had changed and attempts to make sense of their symptoms.

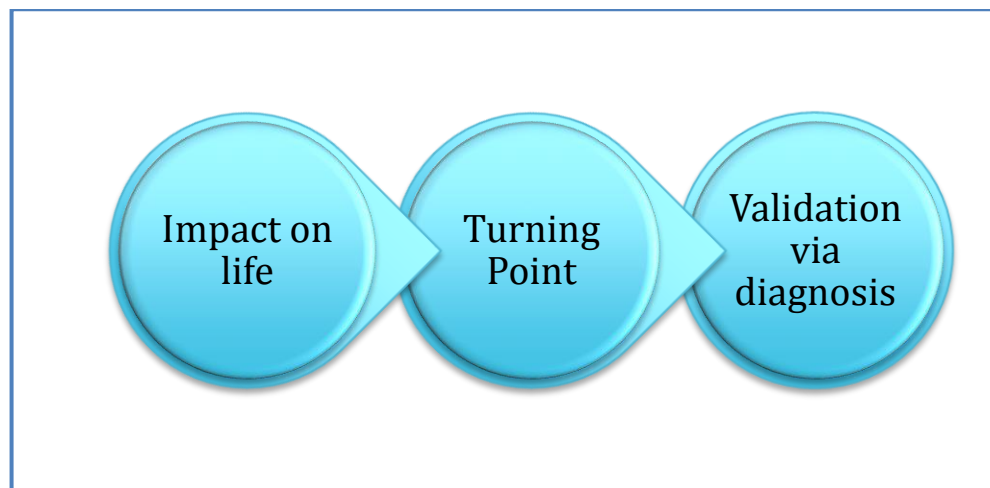


Figure 9: Pictorial representation of relationship between subordinate themes.

## Subordinate theme: Impact on life

Rupert: *'I used to socialise, holidays, everything, it's all gone' (983-984).*

Experiencing any major life-event could lead to life-changing consequences. For participants, symptoms of their mental illness created conditions for a major life-event. The effect of the buildup of their symptoms resulted in changes in their mood, behaviour and way of being in the world. During this time participants noted an increase in awareness of their symptoms, these included experiencing distressing thoughts, suicidal ideation, anxiety, very low mood, panic attacks and agoraphobia. Symptoms were explained from the perspective of having received a mental health diagnosis and therefore the language, knowledge and framework for understanding are in place, which were lacking pre-diagnosis. For many, changes were characterised by a gradual withdrawing from social contact due to a lack of personal resources to engage with others. This was highlighted by Rupert who had tried to cope with his symptoms over many months.

*Well I'd always been a happy-go-lucky person, out, sort of out, like I said I had a [job] so I used to know loads of people, talking all time for hours on end, but it just, I just couldn't be bothered, really really couldn't be bothered. I was getting effort to go out in the morning, really had to push myself, until like I said it got too much an' I just phoned my boss up an' I can't do it anymore (Rupert: 143-152).*

There is a definitive change in Rupert's behaviour from *happy-go-lucky* to *couldn't be bothered*. Over time his symptoms had a huge impact on his life and he became unable to cope. His emphasis of *really, really* indicates the extent to which he felt the pressure of his symptoms: a weight that required additional physical effort to continue his daily life. Stating *I can't do it anymore* shows his lack of agency in controlling these symptoms and there is a sense of having no choice in his use of the word *can't*. Repetition of *couldn't be bothered* hints towards a disbelief and indicates the difficulty in coming to terms with the impact of the symptoms.

Managing, or just coping with symptoms, became the focus for many participants. Subsequently other future life goals were either put on hold or disregarded; changing an expected life trajectory. Disruption to these goals impacted on lifestyle and for

John a lack of ability to continue in education influenced his career prospects in adulthood.

*...it was too much, to try and do my you know my routine and education I couldn't, my body couldn't cope with coping with the two then, and I chose, we'll say the [condition] (John: 1617-1620).*

John felt that it was *too much* to manage his mental illness as well as his daily life. He expresses the impact of his symptoms in terms of a physical concept; *my body couldn't cope*. As with Rupert, John noted how the physical manifestation of the mental illness, and the behaviours it elicited, interrupted his chosen life-goal of education. John states that he *chose* his mental illness over remaining in education, suggesting that he made a conscious decision to attend to the symptoms rather than education. Lacking an ability to manage the symptoms, John acquiesced rather than try and control them.

As the topic discussed was retrospective in nature, the passing of time aided sense-making, through reflection, on the progression and impact of symptoms. Due to the age of onset of her condition Steph, like John, contextualised the impact of her symptoms within the school environment. Although more subtle than the 'choice' John made, the impact the symptoms resulted in disruption to her schooling.

*...disturbances at school, not going to school, that was a big part of it as well, erm, so it'd been a very long time that I'd been suffering on and off, erm, there's also, sort of relationship issues, issues with erm, peers what else was there (laughs), sort of body issues, issues with my identity as well, had been present from quite a young age (Steph: 214-222).*

Steph notes her experience of symptoms, and subsequent behaviour, do not occur at one specific point. Rather they are *on and off* and her awareness of them parallels this, a point echoed by other participants, showing the nebulous onset of mental illness. Her use of the word *suffering* shows the oppression she felt accompanying a sense of limited control over her experiences. The incongruous laughter when listing her symptoms and a difficult time in her life, hint Steph's understand that her experiences went beyond the expected transitional adolescent period.

Interactions and relationships with others changed during the development of symptoms. A minority felt their mental illness caused relationships to change and

end. During the long-term relationship Tony had with his partner, she had seen deterioration in his mental health. She chose to end the relationship after diagnosis, which led Tony to question the cause of the break-up.

*I did lose my partner, undoubtedly because of it [condition], I think...now whether that was the effect of behaviour for 12 years before, or her having to deal with the diagnosis and not being able to support me through the diagnosis, I don't know, but er, fundamentally, er, the relationship ended, effectively (Tony: 638-649).*

Tony believed *undoubtedly* that his mental illness was the key influencing factor in his partner's decision to end their relationship. He goes on to say *I think* and in doing so shows he questions whether his judgement would be shared by his partner.

Reflecting back, Tony remains uncertain of the specific cause and assumes his partner would have felt pressure to *deal with the diagnosis* and *support me*. This suggests he recognises the impact his mental illness had on others; it was not only he who had to *deal* with the diagnosis. Use of the word *fundamentally* and *effectively*, shows Tony's resignation there would be no change in her decisive action.

Simone also acknowledged the impact her undiagnosed mental illness had on her relationships, which left her disempowered.

*I've been taken advantage of through that weakness by, men obviously, trying to control me with finances and using that, using me for sex, whatever it be, so abu', the word abuse comes into that because we are abused when we don't know how to think about our own sanity, what our own wants and needs in life, it is a very mixed up mind to be in because you're trying t' please everybody (Simone: 162-171).*

Simone viewed the symptoms she was experiencing as a *weakness*; leaving her open to exploitation. Others controlling her life led to her having a *mixed up mind* that did not allow consideration of her own needs. Expressing her experiences as *abuse* shows the strength of her feelings and retrospective insight into what was happening when men were *using me for sex*. She shifts from using first person to third when she begins to frame the experience as abuse. Consistently using the third person from then on indicates she now recognised there are others familiar with living in this type of environment.

The participant's process of 'sense-making', as the superordinate theme suggests, is motivated by the need to understand and be understood. The impact of the mental illness had on participant lives and a lack of understanding at this time, led to a point where action was taken to change the situation. This is captured in the subordinate theme *Turning point*, which will now be explored.

### **Subordinate theme: Turning point**

Katherine: *'...so I realised this isn't right, this isn't normal, I need to do something about it' (101-102).*

In the lead up to diagnosis, participants experienced a range of uncomfortable and often distressing symptoms. At different stages participants, or those around them, came to the recognition that the situation needed further response. Accompanying this was a process of awareness and acceptance of having a mental illness. This was not an immediate realisation, rather it came gradually through recognition of being unable to (or only just being able to) function in daily life. For a time Keith managed the changes in his mood by covering up his distress when outside the family home.

*...my mental health was getting erm, progressively worse, my ability to cope with just, just life in general really, and I was getting, I was sort of coping with the day and then coming home and just being upset and just tearful, crying you know and we were fortunate in that we had a family, a family friend who was a GP and my wife was erm, concerned enough about me to sort of ask for advice (Keith: 67-74).*

Keith's inability to cope with work extended into other *general* areas of his life. It became increasingly difficult to disguise the *upset* he masked in work, even given its outlet at home. Although Keith was able to recognise the deterioration in his mood, it was his wife who contacted professional support, showing he lacked the agency, or knowledge, to change his situation. He considered having a family friend who was a GP, *fortunate* as it provided a way of navigating the healthcare system. This perspective indicates the difficulty others may have gaining advice about their mental illness in the first instance.

For those who accessed support independently the turning point was prompted by a stage of contemplation of the self. This was the case for Joseph, who spent time reflecting on his mood in relation to others.

*...of course with any emotion, it's it takes a certain degree of introspection to almost even realise how you're feeling, I think that you know, it's not like if you're feeling a bit blue one day you get a letter saying, 'hello you are now sad', so often it's actually it's other people, who are like "are you OK?" and your instinct would be to go, "yeah of course I am" you know, but then you stop and you think about it and you go, actually (laughing) am I OK? (Joseph: 119-129).*

Joseph notes the instinctive nature of human beings to hide feelings that are not *OK*. This did not stop his mood being reflected back to him through the response and concern of others. The analogy of receiving a letter stating you are *sad* represents his wish for objective validation by others; for responsibility to be taken from him through a label being given to him. This resonates with his wider wish for 'sense-making' of his experiences via the medical profession. In this statement Joseph gives an impression of momentum; if no time is taken to *stop*, life continues regardless. Only in taking time to reflect is space created to *go* and question the status quo, prompting him to access support.

For some participants the point of coming into contact with services was prompted by suicidal thoughts. Both Lisa and Tony experienced suicidal ideation, however neither disclosed their thoughts. A change in Tony's behaviour was noted by his partner which led to her intervening.

*I started saying goodbye to people, they didn't know that, but in my mind, I was saying goodbye. Saw a load of friends, saw my family, er, went to see my father, and planned after Christmas and the New Year er, to end it all, er, and I think my partner must have twigged that and started phoning you know, counsellors and persuaded me in the end to go to the GP...I had a kind of ra', you know a bit of, a period of rational thinking for about a month, which enabled me to go er, into the ladder of treatment (Tony: 433-465).*

Tony was in contact with *loads of friends* and family members at the time of his thoughts of suicide. However this did not equate to a sense of being able to cope and hints at the isolation he was feeling. Even with additional support from his partner, he still took coaxing to access support. It was during *a period of rational thinking*, without judgement clouded by his symptoms, he was able to enter the healthcare

system which he describes using the analogy of a ladder. This gives a sense of an ascending process where steps are taken to access treatment and support.

Lisa acted on her thoughts of suicide and attempted to take her own life. This act led to her being admitted to the local toxins unit and her 'turning point' where she subsequently had a cathartic experience.

*...the first time, like I say, that that first erm, attempt at suicide, the night itself is is quite a blur, erm the morning after was when I was when I was with the psychiatrist...how do I describe it (pause) it was like, it was like somebody had sort of put a knife down the middle of me and opened me up and let everything out (Lisa: 442-451).*

Lisa explains the experience of sharing her life story through the analogy of being cut open. There is a sense of expelling the hidden violent relationship she was in, through the releasing action of telling her story. There could have been potential for such a deep cut to leave her vulnerable. However, Lisa did not feel defenseless or disempowered, rather she recognised the comfort and benefit she gained and subsequently talking became a main coping strategy.

For others the turning point came in a less intense and critical form. Taking action for Steph had an additional layer related to her age; an influence that delayed her turning point. Although she initially sought help, she subsequently disengaged with services until she was an adult and could make her own decisions and disclosures.

*I went back to the doctors again to say you know I still don't feel very well, I still don't feel (pause) like erm, I'm operating, or functioning normally I s'pose (laughs) people do say, but yeah it was very soon after my [age] birthday (Steph: 183-188).*

Steph's use of clinical language in *operating* and *functioning* is indicative of her contact with services. She acknowledges the use of this language through her laughter, recognising it is unlikely to be the language of her peers and she attempts to distance herself from it, stating that is assigned to 'others' i.e. healthcare professionals. Steph is also highlighting the fact she is aware of what is considered *normal* in society in relation to her experiences and interactions with others. This

perception gives her a baseline to consider differences in her own way of being in the world and echoes her earlier reflections in relation to her school peers.

The *Turning point* led to contact with mental health services. It was this contact that resulted in participants receiving a mental health diagnosis which essentially allowed them to make sense of their experiences and receive *Validation via diagnosis*.

### **Subordinate theme: Validation via diagnosis**

*Katherine: '...it was a relief more than anything, yeah 'cause I've not quite known what was wrong...an explanation for what was wrong with me and a pathway to help yeah' (409-450).*

Receiving a mental health diagnosis was not always accompanied by acceptance of a mental illness per se. Rather it was acceptance that they were no longer able to continue as they had been. Most participants felt little surprise on receiving a mental health diagnosis and within this there is acknowledgment that accessing services may result in diagnosis. The feeling of validation the majority of participants had on receiving a diagnosis, was accompanied with a sense of relief that something could be done to alleviate symptoms. In all cases the consultation resulted in prescribed medication, which further validated that they were 'ill', and importantly offered justification of their experiences.

The actual experience of receiving a diagnosis varied amongst participants. Some gained a diagnosis after a number of sessions and others received it in one appointment. These experiences incorporated the therapeutic relationship and the route taken to diagnosis i.e. private or public services. Tony described his experience of receiving a diagnosis, by paying privately, as lengthy and iterative.

*I think the key point for me is that it was a journey, it wasn't like walking into a room and you're diagnosed of, you know, with [condition]. I don't know if that's common, but it did seem to be the kind of journey that [Dr. A] was taking me on, erm, and you know the mood charts the mood diaries, the scoring every session, you know, trying a drug seeing what the affect was, erm and you know I guess you need a body of evidence before you can tell someone that, in the same way as a physical condition, you do blood tests, scans and everything else (Tony: 583-597).*



Using an easily accessible framework of physical illnesses, Tony is able to explain the process he went through. However it also indicates the sense of being an object tests are done 'to' rather than in collaboration 'with'. In needing to build up a *body of evidence*, Tony felt he was being treated as a *medical case* rather than a person. This is reinforced by the power imbalance he explicitly indicates stating that his psychiatrist was *taking me on a journey*, as opposed to journeying together. Tony accepted the necessity of this validating process to enable full understanding of his symptoms prior to diagnosis.

Rupert's experience, in contrast to Tony, did not involve a number of appointments and information gathering. He was diagnosed during the initial appointment with the GP and was not given his diagnosis verbally, rather he was left to surmise it through prescribed medication.

*They [crisis team] said see your GP sort of thing, so appointment and seen [GP], you just blurt out everything like that an' [medication], [GP]'s more-or-less writing out that before we'd finished (Rupert: 278-282).*

Similar to Tony's *medical case*, Rupert explains his experience as being part a routine procedure. In his statement the fact he jumps from one word to the next, often missing connecting words, appears to correlate with his experience, where the missing nuances characterise a lack of human connection. This represents the clinical coldness of the process, resonating with Tony's experiences. During this interaction Rupert did not gain the sense of being understood or validated that many participants reported.

Diagnosis for Keith, Lisa and Zoe was seen as a positive outcome. Having a healthcare professional reflect back in medical terms what they had been experiencing, allowed a new perspective on it. It took away the uncertainty and subjectivity and it became an 'illness'. Keith's experience with his GP was in contrast to Rupert's, although both were diagnosed within the initial appointment, Keith's GP took time to understand his experiences and continued supporting him.

*...the GP said that I'm ill, this isn't just me being weak this isn't just me being pathetic, this isn't just me not coping and needing to shake myself and you know, er this is me being, you know there is there is something wrong with me, and so*

*that, I suppose it takes that, sort of responsibility (laughs) off of you, and that sense of relief is huge (Keith: 296-303).*

Keith's attitude towards who is to take *responsibility* of the mental illness is shown here. Having contact with a healthcare professional who explained his symptoms as a mental illness, gave Keith permission to take the pressure off himself. The sense of *relief* being *huge* indicates the 'huge' pressure he also felt and he no longer needed to blame himself for *being weak* or *pathetic*. However his laughter shows he remained uncomfortable in his need for someone else to take responsibility.

In feeling understood and listened to, Lisa's experience of receiving a diagnosis echoed Keith's. Again there was a sense of validation through understanding they had an *illness*.

*...I'd say there was probably a few weeks previous to the suicide attempt where I was feeling depressed, but obviously didn't know what that was, erm, an' in that particular session with [psychiatrist] that was the first time I was made to realise it's actually ok to feel how I'm feeling, erm, this, you know it's an illness, this is something that (pause) I think the way it was described to me, there's you know, there is a part of my mind that is very much overwhelmed, and as much as I've tried to control it, I can't control it (Lisa: 458 - 468).*

The diagnosis for Lisa was a liberating moment. It was *the first time* she was *made to* acknowledge the way she was feeling was a legitimate reaction to her circumstances and experiences. This gives an indication that she had dismissed this explanation in the past and the *first time* she accepted it was *actually ok feel how I was feeling* was when a healthcare professional explained it as part of an *illness*. The sense the psychiatrist *made* her realise this, gives a hint to the trust and high regard Lisa held for the psychiatrist. The illness was explained as *part in my mind that is very much overwhelmed* and although she had *tried to control it*, her inability to do so was justified. Therefore, like Keith, the responsibility was no longer hers.

For Zoe the process of diagnosis was also validating and, as with Tony, took place with a privately paid psychiatrist. Zoe echoed Lisa's experience of feeling listened to and understood.

*...my lived experience, erm (long pause) it sounds really ridiculous, to say the diagnosis is like the cherry on the cake (Zoe: 1746-1749).*

For Zoe diagnosis was the pinnacle to understanding her experiences. She represents the process of writing her story, as the psychiatrist had requested, as bringing together ingredients for a cake. To have someone stand back and make sense of what she had written, was indeed the finishing touch to understanding; the cherry on top. Zoe's hesitation and the statement *it sounds really ridiculous*, shows her understanding that gaining a mental health diagnosis would not naturally be seen as a highpoint. However this feeling is overridden as she feels *my lived experience* is as valid as any other and gaining a diagnosis legitimised this.

The symptoms participants had been experiencing often led them to research and make assumptions in an attempt to gain understanding. Some surmised a diagnosis, accepting that there was likely to be one, and Steph pushed to have this clarified, confirmed or refuted. However she found support post-diagnosis was not guaranteed.

*...someone's recognised your symptoms as being erm, part of this diagnosis, but on the other hand you're not severe enough to receive any sort of, any sort of concrete help, any concrete support and you're almost being erm, palmed off, that's the feeling I got with it...it was quite a mixed bag of emotions. It was very erm, it was a very unusual type of scenario where it's the culmination of, it felt like two years solid work to get somewhere with it erm, but also having the experiences and the (pause) process affect the actual relief that I felt (Steph: 709-727).*

In one way, diagnosis for Steph allowed her a sense of *relief* and validation. Healthcare professionals acknowledged her experiences had a name, a set of symptoms and was an issue for her. The fact she had invested *two years solid work* into gaining a diagnosis indicates she felt this was a 'job' and expected a sense of achievement following diagnosis by way of *concrete support*. Finding that this solid, reliable support was not available she felt *palmed off* and in an *unusual type of scenario*. Although her symptoms were 'enough' to be diagnosed she was deemed *not severe enough* to qualify for help. The reality of diagnosis handed her a *mixed bag* of relief and disillusionment.

A minority of participants were unsatisfied with their diagnoses and hinted at seeking further input to address this. Zoe, Joseph and Katherine felt their diagnoses did not

fully represent their entire experience. For both Katherine and Joseph the additional motivation for seeking a secondary diagnosis was to help facilitate their need to be understood.

*Yeah, more of a justification of, I wasn't just attention seeking or anything, I wasn't shirking out of responsibilities, sort of hiding away from going and seeing people, there was actually something wrong with me (Katherine: 1390-1394).*

*...with [undiagnosed condition] I do feel a bit mixed, I feel that more or less I would like to identify as an [undiagnosed condition] sufferer but at the same time I feel like an imposter, because if anyone was to go well, show us your [undiagnosed condition] badge or something, oh I haven't got mine (laughing), I didn't qualify (Joseph: 1120-1125).*

Katherine felt part of her past experiences went unrecognized; this highlights the importance of the role of healthcare professions in the process of sense-making. They provided a retrospective *justification* and explanation for *shirking out of responsibilities* and *hiding away* when Katherine felt she was unable to cope. Having a diagnosis something was *wrong with me* indicates she felt there was a societal 'right' way and permission was needed to be excused from this. On receiving an additional diagnosis, Katherine would have felt less responsible for her behaviour and subsequently she may have found her friends less judgemental.

Joseph also felt the need to justify his behaviour to others, something an additional diagnosis would have allowed. He shows how diagnosis acts as a direct route to accessing support and without the specific diagnosis he is a 'fraud' as he did not *qualify* for an exclusive club. Here Joseph creates a metaphorical membership *badge* that allows him to feel confident joining a community rather than approach as an *imposter*. He indicates reticence in feeling a *bit mixed* and that he would *more or less* like to identify as a *sufferer*. An explanation for this can be found in the juxtaposition of empowerment on joining a group coupled with disempowerment that comes with being a *sufferer*.

Most participants felt their mental illness fluid and changeable, which resonated with their experiences pre-diagnosis. Receiving a mental health diagnosis did not alter this view to becoming a constant and absolute entity. There was recognition that there may be crossover in experience of different mental illnesses in the future: their

condition could lead to receiving a different diagnosis or additional diagnoses. The dynamic and changing nature of mental illness was accepted as part of the experience of having it. Nonetheless, the fact they had a mental illness was accepted as absolute and therefore there was a sense they would never be without it (regardless of symptom changes in the future).

## **Superordinate theme 2: Discernment of ‘them and us’; self-perception and society**

Post-diagnosis participants began to integrate a different perspective of their self. This resulted in discernment of ‘them and us’: ‘them’ without mental illness and ‘us’ with. After receiving a formal explanation of their experiences, questions arose around how others would now view them. Participants developed a different sense of themselves post-diagnosis incorporating this surmised view. However the ‘them and us’ division was not wholly negative and, for some, being part of ‘us’ was accompanied with a sense of pride. This reinforced the strong sense from participants that only those with lived experience can truly understand others with lived experience; a common experience shared between a diverse group of people.

Whether to disclose or not, came with a cautiousness and a complex set of self-imposed rules. These boundaries were adjusted and re-evaluated over time as responses were experienced. Disclosure was noted as facilitating connecting with others who had lived experience of mental illnesses and this subsequent support assisted in the management of their condition.

The narrative now turns to the subordinate themes within ‘Discernment of them and us’. The post-diagnosis subordinate themes do not follow the same linear pattern as those in superordinate theme 1 and are more overlapping in nature (see Figure 10 and 11). The analysis below begins with the subordinate theme *Stigma*, before exploring *Selective disclosure* and finally *Connection to others*.

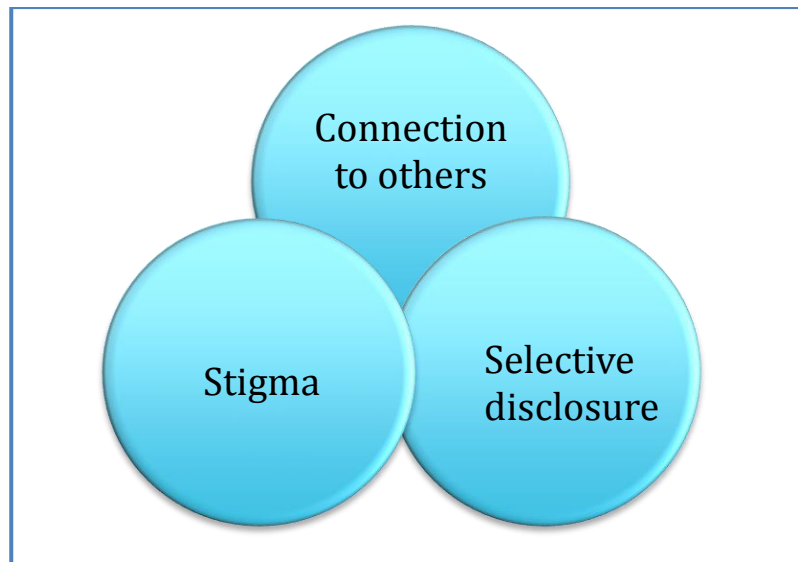


Figure 10: Pictorial representation of relationship between subordinate themes.

### **Subordinate theme: Stigma**

*Keith: ‘...people who don’t have a mental health problem can sometimes erm become very negative about mental ill-health’ (1013-1015).*

The existence of discrimination and stigma in society was acknowledged by all participants. Some had not recognised this prior to their own lived experience or prior to receiving a diagnosis. Only after reflecting and making sense of previous situations did participants recognise negative attitudes. This came in the form of limited access to life choices they felt they had prior to the mental illness. Paid work and career choices were highlighted as being affected by discrimination; positively as well as negatively.

Both Tony and Zoe attributed the disruption to their careers directly to having a mental illness. Tony recognised a change in his employer’s attitude and met this with defiance in the form of legal representation. Zoe, however, at the time did not characterise her employer’s responses in the frame of discrimination.

*...I said to the solicitor, you know this could be constructive dismissal er, an’ I, and so [he/she] wrote and said I don’t want to engage anymore, everything has to be minuted, the solicitor needs to be present because Tony is [condition], and they suspended me, so, er, that was their response. So I got a huge pay off out of*

*that, but I couldn't explain to my professional colleagues that I was [condition], because I would never have worked again (Tony: 1041-1053).*

*...well the last time, so when I, just before I took voluntary severance erm, it wasn't overt but definitely my two, my line manager and my director, definitely undermined me because of my mental health, they took advantage (pause) or, erm, you know said things to undermine my confidence (Zoe: 1350-1356).*

Tony indicates his concept of incorporating his diagnosis into who he was; *Tony is the condition* rather than 'Tony has' the condition. This attitude contributed to the personal affront he felt and his sense of unfair treatment. Tony shows his disappointment at their decision to suspend him; *so, er, that was their response*, representing the lack of care and support he felt he was shown at a time he felt most in need. The stigma is also apparent in the way he remained guarded about disclosing his condition due to his perceived employability: indicating the interlinking nature of stigma and disclosure.

Zoe's mental illness led her to taking time off work. During this time she had felt vulnerable and disempowered by her employers who *took advantage* of her using her current emotional state to further *undermine my confidence*. Her use and stress on the word *definitely* shows her conviction that she experienced discrimination *because of my mental health*. Although at the time Zoe did not sense unfairness, as Tony had, in retrospect she acknowledged injustice in the treatment she received.

Participants often made assumptions about the judgement of others. This was during the process of assimilation of new information (diagnosis) and what this meant in relation to their everyday interactions. Response to this led some participants to protect themselves via non-disclosure. However even without disclosure John felt others were judging him due to the behaviour he displayed, which he felt indicated mental illness.

*...where I live people will probably assume that there's something wrong with me because of my routines and rituals as in cleaning and being particular and I come back to the word normal, normal people probably don't do that routine...I would imagine people are already sort of making comments....but that doesn't worry me because erm, (pause) if I'm happy doing it, is it their concern? erm, you know I'm a firm believer that if I was to ask them to wash my drive everyday that's when it would concern them, but it doesn't concern me, but it's probably (laughing) not the right way (John: 1354-1378).*

Even though John states confidently that he is unconcerned with what the neighbours thought, he remained very conscious of it. He had a strong sense that there was a difference between himself and wider society: 'them and us'. Alongside this he maintains a strong sense that his mental illness is a private matter that does not cause him undue *worry* and his behaviours make him *happy*. His questioning of whether his behaviour should be of *concern* to his neighbours and his laughter, indicate disquiet. The discomfort he feels does not come from within himself rather it is relative to those around him and *normal* societal behaviour and a *right* way to live hinting he is living the 'wrong' way.

Like John, Lisa also overtly questions how others see her. This is in response to the changes diagnosis brought about relation to what she knew of herself.

*...it was, there was that feeling of (pause) well what's wrong with me t', why have I got [condition], what does that make me? am I a nutter? an' I think tha' that's the stigma with, with mental health, erm, because you know what, what does that stand for you know what, why have I got [condition], erm (pause) why me? you know I come from a normal family and a normal background, why? (pause) (Lisa: 521-528).*

Her questioning of *why* she has mental illness hints at a presumed origin of its development. She considers herself *normal* thereby distinguishing herself from those that are not so, i.e. those likely to develop mental illnesses. She recognises her previous frame of reference of mental health holds *stigma* and even uses the derogatory term *nutter* to describe her 'new' diagnosed self. Asking *what does that stand for?* shows a recognised difference between what diagnoses represent in society and the normality with which she viewed her own life. She now questioned her standing in society post-diagnosis and whether her status has changed because of it, *what does that make me?*, indicating the process of integration of new information.

Some participants used well-known derogatory slang when discussing their mental illnesses. Seeing themselves through society's eyes changes the way they have viewed themselves and the judgements they perceive others are making. John uses the term *the fruit and nut case* to describe himself through the eyes of others and Tony refers to himself as a *lunatic* and *mad*. Zoe stated that she was *allowed* to refer



to herself as *bonkers* due to having lived experience. Here she hints it would not be appropriate for others without a mental illness to do the same; thus reinforcing discernment of 'them and us'.

Stigma was also intrinsically linked to accessing services, which enhanced discretion in disclosure. Although Rupert did access services he was aware of the shifting view society held of his condition.

*...the only thing is now, I've found nowadays, I tend not to say it so much because it's become like the new bad back now haven't it? I mean you see programmers on TV like and you've got kids oh I got [condition] and [condition] an' you think, people, I'd say nervous breakdown if I was to go on to somebody now (Rupert: 667-679).*

Rupert here uses the stigma from a physical illness to explain the stigma he feels accompanies his own diagnosis. By associating his mental illness with a *bad back*, he indicates he does not believe others would consider his condition legitimate should he disclose it. This hints at the wider societal distrust in mental illness when it results in being unable to contribute to society via employment. This assumption led Rupert to reframe his condition when disclosing it to others and he chooses to use an antiquated term, *nervous breakdown*. This he felt carried more credibility and therefore less stigma, highlighting how societal perceptions of specific conditions change over time.

Both Katherine and Steph recognised the impact of stigma within services. Although having different experiences both noted a discriminatory attitude adopted by healthcare services post-diagnosis, resulting in changes in service provision for them.

*...but as soon as I went into the doctors and said I'm pregnant, straight away said right well you're guna need to be under consultant care... well as a side effect of you being mentally ill, we need to watch you (Katherine: 550-568).*

*I found that when I got the diagnosis within the setting that I was in, they were very quick to want to (pause) wind down...from what I understand now, it's quite common, because you can have someone with my condition in your service for years and years (Steph: 1101-1112).*

Katherine infers the *need to watch* her comparable to 'big brother' and implicit in this was the lack of trust in her ability to care for herself and her baby. The explanation given for the automatic provision of additional care she states as a *side effect* of her mental health condition. Thereby suggesting the focus of monitoring was related to her mental illness and not her as a person, thus separating the two; a concept Katherine disagreed with.

For Steph rather than having additional services on diagnosis, found a withdrawing of support. The *quick wind down* of support offered, is in opposition with the lengthy build up of effort and tension in the process of gaining a diagnosis. Removing support at the point of diagnosis, resulted in her feeling a dismissal of the energies she had expended and she was left with limited help to cope in the *years and years* to come. This experience highlights the fact that diagnosis does not equate to cure and, as other participants suggested, it was at this point that the journey started.

More generally Simone draws attention to the impact societal perceptions can have on initial recognition of mental illness. Like Lisa, she highlights the association of mental illnesses with certain groups considered 'likely' to develop it.

*...but to have a diagnosis, [condition], people generally hear that in relation to veterans and it's very sad that it isn't applied to everyday people because there's more people here than there are veterans really, and we all do suffer from it from time to time (Simone: 127-132).*

Simone developed a view that everyone experiences mental illness to differing degrees. Taking on this view post-diagnosis, she felt connected with the wider population and saw herself as similar to *everyday people*, rather than separate from them. She emphasises the detrimental impact stereotyping can have when it restricts awareness and results in a lack of support for those that need it, which she finds *very sad*. Simone's diminished discernment of 'them and us' post-diagnosis, places her in a minority of one in relation to other participants.

The next subordinate theme is closely linked to the theme of *Stigma*. However *Selective disclosure* also stands alone due to the complexities in decision-making involved and the perceived consequences of disclosing a mental illness.

## Subordinate theme: Selective Disclosure

Simone: *'When there was a need, there was a need to say and when I wasn't, I didn't particularly keep it a secret, I found it made things easier' (709-711).*

The language needed for disclosure came with diagnosis. However it did not simply follow that disclosure was the natural next step and all participants expressed the use of selective disclosure. There was careful consideration when and where to disclose their mental illness, if at all, the essence of which choice was trust, influenced by the surmised responses of others. However, as Tony indicates, even when trust and support are guaranteed, it remains a complex process.

*I felt isolated, er I felt ashamed I suppose overall, I felt unable, I didn't tell my family for four years, and my friends, my closest friends most of them I've known since I was six (laughs)...for five years because I was ashamed of it you know and I was ashamed I was, I s'pose wary of other people's reactions (Tony: 623-832).*

In both personal and professional life Tony felt *unable* to disclose. Feeling *ashamed* left him with no choice in whether to disclose, such was the extent of the emotion felt. His repetition of the word *ashamed* and the *overall* sense of which he felt this evidence this. Even though he had known his *closest friends* the majority of his life, he was still *wary* and chose not to share his diagnosis due to his sense of shame, indicating the responsibility he held for having it.

As Tony suggested earlier, disclosure was dependent upon a variety of factors including environment, i.e. inside and outside work. Zoe's choices of disclosure in work also related to the potential repercussions and she indicated how these choices changed over time.

*I probably told people who knew me at work you know, but I never did the big HR [Human Resources], Occupational Health thing because it didn't, it wasn't a work thing you know, but when it became a work thing years later then I was always very open about it (Zoe: 1309-1314).*

Initially Zoe felt mental health was something to be kept close, personal and secret. Therefore when disclosing she considered the power held by people working in certain positions. Subsequently she chose not to disclose her mental illness at an

organisational level and due to the potential negative ramifications it could become a *big thing*. As Zoe went on to find employment among others with lived experience, her attitude changed. She was more open and felt communication between all those that support her, i.e. Occupational Health, employers and friends, would only benefit her.

Working in an environment with a supportive and sympathetic approach attracted other participants into paid employment or voluntary work. Like all participants who went onto employment in the third sector, Keith had not contemplated working in mental health service provision.

*...you know if you work in sort of an [specialist area] environment or working for a charity, this type of thing, generally people will tend to be you know quite, quite, quite nurturing, quite caring people you know generally anyway really erm, I've never erm never really felt that er, any sort of particular stigma (Keith: 1200-1206).*

There is an implicit assumption that Keith believed stigma would not be present in certain environments and therefore disclosure would be easier. He found it necessary to work in a place that allowed disclosure of this mental illness and that formed an extension of the *nurturing* support (provided at home) he needed to manage his condition. This suggests his awareness that not all environments have such an approach to supporting employees with mental illnesses. However repetition of the word *quite* and use of *generally anyway* hints even in these *caring* environments, negative attitudes may still be present.

This suspicion is echoed by another participant who worked in a mental health charity and chose not to disclose their specific condition due to expected stigma. This highlights the connection between stigma and the 'selective' nature of disclosure the participants indicated. Joseph also noted predicted supportive responses to disclosure from others with mental illnesses were not necessarily guaranteed.

*I've found it has had very mixed results, even amongst people who have also have diagnoses [sic], [to himself] diagnosis? (Joseph: 645-647).*

The different response Joseph received *even* from those with a diagnosis, suggests he expected an accepting response. Therefore receiving *mixed results* in reality

underlined a lack of consistency and subsequently a questioning of his initial trust. With these experiences his future disclosures and anticipated responses of acceptance, would have to be revisited and approached with added caution. His incorporation of an unfamiliar language is also present here when he questions the plural of diagnosis. Tackling a new language represents the new realm he found himself in with new rules and etiquette.

As noted by Zoe, choices made concerning disclosure changed over time. For Katherine the rules of disclosure changed from secrecy to announcement.

*...I put up a status on Facebook, just one of those notes, just with everything in it and I thought it's bound to come out, I've had enough now hiding, it slipping out with people occasionally...I thought I just want make sure everybody knows now, blanket out there, 'cause there's no point in me being assumed about it, I've come to accept it more (Katherine: 845-855).*

By disclosing her condition on FaceBook Katherine took control. In choosing a time and way of disclosure she was able to feel strong enough to cope with all responses. As well as this being a stage of acceptance for her, she also had *had enough now hiding*. Hiding her mental illness took energy in containing the symptoms of her condition and stop them *slipping out*. She clearly wanted to disclose in one place and time, helping curb assumptions made about her. Telling everyone in one space and time covering her entire social circle, was much like a throwing a *blanket* over them; the blanket she had been hiding behind became an instrument of liberation.

Katherine, like other participants, found they received a positive response from others on disclosing their mental illness. Taking into consideration that all participants noted the existence of societal stigma, this positive response may be due to their judgement in who and when to disclose, rather than an indication of societal acceptance of mental illness per se.

The final subordinate theme is *Connection to others*. Through diagnosis, acceptance and a level of disclosure, participants came into contact with others with lived experience of mental illness.

## Connection to others

Katherine: *'...barriers are broken down so much easier, because I understand, I sympathised, I can empathise, and it just makes me better and nicer' (720-723).*

There was a strong sense to truly understand what it means to have had a mental illness, one has to have personal lived experience of it. This is the creation, post-diagnosis, of a new 'connection' to others. There was no indication participants had proactively sought to engage with people with mental illnesses prior to diagnosis and indeed many had not given this much thought. Connection with others with lived experience of mental illness resulted in additional support and understanding of their condition and subsequent management of it. For many this was a two-way process and support was informally offered by them as well as received. However the picture remains complicated and even though he gained benefit from 'connecting to others', Rupert maintained a self-protective distance from others with lived experience.

*...well it's funny 'cause you're talking about things with people who can sympathise or empathise with it, because they've been through it or are going through it (Rupert: 1005-1011).*

The distance Rupert feels from others is rooted in the objectification of the mental illness as *it* and feeling he is *going through it* indicates a sense he expects an end. Rupert believes this 'end' will be as a result of his death, rather than recovery. The fact that *it's funny* talking with others with lived experience of mental illness indicates his disquiet and potential distrust of the new acquaintances. This paradox of *empathising* but not fully 'identifying' with others with lived experience may be indicative of the 'resigned' acceptance he has of his own mental illness.

Connecting to others was also a time where consideration of the self is given in relation to a new group. It was at this point Lisa began challenging her own preconceived ideas within a new post-diagnosis frame of reference.

*...I took part in quite a few erm group sessions and (pause) it was, that was an eye opener to me 'cause I remember one of the sessions and I was looking around and thinking, well these all look normal and it was a shock...and that that was quite self-evaluating for me because I sort of then looking into my own little world from outside thinking, well I am quite normal, you know I'm bog standard, there's nothing abnormal as such, but I was, yeah I was quite shocked to look*

*around the room and think, she looks normal, he looks normal, so that would have been probably the first time that I related to others with it (Lisa: 971-985).*

On reflection Lisa felt she was going through life in her own *little world*. This limited view resulted in a 'them and us' *abnormal/ normal* divide and led to her feeling *shock* when she found this challenged. Through *self-evaluating* she developed a way to cope resulting in her bringing the group members into 'her' world. Through seeing them as *normal* she was able to avoid relating herself to the *abnormal* and sustain a perception of herself in relation to the new information. However Lisa hints by saying there is nothing abnormal *as such*, that she recognises the complexities surrounding questioning what is normal.

Tony chose not to take the opportunity to mix with others with a mental health diagnosis for support. This was based on previous negative reactions to a support group.

*I didn't go into any of the support meeting, which was why I joined was to go to support meetings, but I didn't go because I wasn't sure what room I'd walk into. Er, erm and I'd been to [support group] previously to recover from [addiction] er, and it was useful, but not wholly productive to be in those meetings...and there was you know wallowing in the condition and I was afraid the [condition] support group would be the same thing...so, I wasn't sure that would be what I wanted, so I chickened out, of that (Tony: 693-711).*

Tony would only attend a support group if he deemed *productive*. He felt he now needed something more proactive to enable him to move on rather than *wallowing* and staying stagnant with regret. His decision not to join the group was made early post-diagnosis and his fear of the unknown were factors in this; he *wasn't sure what room I'd walk into* and was *afraid*, so he *chickened out*. His self-protection in choosing not to attend indicates his vulnerability at the time and, linked to this, his wish not to ruminate over the changes in his mental health.

The remaining participants were immediately proactive in their search to relate to others with similar experiences. Here Joseph and Steph noted the difference between public sector and third sector services.

*...it felt like there was no real support that came from the professional services, it was only the independent thing, places like [organisation] and stuff, where it's*

*communities, it's other sufferers they are the ones that help me with the advice, not the professionals, which seems a bit str', backwards (Joseph: 1365-1371).*

*...so I find that it's a community, an' it was important for me to be able to identify people that I could go and touch base with and that I could really engage with in my experiences (Steph: 1255-1259).*

Joseph shows his expectations were different when first entering the system pre-diagnosis. Support from healthcare professionals was lacking in reality and he felt this *a bit backwards*. In choosing not to finish the word *strange* and instead use *backwards*, Joseph reinforces the importance of momentum to help him move 'forwards' and manage his condition, similar to Tony. This was also the case for Steph who found on diagnosis, public sector services were limited, therefore she proactively sought a *community*. This gives a sense of a supportive and nurturing space and suggests a closed group i.e. 'them and us'. Joseph refers to those with lived experience as *other sufferers* like himself, thus promoting a sense of disempowerment. Steph takes a different tone indicating action and control. To *touch base* with others who could *really engage* with her, would help her *base* or 'ground' her experiences and help manage the volatile nature of her condition. As touching base is also a term used in baseball, it represents her sense of being part of trusted team, all working together to achieve symptom management.

Some participants noted that having lived experience of mental illnesses had made them a better person. This was an important aspect for Zoe who had gone on to work in mental health services to share her knowledge.

*But I think my experiences, my lived experience has made me a better person I think it's made me, you talking about how I view mental health, it's made me more, erm it's given me a higher degree of empathy (Zoe: 1726-1731).*

Zoe shows that her *lived* experience is different to experience per se. Her experience of having a mental illness resulted in becoming more than she had been. In fact she feels *it's made me*, the sense that she was 'unmade' before her *lived experience* suggests coming to completeness was only achieved through this. This is linked to her belief that her ability to connect to others, which she felt was always there, was now *higher*. The impact of her mental illness has taken her empathy to a new level; one only others with lived experience can achieve.



Although Tony chose not to access support via others with a mental illness it did not eclipse his identifying to others with lived experience and, like Zoe, he aligned himself with them.

*I mean it's not quite pride but its 'ell right well I'm, to be honest I'm in the box you know, I'm not like you, I know I'm, you know I see myself as mad I suppose [smiling] and er, I know I'm different to you, you don't know what's going on in my head you know, you're talking to me, you think I'm normal [laughs] and there is a bit of that going on and sometimes that's funny and sometimes it's isolating, yeah (Tony: 968-979).*

Tony strongly shows his belief in the concept of 'them and us' with being *different* to those he perceives are without lived experience. He also hints at his ability to maintain an outward *normal* image, which he saw as an important part of engaging with society. However his laughter suggests the 'secret' he holds is accompanied by a vulnerability as well as, like Zoe, a sense of superiority in this difference. His vulnerability is related to seeing himself *in the box*; limiting his maneuverability as it becomes what defines and separates him. Over time he experienced something similar to *pride* in having a mental illness; embracing the 'them and us' separation.

Receiving a diagnosis helped participants understand experiences retrospectively. Language and legitimacy gained through diagnosis aided disclosure and provided a framework for sense-making to explain past, recent and current behaviour. This 'new' information was also considered an important aspect in expediting family and friends understanding, perhaps fuelling the wish for attaining it. Engaging with others with lived experience only came about post-diagnosis highlighting the role it plays in accessing support to manage the condition.

### **Superordinate theme 3: Assimilation of mental illness into everyday life**

On gaining a diagnosis participants recognised this was the start of a process rather than the end. It came with an additional level of acceptance and resulted in different responses involving multiple levels of integration. The concept of recovery was seen from a physical health frame of reference and in absolute terms and therefore did not

resonate with their expectations of the future: 'living with' the mental illness, as opposed to 'recovering from' it, was the main sentiment accompanying this. Although there was a sense of resignation for some, this did not equate to not 'thriving' post-diagnosis for others, highlighting a difference between participants on their post-diagnosis life trajectory.

Changes in their approach and view of their self and their life post-diagnosis, formed part of the reframing that occurred for participants. Some integrated their mental illness, seeing it as an integral part of themselves, however this did not directly relate to channeling their experiences in a positive life direction. Just over half went onto volunteer or work in the third sector because of their lived experience and were empowered to use it to create a new life direction. For the others it became a disempowering experience that continued suppressing their life choices. This process of assimilating the mental illness, of 'living with' and 'integration and reframing', was by no means complete or conclusive in nature. Rather it is indicative of the continuing and developing process of managing a mental illness.

The final superordinate theme consists of two subordinate themes: '*Living with' as opposed to recovery from* and *Integration and reframing*. These two themes are again interlinked, further representing the complex picture that appears post-diagnosis (see Figure 11).

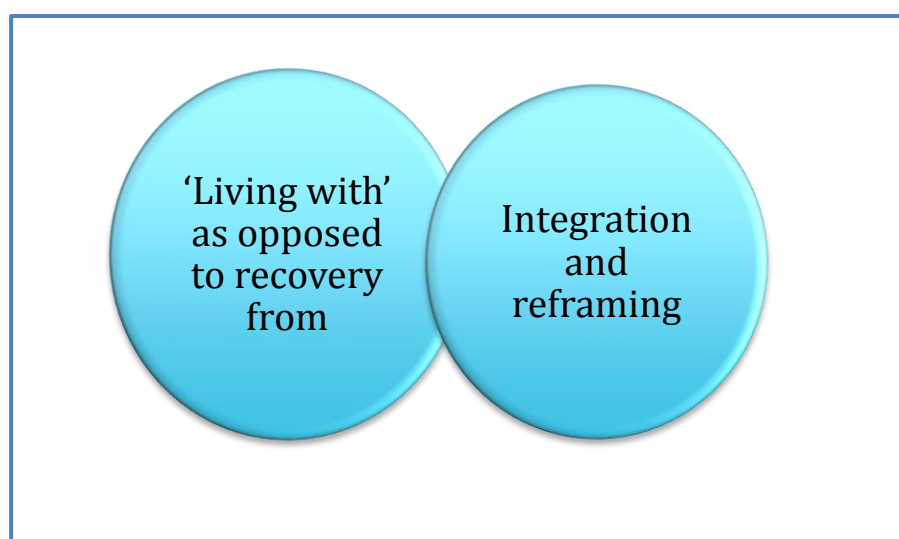


Figure 11: Pictorial representation of relationship between subordinate themes.

### Subordinate theme: 'Living with' as opposed to recovery from

Keith: *'Well, I think, I think recovery is, is this, it's coping with it, it's managing it, it's dealing with it you know... I think recovery really is about managing it, it's about living with it, it's about continuing to understand it more' (1287-1297).*

The concept of 'living with' the mental illness was discussed when considering recovery. It is inextricably linked to management, acceptance and integration of the condition into daily life. Seeing mental illnesses in this light indicates an acceptance that the condition will remain and therefore needs to be managed. This did not necessarily exclude living a fulfilled life and the adopted attitude of 'living with' was by no means wholly negative for participants. Awareness and control of symptoms came post-diagnosis for Simone through the development of understanding and acceptance.

*...so these things are always gonna be there, it's like the fear that I tried to deny all my life, if I accept that they're there, then (pause) as long as I accept that they're there and they could pop up at any time (pause) I think I've built up an awareness (pause) to let things keep going really, because I would be recognising within myself the change of feeling really, I was so, so disconnected from my feelings before, not wanting to, not feeling sorry for myself at all (Simone: 1023-1132).*

Through diagnosis Simone felt her experiences were 'legitimised'. Needing this approval hints towards the societal view that excessive concern and attention on the self is seen in a negative light. In the past she had adopted a harsh judgement of her feelings and to allow her to cope with this she *disconnected* herself from them. She had separated part of herself to stop herself from *feeling sorry for myself* and the change to *let things keep going* indicates that this disconnection had stilted her progress in managing her mental illness. She was only able to move forwards and engage all of herself on accepting the mental illness: *the fear that I tried to deny all my life*. This acceptance was the key to her taking control to manage her condition.

Participants unanimously held the view that recovery from their mental illness was unlikely. This was seen as an unachievable absolute and came with the recognition that diagnosis did not mean cure. Rather the necessary focus became managing their condition with the aim of alleviating symptoms i.e. living with it. The potential result of this would allow them to engage with and function in society at their chosen level.

This was important for Tony who felt his medication allowed him to re-connect with his sense of self.

*I was Tony again, but a different Tony, but Tony again...you can spot the symptoms, it's like the 'b' in bang isn't it? You know, so I can feel it building up and I can start doing the self-control, er, and an easy self-control because obviously I still get highs and lows, you can't stop that, but it's like the top of the spike has been trimmed off and the bottom of the trough has been trimmed off (Tony: 729-884).*

Although he recognises that he is not the person that he was pre-diagnosis and treatment, he feels he is 'Tony' again. This difference, he explains as trimming of the spike and the trough, leaving a bounded central area that he feels still defines who Tony is. The medication made neat work of trimming away the intensity of the *highs and lows* and in doing so addressed the behaviour that had restricted his engagement in society: the *bang*. Therefore this was not only important for him in regaining a representation of himself, it also allowed this to be reinforced through the act of re-engaging in society after a period of self-stigma.

Participants expressed different approaches towards living with and management of their mental illness; not all adopted Tony's view of *easy self-control*. Lisa felt her mental illness was a separate part of her that demanded constant vigilance lest it take over.

*I can be at a very good level but that drop is imminent, it can come so quickly, an' I suppose that's where the control comes into it, because I do live life on the wary side, looking out for that black cloud (Lisa: 686-690).*

However Steph's approach was different and there was no concept of having days without it: it was integral to who she was.

*...you're never going to be able to live fully out of that state of mind, I don't think, because that is part and parcel of you, you've grown up so long with that, erm, it is very much about management (Steph: 903-907).*

The difference between these two responses highlights the complexities of acceptance. Lisa's living *life on the wary side* is opposed to Steph's *part and parcel*, indicating the different views influencing their relationship with it and approach to it.

There is a sense of fear for Lisa in relation to her mental illness; the fact she sees *that drop as imminent* gives a sense of walking on a cliff edge. Without constant vigilance to the location of the *black cloud* that lurks off shore, it could *quickly* sweep in and take her over the edge, dramatically changing her mood. Therefore her mental illness was something to gain control over and her condition separate from her; a *black cloud* that she must remain alert to and keep out at sea.

Steph's acceptance is related to the length of time experiencing her mental illness. She focuses on working 'with' her symptoms as opposed to Lisa's focus of overcoming and gaining control of them. Steph also talks of her mind, but rather than separation within it she sees it as a total entity and one which she cannot leave or separate. In doing this she would begin to undo the *parcel* that makes up everything she is would unravel; losing the essence that ties her up in a neat package. Indeed taking away her symptoms would leave her unsure of what would remain.

Lisa and Steph show the post-diagnosis, ongoing nature of mental illness. Lisa constantly *looking out for that black cloud* and Steph's *very much about management* are sentiments echoed by many participants. Over time, Rupert recognised that challenging and fighting his mental illness was futile and rechanneled his energies into understanding and working 'with' it.

*...you learn certain things, an' you try and put as much erm, (long pause) er much (pause) irrational thoughts then, out of your brain as possible, you still can't eradicate all of them, but you can get rid of a lot of them, an' then when you have a [symptom] now, don't get me wrong it's not nice but, you can manage it better than when you don't know what's happening (Rupert: 903-912).*

When experiencing symptoms pre-diagnosis, Rupert talks of not knowing what was happening. This contradicts the idea that in the experiencing he would have known of them: his distinction is in terms of his being able to understand and make sense of them. Although post-diagnosis Rupert was better able to manage his symptoms, he would still like to *get rid of them*. He saw his symptoms as originating in his brain and being able to *eradicate all of them* remained the ultimate goal. Rupert quickly switches from first person to third, indicating he feels there is only so much he can personally do to reach this goal. As with others, he came to realise that being able to

*learn certain things* in condition management was not a panacea and symptoms remained *not nice*.

Joseph adopted a similar approach to Rupert in condition management. However an initial battle with the mental illness did not drive this, rather Joseph was immediately proactive, researching into the management of his condition.

*...(pause) I guess recovery is an odd word 'cause that makes you think that there is one state and you will leave it and I'm not inclined to say, you know you do', recover from [condition] certainly that's er, I think that I (pause) am working towards getting to a point were, thin', thoughts and worries have less control over me (Joseph: 1328-1334).*

The one *state* that Joseph refers to relates to the constant state of his 'self': the 'state' is not left as you do not leave your 'self'. This resonates with other participant's rejection of the concept of one day being without a mental illness. Indeed Joseph is *certain* of this fact and he again shows his sense of momentum in *working towards getting to a point*, where the goal is not to be without the mental illness, rather to gain control over it. Joseph shows a sense he feels more control over his symptoms than Rupert and by staying in the first person when talking about his level of control, indicates he feels he can achieve this goal.

For some, adopting the attitude that mental illness would persist was linked to the causal explanation received. On diagnosis, Katherine was told her mental illness was due to an inherited chemical imbalance, initiated by life events.

*...the things that have triggered, like the memories I have, they're always guna make me sad, they're always guna make me frightened because that's just what happens when you have those memories, but so if you took me off the medication there's never guna be a time when it's not guna hurt, so tha's (pause) that's just a fact, so there'll never be a recovery from that, which I don't see ever happening, it's coping with it (Katherine: 1217-1227).*

It is clear to Katherine and *just a fact*, that her memories will remain and subsequently her mental illness. Katherine's use and repetition of the absolutes *ever*, *never* and *always*, indicate her level of acceptance as well as the exclusion of recovery (in absolute terms). The *frightened* and *sad* emotions her memories elicit, is managed

by her medication and assists her *coping* and rather than full recovery, living with her mental illness becomes the solution.

All but one participant felt their mental illness was unlikely to remain constant. There was recognition that symptoms and diagnosis may change over time, but the need to cope with a mental illness would endure. Indeed John, as with Steph, showed anxiety on suggestion of making a full recovery.

*Well, I, I, really don't know because erm it's always been with me from a child, so to me it's quite normal, it is normal, whereas somebody can just jump out of bed an' if the house hasn't been cleaned, they just go about their day with work or whatever, er, I, I, probably consider that normal er but I can't do that (John: 669-676).*

John recognised the lack of management of the symptoms of his condition. This was something he had accepted and did not believe would change. He felt the life he was living was *normal* to him, but to the outside world it's not *normal*. In comparison with the rest of the participants, 'living with' for John was in a different context. His symptoms being 'socially acceptable' and did not attract much unwanted negative attention and subsequently he has never had to gain control over them and they have dictated his life. His sense that he *can't* change his situation shows that he felt he has no choice.

The second and final subordinate theme within 'Assimilation of mental illness' is *Integration and reframing*. This links with the previous subtheme above, however it develops the underlying processes of 'living with' a mental illness and echoes the same changing nature.

### **Subordinate theme: Integration and reframing**

*Tony: I think it's better to try and get engaged and be part of society and be presented as normal if that's the right word (1003-1006).*

The integration of a mental illness is a related but different concept to that of 'living with'. It emerged from the interview data through comments on the effect of how participants evaluated their mental illness. The process of reframing their view as a result of their mental illness, resulted in forming a post-diagnosis concept of

themselves. This elicited different responses; some felt it a valid, justified element that contributed to their self and it became part of sense-making, although uncomfortable for some, it related to their individual processes of acceptance. This was not the case for all participants and there is a complex interplay, which did not result in a clear absolute path and indicated a much more inconclusive picture. Integration and reframing had an empowering outcome for some, whereas others were on a continuum towards disempowerment.

Although some were resigned to having a mental illness this did not equate to a lack of agency and they were motivated to turn what they saw as a potential negative into a positive. Tony's experience highlights the nature of the complex, fluctuating process that takes place post-diagnosis.

*I s'pose for a year or two you start looking for reasons and then I stopped and thought no, I'm guna find a new way of living, a new identity, er, and try and get happy with that (Tony: 674-678).*

The process of integration of his mental illness took time and was accompanied by an internal shift in self-perception. Post-diagnosis Tony began *looking for reasons*, which led him to question and blame himself. His switch from third to first person represents his sense that others who have received a diagnosis also share this response to make sense of it. The clarified focus when he *stopped and thought* was conscious and deliberate and he began to re-focus to *find a new way of living*. Tony's need to reframe and develop a *new identity*, as well as way of living, showed a need to re-invent himself in order to create a life worth living post-diagnosis. In his aim to *try to get happy* with his re-invented self, he indicates the uncertain outcome he senses alongside the effort required in doing this.

The process of integration and reframing for some resulted in fuller engagement in life and society. Keith and Zoe evidence 'reframing' their mental illness in choosing to work in third sector mental health organisations post-diagnosis. Like Tony, taking responsibility was key for Keith in becoming empowered and gaining control of his future life direction.

*I'm not sort of blowing my own trumpet with this, I think it was erm it was a case that after a while when you bec', when you come to yourself, you know when you,*



*you, you come, become more realistic and you become, you understand what's happened to you and you can, you know you are ready to move forward, it's a sense of sort of pride and achievement (Keith: 1030-1037).*

Having gained insight through the process of psychological support he felt able to *come to yourself*. Like Tony, there is a sense here of a journey; travelling away from and returning to himself. He indicates that the process of understanding himself helped him become *more realistic* and prior to this he had not been *ready to move forward*. He developed agency and momentum through this understanding and decision to abandon his focus on the causes of his mental illness. This move from being disempowered to empowerment was accompanied by *a sense of pride* in re-engaging in his role as father and husband. Even given his *pride*, speaking in the third person and not *blowing my own trumpet*, indicates Keith's tendency to focus on his flaws and a continued struggle to recognise his abilities.

Zoe also chose to see her lived experience as an enabler for herself through helping others. As with Keith, gaining understanding and control of her symptoms became an important aspect in reframing her life.

*I've made it a vocation...I wouldn't have gone for this job had I not had the lived experience, so I've turned what I deem to be a negative into a positive...I'm not saying my work is easy and it's not, and tha' sometimes it can be too reflective, sometimes I feel in terms of how the label I suppose...and I think some people who are diagnosed may become labelled or stereotyped, erm so they put them all into a group you know (Zoe: 1456-1477).*

Zoe refers to her mental illness as a *negative* that she has turned into a *positive*. Within this attitude and action Zoe has taken control of her response to her mental illness and used it to her advantage. However working in the field of mental health is double-edged as she felt unable to separate herself from her work due to her lived experience. Her reference that *sometimes it can be too reflective* an environment and stating that her work is not always easy, indicates a sense of immersion she felt. Introducing labelling and stereotyping hints at a discernment of 'them and us'; *they put them all into a group*. Although Zoe is empowered by the role she shows the complexities of maintaining personal identity alongside being stereotyped into a specific group.

Simone also experienced a feeling of post-diagnosis empowerment, however this was not accompanied by a post-diagnosis sense of 'them and us'.

*...it's made me look at things a lot more positively, and I do something with what I have got, and not allow myself to be dictated to and cornered and boxed and isolated, because I do like it there actually. I've learned to like all of my disabilities, I work with them, but they're not a problem anymore (Simone: 1035-1040).*

Simone's perception of her life has been reframed through developing insight. She sees things *a lot more positively* and has moved on from being *dictated to, cornered, boxed, isolated* and in the control of others. She admits to *like it there actually*, indicating the comfort that accompanies a lack of control. However although she sees her *disabilities* as limitations, this is outweighed by the control she has gained. Her *disabilities* have been integrated and accepted as she *learned to like* them and *work with them*, therefore reframing them as enabling and subsequently *not a problem anymore*.

Katherine showed a similar sense of empowerment post-diagnosis. Like Simone she also did not wish to be seen as a victim and, like Zoe, she also took a position in a third sector charity due to her lived experience.

*...so I've got into the line of work because I feel very passionately about, 'cause I've lived it myself, I did my Masters and carried on, so I pulled myself out of it and I'm guna help other people, but there are people in there [work place] that don't understand that, so I've got all the [mental health campaign] posters all around, I have [condition], no problem you can ask me anything (Katherine: 632-639).*

Katherine gives a feeling of ownership of both her mental illness and life experiences. Over the years she had become fully immersed in them which led her to *feel very passionately about* them and has spurred her on to *help other people*. Having *pulled myself out of it*, Katherine indicates the effort required to leave the situation she found herself in and move from a position of disempowerment to empowerment. She still hints at a sense of 'them and us' notwithstanding the environment she works in; *there are still people in there that don't understand*. Although she is motivated to *help other people* she recognises there is only so much she can do to positively influence attitudes towards mental illness.

For Steph the process of integration was complex, influenced by her views on how society sees her mental illness. Although she integrated the diagnosis that resonated for her, there were elements that were more uncomfortable for her to accept.

*I do think diagnoses [sic], they're a double-edged sword, they come with a set of loaded stigma or taboo, or, erm they come with a really weird sort of internal process, but they also come with, like I said a community, they come with a certain set of ideas erm, treatment options they, they do offer something quite important that I can't quite put into words (Steph: 1921-1930).*

Steph's strong sense of 'them and us' interrupted the process of integration. The *loaded stigma or taboo* that accompanies mental illness led to a *really weird sort of internal process* where she is in conflict accepting and integrating the diagnosis due to societal stigma. Therefore diagnosis being a *double-edged sword* indicates Steph remains in a place of conflict: she appreciates the support and sense of *community* that she was lacking prior to diagnosis, but feels the need to maintain caution in disclosure. The process of integration and reframing leaves her both empowered and disempowered simultaneously through her supportive community and societal stigma, respectively.

Although not related to societal stigma, Lisa shares Steph's sense of conflict. Lisa had integrated her mental illness as a 'valid' part of her, however conflict lies in not feeling fully in control of her mental illness.

*...I think [condition] has more control than I have (pause) and it's like a little battle sometimes who can have more control, me or the black cloud erm, but then again very recently in the last couple of months, you know I've been sort of finding myself again erm...trying to find a little bit of that person, before [age] to try and overcome it you know, overcome the [condition], part of my mind erm (Lisa: 714-725).*

Here Lisa shows the complexities of integration and reframing. She accepts she has an illness and has integrated it into her life by seeing it as a *part of her mind*. However her attitude towards this *part* is indicated in her seeing it as a separate part that she must *battle* with to *overcome* her condition and win control. She shows the ongoing process of integration and to *try* to win, she indicates she remains uncertain as to the result. In repeating the word *overcome*, she emphasises her view that this is

the only way to *finding myself again*. This is in opposition to the above participants who felt empowered through integrating their mental illness in order to reframe their lives.

Although Joseph does not feel he is in complete control of his diagnosed mental health, it has been integrated. However his want for an additional diagnosis is disempowering and leaves him unable to fully make sense and therefore unable to fully reframe his life.

*...but for the most part, everybody else lives in the world and I'm just behind this screen and I'm, I have a limited (laughs) amount of control and interaction, and again everybody else has the rulebook and they know exactly what they're doing an how to interact, whereas I'm figuring it out as I go along through trial and error (Joseph: 841-847).*

Joseph felt his diagnosis inadequate in representing his sense of distance from the world. Watching from *behind this screen* with *limited control* is a very disempowering experience for him. He watches with envy as the majority who hold the *rulebook* of life, leave him deficient and his struggle goes unnoticed. A label and ability to explain his behaviour would empower Joseph, enabling him to confidently continue in life without changing his behaviour but being able to justify it. Subsequently this would allow him to reframe and live happily without the *rulebook* and without fear surrounding his *trial and error* approach.

There was an overriding sense of resignation from Rupert in integrating his mental illness. The impact it has had led him to feel a lack of agency and subsequently his reframing incorporates this.

*...you're a big vacuum at the moment an' I think to myself right, I'm [age] you see and a lot of people dying in their 50s and 60s an' I'm not that far off, you know an' you think, well what have I got? You know a bit of self-pity that's all, we all get that, anyway d'you know what I mean, but it's just one of those things, I don't regret anything because there's nothing you can do about it anyway (Rupert: 818-826).*

There is a huge sense of loss and disempowerment for Rupert. Reflection on the life he used to live and the one he finds himself living now, has resulted in him reframing his current life as a *big vacuum*. The empty space represents all he has lost and links

to his sense of impending death. Referring to it in the third person hints at a fear in facing the future when there is nothing there. Although he *don't regret anything*, the fact that he feels *there's nothing you can do about it anyway* highlights this lack of control is indeed accompanied by the regret he denies. However in stating *at the moment* he is a vacuum, there may be a hint of hope for Rupert that things may change in the future; once this 'moment' has passed.

As with Rupert, John felt resigned to his mental illness. This had also been integrated into his life but from an early age and therefore rather than reframing for John it had essentially 'framed' his life.

*...I've been on medication and what have you but erm, it's [condition] always with me...what people don't understand you know Nicole is, erm, it's quite tough, you know it's hard erm, (pause) it's quite hard to (pause) address it on a daily basis then, you know 'cause it's constantly with you (long pause) (upset)...mmm, you know, I don't know really, the word erm, normal, it would be nice to be normal (John: 370-391).*

The use of the word *tough* and repetition of the word *hard* show John's struggle in his daily life with his mental illness. This is reinforced by the lack of understanding he feels others have regarding it and is indicated by his emotional response when discussing it. For John, his mental illness and behaviours that accompany it, are something he can never be liberated from. The constant need to *address it on a daily basis* takes his entire focus and consumes his life; disempowering him. His wish for life and himself to be *normal* shows his wish to be free from the constraints that it imposes and the mental and physical exhaustion that accompanies it.

Acceptance, integration and living with a mental illness, were complex concepts that took place on many levels and resulted in a variety of responses and subsequent life outcomes. Integrating mental illness as part of the self was, for some, a pathway to gaining power over it to reframe a more positive future. Accepting and working with the mental illness did not necessarily equate to an empowering experience for all participants and some reframed with a note of resignation.

## **Summary**

Participants gave a strong sense of a difference in their lives pre and post diagnosis. Distress and difficulty were experienced pre diagnosis and reported feeling limited control. Having reached a point at which action was taken and support accessed, many developed an understanding and received validation of their experiences. For the majority this also became the starting point to managing the condition and connecting with others with lived experience. This stage was accompanied by perceptions of stigma and decisions surrounding disclosure.

The process of acceptance threaded its way through all interviews. It was noted to be a complex multi-layered process taking place over time and on many levels. Linked to this was taking responsibility for the management of the mental illness and learning to live with it rather than recover from it. This empowered some participants post-diagnosis as they continued their lives within a different frame of reference. However this was not the case for all and some remained wanting and disempowered.

## Chapter 5: Study 2 findings

### Introduction

As introduced in Chapter 3, in Study 2 focus groups were conducted as part of the current research. All participants worked in either statutory or non-statutory mental health service delivery in South Wales. The research design incorporated the use of emergent themes from Study 1 interviews (see Appendix 1) as the basis for discussion in these groups. To introduce these to participants, they were given the task of ordering these themes in terms of importance to the service user. This generated reflections on the experiences of those accessing services from the service user perspective. From this exercise the discussion guide (see Appendix 13) directed the staff to explore their experiences working in mental health services. Importantly using the emergent themes in this way facilitated the group discussions in focusing on the service user experience, indeed this starting point was integral to the conversation that followed.

There were notable differences between the approaches of the staff groups in the task of ordering the emergent themes. Third sector staff did not hesitate in creating a linear order of the themes, indicating a confident sense of empathy with service users. The statutory staff (medical staff and occupational therapists) however, were more questioning of the task and explained they found it difficult generalise the unique experiences of service users. Instead they chose to group similar themes together rather than impose a questionable order of importance. This, nevertheless created discussion which resulted in overarching and subthemes explored in this chapter.

Thematic Analysis was used to generate the focus group themes (see Chapter 3 for this process). The analysis presented differs in tone from the previous findings chapter, as latent meaning is not the focus of the analysis, therefore it does not involve a deeper interpretation of the content of the discussion or group dynamics. The focus groups concentrated on two areas within the mental health services: the experiences of services users and the experiences of staff. These formed the overarching themes of the analysis: *The service users' journey* and *The realities of*

*practice*, which produced a picture of service use and provision from a staff perspective. Although participants shared the commonality of working with people with mental illnesses, the discussion held divergences as well as similarities. These were influenced by the approach and position of each group towards working in services and which are highlighted through the divergences.

As Table 5 shows, the two overarching themes are made up of subthemes. The first overarching theme, ‘The service users’ journey’ has three subthemes; *The impact of mental illness: services’ raison d’être*, *Implications of diagnosis* and *Recovery is ‘living with’*. The second overarching theme ‘Realities of practice’, contains two subthemes; *Pressures on practice* and *Future re-focus*. These subthemes allow a more detailed account of the divergences between the three groups which are explored below using participant quotes.

<b>Overarching theme</b>	<b>The service users’ journey</b>	<b>The realities of practice</b>
<b>Subtheme</b>	The impact of mental illness: services’ raison d’être	Pressures on practice
<b>Subtheme</b>	Implications of diagnosis	Future re-focus
<b>Subtheme</b>	Recovery is ‘living with’	

Table 5: Focus group themes.

For the purposes of this narrative and use of transcript quotes, I will refer to the groups as follows; third sector staff: ‘TS’, medical staff: ‘MS’ and occupational therapists; ‘OT’ (see Key for reference). As both the MS and OT staff were working within the National Health Service (NHS), those they provided a service for were referred to as ‘patients’, whereas the TS group adopted the term ‘clients’. These differences being naturally present, the quotes will remain unchanged, however for ease of reading the generic term ‘service user’ will be applied to the analysis (see Chapter 1 for note on terminology). To maintain anonymity when using participant



quotes, 'M' and 'F' refer to male and female participants and the numbers denote the staff member speaking.

TS	Third sector staff
MS	Medical staff
OT	Occupational therapists
M	Male
F	Female

Key: Participant quotes used in narrative.

What now follows is an analysis of the responses of each focus group to the emergent themes (see Appendix 1) and their experiences in working in mental health services. This will start with the first overarching theme, *The service users' journey*, and its three subthemes; *The impact of mental illness: services' raison d'être*; *Implications of diagnosis* and *Recovery is 'living with'*.

## **Overarching theme 1: The service users' journey**

The impact of the use of emergent themes to influence participant discussion was significant. This formed the starting point and naturally led staff to discuss the experience of the user of mental health services and highlighted the different perspectives and approach to working of each group. Each of the emergent themes were discussed in an attempt to order them and this exercise prompted discussion on the 'journey' of the service user through services.

Even given divergences in discussion each group felt the emergent theme 'Impact on life' (of mental health symptoms) was an important aspect of the experience of the service user. This was the feature that ultimately prompted the individual to access services and gave staff their reason for their daily work. This led the groups to reflect on the purpose of their work, which highlighted their strive to achieve different objectives with the service user. Continuing this discussion, diagnosis was given much time and consideration by each group. The personal response of the service user, as well as the wider context of service provision, concluded that diagnosis was both helpful and unhelpful in equal measure. The emergent theme 'Living with'

mental illness, as opposed to recovery from it, yielded discussion indicating staff felt this was a tautology: recovery was living with the illness.

These main discussion points will be explored in more detail within the three subthemes of 'The service users' journey'. Quotes will be used to emphasise the shared opinions and divergences between participants and groups. Beginning with *The impact of mental illness: services' d'être*, the narrative will move onto *Implications of diagnosis* and conclude with *Recovery is 'living with'*.

### **Subtheme: The impact of mental illness: services' raison d'être**

MS, F2: *because I mean (sigh) that seems one of the central things isn't it is everything else feeding into the overall impact that it has on your life (427-429).*

Although all participants work with mental health service users their roles within service provision varied. These roles were indicated during discussion of the emergent theme 'Impact on life'. This was acknowledged as a fundamental aspect of the service user's experience of mental illness and the changes as a result of unmanaged symptoms were felt to have far reaching effects. Loss was considered the overall change that occurred as a result of the impact of mental illness as well as the adjustment in response to this. Third sector staff indicated their understanding of these changes had developed outside of work, as well as within: in this some indicated a shared empathy with the service user.

TS, F1: *I think even friends that are unwell, they work just about, but their jobs are smaller, they work less hours, they have less money, their social lives is tinier, whereas before, before they were unwell they had a bigger life, their life shrinks, it does shrink (478-482).*

TS, M2: *it's the impact it had on my life, you know I had to give up work and everything, accepting I got a problem, getting a diagnosis, learning to live with it that it's not going to go away, owning it and then connecting with others that's got a similar things to you and then in the end I got a job here (458-463).*

Although the statutory staff did not share personal experiences of the impact of mental illnesses, they nonetheless noted its significance. Occupational therapists noted this in relation to the direct functional changes in someone's life, as the third sector staff had. This shows the focus of their shared intervention in practically

addressing the difficulties of the service user at that time. Medical staff however highlight a more essential and subtle form of change in the individual's identity. This shows their focus on the more abstract concept of the self and is related to their role in the process of diagnosing mental illnesses.

*OT, F4: ...it's that impact whether they accept it or don't, whether that changes or it doesn't, it's the impact at that particular time isn't it? (247-249).*

*MS, F1: ...there is going to be an impact and there is going to be a change and that their previous sort of persona, is not necessarily going to be the same (180-183).*

All three groups acknowledged the impact on the life of the service user that resulted from mental illnesses. As mentioned, they recognised the link between 'Impact on life' (emergent theme) and their role in the service users life: the impact on someone's life was their reason for employment. For the medics this role took form at the start of the service user's journey to help them make sense of the symptoms they were experiencing. Diagnosing was an important link for service users in beginning to understand their mental illness and address its impact. This was also for many service users the start of accessing support in order to manage the symptoms they were experiencing.

*MS, F2: that's what people consult you for*

*MS, F3: yeah, "what's wrong with me?" (110-112).*

The journey for the service user, post-diagnosis and input of medical staff, then focused on establishing control of the mental illness and rehabilitation. This was the role both third sector and occupational therapy staff felt they played in addressing the resultant impact of the mental illness with the aim of continuing to live in, and engage with, society. Part of this role was supporting the service user to develop skills in managing their mental illness, something both groups felt involved regaining control through development of skills. This clearly links with the development of understanding given by medical staff via the process of diagnosing.

*TS, M1: well that's that's our job isn't it that's why we're here, more often than not is to put people with skills or we come up at crisis point and we've got to think, right and we try and lead them to these factors in order to regain control (549-553).*

*OT, F4: that brings us back to the impact on life isn't it? I think that's what we're interested in whatever the diagnosis held, this is people's lives, how is what you're going through actually impacting on your life now and how we can help you (519-523).*

Diagnosis being the main focus for the medical staff indicates the early stage of the journey they are accessed by the service user. For the remaining participants focus concentrated on supporting the service user to engage with society through managing their mental illness. This again highlights the stage the service user is likely to come into contact with these staff i.e. post-diagnosis when the service user has developed some understanding of the symptoms they are experiencing. Linking the impact of the mental illness on the service user, with their role in the service user's life shows the connection staff made with their *raison d'être*.

The next subtheme explores the reflections of staff, prompted by the emergent themes, on the process and impact on the service user of receiving a diagnosis: a process that generated wide-ranging discussion.

### **Subtheme: Implications of diagnosis**

*MS, F3: ...one of the things we talk there [clinic] about is diagnosis and erm and you know what's positive about, you may have the condition, if somebody gives you this diagnosis, what are going to be the positives for you and what are going to be the negatives (224-228).*

The complex nature of diagnosis was noted in each of the focus groups. It became clear staff were aware of the helpful and unhelpful sides to receiving a mental health diagnosis. The emergent theme 'Validation via diagnosis' prompted this discussion and staff explored the positive sentiment behind the statement in relation to the other themes. Connections to 'Stigma' and 'Selective disclosure' were considered alongside this theme, as well as reflections on the structure of services.

Staff recognised the need for diagnosis to help service users begin to gain understanding. Medical staff saw diagnosing as an integral and important part of their work and diagnosis was seen as essential in enabling service users make sense of what they had been experiencing and through this gain some control in managing

it. For this group, diagnosis offered justification of the changes that had taken place in service users' lives and, through understanding, relieve some of the distress that accompanied symptoms. In this manner diagnosis became important due to the validating role it played and subsequent clarity it brought.

*MS, F1: one of the things important things that we in our practice find is the big important thing is the validation and the diagnosis, it's having the label almost, it's being, it's it's allowing it, that's the thing and it's one of the big things that's what we get and people are often much more relieved once they get that (103-108).*

In considering diagnosis, a tension arose for the occupational therapists. Its importance was acknowledged, however they preferred practice without this as the focal point. These healthcare professionals recognised the need for diagnosis, however their intervention, as hinted above, focused on the impact of the mental illness. In an attempt to move away from diagnosis they practiced with a needs-led focus, however was not always appreciated by service users and they noted a minority considered diagnosis an important enabler to integrating their experiences. Therefore minimising the diagnosis, was seen as minimising distress and staff found even with a focus of management of the mental illness, service users maintained a need for diagnosis to move forward.

*OT, F2: ...I tend to say you know in some ways I'm very much not focusing on your diagnosis, as an occupational therapist I'm looking at you and your functioning...and 99.9% of them appreciate that and are much more comfortable with that and then there's that 0.01% that "oh no I want a diagnosis, I want to be clear" which is why some of this [emergent themes] is interesting*  
*OT, M1: or you're not taking it seriously*  
*OT, F3: yeah (454-467).*

Adopting a needs based approach, this group of participants highlighted what they considered unhelpful aspects of diagnosis. Focus on receiving a diagnosis and the diagnosis itself was seen as potentially limiting for the service user. This viewpoint linked with third sector staff who also acknowledged that rather than allowing the service user to gain understanding and control to manage their mental illness, diagnosis had the potential to disempower the service user. The risk that accompanied it translated to the service user, on diagnosis, not needing to take responsibility for their behaviour. The example given by an occupational therapist

was of the impact of a service user self-diagnosing rather than receiving a formal diagnosis. For third sector staff this disempowerment also resulted from a change in perception of the self, as well as access to services that alleviated responsibility.

*OT, M1: ...and at one point [patient] actually reflected back to me that erm that when [patient]'d self-diagnosed with a bipolar affective disorder, [patient]'d become a self-fulfilling prophecy erm and that erm [patient] behaviour had started to deteriorate because [patient] no longer saw any need to control it (595-600).*

*TS, M1: ...like if you're given a diagnosis then it's right, "ok I'm this I'm that", and then you get the trapped in that kind of benefits cycle you cant work, "I have this" and I suppose that's what they do now, the changes they're looking at what they can do*

*TS, F1: it's the psychological*

*TS, M1: "oh no I can't do that, I've got depressive disorder"*

*TS, F1: so it's the messages the patient receives from services (773-785).*

Self-stigma is evident here as a way of diagnosis disempowering the service user. Another implication of receiving a diagnosis recognised by all groups was the prevalence of stigma surrounding mental health in society more generally and the negative impact on the service user. Third sector staff noted the impact of societal stigma varied depending on the individual response of the service user and the length of time spent in services. Those that were new to services and newly diagnosed were more affected by societal stigma, whereas those who had been in services for a number of years were less so. This was attributed to process of acceptance of the mental illness, alongside the time necessary to develop abilities in managing it.

*TS, F1: I find a lot of the people I work with are not that bothered about it [stigma] really*

*TS, F4: we've got one who's a bit bothered haven't we?*

*TS, F1: 'cause of his age*

*TS, F4: yeah, he's young and he is bothered about it*

*TS, F1: and he's new to it you see, most of my clients have been in mental health 40 odd years (336-347).*

Medical staff highlighted the impact of stigma in relation to service users' disclosure. Reticence to disclose mental illness was felt to be related to the potential impact this would have and they acknowledged and understood the choice service users had in personal disclosure. Medical staff were very aware of the negative impact disclosure could have on employment and family life, due to its accompanying stigma. However

legislative restrictions on their practice influenced their choices in this and they recognised their duty in reporting mental illness in medical notes. Medical staff had to balance the additional external pressures i.e. committing fraud, with the services users wish for them not to disclose, which at times left them in a difficult position.

MS, F2: *and the selective disclosure one [emergent theme] is a very interesting one because I think what you say, there are times when people obviously will want to choose who they can disclose to but then if you don't disclose you could be*

MS, F1: *absolute fraud*

MS, F2: *committing fraud can't you?*

MS, F1: *mmm*

MS, F2: *so there's huge pressures there*

MS, F1: *and because the way medical records are done now, if there's been any sort of significant event that it's locked in the medical records and we can, they can be asked to take or blocked out or whatever, but then there's obviously a gap (504-521).*

Another implication of diagnosis related to the nuances within the stigma surrounding mental health. Reflecting on the fluctuations in stigma occurring over time, both statutory sector groups highlighted the disparities in stigma attached to specific diagnoses. Not only had mental health stigma in general diminished, stigma attached to each diagnoses had also seen vast changes over a relatively short period of time. These fluctuations were seen to influence the response of the service user and subsequently the acceptance of their condition. In addition to the influence of the time in services and age of the service user, the quotes below introduce the influence of the stigma surrounding specific diagnoses.

MS, F2: *obviously mental illness is a massive area and the type you know the type of illness you suffer with, you know some are far more acceptable (203-205).*

OT, F2: *...they will then cling to an older diagnosis because it has a different kudos, so you know I'm bipolar, I'm not personality disordered or I'm I'm erm schizophrenic, I'm not pre', and people will have different personal interpretations*

OT, M1: *even that, even that's shifting in my experience the diagnosis of personality disorder is less stigmatised than it was a number of years ago*

OT, F2: *oh yes*

OT, F3: *definitely (229-241).*

Medical staff, given their role in diagnosis, were aware of the stigma that surrounded this process. This they saw as taking away the validation that were attempting to give

the service user, consequently diagnosing simultaneously helped and hindered service users. This being the case the medical staff distinguished between the positive help they give via diagnosing and the hindrance society places on the service user through negative attitudes towards mental health. Much of this process they acknowledged was influenced by the unique response of the service user and whether a diagnosis was viewed as validating or invalidating, was dictated by this.

*MS, F1: ...which again makes the validation important for us as well as professionals because you don't want to put the stigma...on people unnecessarily you know...I don't think stigma's are necessarily negative, the definition of stigma I suppose is, but I, I think that a label I don't think is necessarily negative and I think it can be helpful*

*MS, F2: mmmm, it's important for some people*

*MS, F1: yeah (525-544).*

The concept of misdiagnosing was another implication noted by certain staff. Third sector and occupational therapy staff noted not only the difficulty in gaining a diagnosis per se, but the impact of the fluctuating nature of mental illnesses. They recognised the intrinsic difficulties in diagnosing and the responsibility the medical profession held in relation to this, however their focus was on the impact of misdiagnosing. The length of time it takes to receive a diagnosis and the idiosyncratic nature of each member of medical staff, often led to changes in diagnosis. This resulted in confusion, frustration and lack of clarity for the service user, which subsequently diminished their agency to manage the condition. This highlights the importance a service user places on understanding their experiences and the complicated process of diagnosis.

*OT, F2: ...some have been given a pre-emptory diagnosis which happens a lot because people are desperate for a diagnosis and then having got one if then that changes over time because as you get to know the person more and experiences progress, particularly with people that have personality disorder issues, it's not something that's first line diagnosis its very often almost like trial and error to discover that's the major difficulty behind things (221-229).*

*TS, F3: ...sometimes [service users] have been diagnosed with different mental health issues and when they've gone for another diagnosis it's been completely different, the symptoms obviously and what they've read about on the...internet and things would sort of say that it was this that or the other, they get confused about it, so they don't wana move forward until they get a proper diagnosis, which you know can be three or four times going to see a different psychiatrist (281-289).*



Medical staff highlighted the difficulties in diagnosing from their perspective. Diagnosing in itself was seen as complex and difficult which was made more so, when the service users were in disagreement with their conclusions. The choice of whether to have a diagnosis or not, was not considered by the other two groups, yet the medical staff often deal with this on a daily basis. They regularly came into contact with service users who were not seeking a diagnosis or interested in understanding their experiences via this process. These service users often had more severe mental illnesses and without compliance, intervention became an enforced process. When in disagreement, medical staff maintained their professional opinion and work with the service user agreeing to disagree. This took a sensitive approach as medical staff remained aware of their duty of care for the safety of the service user and public.

*MS, F2: ...we probably have two distinct groups of people don't we?...we have those who come to us seeking a diagnosis and feeling that diagnosis, having a diagnosis will bring something positive and then we have others that we're sort of (smiling) forcing a diagnosis on*

*MS, F3: "there's nothing wrong with me, why are you saying there's something wrong with me, there's nothing wrong with me" you know erm and that's that's totally different isn't it?*

*MS, M1: yes (160-173).*

Leading on from the lack of choice in receiving a diagnosis, was recognition of the implications of not having one. Diagnosis was seen as a route to treatment and the only way of accessing statutory services to manage mental illness. Subsequently even if service users were reluctant to receive a diagnosis, as support is intrinsically linked to it, it remained fundamental to receiving help. Statutory staff working in the healthcare system, rather than the third sector group, highlighted this connection. Medical staff saw this as a positive process whereby service users accessed support, however occupation therapy staff maintained focus should be on the needs of the individual rather than the diagnosis.

*MS, F3: sometimes you have to get the label or the help won't be there*

*MS, F2: mmm*

*MS, F1: yeah*

*MS, F2: and for a lot of our erm patients, lots of things they need which others will need anyway, housing etcetera erm, you know subsistence and things, having a diagnosis can facilitate that in various ways can't it so*

*MS, F1: yeah (653-665).*

OT, M1: *...diagnosis is almost your entry ticket to services isn't it? It's the basis for prescription, it can give you access to*

OT, F3: *benefits*

OT, M1: *this that and the other, but then on the other hand we're wanting to talk to people, "actually that's not what's important, what's important is you as an individual" (505-512).*

Both groups recognised the limitations this route to treatment produced in the system. Those who would benefit from interventions could not necessarily gain access to services if they did not have a specific diagnosis. The occupational therapists saw this as a flaw in the system, which subsequently had potential to motivate the wish to gain a particular diagnosis as a way of accessing support that accompanied it. They felt services should address the needs of the service user rather than be diagnosis driven, something medical staff hinted at. Here lies the tension indicated earlier for this group of healthcare professionals who felt a change in the approach of service provision, away from the medical model, would enable people to use the services based on difficulties rather than diagnosis.

OT, F3: *yep, because some diagnosis will link you into certain things, whereas some won't and when people feel they have needs to be met and some are being met by having this particular diagnosis*

OT, F3: *yes*

OT, F2: *and then if the diagnosis changes then they are actually pre, they see it as being prevented from accessing those and if they're something they found really helpful then there's an added impulse to want to have that diagnosis (257-268).*

MS, F3: *so so yes, so that the label becomes sort of like the passport to help, when in actual fact it should be the needs that*

MS, F1: *yes*

MS, F2: *mmm*

MS, F3: *you know so it's er, I don't know if it's variation in service provision [emergent theme] it's maybe the method in service provision (621-631).*

The occupational therapists repeatedly called for a 'needs led' access to support. This view was reinforced by the belief that an unhelpful implication of diagnosis was its ability to enhance dependency on the system. This was also hinted by third sector staff earlier emphasising self-stigma and subsequent self-limiting behaviour. Occupational therapy staff felt once labelled as 'ill', it was difficult to redress this in light of making progress as signals from services reinforced the sense they remained

unwell. This is accompanied by an acknowledgement of the reluctance of services to discharge service users, as they may need access to support if becoming unwell in the future. Therefore once diagnosed both the service user and the service were reluctant to terminate the alliance, indicating an unhelpful dependency.

OT, F3: *...in my view [patient]'s recovered and done really, really well but [partner] can't accept that [patient]'s recovered because [patient] has a bad day now and again and yeah*

OT, F4: *and [patient]'s still got the diagnosis*

OT, F3: *yes*

OT, F4: *"I've got the diagnosis"*

OT, F3: *[patient]'s still involved with people from mental health and [patient] still has visits from the CPN "so I must be ill" (laughs)*

OT, F4: *absolutely, "I've been diagnosed" (laughs)*

OT, F6: *reinforcing it (1218-1234).*

In contrast, medical staff believed longer-term access to services was a positive outcome of diagnosis. Access to a variety of support via diagnosis was seen of help to the service user, enabling them to develop foundations to manage their mental illness. Without such all round support the service user was likely to struggle in their daily life and subsequently their mental health would deteriorate. Diagnosis was the element that eased the transition of not coping, to coping with mental illness through the support that then became available.

MS, F3: *...it is it's very hard, because if you're out there now, supposing you're on JSA [Job Seekers Allowance] and you're having to do this that and the other, it's extremely stressful and if you're already poorly functioning, if you haven't got that label to say "look I've got 'x' you know erm this is going to really impact on me", it's hard then to persuade anyone else, I suppose that comes back to validation really*

MS, F2: *mhmm*

MS, F3: *that you need to have that kind of erm allowance made (676-688).*

The varied implications of receiving a diagnosis drew the conclusion that it was simultaneously helpful and unhelpful for the service user. Diagnosis being the focal point for interventions led staff to reflect on the functions of the system as a whole and how helpful or unhelpful this was to service users and their own practice. (This aspect is further explored in the second overarching theme; specifically the subtheme 'Pressures on practice'.) Discussion of the implications of diagnosis, naturally

incorporated the service users' management of the mental illness post-diagnosis, which explored below.

### **Subtheme: Recovery is 'living with'**

*OT, M1: ...now there's probably as many different definitions of recovery as there are people you speak to about it, but the one I'm most used to is exactly that, that recovery is managing and living with a a a mental health condition (166-175).*

Staff drew attention to the emergent theme 'Living with' mental illness (as opposed to recovery from it) believing it to be tautological. From their perspective learning to live with the mental illness was indeed a form of recovery. This discussion incorporated many other emergent themes; 'Connecting to others', 'Regaining control', 'Acceptance is complex' and 'Ownership of mental ill-health'. These emergent themes staff felt, influenced service users journey of recovery post-diagnosis.

Each group commented on what recovery meant from their perspective of working in services. This provided the strong indication that the approach and the framework they worked within, was based on the concept of recovery as learning to manage and cope with the mental illness. Defining the term recovery as 'living with' integrated the essential development of skills and knowledge of mental illness in order to promote recovery. It is perhaps unsurprising that staff delivering services in mental health adopted this approach, as this builds on the 'raison d'être' of services; management of mental illnesses equates to, and extends to, the management of the illness longer term.

*OT, F2: good recovery is being able to cope, continue your life as normal and if it happens again, have the skills to be able to cope with it again (209-212).*

*TS, F1: living within your abilities, within your illness really (567-568).*

*MS, F2: because how you own it and accept it and then find ways living with it in will dictate how much of an impact things have on your life  
MS, F1: yeah (345-349).*

For third sector staff recovery for service users was interwoven with acceptance. Therefore the acceptance of the mental illness, or not, influenced the recovery of the service user. They acknowledged this was a complex and multi-layered process that was not linear in nature and, as indicated earlier, influenced by the service user's age and time spent in services. Staff highlighted the fact that diagnosis did not mean cure, and in doing so acknowledged the process of acceptance that learning to live with the mental illness followed diagnosis.

*TS, M1: I go with [TS, F1] I think erm, getting your head around living with it, not that you're going to get cured from it is a big thing and the impact that it has on your life, erm, (pause) er, acceptance is guna come in with that (298-302).*

Medical staff felt the emergent theme 'Regaining control' had an important part to play in recovery. This was in relation to their acknowledgement of the power they held over service users' lives. Although one participant questioned its importance the remaining participants were unified in their understanding of the impact this had on service users' sense of autonomy. Their role incorporated use of restrictive and controlling powers, such as Community Treatment Orders, in instances where service users are unable to manage their mental illness. This highlights the fact that learning to live with the mental health illness post-diagnosis, is not done in isolation and staff recognised the importance of facilitating the balance of power back into the hands of the service user in facilitating recovery.

*MS, M1: is this is important? [emergent theme 'control'] I don't find it very important, in control (pause) or significant*

*MS, F2: mmm, I think because for a lot of our patients we take away control, don't we? and that can, and we have to frequently you know using the Mental Health Act and things that at some point you have to be able to move that back to the person having, having control and even within that setting when we're taken overall control, it's still important to give them what we can, so they don't feel totally you know they've lost all autonomy and (pause)*

*MS, F1: it's funny 'cause it's still it's still their life*

*MS, F2: mmm*

*MS, F3: mmm (266-282).*

Part of learning to live with the mental illness integrated 'Connection to others' with mental illnesses. The three groups reflected on the importance of this for service users to feel supported. Both the third sector and the occupational therapists recognised the worth of accessing support from others with lived experience of

mental illness. For third sector staff this extended to service users becoming empowered through forming a group to challenge mental health stigma. Therefore these staff felt frustration and despondency that this opportunity was often missed through influences outside of their control. Although they understood self-help groups' role in recovery, it was often hampered by inappropriate referral or simply not having the resources to support the service user to attend.

*TS, M1: ...but maybe with the stigma, the selective disclosure and connecting with others [emergent themes], like if you said "right everyone in the world mental health is a big problem if you're feeling depressed come here we'll talk about it", 'cause I've been to some like groups recently but no one ever turns up, it's like ten people in a room and some bloody church and then no one goes to the next session, 'cause people given it perhaps aren't you know, perhaps aren't you know, it just doesn't feel like that big movement you know and you know, I don't know it just seems naff (1045-1054).*

*OT, F2: but I'm also hugely frustrated by the fact that you know this group's gonna do somebody really, really good but there's not enough of you to make sure they get there*

*OT, F6: that is the crux often isn't it?*

*OT, F1: or get them the skills to be able to get that*

*OT, F2: that's the*

*OT, F1: the support to get to, the confidence (959-969).*

For medical staff however, recognition of the benefits of connecting to others had not come naturally. Working in mental health services they had developed an understanding of the need of some service users to gain support from others with lived experience. Over time they recognised the importance of the role this played in building the support network necessary for recovery, as well as helping challenge the stigma accompanying mental illness. Their current practice routinely involved discussion of support groups to facilitate recovery and support service user to live with their mental illness.

*MS, F1: ...everyone with a diagnosis we had to give them a sheet of our local help group on that condition...I used to smirk at the time but people do, people like having this sort of camaraderie with a lot of these, a lot of these things so and I think while it may not be high up on my important list I think that a lot of patients do really like it*

*MS, F3: I think so, I think it's a question "I think nobody understands me" and then you connect with somebody that does understand you and has been through what you've been through*

MS, F2: *and I think that's really important, probably partially because of the stigma*

MS, F2: *yeah (365-379).*

This first overarching theme, *The service users' journey*, was developed from the discussion on emergent themes taken from interviews on the experience of receiving a mental health diagnosis (Study 1). Using the emergent themes in this way facilitated conversation on the experience of mental health service users, from the perspective of staff delivering services. The second overarching theme 'The realities of practice', captures continued conversation directed by the discussion guide concerning current service provision and practice. This overarching theme is made up of two subthemes; *Pressures on practice* and *Future re-focus*, these areas are explored in the narrative that follows.

## **Overarching theme 2: The realities of practice**

When prompted staff discussed their current practice and mental health service provision more widely. Although this discussion did not speak directly to the emergent themes presented, it grew from them, building on the conversation to that point. This discussion incorporated reflections on influences on their work and the impact this had on the experience of the service user. The subtheme *Pressures on practice* incorporates the frustrations staff expressed in their work within a poorly funded system. This lack of resources in mental health services was felt to have significant impact on both service provision and their daily practice. The result of a dearth in resources led to what was considered a shortsighted focus on crisis management, as opposed to a relapse prevention recovery focus.

Some staff felt this was a result of the system in which they worked. A binary approach to mental health medicalised symptoms and ultimately alleviated responsibility for behaviour. The system was seen as paternalistic and risk-averse which encouraged the unrealistic expectations of the public and service users. To further compound this, the media was felt to have a significant influence on expectations and consequently increase pressure on services.

Throughout this discussion staff naturally suggested ways in which services could be changed. The second subtheme, *Future re-focus* highlights these suggestions. Modifications to the system were considered necessary to address pressures and produce a more sustainable future. They advocated a preventative community-based approach that encouraged service user responsibility alongside a wide reaching public mental health education programme. This would be supported by the normalisation, rather than the medicalisation, of mental illness. The call for additional resources was accompanied by the need to work differently: up-skilling staff and cohesive team working across sectors through enhanced communication. The two subthemes of *Pressures on practice* and *Future re-focus* are now turned to in more detail.

### **Subtheme: Pressures on practice**

MS, F3: *services are finite and money is finite and you know in the end you er, do what you can do (835-836).*

All staff noted the limited resources available in mental health services. Resources received in physical health were seen to far exceed those in their own sector and this was a cause of frustration. Most were resigned to this fact and felt little was likely to change financially for mental health service provision. All recognised the role the government played in this, indicating there are choices in providing financial backing to services and their work was influenced as a consequence. Limited funding resulted in lack of adequate and timely treatment options available to staff and service users. Supporting this, medical staff noted the long-term nature of the development of treatment options owing to the research needed to underpin timely and appropriate interventions. Third sector and occupational therapy staff felt this led to a focus on medication and acknowledged this was not a panacea, with symptoms of mental illness often not being adequately managed.

MS, F2: *and it's also politically driven isn't it where you put your resources and also some of the interventions are they've only been developed really relatively recently, some of the some of the work that you can do with these people they're only now sort of developing a good evidence base for many lines of interventions, which can actually deliver reasonably sort of efficiently and things, so hopefully those sort of interventions will develop, but (pause) (842-850).*



OT, M1: *...the resources are not in a sense financial resources, but just what is available to to erm alleviate the distress that people experience is erm, virtually all very long-term and requires the involvement of the and the buy-in of the individual, there really aren't any quick fixes in mental health, most people think there are, but most medication doesn't work quickly and those that do the doctors won't prescribe (laughs) (748-756).*

TS, F3: *...some of the clients I've worked with have been to see the psychologist and the psychiatrist an' all you know for a review or something, if clients are not managing as they call it with the medication, they sometimes get to the stage where you're thinking you know "what else can we give you? there's nothing else we can give you, because obviously this doesn't work, that doesn't work that gives you side effects" (749-756).*

For third sector staff limited resources translated directly to changes in the focus of their intervention. In the past they had approached work with service users in a holistic manner, based on individual needs. Recent changes in funding provision resulted in staff being guided to support service users to maintain tenancies, rather than focus on any other difficulties they experienced. This they felt was not only impossible and inhumane, it was also shortsighted in that it did not support a sustainable approach in service provision. They took the view that all aspects of a service user's life impacted on their ability to manage their mental health and subsequently maintain their tenancies with the organisation. Therefore a holistic approach was essential that supported service users in all aspects of their lives.

TS, F4: *yeah, if we lose our funding, there are a lot of people that we work with who are guna struggle*

TS, F1: *they will*

TS, F4: *and there's guna be a lot of uproar and I mean I'm talking, there's guna be raising debt, you've got people who are not guna be able to pay rent, go the the doctors, they won't even be able to go the job centre and say "hi, I've got mental health issues this is why I can't work, cause I'm this bad" because they can't even walk in there, they can't even pick a phone call up to have a conversation on the phone (1155-1167).*

Accompanying this point they also noted the overstretched system had resulted in changes in the practice of healthcare professionals. Limited time exploring the causes of mental illnesses did not address the root of the problem and therefore the 'sticking plaster' of medication was used. Without consideration of the past of the service user, the present and future could not be made sense of and therefore current

treatment options were not considered beneficial in supporting the service user to manage their condition long-term.

TS, F2: *'cause that person might not have anyone to talk to and they just wana sit down and be able to speak to somebody on a professional level who can give them a helpful answer*

TS, F1: *practical advice*

TS, F2: *but it's just easier to give someone medication*

TS, F4: *nobodies focusing on their past lives anymore, it's just drugs (954-965).*

Given the limited time with service users noted by third sector staff, there was a discrepancy as to how helpful infrequent outpatient appointments were seen to be. Third sector staff saw these appointments as little more than a 'tick box exercise' that left staff frustrated with the lack of input from statutory services. They felt the limited time spent with the service user, resulted in a lack of understanding about them and their needs, which was of little benefit to those they worked with. However medical staff saw an advantage to the service user of these appointments, no matter how infrequent they were. They felt the validation that came when service users' saw their consultant or GP, had a significant impact in assisting management of mental health and life in the community. Withdrawing these contacts would lead to deterioration in mental health that would have far reaching implications.

TS, M1: *...I've been to a load of meetings with clients and the CPN [Community Psychiatric Nurse] or a consultant where they don't actually know them [service user], it's just know the person in their diary and they come in and they say, "oh I saw you six months ago, how you doing?" and they'll be like "alright" and then they go "ok then, cool, come back in six months", I don't know it just seems like waste of money*

TS, F3: *yeah it does (787-796).*

MS, F3: *...we're talking about secondary care being there for just the sort of the stabilisation and then get people back out reconnecting but a lot of people feel very emotionally supported just by seeing an outpatients once every*

MS, F1: *yeah, yeah*

MS, F3: *six months*

MS, F1: *yeah absolutely*

MS, F3: *and then you take that away and people then feel very invalidated*

MS, F1: *absolutely (1077-1093).*

As a result of limited resources in services, staff felt there was a consequential inherent focus on crisis. Interventions concentrated on service users whose mental

health had deteriorated to such an extent they became a risk to themselves or others. This attention on managing crisis was likened to 'fire-fighting' by medical staff who also recognised this approach in wider service provision, such as social services. Both groups working in statutory services acknowledged this focus restricted any ability to act in a preventative manner. Occupational therapy staff found an irony in this where the approach of the system reinforced the dysfunction of it.

MS, F3: *I think a lot of you know just the same as every service at the moment, erm services will tend to do what is immediate and urgent in front of you*

MS, F1: *absolutely, knee jerk*

MS, F2: *mmm, yep (796-802).*

OT, M1: *services you know whether we like it or not are are (pause) more I can't think of the right word, rewarding of of you know of crisis of illness, of negative things*

OT, F4: *yeah*

OT, F3: *I mean*

OT, M1: *we've got that the wrong way round haven't we? (412-422).*

For medical staff, limited resources left many service users to endure distressing symptoms. Concentration on crisis management and those in need of continuous ongoing support, focused resources away from those just coping in society. This pressure on the system led the medical staff to be restricted in their focus to service users in crisis and/or with more extreme mental illnesses. This, third sector and occupational therapy staff felt to be a blinkered, unsustainable, self-defeating process, that caused service users to enter a vicious cycle where interventions were only available when they reached a state being extremely unwell. This perspective highlights the recovery and rehabilitation focus of the two staff groups and their frustration in the lack of focus on preventative intervention. For medical staff this related to the lack of comprehensive care across GP practices and community teams, which left a large group of people without essential validation and support from medical staff.

MS, F2: *yeah, so some people with severe enduring illness who need on-going contact, erm but there is there is erm a group of people who have perhaps the more what we would term as the neurotic conditions but there's an awful lot of suffering you know associated with that*

MS, F1: *yes*

MS, F2: *you know so that's an area that perhaps falls between the two stalls really at the moment, isn't it, it's difficult to manage in primary care isn't it but it isn't really reaching our [secondary services] threshold (768-779).*

OT, M1: *...what we've already identified is that sort of sense of that people have to get worse and worse and worse before they get any*

OT, F2: *yep*

OT, M1: *any input (995-1001).*

TS, M1: *because the waiting list is so long for any sort of therapeutic assistance for recovery*

TS, F1: *it's ridiculous*

TS, M1: *or sustained recovery*

TS, F1: *it doesn't seem to exist really (650-657).*

Although all staff commented critically on statutory services, the third sector and occupational therapy staff were particularly disparaging. They felt the system was risk-averse, hierarchical and restrictive in nature and worked in a way that ultimately disempowered service users. Use of the medical dichotomy of illness or wellness, was considered by the occupational therapists to be unhelpful as it served to maintain the service users' dependence on services. Once a service user was in the system, it was almost impossible for them to leave services, firstly through the dependency that is developed and secondly due to the concerns that a service user may become unwell again. Third sector staff felt that this dichotomous approach of the system (well/unwell) led to a dismissal of the complexities of service users and their lives. This resulted in an expectation that support staff would address the multi-layered problems of the service user. The long-term result of this unsustainable approach was likely to be staff burn-out and subsequently lead to poorer service provision in mental health.

OT, F3: *it's quite frightening really how we [services] can grab onto people and they can become dependent and institutionalised*

OT, F6: *it's a very paternalistic model isn't it*

OT, F3: *very (630-635).*

TS, F3: *they're not gonna want to address their substance misuse you know so therefore their mental health ain't gonna be supported with anyone really, 'cause as soon as you say, 'oh [client]'s drinking or taking drugs' that's it, hands up can't work with you, you know "can't come in to see you today 'cause you're under the influence" and that's left for months and...these frontline staff, well practically taking on every other person's mental health, substance misuse*

TS, F1: *we're juggling really*

TS, F3: *every bit of a person's mental health, substance misuse, relationship problems everything*

TS, F1: *they're not little things are they? (1585-1600).*

Another pressure of staff practice was noted to be caused by the media. Staff working in the statutory sector felt the media influence was both good and bad. Encouraging the public to view services in a certain way had led to unfair and unrealistic expectations of what services could offer. For the occupational therapists, this careless approach reinforced the message that services could not only address all issues, it also reinforced the dependency of service users on the system. Medical staff, who noted the good that can come from media campaigns that support public health messages, offered a balance to this perspective. Media was seen as also creating agency in service users, empowering them to take responsibility for their health and access services in a timely manner. In the long-term, this preventative focus could result in cost savings as the public becomes more educated and aware of what they could do to improve their own health outcomes. In the short-term however, it was noted that media input essentially increased pressure on the system by raising awareness and consequently people accessing support. Whether unhelpful or helpful, the two groups agreed on the influence and opportunity the media had in helping sustain health.

OT, F6: *and then you've got that sort of media representation haven't you as well, the way that the media holds mental health services responsible for fixing everybody's mental health regardless of whether it is actually coming from a health issue or not, sometimes it's just a bad behaviour erm and it misses the media misses out the whole area of personal responsibility, family responsibility, society's responsibility, community responsibility and self-management*

OT, M1: *mmm and that's*

OT, F6: *and that must be confusing for people*

OT, M1: *yeah (717-731).*

MS, F1: *but saying about soaps and things, it's not quite mental illness but the Jade Goodie [celebrity] effect on cervical smears was another big thing, so that's just proving that anything that's out there really does and I think that erm, certainly the media has a responsibility about how much they they push this and I think a lot of these soaps and things at the end say if any of this has affected you*

MS, F2: *if you've been affected by any of the issues today*

MS, F3: *there's a helpline*

MS, F1: *they used to have a [resource] sheet, they have a helpline now (laughs) (1024-1038).*

All groups commented on the difficulties dealing with unrealistic expectations of service users. These went beyond a reasonable expectation of having support from well-informed staff to manage health issues, into the realm of being all-knowing and possessing the ability to cure-all. For the occupational therapists, these unrealistic expectations were indicative of service users not sharing responsibility for their health. This inherent attitude, held by the majority of service users, reinforced a vicious cycle, where services disempower the users of those services by encouraging them to take a passive role in their health.

OT, M1: *...it's almost become a currency you know that asking for help is "you've done your bit" and then it's up to the rest of us t' t' to pull out all the stops (744-747).*

For medical and third sector staff, service user expectations simply morphed into the unrealistic. Carrying a customary magic wand in their medical bag for daily practice, was the tongue-in-cheek response of medical staff. With limited resources and limited treatment options, medical staff found it laughable that service users should hold such high hopes of them as professionals. Third sector staff, however indicated their frustration that service users were so unrealistic in what support they could offer. Both groups felt the subsequent additional pressure to have all the answers and to hold the elixir to resolve all difficulties. As we can see in previous quotes, staff hinted these expectations were, in part, generated by the media and the resultant impact was seen on an almost daily basis.

TS, F3: *...and they [service users], you know, seem to think that we've got this box of tricks in front of us where we can do it all*

TS, F1: *magic flags*

TS, F3: *we can just you know solve all their issues all their problems, out of one person, it doesn't work like that*

TS, F1: *you can't, you cannot do it (1556-1565).*

MS, F2: *yeah, I also do think that some people have this sort of mental image that the psychiatrist has some magic, got powers to fix to sort me out this is the*

MS, F1: *(smiling) we do*

MS, F3: *"you're the psychiatrist"*

MS, F2: *and quite often you get people coming in and you're trying to find out what what they're seeking and they just need someone to sort them out sort of thing and (laughs) perhaps a psychiatrist can do that when other people can't*

MS, F1: *it's just so easy (laughs)*

MS, F2: *(laughs) (1178-1194).*

Leading on from the previous influence of the media, statutory staff noted the impact of a reduction in the stigma of mental illness. This, together with the availability of information on mental health, had resulted in service users self-diagnosing and approaching services to have their prediction confirmed. In the past this information had not been so freely available and this change had led to service users to approach services in a different way. They felt the media, highlighting celebrities that had experienced mental illness or certain story lines, had also affected stigma. This reduction in stigma had consequently put pressure on their practice to apply a label or diagnose a mental illness when a service user felt they had one. For the occupational therapists, again this offered a way for services users to find a reason not accept responsibility for their behaviour. However for both groups the underlying concern was the link between celebrity status and appeal of mental illness, as opposed to genuine need for support of services.

OT, M1: *...the stigma is going out of labels in fact there's almost a sort of desirability (laughs) about them, you know a bit like you were saying [G3, F3] I think you know people are coming along with an agenda this is what I've seen on Eastenders and this is what I want you to tell me I've got (laughs)*  
OT, F4: *this can explain to my family, why I behave at the time*  
OT, F3: *excuses (572-582).*

MS, F2: *I mean things like what's happening in the soaps you know I mean what diagnoses as well are acceptable and wanted and what diagnoses aren't as well in terms of stigma, I think you know I think, I don't think many people come wanting a diagnosis of schizophrenia, I think many people would like a, wouldn't mind a, come to us specifically saying I think I've got*  
MS, F3: *bipolar*  
MS, F2: *bipolar*  
MS, F1: *yeah*  
MS, F2: *affective disorder (911-925).*

Although staff noted numerous pressures on their daily practice and contact with service users, they also naturally shared ideas to address some of the deficiencies in the system. These are presented in the final subtheme, *Future re-focus*, which illustrates some of the suggestions to reduce pressure and provide better service provision.

## **Subtheme: Future re-focus**

*MS, F3: well we have to be realistic, I think you know we can say, "we could have this, we could have that", there isn't the money so the only thing we can think of doing is working differently, which is something that we've actually been talking a little bit about, about looking at how we work (1072-1077).*

Alongside comments made regarding the pressures on staff, were thoughts on how things could be done differently. The discussion guide prompted many of these, however others occurred naturally alongside the difficulties that were expressed. Thoughts focused on making changes that would improve the experience of service users as well as reducing pressures on the system and staff. Perhaps unsurprisingly, all staff suggested employment of additional staff in their area and mental health services more widely. However other suggestions centered on how the service user could support the system by collaboratively working with services rather than absolving responsibility. Third sector and occupational therapy staff suggested educating the public in maintaining mental health could engender this approach.

Third sector staff regularly educated service users about their diagnosed mental illness. They felt medical staff generally neglected this type of intervention at the time of diagnosing and it subsequently became an essential focus for third sector staff. Helping service users understand their condition was a significant step towards them managing it and therefore felt to be a missed opportunity earlier on in the process. In fact they extended the concept of education much wider than just with service users and suggested a comprehensive approach to involve the general public. Their focus was on increasing awareness across society, facilitating understanding and encouraging a more accepting, compassionate approach to those experiencing mental illnesses.

*TS, F1: well, you have to start at the bottom don't you, I mean education, knowledge and understanding of human things...maybe we can get in at a younger age and help these young people understand and as they get older and evolve into young adults that they accept this is mental ill'...it's understanding and connecting, I don't know I just think it's massive*  
*TS, M1: be more humanist about it, and just accept*  
*TS, F3: yeah*  
*TS, F1: yeah (1068-1091).*



Occupational therapy staff also promoted the approach of wide-scale education. This would link with the promotion of a preventative community-based approach to healthcare with individuals, communities and society recognising their own responsibility in maintaining mental health. Wide reaching educational programmes would not only allow for a more tolerant society, it would also support the overall mental health of society. This would have the subsequent effect of reducing pressure on the system over the long-term, through building community support networks that maintained the mental health of those within them. This they noted was linked with the original concept of a sustainable public health service that focused on prevention and personal responsibility.

*OT, F2: ...you know the whole set up of the health service was with this idea that if you caught people early enough and made sure they kept well then wouldn't need all this treatment and see how well that's worked for us (laughs), it takes more money and it takes more input and it means you get start, from the very start and you teach mental well health, mental, yeah, mental health from day one*

*OT, M1: at the schools and everything*

*OT, F2: well even before that you know pre-pregnancy, pre-mothers pre pre everything and there is more money into that but not at the level that's going to impact on us in a long time, I don't think (806-823).*

This also extended to the messages service users receive from services; i.e. the ill/well dichotomy. All staff mentioned the spectrum of mental health to mental illness and the importance of normalisation of mental illness in the process of improving services and challenging stigma. This connects with the suggestion of education programmes that incorporate the breadth of mental wellness to mental illness. Third sector staff noted the need for service users to understand what is 'normal' in order to evaluate their situation from this perspective. Promoting mental health and illness as part of 'normal' life experiences, would serve to bring people together and strengthen the support networks of those experiencing difficulties.

*TS, M2: that's quite important, er connecting with others realising they're not the only people with it and we've got one that always goes on about normal people*

*TS, F4: yeah yeah*

*TS, M2: and*

*TS, F4: and we try to say that "no-one's normal" don't we?*

*TS, M2: yeah (312-323).*

Statutory staff noted the importance of services role in normalisation of mental illnesses. Occupational therapy staff approached this from the perspective of natural changes that occur through life and the events that people have a negative response to. Fluctuations in levels of stress and ability to cope, were seen as normal aspects of life and therefore the label of a mental illness and medication of symptoms should not be the main focus. Rather, they felt reiterated reducing attention on diagnosis to concentrate on developing abilities to cope, which they felt would benefit the service user and reduce pressure on the system.

*OT, F2: well it's more about trying to help people recognise that the spectrum of your own mental health is normal*

*OT, M1: it's part of life*

*OT, F2: and it's not you have ill-health or you have mental health, it, you have you know we're all on that scale and there are times when it will become problematic and there are times it will won't and the diagnostic bit is just in the middle (1145-1155).*

For medical staff, 'normalisation' of mental illness came with the added complication of diagnosing service users. A central part of their role involved using a continuum that ranged from what society considered 'normal' to what it did not. Although third sector and occupational therapy staff promoted the need for service users to see their difficulties as part of normal human experience, the perspective of medical staff highlights the complex nature of mental health and illness and, subsequently, diagnosis. However the underlying message remained the same: mental health is on a continuum and diagnosing can be unhelpful when it serves to separate service users.

*MS, F2: but you sort of think especially because a lot of these conditions, they're not discrete conditions they are sort of manifestations of traits we all have to a greater or lesser degree and at what point do you draw the line and say someone gets special treatment compared to someone else? as opposed to the fact that we have all differing IQs and you know taking out the learning disability, but, but you wouldn't sort of examine people separately because they happen to have a IQ ten points lower than the person, person next to them so erm (1013-1022).*

There were other points of discussion that highlighted actions within staff's influence to facilitate a more efficient service provision. Increasing communication and cohesive working practices between the broad range of services, was something third sector staff felt would improve the service user experience. They had experienced many difficulties working alongside statutory services, which had led to frustration

and a sense they were not valued. However they understood the necessity of working more cohesively in order to share the knowledge gained from their close work with service users. Being involved in this way would challenge the simplistic approach taken by statutory services and ultimately benefit service users.

*TS, F2: ...we have to kind of bend the rules a little bit we're the ones that look at things like there's very much a grey area, and that nothing is black and nothing is white*

*TS, F1: we work in grey*

*TS, F2: I feel my own point of view sometimes it is very hard and it is a bit like a war, when everyone should be that team (1872-1881).*

Medical staff also suggested working differently in teams, however their focus was within teams rather than between teams. Ways of easing the pressure of increasing demands on limited sources, led them to consider the areas of their role that could be transferred to other healthcare professionals. Up-skilling other members of the healthcare team was an approach also noted by occupational therapy staff. Although they recognised services users were becoming more accepting of this change, they emphasised the confusion that may occur when adjusting to new blurred roles. It was accepted that introducing this model into mental health service provision would expedite interventions and in turn ease the pressure, however both groups recognised some boundaries remained.

*OT, M1: ...I mean non-doctors do the majority of front-line assessments these days, which never used to be the case, erm but of course legitimately you can't diagnose so you end up having to say to people things like being very clear you're not a doctor and that your role isn't to make a diagnosis, but in*

*OT, F2: you do a formulation with them*

*OT, M1: yes, exactly yes and that that I think it works quite well but part of what we're doing there is skirting round the issue isn't it you know that we kind of do the doctors job for them in a sense, but perhaps in a more helpful way (1105-1118).*

*MS, F2: ...now there are certain things that only the doctor can do because they're the only one who's got the expertise to do that, but there are other things and other interventions that can be applied by anyone you know with a moderate amount of training and things and so it's working you know using other people effectively to do those things*

*MS, F3: and it's and that's what a lot of other serv' like you were saying you know cardiac rehab, but if you go to outpatients nowadays more often than not you'll be seeing a nurse (1122-1133).*

The need for increased involvement with other healthcare professionals, again highlighted the lack time of and resources available in mental health service provision. For third sector and occupational therapy staff this resulted in poorer interventions with service users. The lack of focus on building a therapeutic relationship between staff and service users, was seen as a missed opportunity in maintaining mental health. Having contact with a caring member of staff, with time to listen, enabled the service user to feel valued and this foundation was considered an essential aspect in the service user managing their mental illness. For occupational therapists this relationship is an opportunity for the normalisation of mental illness, for third sector staff the focus was on connection and building support.

*OT, F4: ...I think we perhaps we've got more time than medics to actually sit and listen and I'm sure some people just want to offload they just want to be listened to, they'll think they'll be quite happy perhaps just to leave and think oh I've been listened to there isn't anything really wrong with me, I think it links very much in with the actual validation doesn't it? I think some people who think I've got to have this diagnosis to get the help that I think that I need when perhaps I just need somebody just to just listen to me*

*OT, M1: yep*

*OT, F4: to be there in that situation at that time*

*OT, M1: yeah so it's about validation almost without the diagnosis isn't it?*

*OT, F4: yes (877-895).*

*TS, M1: erm, I don't know, just think the main thing that we're getting so upset means that it's not quite right yet and personally I think nothing helps people like people, so get more people involved in care (1797-1800).*

Pressures on practice were noted to arise from many different areas. In recognising these influences on their daily work, staff also suggested solutions they felt would positively impact on their experience and that of the service user.

## **Summary**

During discussion, the three focus groups with staff noted the importance of the impact mental illness and service users' unique responses to it. This was accompanied by recognition of the link between this and their role in the life of the services user, helping them manage their mental illness. They understood service users wish to gain understanding of their experiences through diagnosis and the connection of this to treatment and support. However they also acknowledged the

stigma that accompanied it and as a consequence of this likelihood that diagnosis could also invalidate a person and disempower them. The opposing nature of this within diagnosis led them to conclude it could be both helpful and unhelpful for the service user.

Once diagnosed staff recognised their role, in differing ways, in the life of the service user to facilitate management of the condition. This led to reflections on the service provision and, influenced by a lack of resources, the limited treatment options available. In response to this they called for more resources and an increase in staff and support for service users and different ways of working were suggested. Collaboratively working with the service user as well as between and within teams was advocated. Approaching mental illness as a normal part of human experience would come about through a national educational programme to enable understanding and support networks. This would provide sustainable service provision for the future and help maintain public mental health as well as reduce the stigma attached to it.

## **Chapter 6: Discussion**

### **Introduction**

This chapter begins by revisiting the novel concurrent design of the research due to it going beyond traditional IPA studies. The discussion then addresses the final objective of the research; to draw together analyses from Studies 1 and 2 to identify recommendations for practice in mental health service provision. In achieving this, the chapter explores the experience of receiving a mental health diagnosis from both service user and staff perspectives. Through this process, recommendations for practice in mental health service provision are identified and presented before turning to consider the limitations of the current research and reflexivity.

### **Concurrent multi-method design**

As explained in Chapter 3, the 'bolder design' for the current research was innovative in nature. It has been explained for others to replicate it, however it is important to discuss it here in light of other researchers' use of it. Its development was in response to the specific aim and objectives of the current research and driven by my approach. The voice of those with lived experience, whether that be of mental illness in the case of the current research, a different health condition or life experience, is essential in grounding the research in real life. As noted in the methodology this compliments the academic focus of the AST, which in most cases is an expected component within academic research at this level. The use of both an AST and the RAP, challenges the researcher to review their understanding of a subject and ensures transparency in their thinking and progression throughout the research.

Other fundamental factors that are essential to the design are the combining of two separate but linked participant groups, the use of IPA and the use of different qualitative methods for analysis. It is vital that the participants involved in Study 1 and Study 2 have some connection to allow for the emergent themes of Study 1 to resonate in some way with the participants of Study 2. The use of IPA in Study 1 is also an integral component. Understanding the philosophical foundations of IPA and following the steps suggested by Smith *et al.* (2009) in applying it, allows for a level of

immersion that is firmly rooted in the data. The level of work necessary to produce emergent themes, ensures a connection and deep understanding of each participant story before moving onto creating higher level themes (superordinate and subordinate). It is for this reason IPA is well suited to this design as it assists the researcher to get 'experience close' in developing these initial themes that are closest to the raw data.

The development of these themes continues concurrently to the recruitment and running of focus groups (Study 2). It is here however in Study 2, a certain level of flexibility in the design can be found in the choice of method for analysis. The multi-method design, as noted above, employs IPA for Study 1 and necessitates that the researcher uses qualitative methods for both studies (i.e. it is not 'mixed-method' design). The use of groups for Study 2 is also intrinsic to the design as discussion between participants heightens the understanding of the researcher through the different perspectives presented. The choices made for the method of analysis of Study 2, must be with the knowledge of the final aspect of the design: drawing together Study 1 and Study 2. This concludes the research and is done with the purpose of creating new understanding through the discussion of both sets of findings. Therefore although both studies are conducted separately, they have a fundamental connection throughout that leads to this end result.

In summary, to replicate the concurrent multi-method bolder design presented here, studies must incorporate a RAP as well as an AST, use IPA in Study 1 and the resulting emergent themes must be used in Study 2. The development of these themes using IPA, takes place concurrently to running the focus groups of Study 2. The choice of analysis in Study 2 has some flexibility with the caveat that the findings from this are accessible to achieve the final goal of synthesising them with the findings of Study 1.

### **Synthesising Studies 1 and 2: Both sides of the table**

The research design guided the gathering of data from two separate but intrinsically linked sources. Therefore as a starting point in drawing together these two sets of findings, it is helpful to remind ourselves of the themes developed for each of study (see Tables 4 and 5). This synthesis will integrate the literature provided in chapter

2, as well as introducing additional relevant empirical research, to further the knowledge of the experience of receiving a mental health diagnosis. In previous chapters, both those involved in Studies 1 and 2 have been referred to as 'participants'. As the following discussion combines the findings from both sets of data, the term 'service user' will be adopted for participants in Study 1 and 'staff' for Study 2.

Although approached from different positions, there are three areas that emerge when bringing together the findings from Studies 1 and 2. These will be explored under the headings *The need for diagnosis*; *Expectations and expertise*; *Stigma: its influence and impact*. The following narrative links the findings from each study, provides evidence of similarities and differences between the two perspectives, includes my comment and is supported by literature, thus placing this synthesis in a theoretical context.

### **The need for diagnosis**

Both the service users and staff involved in the research recognised the need for diagnosis, however their focus and motivation differed. In Study 1 service users were asked about their experience of receiving a mental health diagnosis, the first (pre-diagnosis) superordinate theme found was *Sense-making: the need to understand and be understood*. This in itself makes overt the service users' motivation to bring some understanding to their own experience and echoes research conducted by Bilderbeck *et al.* (2014) on seeking a diagnosis. Another aim accompanying this was to address their symptoms, which primarily manifested as an expectation of receiving medication. Indeed all service users interviewed, had been prescribed medication to help manage their symptoms and in many cases this had had the desired effect.



Superordinate and subordinate interview themes			
Superordinate theme	Subordinate theme	Subordinate theme	Subordinate theme
<i>Pre-diagnosis</i>  <b>Sense-making: the need to understand and be understood</b>	Impact on life	Turning point	Validation via diagnosis
<i>Post-diagnosis</i>  <b>Discernment of ‘them and us’; self-perception and society</b>	Stigma	Selective disclosure	Connection to others
<i>Post-diagnosis</i>  <b>Assimilation of mental illness into everyday life</b>	‘Living with’ as opposed to recovery from	Integration and reframing	

Table 4: Superordinate and subordinate interview themes (Study 1).

Overarching theme	The service users’ journey	The realities of practice
<b>Subtheme</b>	The impact of mental illness: services’ raison d’être	Pressures on practice
<b>Subtheme</b>	Implications of diagnosis	Future re-focus
<b>Subtheme</b>	Recovery is ‘living with’	

Table 5: Focus group themes (Study 2).

Without diagnosis, access to this medication was considered unlikely, if not impossible, therefore the need for a diagnosis to access treatment in the form of drugs, indicates its essential link. This highlights the influence of the historical structure in mental health services, namely the medical model, and the prevalence of a biomedical approach to mental illness. As Campbell (2009) and Bentall (2009) argue, this approach has led to the dehumanising of service users who are seen as a machine that needs to be 'fixed' through medication. Some service users in the current research also reported feeling they had been reduced to their condition, whether in the eyes of others, or indeed their own. This evidences the simultaneous disempowering and negative impact diagnosis can have, alongside empowerment of the service user through gaining knowledge also found by Pitt *et al.* (2009).

The pre-diagnosis subordinate themes create a picture of the processes that led to receiving a mental health diagnosis. Recognition of the impact symptoms were having on their lives led to an admission they were no longer able to cope and needed support. Although many had used the internet to begin to gain understanding, there remained a need for a healthcare professional to 'validate' their conclusions and, as noted in the findings, their experiences. Integrated within the understanding a diagnosis brought, was an opportunity to gain control over the symptoms using the new information received. This was also the start of managing symptoms, accessing support, learning the language needed to explain their experiences to others and integrating a new concept of themselves. Indeed Westin (2016) suggests diagnosis provides not only the language and understanding, but also empowers the individual through adding to the knowledge of themselves. Therefore, she argues, diagnosis can contribute towards a continual 'self-becoming', indicating the important role the medical profession plays and the subsequent need for service users to access these experts. Westin's (2016) conclusions are supported by the service users in the current research through their active seeking of explanations from healthcare professionals. This point emphasises the contentious issue that arises between those disputing the worth of diagnosis for the individual (such as Bentall, 2009 and Beresford, 2009b), and the value of it for service users. There remain many who argue that diagnosis maintains the power imbalance between clinician and service user, leaving the service user disempowered. Findings of the current research indicate some service users felt a sense of disempowerment due to the 'bedside

manner' of the medical staff, rather than the system as a whole. As the healthcare system in the UK remains a longstanding and well-known, important channel to access expertise and gain understanding in matters of health, it will continue to be utilised by service users. It is at this point that findings from Studies 1 and 2 collide.

One of the two overarching themes developed from the findings in Study 2 was *The service users' journey*. In focus group discussion, which concentrated on staff responses to emergent themes of Study 1, staff acknowledged there was a process and a journey for service users. The start of this journey was experiencing symptoms and recognition of the impact this had on the lives of service users; captured by the subtheme *The impact of mental illness: services' raison d'être*, which indicates the part staff felt they played in this journey. The fact that symptoms had an impact on service users' lives created a need to try and make sense of them through contacting services. Both the service users and all staff recognised the importance of, and need for, diagnosis to meet this aim, however the staff focus extended further than the symptom relief sought by the service users. Accessing treatment to help manage a diagnosis in the longer-term and improve quality of life, accompanied this immediate need to alleviate symptoms. These different approaches indicate the different focus of service users and staff noted by Vellenga and Christenson (1994). They suggest that miscommunication can occur due to the short-term focus on symptom relief of service users and the longer-term rehabilitation and condition management focus of staff.

As the findings indicated, this was also nuanced by the particular focus of the staff group the service user was in contact with. The attention given to symptom relief by the medical staff differed from the rehabilitative focus of the occupational therapists and staff working in the third sector. It is doubtful a service user with little experience of services would distinguish this nuance immediately. Service users in the current research did not take long to recognise the limited role the medical staff played in rehabilitation and the need to access support for this elsewhere. This support mainly came in the form of the third sector and connection with others with lived experience of mental illness. The service users' need for diagnosis to gain understanding was acknowledged by all staff and was their 'raison d'être': the reason the service user had come into contact with them. The different focus of each staff

group was notable in the discussion held in each of the three focus groups, where the medical staff concentrated on the point of diagnosis and remaining two groups held a post-diagnosis focus. This is indicative of how the mental health system is set up with access to statutory support from other healthcare professionals, being gained through referrals from medical staff. There remains a power imbalance within the healthcare system where allied healthcare professions can only gain access to service users through the medical staff who act as gatekeepers. This reinforces the view of consultant psychiatrists and GPs as the experts, diminishing the contribution of other trained and knowledgeable staff or indeed the service users themselves. This differs from the third sector where support can be accessed through self-referral, with or without disclosing a specific mental illness. There is a tangible difference in approach to mental health held by those outside of statutory services, where the medical model of illness is less influential and the voice of the service user holds more weight.

Medical staff were very clear about their role and the need for diagnosis: *“that’s what people consult you for”*. Indeed Rose and Thornicroft (2010) highlight diagnosis as an important aspect for service users through its reinforcing of the relationship between services and service user, via the psychiatrist. Based on symptoms reported by the service user, medical staff drew upon their expertise and experience to diagnose where necessary. This exchange of information emphasises the collaborative nature of diagnosing, to which staff believed they brought a clarity that met the needs and expectations of the service user. The service users’ active seeking of medical staff for the purpose of diagnosing, implies the paramount importance they also place on medical staff in addressing this need.

There was also a need for service users to feel understood within this interaction, something they reported could only come from medical staff and a process achieved by sharing their ‘story’. This sharing of experiences, Kirkpatrick (2008) noted, has the opportunity become an empowering interaction for service users that can facilitate recovery. Indeed this was indicated by the sense of ‘validation’ that came with diagnosis when an ‘expert’ had made sense of their experiences and given it a label, as Steph noted in the relief she felt when *“...someone’s recognised your symptoms as being erm, part of this diagnosis”*. This interaction consequently addressed the need to be understood as well as to understand. The findings from the

current research offer little suggestion of change in the process of diagnosis, with both sets of participants playing the roles expected of them. This is important given the responsibility service users are encouraged to take for themselves and their communities with initiatives such as Prudent Healthcare (Bevan Commission, 2015). Without an attitudinal change from 'both sides of the table' a change in culture is unlikely, even given the messages from Welsh and UK Governments.

Diagnosis remained a fundamental need for staff due to the role it played in providing the legitimacy to access services. In this light it was seen as a positive step towards managing symptoms by medical staff who noted it opened up many different resources to the service user, such as supported housing and benefits. Findings supported the service users' need for diagnosis to make sense of their symptoms, however accompanying this was the want to explain their behaviour and feelings to others such as employers. This echoes the research of Pitt *et al.* (2009), where diagnosis was found to both hinder and help. In contrast to the positive view held by medical staff, third sector and occupational therapy staff indicated a cautious view of diagnosis, suggesting it should not be positioned as a vital component to gaining support. These staff groups were more inclined to consider the needs of the service user as more important than the diagnosis *per se*, indicating a more holistic biopsychosocial approach to mental illness (see Pilgrim *et al.*, 2009). Both groups' focus remained on addressing the impact the symptoms had, with the occupational therapists reiterating the wish for needs-led service provision. This request would require a cultural and attitudinal shift for the majority of those working inside the healthcare system and the systems surrounding it.

Third sector and occupational therapy staff also commented on the importance service users placed on diagnoses. Each group recognised the current framework, in the medical model, dictated the need for it and therefore prominence of it. This may be attributed to the lack of alternative frameworks available in mainstream society for viewing mental health. The dominance of the medical model is evidenced here by the lack of resources invested in promoting alternative views or support that resides outside of the mainstream. However the rise and influence of the service user voice via social media, is providing a different way of viewing mental health. Moving away from the 'dis-ease' model of illness, groups such as the Hearing Voices Network

(2018) offer a different approach to the symptoms often associated with a diagnosis of psychosis or schizophrenia. Many service users and healthcare professionals approach the 'voices and visions' with a focus of understanding their content and the explicit goal of learning to live with them. However as Pilgrim (2007) noted, these alternative approaches are a direct challenge to the many structures in society invested in maintaining the status quo and social control. Access to different views on diagnosis does not dismiss the fact that many (such as those within the current research) actively seek a label for their distressing symptoms; thereby emphasising its importance to them and reinforcing the processes in healthcare.

The antipsychiatry movement of the 1960s that criticised mental health service provision and the medical model, has not shifted the importance of diagnosis for many service users. This is an interesting conflict as it is within the service user movement that many of the dissenting voices arise, yet service users in the current, and in other research, suggest diagnosis was helpful to them. As noted (see Chapter 2), diagnostic manuals as a way of classifying mental illness have been criticised and many highlight diagnostic inconsistencies that can arise (see Jablensky, 1999; Timimi, 2014). Categorisation as a way of making sense of a unique individual experience, where the nomothetic meets the idiographic, has been the subject of much unease (see Bentall, 2009). However these criticisms have not impacted on the manuals' prominent and prevalent use across the world in the categorisation of mental illness and diagnosis remains vital in accessing statutory services in the UK. This need to impose order and a system of monitoring through the categorisation of mental illness in the UK and worldwide, diminishes the chances of either manual being wholeheartedly rejected. Although criticisms of diagnosis continue to form an important part of the rhetoric surrounding diagnosis, they were not discussed directly by participants other than with reference to misdiagnosis. This aspect was discussed by service users, third sector staff and the occupational therapists and, notably, not by the medical staff. This highlights the different paradigms the staff groups occupy.

Although misdiagnosis and multiple diagnoses were seen as a problem for service users, the conclusion was not to dispense with it, as Timimi (2014) suggests, rather to refine its use and improve its reliability. The service users were under no illusion

that their diagnosis would remain constant as they viewed fluctuations as natural responses to their changing experiences. Third sector staff however, were concerned with the propensity for inconsistencies in diagnosis and the impact this has on the service user. The motivation to understand and be understood, remained the driving force that supported the need for diagnosis for service users, the potential for misdiagnosis was an uncomfortable accompanying factor. For staff, until there are changes in the process of provision of care in mental health services, the function diagnoses played emphasised its need. Indeed the lack of discussion of alternative approaches to viewing mental illnesses emphasises the imbedded nature of the current system for those working within it and accessing it; consequently reinforcing the use of and need for diagnosis.

## **Summary**

Combining the findings of Studies 1 and 2, show both service users and staff noted the need for diagnosis. The reasons for this came from different perspectives however there was a point of overlap. The service users' motivation in seeking a diagnosis was for the role it played in making sense of, and justifying, their experiences. Their wish to alleviate distressing symptoms led to expectations of receiving medication and overlaps with the staff's need for diagnosis and reinforces the status quo. For staff, diagnosis related to the processes in the healthcare system that make it vital in accessing services. Here also lies the power imbalance between service users and staff and within the different staff groups working in mental health services: the medical staff act as gatekeepers for the accessing support and understanding so sought after by service users. This links with the second area the synthesis of findings produced; the impact of the approach of services, namely the medical model. Recognising the development of mental health services in light of this approach facilitates understanding of the influence of both the expectations of the service users and questions of who is considered the 'expert'.

## **Expectations and Expertise**

Combining the view of the service user and that of staff, involves incorporating different perspectives and experiences of healthcare provision. The approach of the

mental health system and its influence on service user expectations were developed from three interlinked areas discussed by both service users and staff. The influence of the medical model, the increasing implementation of the biopsychosocial and recovery model and the importance of the therapeutic relationship in mental health services, contribute to this section. Consideration of these three areas reveal the impact on the provision of services and the practice of staff and, subsequently, service users' expectations. The following explores these areas to draw together the perspective of 'both sides of the table'; service user expectations of the expert staff.

Due to the historical biomedical approach to mental illness, both staff and service users hold the premise that they are a treatable condition. The adoption of this approach to mental health service provision consequently impacts on the expectations of service users: seeing mental illness as a treatable encourages service users to expect a cure for the 'disease' from professional 'experts'. Often this intervention comes in the form of medication and indeed service users in the current study sought a diagnosis with the expectation of pharmaceutical support (alongside their need for understanding). However staff concluded the expectation of service users extended beyond the wish to gain understanding and address distressing symptoms with medication. They noted seeing mental illnesses as treatable and themselves as experts, led to service users anticipating staff to be carrying a "*box of tricks*" which would meet all needs. These unrealistic expectations add to the pressures on a system, and the staff working within it, already under immense strain. Added to this all three staff groups noted the point at which service users accessed services, became the point at which they relinquished responsibility for themselves. As one OT noted service users come with a sense of entitlement, once they have accessed services "*it's up to the rest of us t' t' to pull out all the stops*".

This perspective links to the dichotomy in healthcare provision highlighted by Rogers and Pilgrim (2010). Services promote independence alongside messages and processes that promote *dependence*. This was something keenly noted by occupational therapy staff when discussing the "*paternalistic*", risk-averse culture of the NHS. Indeed all staff groups promoted the need to give as much control back to the service user through empowering them to manage their condition, however none talked of incorporating the knowledge held by the service user in achieving this. The



expertise gained through lived experience is recognised as a valuable asset by those in the service user movement (Beresford, 2013; Rose, 2013; Campbell, 2009). The perspective adopted by staff of their 'raison d'être', highlights their belief in the need of them in service users' lives. The healthcare system echoes the attitude held by society on professionalism and clinical practice, where formal training is valued over lived experience. This reinforces the power imbalance between the service user and clinician in the system and is in opposition to the introduction of the 'market-style reforms' of the 1990s into the NHS (see Wallace & Taylor-Goody, 2010). The Government drive was developed with the intention of placing more power in the hands of the 'consumer' to improve quality through competition. This initiative, although supporting challenges to the system by the service user as a consumer, has had the adverse effect of increasing their expectations of it. A consequence of this is to reinforce the lack of need for service users to take responsibility for their health, which has led to an increase in pressure on services. This was reported by staff in the current research, who feel service users had been empowered to expect more from services. However the reality in their daily practice suggested their resources could not match this demand.

From their experience at, and on from, diagnosis many service users came to realise diagnosis did not mean cure. This was something they had not considered when accessing services to help address their symptoms and challenges their expectations of mental illness being a 'treatable disease'. Realisation of this led to an understanding that diagnosis was the start of another stage in their lives; indicated when discussing their ideas and thoughts on what recovery meant to them. Given time to reflect post-diagnosis, they accepted diagnosis was the start of learning to 'live with' their mental illness, however during the consultation in which the diagnosis was given, learning to manage their condition was not something explicitly discussed. This was a conclusion service users came to after engaging with statutory and non-statutory services *post*-diagnosis; reflecting the focus of staff working in recovery and rehabilitation. Here they heard the message diagnosis did not mean cure and began to realise the consequences of this concept on their lives. This links with the findings of Hayne (2002; 2003), who explored the impact of diagnosis on service users: what was considered important changed, their view of the future and past altered, as well as questions arose regarding their identity. In the current

research, associated with their wish for a cure, service users acknowledged that their high expectations of staff and services were often unmet. Although they recognised this was a consequence of a lack of resources in mental health (also noted by staff), they maintained the wish to access all support available to help manage their mental illness, seeing services as an essential feature in the ongoing management of their condition.

The social model of disability, together with the service user movement and advances in pharmacology, provided a backdrop to the development of the recovery model of treatment (see Chapter 2). This approach created a space for the service user to have a say in the decisions made on their care. However many argue this approach of joint collaboration has not been adopted as widely or as fully as necessary to make it more than a token gesture in healthcare provision (Roberts & Boardman, 2009). As noted in '*The need for diagnosis*' above, service users found diagnosis to be a validating experience; allowing an expert to explain and justify their symptoms as a mental illness. This led some service users to reject responsibility for it, viewing it from a biomedical perspective and subsequently accepting it as an 'illness' with a physical cause; its cause or fault laying outside of them. Staff in the current research noted adopting this attitude had the propensity to disempower the service user by giving them justification for not being accountable. Consequently this reduced their sense of influence over the future course of their condition. This again draws attention to the clash between the traditional medical model of viewing mental illness and the integration of the biopsychosocial approach (adopting a recovery focus) in mental health services. As Maddux (2016) points out the 'illness ideology' on which the system and diagnosis is based, does not share the same value systems held by the social construction of mental illness. Therefore the current system, as indicated by staff, remains influential to the success of implementation of the recovery model that supports shared responsibility and where expertise is recognised on both sides of the table. As the expectations of service users have shown, moving away from viewing healthcare professionals as all-knowing experts requires a cultural shift, not only within the system itself, but also from service users. Although there is much legislation in support of the service users having a definitive role in their care alongside clinicians (see Chapter 1), the findings in the current research suggest service users are content with clinicians holding the responsibility for their health.

The meaning of recovery for service users and staff was 'living with'. However staff placed the concept of 'living with' alongside service users' idealistic expectations of what could be achieved towards overcoming their mental illnesses. Staff reported adopting this unrealistic focus led service users to reduce taking responsibility to work towards 'recovery' (i.e. living with). Staff also highlighted the lack of benefit this message gives with some suggesting the system as "*paternalistic*" where labelling mental health services users as 'ill', reinforced the need for medical support (as opposed to a recovery focus). The current focus on biological causal factors for mental illnesses supports this view and as the findings indicate, has the potential to reinforce the lack of service user agency noted by staff.

Staff also implied their adoption of the biopsychosocial approach to mental illness, as opposed to purely biomedical. They recognised and voiced the various potential influences on the development of mental illnesses which, in many cases, made them understandable: echoing the works of Szasz (2009), Laing (1973) and more recently Guerin (2017). Many staff believed adopting this broader explanation, which aligns itself with aspects of the anti-psychiatry movement, increases service user understanding and encourages recognition of their agency and abilities in managing their condition. This was noted by staff not to be the case currently and suggesting mental illness be viewed from a biopsychosocial perspective, was often seen by service users as devaluing and diminishing the distress experienced: due to the implied suggestion that mental illness was, in part, caused by the service user. This indicates the essential role and importance of the therapeutic relationship in healthcare service, where, at times, a sensitive manner is required when offering support. During the consultation trust must be built and respect shown, to highlight the strengths of the service user and encourage their agency. This resonates with the work of Kirkpatrick (2008) and Fallowfield and Jenkins (2004), who emphasise the opportunities this relationship can afford in creating an environment to achieve this. Indeed McCormack and Thomson (2017) add to this, suggesting healthcare professionals hold a vital position in promoting a positive narrative that challenges the potential for service users to adopt a disempowered position post-diagnosis. However this perspective must be seen in light of the restrictive and pressured

environment staff work within, even with the skills necessary, these factors often limit the time and opportunity of staff to spend with service users.

It has been argued that receiving a diagnosis can be a life-changing moment for an individual (Hayne, 2003). Diagnosis may offer relief through the understanding a label brings and the validation of their experiences, however it is also accompanied by many disempowering unknowns for the service user. Therefore the support received at the time of diagnosis, and on from it, impacts on the quality of life of the service user. Life post-diagnosis is influenced by the development of skills and knowledge in the management of conditions and is intrinsically linked to the approach and manner of the staff service users come into contact with. In the current research, service users engaged with statutory and non-statutory services, with a minority paying for private psychiatrists. Their experiences implied no correlation between the standard of service provided and the services funding source, therefore experiences were influenced by the individual approach of those with which they interacted. Paying for private care naturally equated to being provided additional time, but not necessarily a psychiatrist with a good 'bedside manner'.

When engaging with medical staff working in statutory services, experiences were as varied as the number of interactions. Many service users commented on the disempowering impact of the clinical approach adopted by medical staff when giving a diagnosis and the lack of consideration of what that would mean to the service user thereafter. As mentioned the main focus in the interaction was prescribing medication (an expectation from both the service user and medical staff) and service users felt they simply became their diagnosis. These variations in experiences in interactions with staff at diagnosis are also noted by Bilderbeck *et al.* (2014) in research with participants experiencing mood instability. However, in balancing this view, service users in the current research also reported instances where medical staff had treated them appropriately and with care: giving time and listening, leaving service users feeling understood, supported and with agency. Indeed Ong *et al.* (1995:903) state that 'among inter-personal relationships, the doctor-patient relation[ship] is one of the most complex ones' and their literature review indicated satisfaction was correlated with client-centred care, generosity in information giving, listening and time. All of which are included in the *Duties of a doctor* set out by the

General Medical Council (2013) and echo the above sentiments of the service users in the current research.

The staff in the current research recognised the importance of the therapeutic relationship and providing 'good health care' (see Ryan *et al.*, 2017, for examples of this given by hard to reach groups). However staffs' focus centred on the limitations and pressures the system placed on them and the subsequent impact on their ability to implement ways of practice expected from them. Many noted increased caseloads and paperwork resulted in decreased time with service users. Third sector staff reported this especially and believed it to be a short-term solution that consequently created a longer-term problem. Lack of investment in time to build relationships to empower service users, moved the focus away from maintenance and prevention, to fire-fighting and managing crises. The lack of parity of esteem between mental and physical health funding was seen as the cause of this and many highlighted the influence of the changing government and zeitgeist in directly influencing their practice. A lack of resources coupled with the increasing expectations of service users was noted as a challenge for staff, which was compounded by limited investment in research into mental illnesses. They highlighted this resulted in a dearth of evidence-based, successful interventions they could offer and believed this unlikely to change in the coming years. This emphasises the impact of decades of limited investment in mental health services and the lack of trust and frustration felt by staff. Even given the investment by the Secretary of State for Health and Social Care, Hunt (2017) and the developing profile of mental illness promoted by Prime Minister Theresa May (2017), there was a sense that little would tangibly change for them in their practice.

## **Summary**

The historical medical model approach of mental health services places healthcare professionals as experts and subsequently impacts on the expectations of service users. This is in contrast to the promotion and integration of the more recent biopsychosocial and recovery model approach and consequently provides contradictory messages: viewing the service user as an 'expert by experience', whilst disempowering them through maintaining the status quo. The role of the therapeutic

relationship is a vital component in shifting this culture to both provide understanding for the service user and empower them to manage their condition. Some such as Farr (2012), call for the involvement of staff in promoting such change in addressing issues in the sustainability of services. Underlying this perhaps obvious suggestion, is the fact that staff often feel disempowered. Although the intention to work collaboratively with the service user may be present in both healthcare and research settings, 'organisational structures, politics, cultures, policies and procedures may restrict impact and influence' (Farr, 2012:88).

Following on from this is the third and final aspect developed from combining Studies 1 and 2; that of the stigma surrounding diagnosis and its disempowering effect.

### **Stigma: its influence and impact**

Stigma often leads to discrimination due to negative stereotypes held by members of a population against another (Goffman, 1963). Mental health stigma has been of interest within empirical research for decades and the experiences of those with mental illnesses have highlighted the need to address this societal issue (Corrigan & Rao, 2012). Stigma was evidenced in the lived experience of service users in the form of discrimination and from staff who recognised its wider societal presence impacting on their practice. All service users within the current study, recognised the stigma that surrounded mental illness in society and many reported experience of discrimination which, for some, had resulted in changes to their career plans. These experiences of discrimination were both inside and outside of service provision; statutory and non-statutory. Studies have shown that staff working in mental health services hold negative attitudes and beliefs about the service users they work with. This is of importance, as Hansson *et al.* (2013) point out, staff holding these attitudes could subsequently influence the course of recovery: discriminatory attitudes leading to diminished expectations of the future life of the service user. Indeed their findings suggest these same negative attitudes are shared by both staff and service users, therefore they conclude that any intervention to challenge stigma should be targeted at both groups.

In the current research, service users reporting discrimination were affronted by the attitudes and assumptions made about their ability to manage their mental illness by others. Exploring this further also highlighted recognition of a hierarchy of mental illnesses, perceived to be directly linked to funding provision and acceptability in society: certain diagnoses engendered different attitudes from other service users and non-service users. These ranged from more negative and judgemental attitudes about the service user with a particular diagnosis, to the dismissal that certain mental illnesses were accompanied by any distress or had an adverse impact on service users' lives. Researching the literature on hierarchies of disability between impairment groups, Deal (2003) found evidence to support this, with superior attitudes held by groups for other 'out groups'. This was within the public towards service users, as well as within different service user groups, which he argued further reinforced inclusion and exclusion in society. This is an interesting area when considering the need to service users to communicate and access support from others with lived experience. The question arises whether building networks based on diagnosis, offers support and by the same measure enforces segregation both from society and within the different conditions.

Although staff recognised the negative impact of stigma on service users their responses highlight a different perspective. Staff noted the impact of stigma on changes in the approach to service provision as well as the prevalence of mental illnesses in society: they linked fluctuations in stigma to the funding and resources available for certain diagnoses. This was echoed by a minority of service users who had experienced limited support for diagnoses that held more negative stigma in society. Both service users and staff noted discrepancies in services available in mental health, however for staff the limited resources were noted as the cause of discrepancies. Rather than influences related to specific diagnoses (as service users suggested), staff linked the lack of resources and funding to an inevitable focus on service users in crisis. Their concern was for service users that *"fall between the two stalls"*: not quite severe enough for intervention but nonetheless experiencing distress. Both service users and staff felt the a lack of parity of esteem between physical and mental health funding, indicated the stigma that society as a whole, held for the latter. The recent investments and attention in finding a biological basis for

mental illnesses also echoes this trend (see Medical Research Council Centre for Neuropsychiatric Genetics and Genomics, 2018).

The influence of societal trends also played an additional role in services from the staff's perspective. Linked with the expectations of service users, staff highlighted the role the media played in guiding trends in mental health and noted the subsequent impact this had on their practice. They reported a reduction in stigma surrounding certain diagnoses that, through celebrity endorsement, became more desirable. This desirability was subsequently fuelled through an access to knowledge (via the internet), resulting in the empowerment of the service user. Consequently medical and healthcare staff were no longer being seen as the only experts: service users were now able to self-diagnose. Interestingly the democratisation of knowledge, although empowering the service users in the current study, did not negate the need for them to access 'professional' confirmation of their conclusions. Self-diagnosis not only led to some challenges to staff opinion (as reported by staff), but also was seen to be potentially damaging and self-limiting for the service user.

Staff acknowledged the positive impact campaigns and story lines in soap operas could have further empowering service users and challenging the stigma in mental health. However they were frustrated and disappointed in the lack of responsibility the media took and the missed opportunities to make a positive difference. This could be a result of the complex nature of, and interplay between, the educative and entertainment role the media holds, as found by Henderson (2017). Although service users did not comment on the media per se, they did acknowledge an increase in mental health awareness and associated this with a decline in stigma. A minority of medical staff stated as part of everyday practice they discussed stigma at the point of diagnosis. These staff gave service users time to consider their responses to their diagnosis in relation to stigma and to consider the positive aspects of receiving a diagnosis i.e. gaining understanding and access to support to help manage it. Medical staff also discussed the benefit of recognising the separation between the need for understanding that the service user brought to the consultation (i.e. a "*label*") and the stigma surrounding diagnosis. Occupational therapy and third sector staff also reported a focus in their work of the direct impact on service users that stigma and discrimination may have. Although service users did not explicitly express a need for



this topic of conversation during this consultation, they did come to realise the influence and impact of stigma, post-diagnosis.

Another aspect arising from service user experiences, and equally recognised by staff, was self-stigma. All service users in the current study had internalised their diagnosis and the perceived stigma attached to it. This caused the relief or validation on receiving a diagnosis to become double-edged and accompanied by a negative aspect. This has also been found in research by Hayne (2003) and Pitt *et al.* (2009) who note the benefits of diagnosis alongside its detrimental impact. According to Corrigan and Rao (2012) self-stigma is the result of internalising the negative public attitudes surrounding mental illness, which consequently lead to those with a diagnosis responding in a way that is detrimental to their lives. Although the majority of service users in the current study had continued to access services and support (which can become one consequence of self-stigma), all noted a concern of other's views of them after receiving a diagnosis. This aligns with Link's (1987) 'Modified labelling theory' and processes of internalisation that can result in 'self de-valuation' and a fear of being rejected. This was evident for some service users in the current study where self-stigma manifested itself as withdrawing from society for a period of time. This was not only due to the negative influence of their symptoms, but unease about the attitudes of others they may have to face, even without disclosure of their mental illness. Consequently limiting life choices reinforces the diminished value some service users experience post-diagnosis. This self-limiting behaviour can lead instances where service users are unable to engage in meaningful activities, which Whiteford (2000) argues, not only effects the individual, but can also damage the success of the entire community and society as a whole. This behaviour has the propensity to further segregate those with mental illnesses in society through their own volition. However, although Whiteford (2000) indicates an economic and human impact of 'occupational deprivation' there is an accompanying risk of it reinforcing stereotypes and stigma.

Linking with self-limiting behaviour is disclosure: a topic that promoted discussion of rules and boundaries that accompanied sharing diagnosis with others. The service users employed selective disclosure to protect themselves and avoid further negative consequences of their mental illness. Most chose to share discretely with trust as an

influencing factor, however others, given a period of reflection and time, chose to be open about their diagnosis, in the hope that it would challenge the taboo and consequently stigma. This latter response is demonstrative of the recent call to be open and talk about mental health by campaigns such as Time to Change Wales (Hafal *et al.*, 2018). Indeed some service users reported this campaign as their inspiration to disclosing their mental illness, having previously been more cautious. The concept of selective disclosure resonated with third sector staff, who noted the changes in disclosure that occur over the time of accessing services: the longer the service users engaged with services and the older they were, the more open they were about their mental illness. These observations draw parallels with Corrigan and Matthews (2003) study on disclosure, in which they adapt the stages of 'coming out' found in the lesbian and gay community, to those with mental illnesses. Disclosure was not a choice, however, for staff working in statutory services especially when considering legal aspects of mental capacity. Medical staff highlighted their duty of care and the responsibilities accompanying their role, as contributing factors of the need to document diagnosis (whether the service user was in agreement or not).

Disclosure for both service users and staff was viewed as a complex process that came with nuanced and constantly changing boundaries. However, both also noted its vital role in accessing services and, importantly for many, others with lived experience. Connection to others with mental illness for most service users, was crucial in their understanding and management of their condition. It was also a way of gaining strength from others to challenge stigma and its negative consequences, such as self-stigma and discrimination. Some service users joined campaigns to this end and others found joining groups (online and in person) a way of safely engage with society. Indeed the positive impact that accompanies contact with others with mental illness have been highlighted in the literature review by Repper and Carter (2011). Facilitating this peer support and "*camaraderie*" was noted, by medical staff, as a shift in their regular practice as they had grown to understand its significance for service users. Third sector and occupational therapy staff however, were more aligned to this way of accessing support and naturally saw the benefit of using group work to build social capital for socially excluded service users. However they also acknowledged a lack of resources that limited the ability of service users to access these benefits. This is an aspect that Lawton-Smith (2013) acknowledges when he

calls for additional infrastructure to support peer-support in mental health. Although there are many benefits to connecting with others with lived experience, there remains the risk noted earlier for further segregation and reinforcing the sense of 'them and us' that fuels stigma.

## **Summary**

Stigma and discrimination remain an issue for those experiencing mental illnesses, something both service users and staff in the current research were aware of. Stigma was reported to influence staffs' daily practice via the changing view of society on certain diagnoses which resulted in increases in demand through an increase in public awareness. Thus indicating the benefits and risks in the democratisation of knowledge. Although service users did not share similar views on this, the impact of stigma was evident in the form of self-stigma and selective disclosure. The peer-support that they accessed was, in the main, supported by staff and found to be beneficial for many service users in challenging self-stigma and in reengaging with society post-diagnosis.

The above three areas of *The need for diagnosis, Expectations and experts and Stigma: its influence and impact* have synthesised findings from Studies 1 and 2. Bringing a clinical lens to these ideas allows for further development of them, which has resulted in 'Recommendations for practice' to which we shall now turn.

## **Recommendations for practice**

By combining the view of those accessing mental health services and those providing them, the above explored three areas from the findings of the current research. It is of importance to remind ourselves of the influence of the current system on this interaction in order to fully understand it. The roots of this system support that those with the knowledge. Staff are considered the experts and diagnosis is in a position of formalising the relationship between staff and service user, where the latter is able to gain access to services. This structure has been argued, to subsequently disempower and dismiss the expertise of the service user (see Beresford & Wallcraft, 1997). Although some in the profession of psychiatry challenged the assumption that

knowledge only lay in the hands of the healthcare professional, it is not until the recent past that this assumption has been truly challenged and practice began to change. The move towards more collaborative working and shared decision-making in mental health services can be aligned to the on-going promotion of client-centred care, which places the needs and opinions of the service user as the central focus. Adopting this approach to service provision not only supports what is considered 'good practice', but also creates an environment that supports the recovery model. However, there are many that question whether the guidance given through legislation and Government initiatives is actually translating into everyday practice (Russo & Stastny, 2012).

A shift from responsibility of service users' health lying solely with staff and services, to being shared between the two groups, may lead to a reduction in pressure on services. This would result in economic savings in healthcare; an item on the agenda of many recent Governments. The collaborative approach is further enhanced by the increase in freely available knowledge regarding mental illness. This 'democratisation of knowledge' enables both those with mental illnesses and those without, to become informed in the area. Although there are risks attached to this, such as misinformation and unhelpful guidance, the taboo nature of mental health has been challenged by it.

Discussion of mental illness has become more prevalent in society and consequently the stigma surrounding it has been shown to be changing (see Henderson *et al.*, 2012). Although stigma and discrimination remain in the UK, trends show a steady increase in the public accessing mental health services. This not only emphasises an increase in the need for these services, it also indicates the changing acceptability of disclosing mental illness: societal discussion has enabled public understanding and highlighted routes to support. Part of this support, again promoting the sustainability of statutory services, is through non-statutory organisations, the aim of which for many is to connect people with lived experience and aid in the facilitation of support. The third sector is a vital support to the statutory sector, often allowing people to access immediate help whilst on a waiting list for NHS interventions. The resource of the 'core economy' recognised by New Labour in the late 1990s and successive

Governments, is also under huge strain and in need of acknowledgement, support and investment.

Combining the findings of the current research, not only led to consideration of 'both sides of the table' in the process of diagnosis, it also facilitated reflection on aspects of service provision, including the conflict between the medical model and the biopsychosocial approach. Taking the view of the service user alone would have created valid reflections on the provision of mental health services at the point of diagnosis and beyond. However, incorporating the view of staff working in services adds a different and balancing dimension to the narrative. Indeed incorporation of staff into the current research, may have allowed the space for reflection on their values and practice, promoted by authors such as Farr (2012), Stickley (2006) and Faulkner and Thomas (2002). This reflection will have been based directly on the services user experience due to the emergent themes from the Study 1 interviews, being used as the starting point for discussion in each focus group. The experience of service users in receiving a formal diagnosis from qualified medical staff, is never done in isolation. Therefore gaining the perspective of both sides of the table becomes important in adding to the knowledge base of this experience and consideration of the system in which the experience takes place. Combining the two perspectives resulted in 'Recommendations for practice', which fall into three areas highlighting the views of both service users and staff in the current research. These three interlinked areas are *Human to human*, *Diagnosis as a 'teachable moment'* and *A community approach to mental health*, which are discussed below.

### **Human to human**

There has been a steady shift in the culture in mental health service provision. This has seen a move away from the dominance of expertise held by the healthcare professionals, towards seeking greater inclusion of service users' views and opinions. However, the need to understand and be understood remains a driving factor for individuals experiencing symptoms of ill-health, evidenced by the findings of the current research. To this end, access to expert knowledge in helping make sense of their experiences remains a significant focus for service users. This goal highlights the importance on the interactions, manner and approach of staff and the central role

of the relationship between service users and staff. As Hayne (2002) noted, receiving a diagnosis can be a life-changing event, therefore the ability to provide support to the service user at that time is vital. Building rapport and practicing a 'good bedside manner', enables sensitive communication of potentially distressing information and takes into consideration the responses of service users. Medical staff taking a purely clinical approach to diagnosing can result in reducing the service user to a "*medical case*" rather than an individual. When accessing support, additional time with staff is of great worth and value, as well as a personable approach: 'human to human'. Additional time and resources would also allow for the focus to shift from crisis to preventative interventions. Consequently this would save Governments money in the longer term and reduce the distress experienced by the individual. If "*nothing helps people like people*", it is essential that staff are given the resources in mental health to facilitate an environment that allows for consideration of the service users' responses to diagnosis, as well as their needs.

### **Diagnosis as a 'teachable moment'**

At the time of diagnosis there is an opportunity for brief intervention in the framing of diagnosis. The service users' need to make sense of their experience, which diagnosis can aid, expands post-diagnosis to a needing to make sense of their lives in relation to the new information. The question of 'what is normal?' pervades the rhetoric in mental health and is connected to service users' need to understand and be understood in relation to others. Normality and mental health and illness are now not seen as binary concepts, rather they are part of human experience. Blurring the defining line between mental health and illness, challenges stigma and enables service users to accept their mental illness as part of life experience for 1 in 4 of the population. Taking the opportunity to empower the service user by encouraging their involvement in decisions on their care, where possible, facilitates shared responsibility and encourages the locus of control to lie with the service user. This is reinforced when highlighting the strengths of the service user and their ability to 'live with' their condition and continue to engage with society. Diagnosis as a 'teachable moment' in which to frame, or reframe, views towards receiving one, extends beyond the initial consultation. This interaction provides an opportunity to help the service user form a positive perspective, empowering them through connection to others for

support. As Lawton-Smith (2013) points out for this to be applicable in practice, there needs to be investment in the infrastructure surrounding mental health services. An important element of this is the need for consistent anti-stigma messages from those involved in mental health services; thereby supporting the value of the service user and decreasing the chances of exclusion.

### **A community approach to mental health**

Many service users had researched their symptoms prior to, and on from, receiving a diagnosis. The media, alongside the increasing democratisation of knowledge in mental health, has facilitated understanding and empowered service users through connection to others. Research via the internet can be a powerful force for good to be used as part of education in mental health and illness for the general public, as well as via more formal routes. Education aimed at both children and adults, pitched appropriately, could help tackle issues in mental health by increasing understanding of it. The motivation for wide-spread education is multi-layered: it would help challenge stigma surrounding mental illness; highlight the support systems in place; build resilience in the public and empower the public to offer support to those in need. This 'community approach' to promoting mental health and managing mental illness, builds on from each individual, through their community to wider society. Developing the mental *wealth* of the population and promoting the shared responsibility of mental health in communities, would reduce the pressure on services, as well as encouraging more realistic expectations from service users. Alongside this, gaining parity of esteem between physical and mental health services, would result in a more accepting environment for those with mental illness, thereby promoting social inclusion. As Whiteford (2000) notes, being unable to contribute and add value in society, impacts on the individual, their community and society as a whole.

### **Conclusion**

These three interlinked areas create recommendations for practice developed via the synthesis of findings from both service users and staff. The findings show the gradual move towards mental health service provision based on collaboration and joint

responsibility. This continues to require a shift in culture within services and of expectations outside of it, which importantly contribute towards the sustainability of healthcare provision in the UK, promoted by the Welsh Government (2017) 'Prudent healthcare' initiative. Adopting the biopsychosocial approach to mental illness creates space for a recovery based, holistic focus that both promotes the strengths of the service user and the expertise of staff. Parity of esteem between services would create the investment needed to build the mental wealth of the population and, through widespread education, foster an environment where mental health is 'everybody's business'. The ideas in this chapter reinforce much of the rhetoric in current mental health service provision, thereby supporting the ever-progressing move towards best practice in healthcare. However changing entrenched attitudes takes time, persistence and consistency, which is impeded by the continual fluctuations in Government agendas.

The current research has limitations. These are important to note to maintain a clear and balanced perspective of the above discussion and the thesis as a whole. Consideration of these are given below, before revisiting reflexivity to evidence the validity and rigor of the current research, and ending with a conclusion of this thesis.

## **Limitations**

The following will highlight areas that require consideration in relation to the limitations of the current research. The transparency and reflexivity utilised throughout this thesis will have indicated some of these considerations prior to this point, however it is worth drawing attention to bring cohesion and clarity to them.

The idiographic nature of IPA aligns itself with a smaller sample size. The suggestion of six participants for a research using this method of analysis, has been offered by Smith and Osborn (2008). The current research aimed for (and achieved) ten interviews exploring the experience of receiving a mental health diagnosis. Although this is more than that suggested by Smith and Osborn (2008), relatively speaking in the arena of research, it remains a very small sample. The findings from a sample size such as this does not allow for generalisation; an aspect acknowledged by Smith *et al.* (2009). The authors suggest a focus on 'theoretical transferability', where the rich



and transparent analysis is positioned in the existing literature, allowing judgements on the transferability of the research to other similar contexts (Smith *et al.*, 2009:51). The experiences of the ten participants in the current research remain meaningful to them and, through the process of analysis, make a valid contribution to the discussion concerning diagnosis.

The simple fact that criteria were set for participation in the research, results in a certain group of people being interviewed. The research aim and method of IPA chosen, dictated the need for purposive sampling. This led to a homogenous sample recruited with the intention of gaining access to the experience of participants who have received a mental health diagnosis. Again this does not diminish the value of the ten participants experiences. This is reinforced by the point Flowers *et al.* (2006) make in emphasising the unique nature of experience, this point also justifies the choice in the current research not to focus on a specific mental health diagnosis. Even given the same phenomenon under investigation, each individual will have a different understanding and attach a nuanced meaning to it. However it is important to note here the method and location of recruitment of participants to Study 1. The fact that the recruitment took place in a city and it's surrounding area in South Wales, excluded rural areas where access to treatment is vastly different (see Welsh Government, 2016a). Therefore the experience of the ten participants remains specific to a more urban environment where, although services are more plentiful (as compared with rural areas) the demand for them is higher.

Using a mental health charity in South Wales as a gatekeeper, was both a help and a limitation in the research. It not only acted as a support for participants after the interview, but also led to a particular group of people being interviewed. These participants were of a certain mindset, namely comfortable to discuss their experience of diagnosis. However as well as this they may have adopted the culture of the charity. Each charity holds its own philosophy and approach to viewing the area they work within, therefore it is likely that those using their services will be influenced by this. Indeed this can be clearly identified among the participants interviewed who were working in the third sector, for example in their championing of campaigns and repeating the key messages of the charity. I was able to recognise these attitudes due to my own work within this charity and my adoption of the

organisation's philosophy also. Therefore although the influence of the gatekeeper in this research is a limitation, the key messages it promoted encouraging people to talk about mental health, aided the recruitment process.

The decision to use IPA was a 'non-negotiable' component of the research. This was due to my wish to get 'experience close' in an attempt to represent the meaning the participant's placed on receiving a diagnosis. It also aligned with my ontological and epistemological position and belief that we are co-creators of knowledge. IPA allows the researcher, through the use of reflexivity, to make overt the joint contribution of participant experience and researcher interpretation in producing research findings. This method of research however, has been highlighted as having difficulties. Indeed Hefferon and Gil-Rodriguez (2011:758) found it to be often 'misunderstood and misapplied'. This, some authors such as Giorgi (2000) suggest, is due to the often forgotten fact that the foundations of phenomenology lie in philosophy. Therefore difficulties and misunderstandings may arise in applying a philosophical approach to a scientific arena. However, Smith *et al.* (2009) present a thorough narrative of the philosophical foundations of the method and a step-by-step approach to employing it: thereby bridging the gap between the philosophical foundations and the scientific nature of research. Hefferon and Gil-Rodriguez (2011) also suggest the use of a framework, such as that proposed by Yardley (2000), to evaluate IPA research. To further address the issue of the quality of IPA research due to its interpretative nature, the use of reflexivity is recommended (Finlay, 2003). To this end, Yardley's criteria and the use of reflexivity have been utilised throughout the thesis to maintain transparency and aid research validity.

The recruitment and choice of method used in Study 2, also needs to be considered. Many of the limitations share those of Study 1 in relation to the choice of staff groups and location. My connection to the participants in Study 2, as a healthcare professional and third sector worker, drew me to request certain groups participate in the research. Although these choices were driven by my interest in hearing these particular staff opinions, I believe my working experience in statutory services and the third sectors allowed greater understanding of the discussion. The question of insider/ outsider influence is explored in the reflexive section on my approach as therapist and researcher (see Chapter 3), which makes transparent these influences

and my attempts to 'bracket' them. The participation of third sector staff, as mentioned in Chapter 3, was dictated by their manager and therefore they attended without choice. Although finding this out at the start of the group proved a little awkward, I do not believe it changed their involvement and opinions were freely given in the discussion.

The novel design developed for the current research is by its nature, bespoke. It was designed with the specific purpose of meeting the needs of the research aim and objectives. It was also heavily influenced by my position and approach to the research, therefore it may prove unappealing to other researchers who do not have these specific interests. However it remains valid in its own right in achieving the aim of the current research and involvement of a RAP. The incorporation of the RAP in a consultation capacity can be viewed as a limitation, especially given the danger highlighted by Minogue (2009) and others, regarding the 'add on' position that often results from SUI. Although my preference would have been to adopt an approach more akin to Participatory Action Research (see Reason & Bradbury, 2002), time and expectations of PhD researchers restricted this. However, the current research has evidenced the fact involvement of a RAP adds value to research by grounding it in reality and creating the transparency to assure quality necessary in research.

## **Reflexivity**

Chapter 1 of this thesis introduced the concept of reflexivity as a way of supporting 'good' research. As noted, Yardley (2000) suggested characteristics for achieving this, where standards can be assessed with the aim of evidencing the rigor of qualitative research. These characteristics shall now be revisited to provide a framework for reflexive practice in relation to the current research. The chapter will end with a reflection that builds on this narrative through sharing a few points on the personal experience of becoming a researcher.

## **Sensitivity to context**

For Yardley (2000), this characteristic focuses on empirical evidence used to produce the theoretical context of the research. The choice of methodology within the current

research naturally lends itself to building this evidence. Interpretative Phenomenological Analysis (IPA) has an integral philosophical framework and Thematic Analysis (TA) has is used extensively in qualitative research. The theory of these two methods made explicit in Chapter 3 and influenced the approach to the research through a deepened understanding of the foundations of each. Both methods of analysis encourage not only the representation of data, but also the exploration of convergences and divergences within the data and more widely in the broader context of the literature. This is evidenced in this chapter in relation to the literature presented in Chapter 2, as well as introducing additional relevant empirical research in this chapter.

Chapters 1 and 2 also evidence sensitivity to context, by introducing the areas relevant to the current research. The Introduction provided a picture of the current prevalence of mental illness through legislation, statistics and current campaigns. This, together with the empirical literature, encapsulates the development of our understanding of mental illness and integrates the historical context with current practices in mental healthcare provision. The research has been carried out within ever-progressing rhetoric surrounding mental health. This is captured through the theoretical framework of the thesis, which provided a picture of the gradual changes in service provision: the introduction of the biopsychosocial model to the medical model. Intrinsically linked to this developing picture is the practice of Service User Involvement (SUI). The theoretical development of which has been evidenced in Chapter 2, as well as practically in the form of the Research Advisory Panel (RAP) in the current research. This inclusion not only evidences the sensitivity to the current context (i.e. promoting good practice) but also supports in the remaining characteristics Yardley (2000) highlights.

### **Commitment and rigour**

My commitment to the topic of mental health is evidenced in the pen profile given in Chapter 1. I have gained over 25 years of training and working in the field, more than 13 of which as a registered clinician, which has allowed me to develop a solid knowledge base and is evidence of my consistent interest. My commitment extends to the chosen research methods and research design, which indicate the importance of maintaining my integrity in the research process. It was always my intention to

give voice to a group of people that are often marginalised in society, the method chosen to achieve this (IPA), also became a 'non-negotiable' as the research progressed and developed. Using purposive sampling in IPA, as well as incorporating a RAP, enabled me to achieve this aim in very different but interlinked ways.

The RAP facilitated both commitment and rigour in the current research. Discussion with the RAP facilitated my commitment to increasing my understanding of the research topic through those with lived experience. Access to their expertise throughout the research process, assisted rigour through the challenges they made of my choices and findings. Commitment and rigour is also evidenced in the methods employed which support Yardley's (2000:222) suggestion of 'prolonged contemplative and empathic exploration of the topic'. This approach is intrinsic to IPA and consequently one I adopted in TA. Rigour was supported in this process by access to the supervisory team who discussed the procedures employed in the development of themes. Member checking was also used in the current research and transcripts were sent back to the participants for their approval (Study 1) and their reference (Study 2), prior to analysis.

### **Transparency and coherence**

For Yardley (2000) this third characteristic is demonstrated through *constructing* a reality that is meaningful to others. The incorporation of a RAP facilitates transparency and coherence through checking whether findings resonated with the members own lived experience and thereby grounding it in real-life. This has been further supported by presenting the research design and research findings at conferences. Being transparent in this way facilitated interest and challenges to the current research, the subsequent defending and contemplating comments made by peers, academic and clinical staff, fundamentally aided the development of a cogent argument.

The thesis integrates transparency of the methods used in the current research. Chapter 3 shows examples of the process of analysis used for Studies 1 and 2 and further evidence is given in the Appendices; such as the interview schedule,

discussion guide and consent forms. The use of reflexivity also facilitates this characteristic, an aspect the Yardley promotes and which is further evidenced in this final section of the thesis. As a healthcare practitioner, reflective practice is considered fundamental to good practice and therefore encouraged within the profession. Throughout the research process, I have kept a reflective notebook, which I have drawn upon below to make transparent part of my own learning during the research process.

### **Impact and importance**

Although literature does exist on the topic chosen for the current research, it is limited. Setting the context for the thesis in Chapters 1 and 2, allow an understanding of the prevalence of mental illness alongside the dearth of knowledge of what it means to experience receiving a diagnosis. The current research contributes towards this knowledge and helps give voice to service users, who often feel disempowered and marginalised by mainstream society. Therefore raising the profile of this group and providing a conduit for their opinion, is of vital importance in promoting equality and diversity in society.

As Yardley (2000) notes the value of research is intrinsically linked with its usefulness and applicability. Having worked clinically this final characteristic is also of importance to me, consequently when considering the applicability of the current research the most obvious link is to clinical practice in mental health services. The 'Recommendations for practice' above are the outcome of combining staff perspectives alongside the service users' experience, and highlight the practical component of the findings. However the design and findings have further use in a multitude of different areas, such as promotion of RAPs in research. Incorporating the RAP in co-dissemination of their experience of SUI, in and out of academia, will promote the ideas of equality in research and encourage the use of panels and, consequently, the voice of the service user. Building on this theme dissemination of the research to academic and non-academic arenas, will widen the impact of the research and raise the profile of those with mental illnesses, thereby challenging some negative attitudes towards them.

## Personal reflections

I have kept a reflective notebook over the duration of the PhD. This has facilitated working through issues arising over the course of the research and acted as an aid memoir to 'light bulb moments' that have helped in progressing my understanding of the topic. There are numerous subjects covered within the notes, however I have chosen three central areas to share for the purposes of reflexivity: reflections on changes in my identity, the experience of accessing a RAP and consideration of my changing fore-structure.

### Identity

On considering of embarking on a PhD, I read *How to get a PhD* by Phillips and Pugh (2010). This book gave me a good understanding of the commitment needed and of issues that may arise. However the main message that has stayed with me throughout the current research was the purpose of a PhD: to facilitate the student in becoming a researcher. This view enabled me to employ a level of objectivity when needed, however more notably it planted a seed that has grown to contribute to my current identity. Beginning the PhD as an Occupational Therapist, with 10 years clinical experience influenced my approach and focus, however it was not until halfway through that I reflected on changes to this identity. Being a registered professional gave me legitimacy in whatever environment I was in (clinically, as a trainer, when presenting and not least of all with participants in the current research) and therefore something that increased my confidence. Becoming a researcher through the PhD seemed to happen subtly, as my knowledge and experience developed. It was not until my supervisor drew attention to my email signature that I realised there had been a shift in my identity; I was no longer first and foremost an occupational therapist. I now see myself as a healthcare professional *and* researcher in equal measure.

### RAP

Incorporating a RAP into the design of the current research was a 'non-negotiable' component. Although in the past I had included SUI when practicing clinically, it was

not until moving to the third sector that I recognised its true meaning. This gave me experience of promoting equality between service users and non-service users and placed value on the opinions and input of the former alongside, and in some cases over, the latter. This enhanced my view of SUI and its vital role in empowerment, as well as in diminishing stigma. Throughout the PhD, I have been both surprised and disappointed in the lack of SUI in research in academia. The incorporation of a RAP enabled me to include the service user voice within the design of the research, as well as bring a lived reality that balanced the academic focus. The members added value to the research through acting as an objective sounding board for my ideas and facilitating a deeper understanding of my research findings. I appreciated their challenges and support and would endeavour to incorporate SUI in future research I am involved in.

### Changing fore-structures

On reflection, when beginning this research I held the standard therapist's view of the medical model: hierarchical, outdated, restrictive and unhelpful. This I was only partly aware of, however listening to the discussion in the focus groups, my position and perspective became clear to me. Hearing the service users' view of their need for diagnosis and the validation, justification and access to support that it brought, therefore took a while to register with me. Recognising its worth for the service user in making sense of their experiences, has subsequently had me reflect on my view of the model and of diagnosis. Although I am unable to commit to 'flying the flag' for the current system of mental health service provision, I now accept the value it has in enabling people to manage their mental illness. Suffice to say undertaking a PhD has enabled me to develop on a number of different levels and I am certain I will continue to reflect on the experience for many years to come.



## Conclusion

This aim of this research was to gain an understanding of the experience of receiving a mental health diagnosis. Using IPA facilitated access to the story of participants and the meaning they gave to this experience and concurrently gave voice to a group often marginalised by society. Taking these findings to staff working in the delivery of mental health services, added a different dimension to the research and highlighted the opinions of another, often underrepresented, group. Gaining the responses of staff, placed the findings from those receiving a diagnosis in the context in which they are given and where support is accessed. Added to this was the voice of the service user through the RAP. This design led to combining both service user and staff voices to create discussion from 'both sides of the table' and consequently produce an important clinically applicable and practical set of recommendations.

This thesis is framed by highlighting the clash between the historical medical model and the integration of the more contemporary, biopsychosocial approach in mental health services. The widespread use of multi-disciplinary teams in healthcare introduced a new way of working, encouraging the biopsychosocial approach to illness and disease. This, combined with service users' involvement in contributing to their own care and adding to the rhetoric surrounding services, begins to challenge the traditional view of where expertise lies. Implicit in the findings was the importance of the therapeutic approach of staff in viewing service users as more than a medical case or their diagnosis. The recovery approach to mental illness creates the environment that fosters a more holistic view of the service user with agency and expertise.

Findings indicate the need for an attitudinal shift remains important to facilitate a view of service users as able to contribute to their own care and, consequently, medical staff retain their position as 'experts'. The lack of this shift was reinforced by service users through their wish to access support and view staff as holding the knowledge. Acknowledging and combining the expert knowledge of staff (accrued by training) and the expertise of service users (through lived experience), creates a platform for shared responsibility and respect that forms the foundations for a sustainable service. There is a need to continue to promote opportunities and

encourage services users to become involved in their care. This can be supported by showing the worth in the message 'nothing about us without us' through creating real and meaningful change to benefit service users.

In concluding this thesis, it is important to recognise the beneficial role played by the medical model and its implicit objectivity in bringing validation to service users through diagnosis. Although there are critics of the nosology of mental illness, for some, receiving a diagnosis helps make sense of what can be distressing experiences. It provides a common language with which to express these experiences and is the process by which service users are able to access services. Therefore until approaches in mental health service provision change dramatically, the medical model provides a known framework for service users to access services and begin to manage their mental illness. However as noted in the literature and the findings, a mental health diagnosis is accompanied by stigma and consequently carries with it a sense of invalidating and limiting the service user. To summarise this thesis and the experience of receiving a mental health diagnosis, I shall conclude with a quote from Steph on her personal experience:

*...it was sort of bitter sweet really (676-677).*

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## Appendix 1: Emergent themes used in focus groups

<b>Regaining control (pre-diagnosis)</b>
Recognising an inability to cope, leading to self-directed research and accessing support (self-referral or via others)
<i>an' they just come in and said, come on we'll go up [hospital] to the crisis team like (Rupert: 123-125)</i>
<b>Connecting with others</b>
Increased empathy with others with lived experience, through having mental ill-health
<i>yeah I was quite shocked to look around the room and think, she looks normal, he looks normal, so that would have been probably the first time that I relate to others with it (Lisa: 981-985)</i>
<b>Need for personal control (in management of condition)</b>
Maintaining control is of importance in managing mental health condition once support has been accessed and treatments are underway
<i>it's learning what to do with negative feeling, it's learning to identify them and label them, because once they've got a label, they're in your power really (Simone: 441-444)</i>
<b>Validation, for self and others, via diagnosis</b>
Diagnosis helped in making sense of symptoms and changes that had occurred, as well as helping disclosure
<i>here's some kind of identifier that says I'm not lying (Joseph: 603-604)</i>

## Appendix 1: Emergent themes used in focus groups (cont.)

<b>Owning mental ill-health</b>
Recognition that mental ill-health is part of them
<p><i>I've got a diagnosis, just like someone with diabetes would.... it's who I am, what I am, you know it's part of me</i></p> <p><i>(Zoe: 1822-1826)</i></p>
<b>"Living with"</b>
Their mental ill-health was not something to 'recover' from, rather it is to be managed and 'lived with'
<p><i>recovered completely I, that to me is a 100% kind of figure an' I don't think that's possible</i></p> <p><i>(Lisa: 1224-1227)</i></p>
<b>Variations in service provision</b>
Inconsistencies in both NHS and private practice
<p><i>I was very fortunate because around that time I saw three separate GPs and all of them very, very, very, you know sympathetic, very, very supportive and very clued up</i></p> <p><i>(Keith: 375-378)</i></p>
<b>Impact on life</b>
Having mental ill-health impacts on many areas in life
<p><i>I tend to think that the majority, I don't say everybody, but you know the majority of people suffering from alcoholism probably suffer with mental health issues</i></p> <p><i>(John: 1257-1260)</i></p>

## Appendix 1: Emergent themes used in focus groups (cont.)

Selective disclosure
Care was taken in who to disclose mental ill-health to, in what circumstances and to what extent; rarely was there full-disclosure
<i>but I couldn't explain to my professional colleagues that I was [condition], because I would never have worked again</i> (Tony: 1050-1054)
Stigma
Self and societal stigma impacts on perception of self and how they feel other's perceive them
<i>you see the fruit and nut case next door, you know, he's washing his drive again</i> (John: 1367:1368)
Acceptance
Receiving a diagnosis and gaining support does not equate to acceptance of mental ill-health
<i>it's part of me, it's always gonna be part of me, it's not a very nice part of me, but it's still part of me and if I pretend that it's not part of me, I'm just cutting off my nose to spite my face</i> (Katherine: 668-672)

## Appendix 2: RAP Recruitment poster



**I'm Nicole, an Occupational Therapist and PhD student.  
I have worked for \*\*\*\*\* and have over 20 years' experience in  
mental health training and employment.**

**I'm looking for people with experience of living with a mental health  
condition to comment on my work:  
Exploring the experience of receiving a Mental Health Diagnosis.**

**Who?**

I am looking for volunteers and service users with experience of  
mental health within the \*\*\*\*\* network

**Why?**

I would like you to guide my research, help ensure good practice and give  
you an insight into the research process

**When?**

11am – 1pm, Wednesday 5<sup>th</sup> November (refreshments provided)  
The next meeting date for early December will be agreed by the group

**Where?**

\*\*\*\*\*

**Expectations**

To attend and contribute openly and honestly and as a  
sounding board for my research ideas, ensuring the safety  
of the participants I will be interviewing

If you are interested in getting involved in the Advisory Group please contact:

**Thank you and I look forward to meeting you, Nicole.**

## Appendix 3: RAP Terms of Reference

**Terms of Reference** – Service User Involvement in Research.

PhD title: Receiving a Mental Health Diagnosis: Self-perception and its perceived impact on recovery

PhD student: Nicole Burchett 2014 – 2017

**Name of Group:** Cardiff Research Advisory Panel (C)RAP

**Title:** Terms of Reference

**Purpose/ role of group:**

Broad purpose; Service User Involvement to promote discussion, ideas, guidance, give a voice of those with lived experience, act as a sounding board and advise on the progress of the research undertaken for PhD at Cardiff Met.

Established/ by whom; Sept 2014 by Nicole Burchett in consultation with Dr Jenny Mercer (Director of Studies), [service user-researcher], [volunteer] and [administrator]

Aims/ responsibilities; To form an expert panel of people with lived experience to inform and guide the PhD research through providing feedback, making a commitment to attend and being open and honest.

**Membership:**

Membership open to; Closed group within [organisation] network to enable safety and trust. To remain flexible any member can withdraw at anytime and the group will stay open to new members from the [organisation] network (within the restricted numbers).

Restrictions on numbers; seven - ten.

Involvement; The group is open to those volunteering in [organisation] with lived experience of mental health problems and to those using the services of [organisation] to manage their mental health illness.

Representatives from other organisations; None. (Pragmatics & logistics, safety and security of those attending.)

Membership length of time/ extended; Group open for duration of research: 3 years.

**Accountability:**

Reporting back to group; Nicole will report back to the group on progress dependent on stage of research/ relevance to the purpose of the group. Advisory panel will support each other and [organisational] processes.

**Review:**

ToR and value of work; Feedback will be given informally at end of each session and more formally in line with [organisational] processes, where this is appropriate.

### Appendix 3: RAP Terms of Reference (cont.)

Reflection of previous meeting at the start of the next one. Informal biannual review of progress/ future direction of PhD.

#### **Working methods:**

Method; Nicole to set agenda, chair and take notes. Agenda items to be sent to Nicole. No formal minutes to be taken. Option of a rotating chair to remain open. Nicole to email an overview of the meetings to the group. Feedback via individual [organisation] Assoc. where appropriate.

Meetings; Location – [\*\*\*\*\*], [\*\*\*\*\*] and [\*\*\*\*\*] offices available. For ease of access [\*\*\*\*\*] will be used. This is free and refreshments will be available. Timing - mid morning/ early afternoon. Duration - 1 and ½ to 2 hours. Frequency - monthly moving to biannual depending on progress of PhD and appropriateness of meetings related to research stage and progress.

Sharing info; Email agreed to be the best way to communicate. Members have to be in agreement prior to contact details being shared.

#### **Considerations:**

Reciprocity; Although this has been looked into there currently is no budget to pay group members for their time. Covering of travel expenses has been agreed by the [organisation] that the individual is linked with. Refreshments will be provided at the meetings.

Training; [Service user-researcher] will give half day training on process of research and evaluation (based on MacMillan training). Nicole will give an overview of the research and how the group is to be part of this.

Ethics; A resource sheet will be provided for signposting to external support i.e. Involving People, Mind, CALL, Samaritans etc. Nicole will signpost as and when appropriate within the meetings should this be necessary.

Dissemination; Nicole will keep the group aware of any opportunity to co-present experiences at conferences and through publications, regarding the service user element of the research.

## Appendix 4: Participant Information Sheet (Study 1)

### Interview participant information sheet

Reference Number: **0048-SREC-2004(02)**

Title of research project: **Receiving a Mental Health Diagnosis: Self-perception and its perceived impact on recovery**

Name of PhD researcher: Nicole Burchett (niburchett@cardiffmet.ac.uk)

Academic Supervisor: Dr Jenny Mercer (jmercer@cardiffmet.ac.uk)

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*Thank you for taking the time to read through the following information and consideration to take part in the research. Your participation in this research is entirely voluntary.*

*Please let me know if you have any questions or concerns about any of this process and the research, Nicole.*

**About me:** I am currently studying at Cardiff Metropolitan University on a full-time PhD programme. I am an Occupational Therapist with over 20 years' experience in training and employment in mental health. I have an interest in the *diagnostic journey* people with lived experience of mental health have and am keen to understand this further through interviews.

**Background:** There is a growing focus into the impact of mental health illnesses in the UK and both National and Welsh Governments are developing legislation and policies to bring mental health services in line with those in physical health. It is estimated that one in four people in the UK are likely to experience a period of mental ill health. How people perceive themselves and how they are seen by others in their society will impact on their daily lives and, subsequently, their recovery.

**Research design:** My research aims to gain an understanding of the experience and impact of receiving a mental health diagnosis beginning with in-depth interviews. The themes from your interview will then form the basis of focus groups discussions with people providing mental health services.

**What happens to the information collected:** The information collected will provide an evidence base from which best practice guidelines in mental health service provision will be developed. The aim of dissemination and publication of the research is to impact on mental health service provision to enhance good practice.

**Your involvement:** Should you agree to this research you will be asked to take part in an interview, which will take approximately 1 hour.

**Benefits/ risks in being involved:** Your interview information will add to the growing body of knowledge in the health sciences concerning people with lived experience of mental health illness. The interview could lead to disclosure of upsetting experiences which may be distressing for you. It will be within your control



## Appendix 4: Participant Information Sheet (Study 1) (cont.)

how much information you choose to share and you can stop or withdraw from the interview at any time.

**Collection, storage and use of the interview information:** Your interview will be recorded on a digital device, which will be kept in a locked filing cabinet. This information will be destroyed after the end of the research. At the stage of transcribing, pseudonyms will be used for anonymity and a copy of the transcript will be sent to you with an opportunity to add, amend or delete comments should you wish. This will come with a specific date to receive your reply by (should you wish to add, amend or delete any or your comments).

**Confidentiality and withdrawing from research:** If you agree to be interviewed your participation is voluntary and you may refuse to complete or withdraw from the research at any point and have your interviews and information destroyed without any consequence to you. At no point during subsequent interviews will the content of your interview be shared with other participants.

**Analysing the information:** The method for analysis is Interpretative Phenomenological Analysis (IPA). This is the in-depth process of reading and re-reading the interview transcripts to find themes, firstly individually and then across the interviews. Using IPA also makes clear the researcher's interpretation in choosing themes, which may be different from participants' and other researchers'. As this is the case, there will be no agreement of themes with the participants.

**Role of [organisation]:** The research is independent of the [named] organisation that you are involved with. However they have offered to provide rooms for the interviews should this feel comfortable to you. They have also agreed to pay for limited travel expenses to ensure involvement in this research does not impact on your finances.

Thank you for considering taking part in this research and please do not hesitate to contact me should you have further questions about getting involved.

Kind regards,  
Nicole Burchett.  
Occupational Therapist.

Academic Associate/ PhD Student  
Cardiff Metropolitan University  
Cardiff School of Health Sciences  
Western Avenue  
Llandaff  
Cardiff  
CF5 2YB  
e: [niburchett@cardiffmet.ac.uk](mailto:niburchett@cardiffmet.ac.uk)  
t: (office) 02920 201174

Academic Supervisor: Dr Jenny Mercer ([j Mercer@cardiffmet.ac.uk](mailto:j Mercer@cardiffmet.ac.uk))

## Appendix 5: Participant consent form (Study 1)

### Interview participant consent form

Reference Number: **0048-SREC-2014(02)**

Title of research project: **Receiving a Mental Health Diagnosis: Self-perception and its perceived impact on recovery**

Name of Researcher: **Nicole Burchett (aa73032)**

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*Your participation in this research is entirely voluntary. Please read through the following information and, if in agreement with it, initial the boxes and sign the form overleaf.*

*Please let me know if you have any questions or concerns about any of this process and the research, Nicole.*

**Purpose:** This research is to explore the experience of receiving a mental health diagnosis and the responses to this of those who deliver mental health services.

**Procedure:** Should you agree to participate in this research you will be asked to take part in an interview, which will take approximately 1 hour.

**Benefits/ risks in participation:** The findings will add to the growing body of knowledge in the health sciences concerning people with lived experience of mental health illness. The interview may lead to disclosure of upsetting experiences which may be distressing for the participant.

**Collection, storage and use of information:** The interviews will be recorded on a digital device, which will be kept in a locked filing cabinet. This data will be destroyed after the end of the research. At the stage of transcribing, pseudonyms will be used for anonymity and a copy of the transcript will be sent to you with an opportunity to add, amend or delete any sections should you wish. This will come with specific date for the researcher to receive your reply by (should you wish to delete any of your comments).

**Confidentiality and withdrawing from research:** At no point during subsequent interviews with other participants, will the content of your interview be shared with other participants. If you agree to be interviewed your participation is voluntary and you may refuse to complete or withdraw from the research at any point and have your data destroyed without any consequence to you.

## Appendix 5: Participant consent form (Study 1) (cont.)

Consent for research:

Please Initial

1)	I have read the above and been given an information sheet for my reference.	
2)	I have been given the opportunity to ask questions and am satisfied to continue.	
3)	I agree to take part in this study and understand that my participation is voluntary and I am free to withdraw at any time without giving reason and without consequence.	
4)	The storage, destroying and use of information in publication have been explained to me.	
5)	I agree to my interview being recorded and understand that the transcripts will be anonymised.	
6)	I have been given a resource sheet for support and the contact details of the researcher should I have questions in the future.	

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**Name of participant** (print)

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**Signature of participant**

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**Date**

-----

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**Name of researcher** (print)

-----

**Signature of researcher**

-----

**Date**

Your participation in this research is greatly appreciated,  
Nicole.

PhD Researcher: Nicole Burchett ([niburchett@cardiffmet.ac.uk](mailto:niburchett@cardiffmet.ac.uk))  
Academic Supervisor: Dr Jenny Mercer ([jmercerc@cardiffmet.ac.uk](mailto:jmercerc@cardiffmet.ac.uk))

## Appendix 6: Patten's question types

<b>Patton's question type</b>	<b>Related question in interview schedule</b>	<b>Related prompt/ probe in interview schedule</b>
<i>Background</i>	What happened in the run up to receiving your mental health diagnosis/ each diagnosis?	When did you receive it? How did it come about?  Who was involved?
<i>Experience</i>	What has your life been like since receiving the diagnosis/ each diagnosis?	What were your experiences of accessing support?
<i>Opinion</i>		Do you think there is stigma or discrimination in society against people with a mental health diagnosis?
<i>Feeling</i>	How did you feel in the moment you received the diagnosis/ each diagnosis?	What went through your mind?  What emotion did you have?
<i>Knowledge</i>		What were your perceptions of people with mental health prior to receiving a diagnosis/ diagnoses?
<i>Sensory</i>	How did you feel in the moment you received the diagnosis/ each diagnosis?	What did you smell/ hear/ taste?  What do you remember most vividly? Why?

Example showing how questions/ prompts map onto Patton's (2015) question types

## **Appendix 7: Interview schedule (Study 1)**

### **Interview Schedule for interviews**

**Title of project:** Receiving a mental health diagnosis: Service users' experiences and staff responses to emergent themes.

#### **Introduction – prompt for researcher**

Thank you for your involvement today, as you know I'm recording the interview and will send you a copy of the transcript for you to add, amend or delete anything should you wish to. You can withdraw at any time prior to a cut-off date that I will send with the transcript. To protect anonymity, I'm going to change the names of all participants, so would like to offer you the choice of choosing a name yourself or leaving it to me...

As I've explained I'm researching into the experience of receiving a mental health diagnosis, self-perception and the perceived impact on recovery. I'm interested in hearing about your experience as there is limited understanding about what it actually feels like to receive a mental health diagnosis.

We'll be looking at how your diagnosis came about, how it was for you to receive it and life for you after having the diagnosis. This is going to be our focus for the next hour or so. Do you have any questions?...

If you are happy, we will begin the interview.

#### **What happened in the run up to receiving your mental health diagnosis/ each diagnosis?**

- When did you receive it/ them? Time, Place, Age
- How did it/ they come about?
- Who was involved?

#### **2 How did you feel in the moment you received the diagnosis / each diagnosis?**

- Looking back what was the overall sense of that experience for you?
- What went through your mind?
- What did you smell/ hear/ taste?
- What emotion did you have?
- What do you remember most vividly? Why?

#### **3 Have you noticed any changes in how you view yourself since diagnosis/ diagnoses?**

- Did you have a sense of who you were before you received the diagnosis/ each diagnosis?
- How do you think your sense of self changed/ didn't change?
- Did you take the diagnosis/ each diagnosis on board?
- How do you think others saw you when you received the diagnosis/ each diagnosis?
- Has your sense of self changed over time since receiving the diagnosis/ each diagnosis?

## **Appendix 7: Interview schedule (Study 1) (cont.)**

### **4 What has your life been like since receiving the diagnosis/ each diagnosis?**

- Did anything change because of having a diagnosis/ diagnoses?
- Did you tell anyone? What were people's reactions?
- What were your experiences accessing support?
- Was anything offered to you to help you manage your mental health? Did you put anything in place yourself to help manage your mental health?

### **5 What is your experience of living in society with a mental health diagnosis?**

- What were your perceptions of people with mental health prior to receiving a diagnosis/ diagnoses?
- Did anything change after receiving the diagnosis/ diagnoses? New insights?
- Do you think there is stigma or discrimination in society against people with a mental health diagnosis? Have you experienced this personally?
- After diagnosis did you feel better able to identify with a group that you had not before?

### **6 What does 'recovery' mean to you?**

- Some people consider themselves 'in' recovery, rather than recovered, what are your thoughts on this?
- How do you manage your mental health in your daily life?
- Do you think your mental health will change in the future? If so, how? How do you feel about this?
- What hopes do you have for your recovery in relation to your mental health diagnosis/ diagnoses?

### **Concluding comments - *prompt for researcher***

That is the end of the interview. Thank you for sharing your experiences and thoughts with me, it is very much appreciated.

Before we finish are there any reflections you want to share with me about the interview?... Is there anything else you'd like to add?

I'll be in touch with the transcripts, which may take up to 6 months to type up. All information will be stored safely and securely in line with the Data Protection Act.

Thank you once again. There is a resource sheet should the interview bring anything up for you in the next few days and I'd like to check you have the contact details of your local [named] organization and any support you may need.

## Appendix 8: Representativeness of emergent themes

Emergent theme	Participants									
	Z	T	St	J	R	L	K	Jos'	Ka	Si
Regaining control	✓	✗	✓	✓	✓	✓	✓	✓	✓	✗
Need for personal control	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓
Connection to others	✓	✓	✓	✗	✓	✗	✓	✓	✓	✓
Acceptance	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Validation via diagnosis	✓	✓	✓	✗	✗	✓	✓	✓	✓	✓
Living with	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Owning mental ill-health	✓	✓	✓	✗	✗	✗	✓	✓	✓	✓
Variations in service provision	✓	✓	✓	✓	✗	✗	✗	✓	✓	✓
Impact on life	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Selective disclosure	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓
Stigma	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓

Table showing representativeness of emergent themes found across entire data set (✓ = theme found in interview transcript, ✗ = theme not found in interview transcript).

## Appendix 9: Example of subordinate themes quotes

Selective disclosure		
Name	Quote	Line
Zoe	<i>I probably told people who knew me at work you know</i>	1307-1310
Tony	<i>but I couldn't explain to my professional colleagues that I was [condition], because I would never have worked again</i>	1050-1054
Steph	<i>I'm open with the people that I'm closest to</i>	1038-1040
John	<i>I probably wouldn't tell anybody purely and simply because it's none of their business, you know it's my personal thing</i>	1303-1308
Rupert	<i>I'd say nervous breakdown if I was to go on to somebody now</i>	676-678
Lisa	<i>I suppose I've got particular people who I don't, you don't touch on the conversation</i>	1340-1342
Keith	<i>I've always worked in places you know where you're working with people who you know are quite nurturing</i>	1198-1200
Joseph	<i>I still feel that I'm being potentially dishonest if I ever say to a group of friends oh well I'm a little bit [condition]</i>	1431-1433
Katherine	<i>I put up a status on Facebook, just one of those notes, just with everything in it and I thought it's bound to come out, I've had enough now hiding</i>	845-848
Simone	<i>when there was a need, there was a need to say and when I wasn't, I didn't particularly keep it a secret, I found it made things easier</i>	709-711

Extracts from tables of subordinate themes showing quotes associated with 'selective disclosure'.



## **Appendix 10: Participant information sheet (Study 2)**

### **Focus group participant information sheet**

**R&D ref:** 15/MEH/6305

**Study Number:** IRAS Project 191499

**Name of PhD researcher:** Nicole Burchett ([niburchett@cardiffmet.ac.uk](mailto:niburchett@cardiffmet.ac.uk))

**Academic supervisor:** Dr Jenny Mercer ([jmercer@cardiffmet.ac.uk](mailto:jmercer@cardiffmet.ac.uk))

**Title of project:** Receiving a mental health diagnosis: Service users' experiences and staff responses to emergent themes.

#### **Summary of research**

The aim of this research is to explore staff responses to master themes found on the experience of receiving a mental health diagnosis. Themes were developed through detailed analysis of 10 interviews with service-users. Staff working in mental health services play an integral role in the management of mental health, therefore it is important to capture their thoughts on the themes. Two focus groups of between four and ten people will be run with NHS staff on these themes, to facilitate this.

#### **Background**

There is a growing focus into the impact of mental health illnesses in the UK. Both National and Welsh Governments are developing legislation and policies to bring mental health services in line with those in physical health. It is estimated that one in four people in the UK are likely to experience a period of mental ill-health in their lifetime. The experience of receiving a mental health diagnosis not only involves the individual receiving it; it also involves those making the diagnosis and the staff providing the support to manage the condition. Taking into account both staff and service users thoughts on the process of diagnosis and recovery, will enable a discussion on implications for best practice in mental health service provision.

#### **What does taking part involve?**

##### **Participant criteria**

Two focus groups will be run with staff delivering services in mental health in Cardiff and Vale NHS University Health Board. Due to the focus of discussion it is important that those attending are qualified Healthcare Professionals with at least three years' experience in mental health services. Therefore Medical Practitioners and Occupational Therapists are invited to attend profession specific focus groups. Should there be more interest from staff to attend than numbers allow, a waiting list will be formed. Attendance will be on a first come first served basis and those on the waiting list will be contacted in a timely manner regarding their interest.

##### **Length of time of involvement**

Each group will have a between four and ten participants and will last approximately 75 minutes. This will be the only active part of the research participants will be involved in. However each participant will be contacted prior to the group to share details of the focus group arrangements, and after the group to send a copy of the transcript for reference. The themes form part of this information sheet and are included to aid informed consent in taking part and familiarisation prior to attending the group.

## **Appendix 10: Participant information sheet (Study 2) (cont.)**

### **Confidentiality**

In order to maintain confidentiality of those attending, a request will be made to sign consent forms prior to starting the group. The focus groups will be audio and video recorded for the purposes of accurate transcription and the recordings will not be shared in the public domain. The researcher will transcribe the recordings verbatim and, in the process, change any identifying information and allocate pseudonyms. It is anticipated that anonymised quotes will be used in publication and consent to this is captured in the consent form signed prior to the start of the group. A Healthcare Professional will accompany the researcher in the focus groups for observation purposes and will record general information during the group.

It is hoped that the researcher will attend meetings to introduce the research, in this case it may be likely that the line managers of the participants are aware of their attendance through passing on contact details of those interested. For the purposes of transparency and coherence in the analysis, the researcher's supervisory team will have access to the anonymised transcriptions.

### **Securely storing data**

The focus group recordings will be uploaded to the secure computer and server located at Cardiff Metropolitan University. Once transcription has taken place these source recordings will be deleted and the subsequent transcripts securely stored in this location. All consent forms and hard copies of documents from the focus group will be held at the University in a locked cabinet. These will be held for five years post-research in adherence to the Universities policies and governance on storing confidential information.

### **Withdrawing from the research**

Any participation in the focus group is entirely voluntary. Written informed consent will be requested from each participant prior to starting the focus group. This form can be printed and sent to the researcher before the day (at the address below) or collected on the day. Due to the conversational nature of the focus groups, participants are unable to withdraw after the focus group has finished. Each person's contribution is made in the context of the entire conversation and withdrawing will impact on the validity of the data collected. However any participant is free to withdraw prior to attending, during the group or at any point up to the end of the focus group, without consequence to them. Any participant withdrawing during the group does so in the knowledge that comments made to that point will be used for analysis (for the reasons above).

### **Expenses**

Although there is no funding allocated for participant expenses, any reasonable travel cost will be reimbursed. As indicated it is hoped the focus group will occur at a time and place convenient to those attending, thus limiting travel costs and minimising disruption to daily clinical practice.

### **Benefits of taking part**

There are no direct benefits to taking part in this research, however some indirect benefits may occur. The findings from the focus group will add to the existing knowledge of Healthcare Professionals of the experience of receiving a mental health diagnosis and an individual's recovery. Discussion of the themes will act as a learning opportunity and may positively resonate with staff's clinical practice. Via the process of analysis and dissemination, participants will have added to the discussion in health sciences of best practice in mental

## **Appendix 10: Participant information sheet (Study 2) (cont.)**

health service provision. Should participants wish to receive a copy of the final lay-report (due in 2017) they are requested to contact the researcher.

### **Disadvantages of taking part**

Time taken to attend the focus group may disrupt the daily work of the participants. However it is hoped that the group will take place in a pre-scheduled meeting to reduce this risk. As participants are highly skilled it is unlikely that the subject under discussion will cause distress. However a resource sheet will be provided and the accompanying Healthcare Professional will offer support should the need arise. There is a limited risk of participants being identified in publication of quotes due to the small numbers taking part and all data will be anonymised to limit this occurring. No information will be shared between the focus groups by the facilitator and confidentiality will be maintained throughout. Breach of confidentiality may occur if there are disclosures of risk to self or others by the participants; the researcher will be practicing under professional duty of care.

### **Independent contact point for research in Wales**

Health and Care Research Wales:

web: <http://www.healthandcareresearch.gov.wales>

email: [healthandcareresearch@wales.nhs.uk](mailto:healthandcareresearch@wales.nhs.uk)

tel: 02920 230457

### **Independent contact point for complaints**

Dr Jenny Mercer (Director of Studies).

Principal Lecturer & Graduate Studies Coordinator.

email: [jmercerc@cardiffmet.ac.uk](mailto:jmercerc@cardiffmet.ac.uk) tel: 02920 416862

### **Researcher details**

Nicole is currently enrolled on a full-time PhD programme at Cardiff Metropolitan University. She is a qualified Occupational Therapist with over 20 years' experience in training and employment in mental health. She has an interest in the experience of receiving a diagnosis and is keen to understand this further through facilitating focus groups with those delivering services.

email: [niburchett@cardiffmet.ac.uk](mailto:niburchett@cardiffmet.ac.uk) tel: 02920 201175

address: Cardiff Metropolitan University, Llandaff Campus, Western Avenue, Cardiff. CF5 2YB.

## Appendix 11: Krueger and Casey's question types

Question type	Question	Follow up questions	Purpose of question
Introductory	2) What are your first impressions of the themes?	Do any stand out for you? Did any surprise you? Were there any you had not considered?	To provide a way to connect to topic with ease and comfort and capture key concepts from participants.
Transition	3) If you were to order these themes from your perspective of working in mental health services, which ones would you rate as more important than others?	What influenced your choice of ordering? Did some naturally seem more important? Why? What came to mind when doing this?	To capture cohesion and inconsistency in group and between focus groups.

Extracts from table mapping onto Krueger and Casey's (2015) question types alongside justification for its inclusion.

## Appendix 12: Participant consent form (Study 2)

### Focus group participant consent form

**R&D ref:** 15/MEH/6305

**Study number:** IRAS Project 191499

**Title of research project:** Receiving a mental health diagnosis: Service users' experiences and staff responses to emergent themes.

**Name of PhD Researcher:** Nicole Burchett ([niburchett@cardiffmet.ac.uk](mailto:niburchett@cardiffmet.ac.uk))

**Consent for research:**

**Please initial**

1)	I have read the participant information sheet and I have been given the opportunity to ask questions which have been satisfactorily answered.	
2)	I agree to take part in this research.	
3)	I understand that my participation is voluntary and I am free to withdraw at any time up to the close of the focus group, without giving reason and without consequence.	
4)	Should I choose to withdraw during the focus group, I am happy for my comments up to that point to be used for analysis.	
5)	The storage, destroying and use of information have been explained to me.	
6)	I agree to my interview being video and audio recorded and understand that the transcripts will be anonymised.	
7)	I have been given a resource sheet for support and the contact details of the research team should I wish to contact them.	
8)	I agree to my anonymised quotes being used in future publications.	
9)	I agree to maintain the confidentiality of the information discussed by all participants and researchers during the focus group session.	
10)	I understand that relevant sections of data collected during the study, may be looked at by individuals from Cardiff Metropolitan University, from regulatory authorities or from Cardiff and Vale University Health Board, where it is relevant to my taking part in this research. I give permission for these individuals to have access to my data.	

-----  
**Name of participant (print)**

-----  
**Signature of participant**

-----  
**Date**

-----  
**Name of researcher (print)**

-----  
**Signature of researcher**

-----  
**Date**

## **Appendix 12: Participant consent form (Study 2) (cont.)**

Your participation in this research is greatly appreciated,  
Nicole.

**PhD Researcher:** Nicole Burchett ([niburchett@cardiffmet.ac.uk](mailto:niburchett@cardiffmet.ac.uk))

**Academic Supervisor:** Dr Jenny Mercer ([jmercer@cardiffmet.ac.uk](mailto:jmercer@cardiffmet.ac.uk))

**Independent contact point for complaints:**

Dr Jenny Mercer. Principal Lecturer & Graduate Studies Coordinator.  
email: [jmercer@cardiffmet.ac.uk](mailto:jmercer@cardiffmet.ac.uk) tel: 02920 416862.

## **Appendix 13: Discussion guide**

**1) Please tell us your name, the team you work in and what interested you in attending today.**

**2) If you were to order these themes from your perspective of working in mental health services, which ones would you rate as more important than others?**

- Do any themes stand out for you, surprise you? Why?
- What influenced your choice of ordering?
- Did some naturally seem more important? Why?
- What came to mind when doing this?

**3) How do the themes compare with your experiences working with people who have a mental ill-health? Or in your personal experience?**

- Do any resonate with your experiences?
- Do any not fit in with your experiences?
- Are there any areas you feel are missing?

**4) What areas do you feel mental health services concentrate in?**

- What do you think the reasons are for this focus?
- What do you think are the implications for service-users?
- Do any changes need to be considered? If so what might they be?

**5) In summary we have talked about...(the above) in a sentence I'd like each of you to share what you consider to be the most important aspects of today's discussion.**

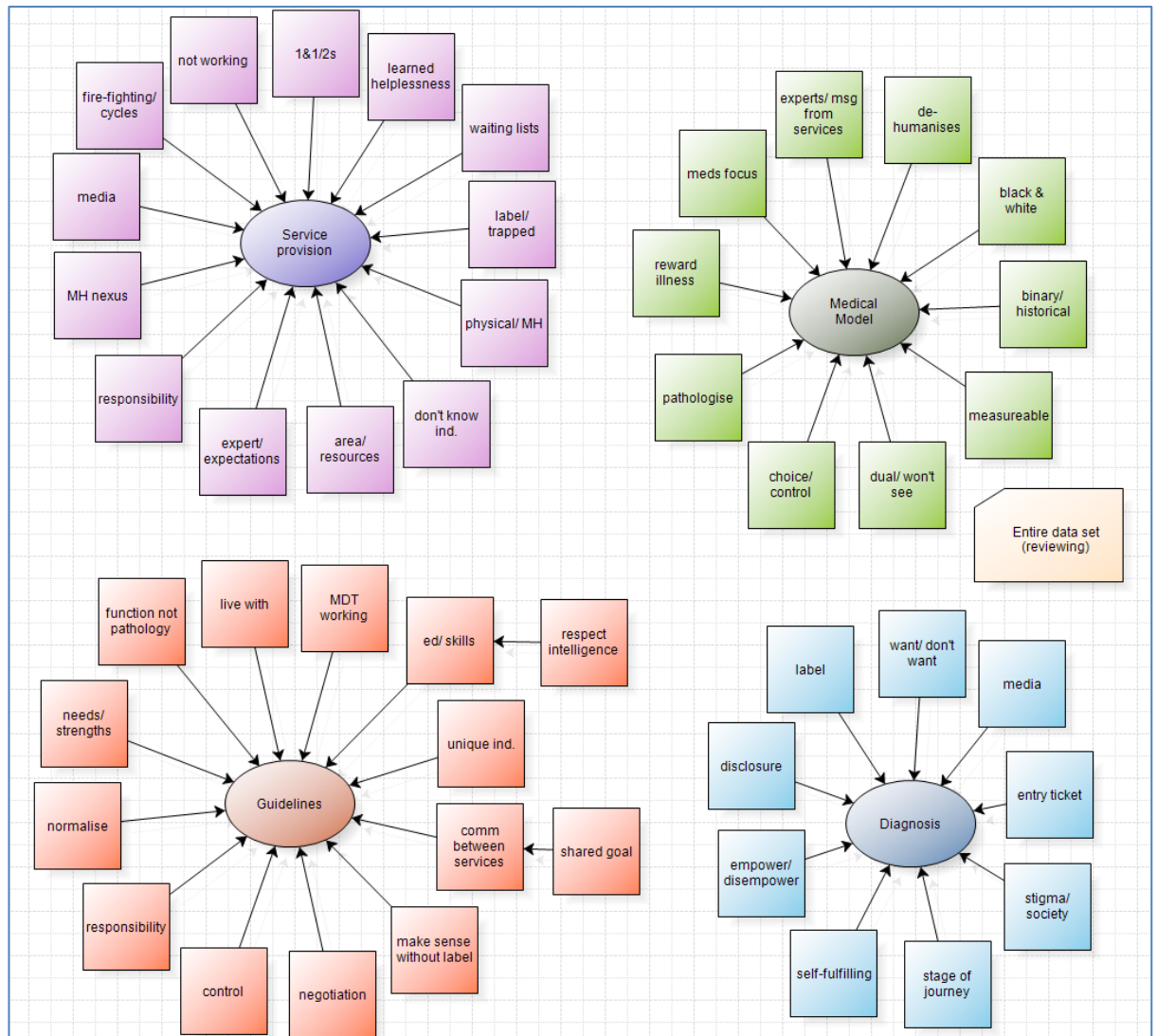
- What has stood out for you?
- Has anything changed in your perspective?
- Any additional thoughts?

**6) Can I request that each of you agree verbally to the use of any comments you have given today for future publications as anonymised quotes. Thank you.**

**7) Is there anything we have missed? We are happy to receive feedback on facilitation and the group experience for future focus groups?**

- Anything you would like to add?

## Appendix 14: Thematic map



Thematic map re-checking themes across entire data set (NVivo).