An IPA study exploring clients' experiences of living with complex mental health needs in a residential care home: some voices are harder to hear.

Alison Chivers

A thesis submitted in partial fulfilment of the requirements of the University of the West of England, Bristol for the degree of Professional Doctorate in Counselling Psychology.

School of Psychology,

Faculty of Health and Social Sciences,

University of the West of England, Bristol

August 2021

Acknowledgments

Firstly, I would like to thank my supervisors, Dr Antonietta Dicaccavo for her consistent, support and guidance and Dr Zoe Thomas for her calm approach. I would also like to thank Dr Hamilton Fairfax who supervised the start of this process and allowed me to follow my heart with this research. Their guidance and words of wisdom were very much appreciated.

I would like to thank the participants who came forward, entrusted me with their stories and shared their experiences with me. Thank you Hazel for believing in me and to the organisations that allowed me to come into their homes, gave their time and support with this research.

I would like to thank my family for their love and support especially my husband John and my children Katy and Charlie. John and Katy for reading and re-reading each draft and Charlie for making me smile, lifting my spirits. I cannot forget my companion, my springer spaniel Bay, who I lost the May before I submitted this research. She gave me a reason to take a break and I miss her terribly.

Finally, two wonderful ladies Eve and Dr Katherine Byron Daniel who without their wise words and continued support I would never have dared to dream I could do this.

Alison Chivers
December 2020

Contents

Abstract

Objectives. The aim of the research was to hear the voices of participants with complex mental health needs, gaining insight into the experience of living in residential care homes. These voices often get lost; as people with complex mental health needs are often seen as difficult to engage and consequently have been excluded from opportunities to influence services.

Design. The research engaged in a qualitative inquiry to explore the lived experience of six people with complex mental health needs who live in residential care.

Methods. The participants were required to engage in semi-structured interviews of up to sixty minutes. Interpretive Phenomenological Analysis (IPA) which was considered the most appropriate methodological approach (Smith, Flowers & Larkin, 2009) was used to analyse the data.

Findings. Four superordinate themes were developed from the analysis (1) Stories of change over time; an historical journey (2) Searching for care; (3) The challenges of living in residential care; (4) Learning to grow as a resident in a residential care home. Subordinate themes were developed for each of these Superordinate themes.

Conclusion. The research outcomes suggest that concepts of power, infantilisation and social justice operate in residential care and are important aspects to consider in people's experiences of long-term residential care. The concept of Psychologically Informed Environments (PIE 2.0) is put forward as a possible theoretical framework to which this research may contribute with the aim of developing greater psychological awareness, creating cultures of learning and enquiry and fostering more responsiveness of services.

Word Count 25,808

Background and Rationale and Literature Review:

Introduction

The following review aims to explain what is understood from the existing research base about the experience of living in residential care with complex mental health needs. This research aims to examine complex mental health needs[1] as a symptom of distress within a framework influenced predominantly by the medical model. The concept of residential care will be examined and will give context to the research to understand how the participants have arrived at this point in their lives, and why their voices are important. The dominant models of mental health: the medical model, the recovery model, and person-centred care will be critiqued. These models are included in this review as they are prominent in the UK mental healthcare of those with complex mental health needs and vulnerabilities and therefore provide a context and framework for this research to be positioned.

Policy and national guidelines for people living with complex mental health needs in residential care will be outlined. This research is important as there are very few explorations into residential services from service user perspective (Faulkner, 2017). The studies that have been done are mostly qualitative and have found to be of poor quality (Krotofil, Mcpherson and Killaspy, 2018). This has made this literature review difficult to compile therefore concepts such as lived experience of complex mental health needs, peer support and 'mad studies' which promotes listening to people considered mad and reflects on madness from their point of view are also considered (Faulkner, 2017; Gillis, 2015). Therefore, the rationale for this study is that historically psychiatric diagnosis pervades and drive non-individualised narratives around patient care. For residential care in particular where clients and their families are more easily ignored this research gives an opportunity to hear the voices that are difficult to hear.

---

[1] Complex mental health needs will be defined using the Health of the Nation Outcome Scale (HoNOS, Royal College of Psychiatrists, 2019), Diagnostic and Statistics Manual of Mental Disorders (DSM-V) (American Psychiatric Association, 2013) and the National Institute for Health and Clinical Excellence Guidelines (NICE, 2011)

Complex mental health needs defined

An individual can be described as having complex mental health needs if they have two or more needs which include psychiatric diagnoses such as schizophrenia, personality disorder (PD) or bipolar disorder (Turning Point, 2014). These adults face a wide range of problems that affect physical, mental, social or financial wellbeing; and often experience a secondary need, such as physical health conditions, for example epilepsy and or diabetes. Typically, people with complex mental health needs find it difficult to hold down employment and some have been victims of domestic violence, social isolation, or trauma described as physical, psychological or social (Turning Point, 2014).

As the concept of complex mental health needs is broad, the researcher will use the 'Mental Health Clustering Booklet' (MHCT) which is based on scores from the Health of the Nation Outcome Scale (HoNOS). The HoNOS is the current measure of complexity in NHS secondary care mental health services (Royal College of Psychiatrists, 2019). This provides a benchmark and ensures a global description of a group of people with similar characteristics, identified from a holistic assessment. Using this system in the current research will ensure that the homogeneity of the sample is maintained as far as possible. Participants included in the sample are in cluster seven, eight, thirteen and seventeen (Royal College of Psychiatrists, 2019). The definition of clusters is described in the methodology - participants section.

This piece of research is helping me (the researcher) to make sense of my own understanding of client distress, diagnosis and how this is experienced by the participants. At this point it is necessary to clarify the concept of schizophrenia and personality disorder (PD) as the participants in the sample have a diagnosis of these disorders. Firstly, schizophrenia is defined by abnormalities in five domains; delusions, hallucinations, disorganised speech, grossly disorganised or catatonic behaviour and negative systems such as blunting, reduced social drive and loss of motivation (American Psychiatric Association, 2013). One of the limitations of the DSM-V is that it is difficult to classify different kinds of distress reliably (Cromby, Harper and Reavey, 2013; Johnstone and Boyle, 2018). This is evident in the case of the DSM-V which made two changes to the diagnosis of schizophrenia, since the publication of the DSM-IV-TR.

According to the DSM-V, PD is characterised by impairments in personality functioning and pathological personality traits (American Psychiatric Association, 2013). These severe disturbances in the personality and behavioural tendencies of the individual are not directly resulting from disease, damage, or other insult to the brain, or from another psychiatric disorder. PD is nearly always associated with considerable personal distress and social disruption; PD usually manifests since childhood or adolescence and continues into adulthood (American Psychiatric Association, 2013).

The participants that have consented and been interviewed to date have been allocated to seven, eight, thirteen and seventeen of the HoNOS. One of the participants has a diagnosis of schizophrenia and alcoholism, two of the participants have a diagnosis of PD, categorised as Borderline Personality Disorder (BPD), and defined as patients that fitted neither the 'neurotic' nor 'psychotic' presentations, as they were on the 'border' (Kernberg, 1967). One participant has been categorised as having schizophrenia co-morbid with Antisocial Personality Disorder traits (APD). APD is defined by aggressive, impulsive, callous traits (Consensus statement, 2018). Once again there has been an inconstancy in diagnosis; the DSM-IV-TR included 10 types of PD which has now be superseded by DSM-V which includes only six types of PD. Consequently, the participants in the age group (44 - 69) that is being researched, have experienced a diagnosis of PD as being controversial, stigmatising and often invalidating (Sibbald, 2016). This is owing to a high overlap of symptoms, many with a severe personality disorder not fitting a specific category, this variation makes it difficult to develop appropriate interventions (Sibbald, 2016). A diagnosis of APD is often higher in men than women, with two thirds of prisoners having a likely diagnosis of a personality disorder (American Psychiatric Association, 2013; Sibbald, 2016). Conversely, BPD has a much higher diagnosis in women than in men suggesting gender playing a role in categorising PD (American Psychiatric Association, 2013).

Brief history and definition of residential homes for those diagnosed with complex mental health problems

Over the last 30 years one of the fundamental changes within mental health services has been deinstitutionalisation: defined as moving care and support for people with mental health problems from psychiatric institutions into community-based settings (The Kings Fund,2018). Deinstitutionalisation began in the 1960s and had three components: discharging individual from hospital into the community; diversion from hospital admission; and development of alternative community services such as residential care (The Kings Fund, 2018).

In 2011, the Department of Health in collaboration with a number of mental health leads set up definitions that include community-based services that are not funded directly by the NHS; such as 24 hours a day, seven days a week, residential nursing home care (The NHS Confederation, 2012). Residential nursing home care is defined as a placement and is different to an 'inpatient' care (The NHS Confederation, 2012). The placement is registered for the provision of care, provided by the local authorities and independent sector, and is registered by The Care Quality Commission (CQC). The placement gives the client accommodation in a multi-occupancy facility, and a care or support package funded by health, social services or occasionally private sector providers (The NHS Confederation, 2012). McPherson, Krotofil and Killaspy (2018) recently recognised the challenge in defining residential care in the literature and developed a brief, categorical taxonomy that aimed to capture the defining features of different supported accommodation models: the simple taxonomy for supported accommodation (STAX-SA). McPherson et al. (2018) defined residential care as providing time unlimited, residential-based support to service users with high needs and offers communal facilities and 24-hour staffing (Killaspy and Priebe, 2020:2021). This research uses McPherson et al.'s (2018) definition to seek residential homes and access participants.

Having defined what is meant by residential care and support packages we will now consider 'The Five-Year Forward View of Mental Health' (NHS England, 2016). This focuses on inequalities for those who are diagnosed as having mental health problems. The five-year plan is aimed at good quality care for all and describes the outline of a pathway that is much needed owing to limited residential placements for those that suffer complex mental health (NHS England, 2016). This plan also recognises that, at present, needs such as a client's social networks and life skills education are addressed in isolation, if at all, which is not effective. If a client is aiming ultimately for independence, life skills and social networks are paramount in ensuring independence is reached and sustained.

According to NHS England, Clinical Commissioning Groups (CCGs) sometimes fail to ensure that people with complex mental health needs do not fall through service gaps, such as repatriating clients back to a place that has no meaning, no support network or potentially harbors unhappy memories (NHS England, 2016 ; Killaspy and Priebe 2020:2021). This exacerbates the silencing of voices, for example re-homing a person without asking the person is inhumane. It may fulfil a service requirement in the mental health system, but does this support an already troubled human being?

Another example of service failure is illuminated in the naturalistic study by Raanaas, Patil and Alve (2018), which considered the relationship among resilience factors, psychiatric symptoms and psychosocial function in a sample of 122 residential participants with psychosis. It was found that resilience factors may predict the severity of symptoms and the extent of psychosocial functioning. Therefore, this emphasises the importance of personalising care for patients affected by schizophrenia, promoting personal resources such as money management skills or health and safety training. There is a lack of personalised care as these clients are often silenced by the systems that they find themselves in, disempowered by a diagnostic label that makes them easy to dismiss, in settings that are underfunded and understaffed. Ultimately more emphasis on personalised care would translate into better outcomes, particularly for clients living in a residential home. The study could have benefitted by being followed up with qualitative client interviews, which would have gained perspective from the individual gaining depth into understanding what those personal resources looked like and how to incorporate them from the service user perspective.

Another example of falling through the service gap is powerlessness; 90% of adults with severe mental health problems and one-quarter of people using secondary mental health services do not know who coordinates their care and have not agreed the care they would receive with a clinician (NHS England, 2016). This may be owing to NHS seeing an increase in mental health referrals and a decrease in qualified mental health practitioners especially as there is a national shortage of mental health nurses. This put's financial and staffing pressure on an already stretched system as well as silencing of vulnerable client voice. Asking clients what they need is time consuming, there is limited funding available and projects such as this piece of research are often undertaken by individuals who like the researcher have little weight within the big corporate systems such as the NHS.

Lastly, one-fifth of people coordinated by the Care Program Approach (CPA) have not had a formal review in the previous 12 months (NHS England, 2016). A CPA review gives an opportunity for service users to meet with a multi-agency support team and have their voices heard. CPA's come with time implications, especially residential clients that may not be placed locally or within the NHS. For this reason, CPA's are less likely to occur for residential care clients in particular as clients can get lost in the system. The reason for this is that health authorities and local authorities are supposed to work closely with service users and carers. This has the potential to fail owing to lack of communication, staff inconstancy, lack of family involvement and staff shortages, leaving a client stuck in a system that is failing them. Secondly, it can be hard to hear how a client may experience their care and can result in practitioners needing to find alternative placements. Alternative placements for clients deemed high risk such as a history of arson can be challenging. As a professional in a position of power by choosing not to ask about client experience can be protective for the practitioner from the painful experience of engaging with the client stories. Without this perspective, unfortunately for clients entrenched in the medical model of care their voices are much easier to ignore, medicate, or dismiss. A CPA is an opportunity to be heard, lack of CPA is itself a systemic silencer. In this section, a brief history has been outlined, including the definition of residential care, the support that is available and some of the critiques around failure in the system.

A comprehensive review of the research relevant to the wider policy and experiential context of residential care.

The Medical Model of mental illness

Another significant aspect of the mental health recovery literature that is frequently referred to is the 'medical model' which is described as focusing on treating and curing disease led by the psychiatrist (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010). Clare (1980) defined the 'medical model' as a scientific approach which involves observations, descriptions and differentiation, which moves from recognising and treating symptoms to identifying disease and developing treatments (Shah and Mountain, 2007). Yet, the 'disabled persons' movement which includes people with complex mental health needs argues the medical model is based on a false notion of 'normality' judged by what people cannot do. The key problem with this explanation is that a psychiatric diagnosis changes what people feel and do, into something they have, for example 'schizophrenia' or a 'damaged defective personality' (Johnstone and Boyle, 2018). The medical model is a framework that is difficult to challenge, for a diagnostic label reduces the likelihood of engaging with recovery because it may suit the practitioner to stick to a medical diagnosis, narrative and plan. This is protective for the practitioner as the framework is comfortable and gives certainty in uncertain situations. Consequently, clients considered 'mad' are easier to dismiss leading to silencing.

A contemporary definition of the medical model incorporates medicine's ideals to facilitate clarity and precision, without denying evidence about what improves mental health (Shah and Mountain, 2007). Patients should be active participants in their treatment, and the psychiatrist's role is to help patients 'take charge' of their recovery using the best available medically informed practice (Shah and Mountain, 2007). A serious weakness in this argument is that often the positive aspects of receiving a diagnosis, such as access to services, are outweighed by a sense of stigma, shame, fear, invalidation, damage, hopelessness, exclusion and disempowerment (Johnstone and Boyle, 2018). In summary, there is tension between the concepts of the medical model's use of language that can act as a barrier to seeing the person and values that are steeped in a psychiatric history of disempowerment. How the medical model is practiced within 'recovery', will now be discussed (Roberts and Wolfsen, 2004).

The Recovery Model in Mental Health

In the last 40 years the 'Recovery model' within mental health has developed beyond traditional understandings of a 'cure' (Perkins and Slade, 2012). Recovery is better described by the realities of living with severe mental health needs and is adopted by many NHS Trusts and the Royal College of Psychiatry. Therefore, it does not describe the symptomology of recovery but describes a more complex understanding of how to manage 'life alongside' severe needs (Roberts and Wolfsen, 2004). This is a shift from a predetermined, diagnosis-led process, to a recovery, people-led process. In this way, recovery describes a nonlinear process of symptom resolution but consists of turning points and goals, whereby certain elements of development interact with one another, facilitating recovery holistically (Pitt et.al., 2007). Often clients in care have histories that have involved multiple diagnosis, polypharmacy, and seemingly little opportunity to be part of their treatment plans which has enabled silencing the unheard (Roberts and Wolfsen, 2004). The 'Power Threat Meaning Framework' acknowledges that the first point of recovery orientated services is to give confidence to individuals to tell their story, hearing unheard voices (Johnstone and Boyle, 2018).

Another significant aspect of the 'Recovery model' is that it emphasises the importance of the individual being more involved in 'co-constructing' the meaning and treatment of their difficulties; typified by the 'Recovery model' ethos 'nothing about us without us' (Slade, Adams and O'Hagan, 2012). This presents a challenge to traditional mental health services which operate from a more expert providing treatment (doing to) to patients, power operating against the client. Consequently, recovery does not mean a ‘clinical recovery’ in which a client presents a range of symptoms and is offered a cure. However, it does imply a client defined ‘social recovery’ which is interpreted as building a life beyond illness, without fully eliminating symptoms of illness (South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust, 2010). More recently, recovery is defined by service users themselves as ‘a deeply personal, unique process of changing one’s attitudes, values, feelings, goals, skill and or roles’ (Anthony, 1993: p.11-23).

Therefore, recovery should be judged by the person living with the experience as a ‘personal recovery’, on a continuum, which is subjectively defined and rated by the person; as they are deemed expert in their recovery (Slade and Longden, 2015). Repper and Perkins (2003) identified key recovery principles of hope, control and access to opportunities to build a life beyond illness. The ‘Recovery model’ enables clients to use the principles of recovery to acknowledge that they are not only expert in their own conditions clinically but in the more social aspects of their lives (South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust, 2010). One major drawback of this approach is that despite important Recovery principles, there is professional suspicion that the philosophy has been undermined by a government agenda of getting people off benefits and into work, in contrast to increasing their life chances (Beresford et al., 2016).

Research into service users experiences of recovery under the 2008 CPA was undertaken by (Gould, 2012). 81 participants were asked about how effective they found CPA’s in promoting recovery and put forward a checklist for good practice for mental health professionals. Gould (2012) argues that Recovery literature has focused on the perceptions and outlooks of dominant groups in society and not addressed social and structural injustice which has silenced the voices for example of woman, members of black and minority ethnic groups or people who identify as gay, lesbian, bisexual or transgender. Therefore, descriptions of recovery may not fit marginalised individuals' ideas of recovery. This research aims to hear survivor experiences of barriers and discrimination to support and develop the non-medicalised individual to counter the dominant medical model.

Person-centered care

Turning now to person-centered care which observes service users, their families and professionals as equal partners in making decisions about care (de Silva, 2014). The narrative approach to personal experience suggests that people experience themselves as persons that take decisions, make choices that mirror their identities as authors of their own story (McAdams, 2015). One of the limitations of shared decision making is the complexity of the decision-making process (NICE 2011). A decision that is defined as shared by a clinician in practice, may not be experienced as 'shared' by the client. In reality, when the client is compliant (conforms), shared decision making is easy. Conversely, when there is a disagreement about treatment, the client is often defined as 'lacking insight', making 'shared decision making' a risk (Deegan and Drake, 2009). Thus, person-centered care could be invertedly silence the voices of vulnerable individuals. This is acknowledged by psychiatry in a 2018 Royal College of Psychiatrists report as an opportunity to examine the person-centered quality of training in psychiatry to address this issue (Adshead et.al, 2018). Anthony, (2004) states that psychiatry needs to embrace that 'people with severe mental illness are people'. Having discussed the dominant models of care and how recovery is understood and informs polices, other interventions will now be discussed starting with NICE guidelines.

National institute for Health and Care Excellence (NICE)

NICE guidelines are evidence-based recommendations for health care in England. NICE sets out the care and services suitable for people with specific conditions or needs and for people in specific circumstances or settings (NICE, 2019). NICE have published the 'Service User Experience in Adult Mental Health: Improving the Experience of Care for People Using Adult NHS Mental Health Services'.

NICE guidance has been developed by the 'National Collaborating Centre for Mental Health' and is the first of its kind to assess the evidence for improving service users' experience of health services in adult mental health (NICE, 2011; p1-31.).

This guidance is specifically aimed to provide a framework for high quality service user experience. Specific to this piece of research, the guidance states that there is a paucity of evidence about interventions that aim to improve experience of people using mental health services (NICE, 2011). NICE guidelines are lengthy and difficult to navigate, especially by non-medical people such as family members and carers.

In the past, government policy for people with complex mental health needs and challenging behavior has put independence, choice and inclusion at the center of its advancements (South London and Maudsley NHS Foundation Trust and South West London and St George's Mental Health NHS Trust, 2010). The 'Valuing People' strategy (Valuing People Now, 2014) set out values for people with complex mental health needs which include real chances for independence. However, as discussed in the dominant models of care a residential complex mental health needs client is within a system with limited funding; limited specialist services and service gaps, limited nonprofessional advocates; lack of CPA's; nothing but the historical medical model diagnosis and practitioners who are disinclined to question. This is a contentious issue and why this research is important.

Policies and Guidelines

In 2011, the government published a mental health strategy which set objectives; improving outcomes, physical health, experience of care of people with mental health problems and a reduction in avoidable harm and stigma (Mental health Task Force, 2016). Despite these objectives, challenges with systems coupled with an increase in people using mental health services has led to worsening outcomes including an increase in the number of people taking their own lives (Mental Health Task Force, 2016).

Over the last five years, public attitudes towards mental health have evolved, with increased awareness and understanding of the experiences of people with mental health problems within and beyond the NHS (Mental Health Task Force, 2016). The task force found that people want care in the least restrictive setting, that is appropriate to meet their needs, at any age, close to home (Killaspy et.al, 2016 ; Killaspy and Priebe 2020:2021). People with complex mental health such as schizophrenia and personality disorder should not be in restrictive settings for any longer than necessary and there should be more step-down support such as residential rehabilitation, with the long-term goal of promoting personal recovery and improving function over time (Killaspy et al., 2016).

This leads to the strategy 'No Health without mental health' (Department of Health, 2011) which is aimed at establishing 'parity of esteem', defined as valuing mental health equally with physical health (Department of Health, 2011). This means equal access to the most effective and safest care and treatment (Department of Health, 2011). Parity of esteem has and should continue to make a difference to people with complex mental health issues.

Other initiatives have also been developed, such as the 'Wellness, Recovery, Action plan' (WRAP), described as a self-designed prevention and wellness process, for individuals to get well and stay well. 'WRAP' was introduced in 1997 and is a good example of evidenced based practice in recovery (Copeland, 2002). However, 'Recovery in the Bin' which is a critical realist and activist collective argue that mental health services should never put anyone under any pressure to 'recover', by over-emphasising concepts such as WRAP (Copeland, 2002). They oppose mental health services using 'recovery' ideology as a means of masking greater pressure. They believe that this rise is a symptom of neo-liberalism in which society believes that mental health is not a symptom of people that work hard, ignoring advantages such as education or class. They argue that this ideology suggests that mentally unwell people are to blame for their failures, even though there is little they can do to change this (Field and Reed, 2016). Therefore, a meaningful 'recovery' is impossible due to unbearable social and economic conditions, such as poor housing, poverty, stigma, racism, sexism, unreasonable work expectations, and countless other barriers. They argue that under-funding and under-resourcing of mental health services means that service users are pressurised to conform to a narrow idea of recovery (Accessed 20.02.2019 https: // recoveryinthebin.org/). Emphasising an NHS that has tight budgets, is wedded to the medical model and historical diagnoses will find being client centred, offer individualised care plans with regular CPA's a challenge.

Let us now consider the Implementing Recovery through Organisational Change (ImROC) programme which was established in 2008 by the Department of Health in England with the aim of helping services to become more recovery orientated (Shepherd et al., 2009). More recently Recovery Colleges (RCs) have evolved with a focus on wellness instead of illness. Recovery colleges are founded on an educational model and use co-production to deliver courses to a mixture of service users and staff (Perkins and Slade, 2012). RCs offer the potential for change for people with lived experience of mental distress encouraging people to feel safe, welcome and accepted, with the aim of rebuilding lives (Anfossi, 2017). Clients are encouraged to share positive stories as a way of putting into practice the recovery approach, hearing voices that aim to give hope to others (Anfossi, 2017).

In Finland, the 'open dialogue system' which was introduced in 1996, focused on the dialogical processes in meeting with clients and families (Open Dialogue, 2018). The person is at the center of the network and the primary aim is to promote dialogue, ensure all voices are heard and increase support for all the members (Adshead et.al, 2018). The approach is based on systemic and family therapy approach and is not diagnosis specific but is a practical response to crisis and generating dialogue, listening and actively responding (Seikhula, 2015). In the UK lack of funding, mental health nurses plus the 24-hour commitment to the client makes this approach an ideal but unfortunately not a sustainable reality within the NHS. In this section, it has been explained how different policies and guideline inform how complex mental health is approached. The next section moves on to consider lived experience of mental health problems and how this can inform practice.

Lived experience

Within the literature there are experts with lived experience of mental health problems such as Mary O'Hagan and Pat Deegan (O'Hagan, 2016; Deegan, 2001).

Mary describes personal experience of a mental health diagnosis and how she has used these experiences to make a difference to the way society and services respond to complex mental distress (O'Hagan, 2016). Mary set up a group called 'Psychiatric Survivors' in the late 1980s and fought to make sure people with mental health needs are seen as human beings, not objects to be acted upon (Deegan, 2001). Deegan argues that she can speak for herself, make a stand about her own distress and not be a submissive casualty of illness (Deegan, 2001). This leads to a person becoming an 'expert by experience' in their own journey of recovery (Deegan, 1988). This emphasises recovery as a unique, individual experience rather than something the mental health system does to a person (Leamy et.al., 2011).

People have been coming together to support each other in difficult circumstances for many years (Davidson et al., 2012). More recently this concept is defined as peer support, which is support exchanged between people who share something in common. Johnstone and Boyle (2018) argue that this is reflective of human propensity to share experiences and help each other. In the US, 'Intentional Peer Support '(IPS) has been used within the recovery approach to refer to how people with lived experience support others to progress in their recovery journeys (Wusinich et.al., 2020). IPS ethos seeks to understand what happened to people, rather than asking what is wrong with them, allowing the creation of new narratives that may challenge their beliefs of guilt, shame and illness (Johnston and Boyle, 2018). Johnstone and Boyle, (2018) argue that like the concept of 'recovery' there is a risk that peer support will be harnessed by mental health services into service-led intervention, overshadowing its roots in help and activism. However, Mead and Filson, (2016) consider that these dialogues, connections and relationships have the power to construct social change leading us to 'mad studies'.

In addition to lived experience and peer support, Faulkner (2017) refers to an academic discipline called 'mad studies' and argues that this could provide a space for experiential knowledge and this research offers an insight to understanding having complex mental health needs whilst living in residential care. Mad studies do not reject models of madness but puts them into a historical trajectory, that questions psychiatry as an interpretation of human mental states (Gillis, 2015).

Faulkner argues that mental health understanding is dominated by professional knowledge, rejecting understanding based on lived experience that people with complex mental health issues can bring. Faulkner argues that in the milieu of evidence-based research RCTs and systematic reviews that are deemed the gold standard, and view clinicians and patients at the bottom, voices of lived experience are marginalised. Faulkner goes on to argue that the lack of research into treatments and services from a client perspective has led to clients doing their own research. In this way, service users have been able to have their voices heard and taken control of this knowledge, and to challenge existing mental health knowledge about services and treatments (Faulkner, 2017). This is also supported in a paper by Field and Reed (2016) in which they argue that mental health service providers ought to empower service users to identify and develop their strengths and resources and take an active role in improving their lives and how mental health services are delivered (Field and Reed, 2016; Martindale and Philips, 2010). Therefore, contributing to the rationale for this important research which aims to destigmatize and hear the unheard.

Social Justice

This leads us to now consider social justice within counselling psychology which acknowledges the significance of equality, working towards increasing equality, decreasing power imbalances and challenging oppression in the role of a counselling psychologist (Winter, 2019). Research has argued that barriers to professionals taking action can be lack of time and the knock-on effect of speaking up or behaving differently (Winter, 2019). Winter (2019) suggests ways in which a social justice perspective can be acknowledged in the work, such as health care professionals' use of self-reflection on power, privilege and the use of social justice perspective in formulations (Winter, 2018). Within counselling psychology, collaboration and shared decision making is a core skill and by collaborating and agreeing to goals enhances outcomes. Treating another with equal worth as a human being enriches relational equality, contributing to social justice (Winter, 2018). Social justice is something that these participants have not had in the past, moving forward these principles are a starting point that counselling psychologist can improve on in the future, hearing the unheard (Kennedy, 2014).

Research – What is known

As the literature is so limited, a search of ‘Psycinfo’ and ‘Medline’ database was carried out using the following search terms: complex mental health; psychosis; schizophrenia; personality disorder; residential; recovery; adult; interviews; IPA. This confirmed that there is no specific research into the experience of having complex mental health needs and living in residential care. As discussed earlier this may be owing to residential care being a difficult concept to define. This is acknowledged in a recent systematic review that explored service user experience of specialist mental health supported accommodation, which included residential care, but acknowledged that definitions of supported accommodation vary widely (Krotofil et al., 2018; Mcpherson et al., 2018). A quantitative study by Mcpherson et al. (2018) have created a STAX-SA tool and claim that this is a promising approach to classifying supported accommodation models that include residential care; they argue that this tool will enable researchers to access more specific research.

Weaknesses

Krotofil et al. (2018) recently undertook a systematic review of qualitative studies that posited, ‘what are the experiences of users of mental health supported accommodation services’ to present a conceptual model. They found studies were of poor quality and there had up until then been no comprehensive literature review about service users’ perspectives on, or experiences of supported accommodation services (Krotifil, McPherson and Killaspy, 2018). One of the limitations of the review is that it excluded service users with PD and dual diagnosis, as it was considered that this would impact the service users’ experience of the residential care. This is a weakness of the review as it is marginalising a vulnerable group, and not recognising that experience of residential care is valid in all circumstances, diagnoses and presentations. Another weakness is that out of 50 studies that were included, the majority of studies were Canadian (19) and only three studies were British. One possible implication of this is that the conceptual model may not be appropriate to residential homes in the UK.

More recently Harrison et al. (2020) undertook a systematic review and meta-analysis of quality-of-life outcomes for persons living with serious mental illness in three types of supported accommodation (1) high support (2) supported housing and (3) floating outreach. They concluded that there is a need to improve social functioning and wellbeing outcomes across supported accommodation types. This research identified a gap in the literature and a need to further identify the factors which create positive living conditions for people while managing risk, developing daily living skills and enabling increased choice and autonomy for service users in supported accommodation. Furthermore, Jose et al. (2021) found that there are only a small number of studies and only limited published research that looked at support and participation for people with complex mental health issues who live in supported accommodation. They concluded that further exploration is required to consider how formal and informal support can enable people with complex mental health needs to support their recovery needs.

Turning now to Chilvers, Macdonald and Hayes (2006), who aimed to compare the effects of supported housing, outreach support and standardised care for people with severe mental health living in the community. However, they reported that from 139 citations, none study met the inclusion criteria and concluded that residential care is a difficult to measure concept and research was needed to identify and quantify. Watson, Fossey and Harvey (2018) undertook a qualitative meta-synthesis of experiences of people with mental illness living in supported housing, arguing that supported living is ‘ordinary’ housing within a general community in contrast to residential settings, considered as communal living with others that experience mental illness. They claim that clients have limited choice about where they live and their daily routines. This study used a qualitative meta-synthesis to integrate findings from previous studies and claim this gains a deeper understanding of a topic, than is possible from individual studies. They found several themes that included a sense of control, stability and security, confidence to rebuild identity and meaning in life.

There is certainly a place for supported housing, however for complex clients this can lead to readmission if the fragile balance of concepts such as social networks, loneliness or boredom are not addressed. For example, in Norway a solution to this is to discharge to an inpatient short-stay community residential after care (CRA). A descriptive qualitative study of 13 participants which included both individual and group interviews, was analysed using a thematic approach (Roos et al., 2017). This study found that the participants experienced this as different from other services, with more freedom and focus on self-care. However, a lack of in-house activities made it ‘like a hotel’ but ‘boring’.

More recently research by Piat, Seida and Padgett (2019) investigated the relationship between personal choice and mental health recovery in supported housing as it had not yet been explored. They found that clients valued three domains of choice to be responsible for one’s life, to organise one’s social life and to be made feel at home.

There are other parallel areas of literature on residential settings for example, the literature on residential inpatient psychiatric care and homelessness. Firstly, Waldemar et al. (2016) undertook a systematic review which identified quantitative and qualitative studies that made explicit reference to the concept of recovery and that were conducted in adult mental health inpatient settings. The results highlight the limited number of studies of recovery-oriented practice in mental health inpatient settings and the limited extent to which such an approach is integrated into these settings. Although not specific to residential care homes it was concluded that research is needed to clarify the concept of recovery and how it applies to mental health inpatient settings. The challenges to recovery-oriented practice posed by the current organization of such settings should be examined further supporting the relevance of this research. Leading us to Eldal et al. (2019) argue that there are few studies that address the many challenges that are faced by staff and patients in the inpatient mental health context. In particular, there is a lack of research that explores first-hand patient experiences in order to establish which treatment practices best assist patient recovery and the barriers to these practices.

Let us now turn to homelessness in which service user experience is encouraged and involves service users being asked about how the service is delivered, the day to day running, how the project is managed, range of services and the way the services are offered (Cullen, 2005). Bui, Shanahan and Harding (2006) argue that there is little on homeless people's perceptions of services for mental health problems. Homeless people have strong views about the adequacy of services to meet their needs. They were particularly concerned about stigma, prejudice and the inadequacy and complexity of services that they have to use. An article by Davies and Gray (2016) makes an argument that client involvement should draw on service users experiences of evidence-based practise stating that researchers and practitioners should recognise the value of service user expertise. These studies from psychiatric in patient and homelessness provide additional useful context to help position this piece of research.

Law and Morrison (2014) claim to have done the first study in understanding recovery from psychosis. They argue that theirs is one of only a small number of studies to consult service users as experts on their own experience. This study is not directly about experience of living in residential care with complex mental health needs but aimed to establish consensus about the meaning of recovery among 381 individuals with experience of psychosis. The methodology was a quantitative web-based and paper questionnaire of 137 statements rated on a 5-point Likert scale. A Delphi method is defined as a method that has been used to determine the range of opinions on particular matters, to test questions of policy or clinical relevance, and to explore (or achieve) consensus on disputed topics (BPS, 2019). Law and Morrison (2014) fail to acknowledge that to understand the essence of recovery in such a vulnerable population a qualitative method of enquiry may gain a deeper and broader understanding of the experience of recovery from psychosis. The main weakness of this study is that statements such as 'having hope for the future', 'feeling positive about yourself', 'having a good, safe place to live' fails to give any deep understanding as to what hope looks like, or how one feels positive about oneself and what exactly defines a safe place to live.

Summary and Rationale

Researching service user experience of residential care has been limited (Chilvers et al., 2006; Krotofil et al., 2018; Parker et al., 2019; Watson et al., 2018; Deering, Pawson, Summer and Williams, 2019, Killaspy and Priebe 2020:2021). At present historical (medical model based) diagnoses pervade and perpetuate non-individualised narratives around a patients care. This is more likely when the clients are in residential care where clients and their families are more easily ignored and an absence of CPA reviews are more likely. Counselling psychology therefore can offer a unique perspective on the experience of living in residential care with complex mental health diagnosis. The application of psychological perspective can attempt to understand the experiences of having complex mental health needs and living in residential care.

This review has defined people with complex mental health needs living in residential care as a homogenous sample, to give clients that have often been marginalised an opportunity to get their voices heard about their experiences of residential care. The researcher acknowledges that this group is made up of individuals who have their own experiences and needs. This research provides an opportunity to hear the voice of clients that often get lost; as people with complex mental health needs who are often seen as difficult to engage and are found in settings that are difficult to define and access for research purposes (Clare and Cox, 2003). However, Killaspy and Priebe (2020:2021) argue that by leaving out the important field of housing services for people with mental health illness just because they are difficult to study is ethically and practically unacceptable.

The researcher's own experience of working in adult mental health has raised her awareness of the tension between clients' dependency on psychiatric diagnoses from the past, and the fact that this frequently conflicts with newer ways of thinking about recovery. Therefore, this research aims to give voice to complex client's experience of living in care within an ever-evolving mental health system. This research challenges the concept of parity of esteem, as the age group that is being researched will have lived through and experienced a time that did not value mental health equally with physical health.

To conclude this section the literature identifies that mental health knowledge is governed by professional knowledge, to the exclusion of knowledge based on lived experience (Faulkner, 2017). Recovery comes in many guises but how do service users with complex mental health needs experience living in a residential care home?

This research is current and necessary as the NHS 2019 long-term plan states that by 2023/24, 370,000 adults and older adults with severe mental illnesses will have greater choice and control over their care; this includes groups with specific needs, such as adults with eating disorders or a personality disorder diagnosis (NHS, 2019). However, historical medical model-based diagnoses pervade and drive persisting and non – individualised narratives around patient care. This is particularly relevant in residential care where clients and their families are more easily ignored, silenced owing to the systems that surround them such as lack of CPA reviews and psychiatric diagnosis.

Therefore, this research has the potential to inform the researcher's own practice and aims to hear unheard voices. Complex mental health clients often carry with them traumatic and painful stories that have the potential to be explored qualitatively and told from clients' unique perspective in their own words (Blackburn, 2012; Walton and Walton, 2012). Having a safe and secure home is regarded as essential for an individual's health. However, this right is not implemented universally and people with mental health illness are among the vulnerable group at particular risk of potentially inadequate housing (Killaspy and Priebe (2020:2021).

This research needs to be undertaken sensitively, with rigour, respect and transparency, as research methods including qualitative used inappropriately can be disempowering (Faulkner, 2017). Therefore, the researcher aimed to capture experience and genuinely involve people with complex mental health needs, making an original contribution to enable new knowledge of client-centered practice guided by the client (Rayner, 2012; Roberts and Wolfsen, 2004; Gerrard, 2010). The next chapter describes the procedures and methods used in this investigation.

Methodology

Aims and Rationale for the Research

The research engaged in a qualitative inquiry to explore the lived experiences of people with complex mental health needs who live in residential care. The research required the participants to engage in semi-structured interviews of up to 60 minutes (Smith, 2007). Interpretive Phenomenological Analysis (IPA) was considered the most appropriate methodological approach, as the aim of the research was to provide opportunities to hear the voices of clients that often get lost; as people with complex mental health needs are often seen as difficult to engage and consequently have been excluded from opportunities to influence services (Clare and Cox, 2003). This research provides an opportunity to empathically hear people's voices, giving voice to people to tell their stories (Blackburn, 2012; Walton and Walton, 2012).

Background to the Research Proposal

The researcher was a trainee counselling psychologist, providing therapy within a registered mental health nurse-led residential care home for adults with severe complex psychological needs. As it is not ethically appropriate for this study to be implemented within the residential home that the researcher works in; participants were invited to take part in the research if they fitted the research criteria and live in other residential homes. For the purpose of the research, residential homes are defined as those which provide accommodation for clients for more than three months with 24-hour support (McPherson et al., 2018).

As complex mental health needs are so broad, the researcher will use the 'Mental Health Clustering Booklet' (MHCT) which is based on scores from the Health of the National Outcome Scale (HoNOS) (Appendix 1) which is the current measure of complexity in NHS secondary care mental health services. This provides a benchmark and ensures a global description of a group of people with similar characteristics, identified from a holistic assessment. This will ensure that the homogeneity of the sample is not compromised. In addition to their complex mental health, none of them were in employment and some were victims of domestic violence, social isolation, or trauma described as physical, psychological or social (Turning Point, 2014). Participants included in the sample had a wide range of mental health problems and were in clusters seven, eight, thirteen and seventeen and as described in the HoNOS (Royal College of Psychiatrists, 2019) (Appendix 1).

Table 1 : Clusters defined by the HoNOS (Royal College of Psychiatrists, 2019).

Cluster	Definition
Seven	A non-psychotic disorder (high disability). The group experiences moderate to severe disorders that are very disabling and will have received treatment for many years. The primary diagnosis is depression, phobic anxiety, obsessive compulsive, dissociative, neurotic disorders and eating disorders.
Eight	A non-psychotic chaotic and challenging disorders. The group presents with a wide range of symptoms and chaotic and challenging lifestyles. This is often characterised by severe, repeated self-harm and other impulsive behavior, chaotic over dependent engagement and frequent hostility with services. The primary diagnosis is personality disorder.
Thirteen	A history of psychotic symptoms which are not controlled. The presentation will be severe or very severe psychotic symptoms and some anxiety or depression. Individuals will have a significant disability with a major impact on role or functioning. The likely primary diagnosis is schizophrenia, schizotypal and delusional disorders.

Seventeen	A moderate to severe psychotic symptoms with unstable chaotic lifestyles. There may be some problems with drugs and alcohol but not severe enough to warrant care associated with cluster 16. This group have a history of non-concordance, poor engagement with services, and individuals are likely to be vulnerable. The likely primary diagnosis is schizophrenia.

Potential Benefit to Counselling Psychology

Counselling Psychology could be perceived as a relatively new discipline, only receiving full divisional status by the British Psychological Society in 1994. The theoretical framework emanates from the phenomenological and existential perspectives and is underpinned by humanistic values, drawing on specific work by Carl Rogers, Abraham Maslow and Rollo May (Strawbridge and Woolfe, 2003). Counselling psychologists move away from being the 'expert' applying specific techniques based on diagnostic criteria to 'being with' the client using a relational approach aimed at exploring and understanding clients' worldviews.

This research provides insight into thoughts internally experienced and emotional challenges that develop out of interaction with the world and others. The research aims to hear unheard voices and inform client-centered practice. It is often the most distressed clients that receive less attention but need the greatest support (Fairfax, 2016).

Counselling psychology is an idiosyncratic approach. The BPS (2017) argue that counselling psychologists work with the individual unique subjective psychological experience to empower recovery and alleviate distress. The research emphasises how counselling psychologists are well placed to initiate and advocate change in diverse settings, for the benefit of marginalised client groups.

Design

Epistemology and Ontology

The study uses an experiential qualitative approach with the aim of exploring how participants make sense of their personal and social worlds (Smith and Osborn, 2007). Analysis has been guided by a critical realist position which adopts a philosophical stance that human knowledge is contextualised and best defined as a set of procedures, rather than as a phenomenon that can be constrained. This gives freedom to explore and involve participants whose voices are often unrepresented to give meaning to their experience of life in residential care, in the clients' own words (Reid, Flowers and Larkin, 2005).

This research is driven by a desire to give precedence to client experience, collecting the information and organising an interpretative framework around what is articulated in the data (Smith, 2007). Therefore, phenomenology is a philosophical approach which fits well with the study of lived experience, and the meanings that people attach to their experiences (Willig, 2008). IPA accepts that it is impossible to gain direct access to the research participant's direct world but will explore participant's lived experience from the client perspective. Yet, it is acknowledged that such an exploration will implicate the researcher's own view of the world and the nature of the interaction between researcher and participant. This will result in an interpretation of the participant's experience (Willig, 2008).

Rationale for chosen approach

Moving on now to consider different qualitative approaches that offer rich descriptions of a particular phenomenon. In contrast quantitative approaches aspire to count numbers or occurrences (Smith and Dunworth, 2003). It is essential that researchers choose a method of inquiry that is able to provide useful and meaningful answers to the research question. Holding this in mind the researcher determined that qualitative design was the preferred approach; a number of methods were considered. Firstly, grounded theory, which is developed by sociologists and builds a theory from the data with an emphasis on understanding the processes. This did not fit with the researcher's thoughts about giving voice to the participants. Secondly, a single case study could not bring the range of experiences that IPA or thematic analysis (TA) could. The researcher felt that TA was not theoretically driven and did not take into account the interpretative elements of IPA. More importantly, within TA the voices of the participants often get lost especially in large data sets.

Therefore, IPA was considered the best fit for the research. IPA has clear and precise procedures, developed by psychologists with a focus on the individual experience. Consequently, IPA is a dynamic process in which the researcher is actively engaged in encouraging an insider perspective (Conrad, 1987). IPA is descriptive and interpretive aiming to capture the quality of individual experience (Smith, 2007). The interpretive aspect of IPA is supported by the hermeneutic philosophy that the researcher cannot access the participants' worlds directly as we are interpretive beings and researchers makes sense of experiences using their own interpretation (Smith et al., 2009).

Therefore, IPA is viewed as a dual interpretative process, known as the double hermeneutic process, in which participants try to make sense of their world and researchers are trying to make sense of participants' sense making (Braun and Clarke, 2013). This procedure requires researchers to interpret and welcomes the researcher's beliefs and assumptions, assuming an insider perspective (Willig, 2013). Braun and Clarke (2013) argue that this is never completely possible because access to participants' experiences is dependent on the researcher's own perceptions. This is an active role for the researcher, viewed as both descriptive, as it endeavours to describe how phenomena appear, but also interpretive because there is an acknowledgement that there is no such thing as a phenomenon which is interpreted (Braun and Clarke, 2013). The success of IPA will not depend upon uncovering the 'pure experience of a participant' but will depend on the researcher doing the most sensitive, responsive job, given epistemological and methodological limitations (Larkin, Watts and Clifton, 2006).

Procedure

Turning now to the procedure, the researcher had an extensive list of professional contacts that have been able to gain access to participants that met the criteria. A letter introducing the researcher was sent to organisations via email and post, inviting participants to take part in the study (Appendix 2). The participants have not been in a therapeutic relationship with the researcher in the past. Firstly, the researcher found an all-male personality disorder residential home that was willing see if any of the clients wanted to participate. However, on visiting the home it became apparent that the residents all had significant history of sexual offences. The researcher excluded significant history of sexual offences owing to lack of professional experience and the researcher was not ethically approved to interview this population of clients. It was considered when asking a participant some of the questions this may have led to disclosure of a nature that would need expert forensic input which the researcher has not had training or experience of. Finally, after approaching several organisations with participants that met the criteria, visits were made to discuss possible interviews. Four participants came from a residential home in a rural setting and two participants came from an inner-city residential home.

Smith et al (2009) suggests sensitivity to context is demonstrated throughout the research process. In particular this can be determined by the researcher's appreciation and interactional nature of the data collection, the interview situation and how access was established with gate keepers bearing in mind how this may be experienced by each participant. The researcher has many years experience of working with individuals with complex mental health. She has developed a heightened awareness of how sensitive the participants may be to other professionals and how difficult it may be for participants to trust her.

After the researcher had contacted the service manager to present the research, the managers were asked to consider if any clients met the inclusion criteria. If appropriate the participant was given a participant information sheet and the researcher was introduced to them in person to individually invite them to interview.

An interview time was arranged at a time that was convenient to the participant in a safe space within the residential unit. The researcher was aware of the power imbalance between her as a researcher and the participants and was sensitive to how this may be responded to by each participant as well as how other residents who lived in the home may feel. The researcher had an informal discussion in which the researcher was transparent and explained the process of the research. The interviews were conducted within the clients' residential home in a private room.

Each participant received a participant information sheet (Appendix 3) which provided detailed information about participation. It is recognised that some participants may have difficulty reading the information sheet and consent forms; all participants were supported to understand these before they provided their consent. Each participant was informed that they were under no obligation to participate in the research and their decision not to do so would be respected. Those who agreed to participate were asked to sign to confirm that they gave their consent for their anonymised data to be used in the research. Consenting individuals who are eligible to participate in the research were asked to provide some basic demographic information including age, gender and ethnicity. Then they took part in an audio-recorded semi-structured interview.

The researcher checked in with each participant placing an emphasis on their continuing right to withdraw their information up to one month after the interview. Each participant was aware that if they wished to withdraw one month from the interview, they could email the researcher as per the information sheet (Appendix 3), or ask a key worker to contact the researcher. The researcher checked that each participant had not been left with feelings of distress following the interview. For interested participants various sources of support were listed and pointed out to each participant on the information sheet, and the care manager and key worker were available if necessary.

Semi-structured interviews were well suited to in-depth and personal discussions and could be flexible to the needs of participants (Reid et al., 2005). The researcher was happy to work closely with the multi-disciplinary team that support the participant and was guided to manage any distress and be sensitive to participants needs, as paramount. This research involved working closely with other professionals such as Psychiatrists, Social Workers and Community Psychiatric Nurses as well as the care homes team. This ensured that each participant was not subject to any distress during the interview process. The audio recordings were then uploaded onto an encrypted data stick before leaving the residential home, ready for transcription. Subsequent data were then analysed according to the procedure identified below.

Participants and sampling

The participants were a purposive homogeneous sample of clients with complex mental health needs and were working age adults. The researchers training and experience gives her the skills to pay close attention to the power and the exploitative potential of interviews regarding the relationship between the participants and researcher (Braun and Clarke, 2013). The researcher's professional experience increased her ability to build rapport with participants who are often difficult to engage (Killaspy and Priebe 2020 :2021). As the participants were vulnerable adults, skills of empathy and gentle pace were used to facilitate one to one interviews and manage potential client distress (Braun and Clarke, 2013). The researcher also utilised other skills such as the use of appropriate language, shorter interviews, appropriate prompts and enough time for participants to think, speak and be heard.

IPA suggests four to 10 participants are a recommended sample size, as IPA is an ideographic approach to understanding a phenomenon in a specific context and is often conducted on small sample size (Smith, Flowers and Larkin, 2009). Smith argues that this is a reasonable sample size for a 'Professional Doctorate' to be able to provide meaningful points of similarity and difference between participants (Smith et al., 2009). Often, small sample sizes in qualitative research are criticised for lack of substance and sophistication (Braun and Clarke, 2013). Smith et al., (2009) warns that it is the number of interviews not the participants that is important and gives an example of four participants interviewed twice, suggesting that successful analysis requires time, reflection and dialogue. Therefore, an ideographic method, small sample sizes are the norm in IPA as analysis of larger data sets may result in the loss of subtle inflections of meaning (Brocki and Wearden, 2007). Participant demographics have been outlined (Table 2).

Inclusion criteria

The inclusion criteria for participating in the research were that participants were working age adults in cluster seven, eight, and possibly twelve, thirteen, fifteen and seventeen of the HoNOS, presenting with complex mental health needs, and living in a residential care home for at least three months prior to interview, had capacity, were able to consent and engage in a forty-five-minute interview (Reid et al., 2005).

Exclusion criteria

Owing to ethical concerns and lack of clinical expertise in the following areas, participants' who had a co-morbid learning disability of cognitive impairment, experienced florid psychosis, had a significant organic impairment, that were in acute crisis, lacked capacity at the time of the interview and had a significant history of sexual offences were excluded from the research. It was agreed in supervision that if the interview did not exceed twenty minutes then it was to be excluded owing to inadequate depth of interview.

Six interviews in total were conducted. The length of these interviews ranged from 34 minutes and 16 seconds to 60 minutes and one second (the average length was 46 minutes and 42 seconds). These interviews took place in participants' homes (six face-to-face,) in a private space within residential homes. Participants described their ethnicity as white British (5) and prefer not to say (1). Participants described their social class as working class (2), middle class (2) and prefer not to say (1) and no class (1). The age of the participants ranged from 44 – 69 years of age (mean was 57.5 years). All interviews were ~~then~~ transcribed by the researcher.

Data collection

Data were collected via semi-structured, recorded interviews; the flexibility of the semi-structured interview means that it was possible to access more comprehensive responses from participants initially reported (Smith et al., 2009). Dependant on the participants wishes, the option of the interview being divided into twenty to twenty-five-minute segments with a comfort break in the middle was offered. Typed transcripts were read whilst re-listening to audio recordings to improve accuracy of transcribing. This formed the data corpus which has been analysed using the procedure below.

Interview schedule

Turning now to the interview schedule, semi-structured interviews require a sensitive and ethical negotiation of rapport between interviewer and interviewee consisting of a relatively small number of open-ended questions (Willig, 2008). Smith et al., (2009) suggest that questions are open and expansive in which participants are encouraged to move between answers that are primarily narrative or descriptive and those that are more analytic or evaluative. As the researcher is required to enter the world of the participants it is imperative that the questions are open-ended and not directive (Willig, 2008). An interview guide was designed following discussions with the residential clients that the researcher works with and was then piloted (Appendix 4). This supported the researcher to test out that the schedule was fit for purpose and enable the researcher to practice building trust and rapport with participants. Therefore, six to 10 open questions, with prompts, occupied 34 to 60 minutes of conversation which is recommended for qualitative interviews (Smith et al., 2009). However, this was adapted for participants with complex mental health needs; for example, questions were asked sensitively, language was appropriate, and participants were given extra time and prompts.

Analysis

The aim of IPA is to explore how participants make sense of their personal and social world (Smith and Osborn, 2003). Good quality IPA will be sensitive to context in which it is situated. Therefore, in the early stages of the research, methodology and rationale were centred around the need for sensitivity of context (Smith et al., 2007). Consequently, good IPA tells us something important about an individual and something about themes that are shared within a homogenous sample (Smith et al., 2007). Interpretative hermeneutic tradition argues that the researcher is central to the analysis and acknowledges interpretations bound by participants' abilities to articulate thoughts and experiences and the researcher's ability to reflect (Brocki and Wearden, 2007).

The interviews were audio recorded and all six interviews were then transcribed and anonymised. IPA begins with a process whereby researchers comment on their early analytic observations about each data section; this is called 'initial' commenting' (Smith et al., 2009). The researcher notes any observations, reflections and thoughts that come about whilst reading the text as part of the six stages described by Smith et al. (2009). The first transcription was closely read, and the initial responses noted about what is interesting and significant. This was followed by noticing patterns within the material, which were identified emphasising convergence, divergence, commonality, and nuance. The coding process in IPA starts by coding the first data section and goes on to develop themes for consecutive data sections (Smith et al., 2009). IPA has two types of codes that are referred to as 'conceptual' and 'descriptive'. Furthermore Smith et al. (2009) describes two levels of themes known as 'superordinate' a theme that identifies patterns of related themes more broadly and 'subordinate themes ' the themes that are more specific and inform the superordinate themes.

As a result, a table of superordinate and subordinate themes have been made for the first case and will be repeated for each case. Following analysis on each case, patterns were established across-cases and put into a table of master themes (Smith and Osborn, 2007). This was organised into a format allowing analysed data to be traced throughout the process. The research supervisors were consulted to test out the interpretation and inform the full narrative. Reflection on the researcher’s own perceptions, conceptions and processes were acknowledged as part of the research process and recorded in a research journal (Braun and Clarke, 2013; Willig, 2008).

More specifically, the analysis of the data followed the protocol recommended by (Smith et al. 2009). The steps outlined below:

1. Firstly, the researcher engaged with one of the transcripts in detail. This initiated an ideographic approach that in turn, helped to identify categories and examples slowly working up to general categorisations.
2. Familiarity with the data was achieved by reading the transcript multiple times. The researcher used mind maps to identify significant interpretations, associations and language that were interesting.
3. Once comments were completed for an entire transcript, the possible themes were recorded with corresponding line numbers. This aimed to capture significant qualities found in the data. There was nothing excluded at this stage.
4. The researcher then made an “umbrella of themes” on separate sheets of paper looking at connections between them. This helped to cluster the themes. As each cluster developed they were checked back with the transcript and close interaction between the reader and text was formed. This was to allow theoretical connection within and across cases that are grounded in what was actually said. The participant phrases were noted and supported related themes by adding the page number and quotes. This was to allow a theoretical analytical order to happen (Smith et al., 1997). At this stage, no attempt was made to omit or select particular passages for special attention.
5. Participants’ understanding was captured in a table of superordinate themes. At this stage some themes were excluded, if they were not supported by participants extracts or they did not fit adequately or were not very rich in evidence within the transcript.
6. On completion of this process with a single transcript, analysis was the repeated with each of the remaining transcripts.

7. Once each transcript has been analysed a final table of superordinate the broad themes, and the subordinate themes which were more specific were then developed.
8. Consultation with the supervisory team was sought to critically examine themes and check on agreement. Refinements were made and this was checked to ensure themes were firmly grounded in the original transcripts.
9. Themes were then translated into a narrative account which constituted the final write-up. The themes were explained and illustrated using verbatim extracts from the original transcripts. Care was taken to distinguish between what the participant actually said and the researcher's interpretation of it. Links were made to the existing literature.
10. A reflective research journal was used throughout the process of data collection, transcription and analysis to reflect upon the implications of personal and epistemological assumption that shape the research.

My research process

The analysis began with thoughts around how the participants were speaking about inside and outside care. There was a sense of a search for care and thoughts around what is my purpose in life and then changes in residential care. I then started to search for themes such as

- Experience of good care.
- Searching and seeking for care.
- Changes to residential care.

Linguistic metaphors and conceptual metaphors were thought about.

- I then made 'umbrellas' for each interview with quotes and then a search across the themes started to begin a narrative to the story that explains the concept of lived experience of residential care.
- I continued to reflect on the interviews thinking about what is the same and what is different.
- I looked for 3-4 superordinate overall categories and 3-4 subordinate categories.

- I put these in a preliminary table and drafted the beginning of a results section.

I hand wrote a table highlighting the themes

- Change over time
- Searching for care
- Learning to grow
- Residential care keeps me safe from the pain of mental illness
- Searching for a home.
- Freedom vs. rules.

I then drew mind maps of each interview discovering more themes.
Once again I drew these using pen and paper and made each superordinate theme into an umbrella. I took this to my supervisory team and began to consider what the overall superordinate themes were and what the subordinate themes that made this up were.

I then added the specific quotes from all participants that informed the analysis.
I then put the themes and quotes into a document and repeated for each transcript. I developed four superordinate themes each with 2 / 3 subordinate themes with quotes alongside.

Trustworthiness and Rigour of the analytic process
Smith, Flowers and Larkin (2009) emphasise the importance of assessing the quality of qualitative research. However, there has been much debate on how this achieved. Smith et al. (2009) highlights the relevance of four broad principles proposed by Yardley (2000) who evaluated qualitative research that used IPA methodology. Each principle will be discussed in turn and related to this research project.

1) *Sensitivity to Context:* Smith et al. (2009) suggest sensitivity to context is demonstrated throughout the research process. In particular this can be determined by the researcher’s appreciation and interactional nature of the data collection, the interview

situation and how access was established with gate keepers bearing in mind how this may be experienced by each participant. The researcher had spent many years working in a residential unit providing therapeutic support individuals with complex mental health. She had developed a heightened awareness of how sensitive the participants may be to new people and how difficult it may be for participants to trust. Firstly, the researcher contacted the service manager by letter then by phone to arrange an appointment to present the research. The managers were asked to consider if any clients met the inclusion criteria. If appropriate the participant was given a participant information sheet and the researcher was introduced to them in person to individually invite them to interview. An interview time was arranged at a time that was convenient to the participant in a safe space within the residential unit. Great time and care were taken in the analysis process to ensure that claims and interpretations were grounded in the narrative of participants and verbatim extracts were used to emphasise salient points. The researcher conducted an in-depth literature review in order to orient the study and place it in context.

2) *Commitment and Rigour:* The interviews were conducted within each residential unit, in a space that was private but familiar to each participant. The researcher took care to ensure that each participant understood that they did not have to take part, that they could ask for their data not to be used in the final write up to 1 month after the interview. The researcher was sensitive to the participants' needs and measures such as short breaks and time for each participant to think and be heard to communicate their experiences with relative ease. The researcher's attentiveness to detail at every stage of the process demonstrates the researcher's personal commitment and investment in the project. Rigour can be considered as relating to the thoroughness of the study. The researcher took great care in selecting the sample by visiting each

residential home and meeting each participant before asking them to commit to an interview. A hand written letter was sent to each participant thanking them for their time after each interview. The researcher's skills as a therapist were utilised to know when to be probe and when to offer time and space during the interview. The researcher utilised her Director of Studies to guide the analysis and when moving beyond the purely descriptive sense of experience to include interpretations.

3) *Transparency and Coherence:* The former refers to how clearly the stages of the research process are described in the write-up of the study. The researcher enhanced transparency by describing in detail how each participant was recruited and was clear that each participant was working age adults. The interview schedule was constructed and tested out in the field of residential care. This was achieved by asking clients what they would like to be asked about their own experiences of living in residential care. A research journal was kept documenting each step in the research process. The completed write up presents a coherent argument with links between themes highlighted. The researcher made it clear that they were positioned as attempting to make sense of the researcher trying to make sense of the participants experience according to the principles of IPA and the personal values of the researcher.
4) *Impact and importance:* Yardley (2000) suggest that the test of real validity lies in whether it tells the reader something interesting, important and useful. This project has contributed to hearing unheard voices that have previously been overlooked in the past. It is proposed that the important messages this research has raised will be utilised in the researchers work to raise awareness using platforms such as workshops and presentations within a recovery complex needs NHS service.

Ethical Considerations

The researcher had Ethical Approval clearance from the University of the West of England (Appendix 5,6, 7, 8, 9, 10 and 11), and agreement from my participant organisations. The research was aimed at a vulnerable group and the researcher used professional experience and supervision to ensure that participants were not open to manipulation and exploitation (Braun and Clarke, 2013). Participants were not subjected to known risk and the researcher has been honest and accurate in reporting results. The researcher used reflection, supervision and professional experience to consider the implications of consent or communication difficulties. Therefore, the researcher was flexible and offered a break in the middle of each interview and, dependant on each individual, extra or shorter interview time. Each interview was followed by a debrief, and each participant was signposted to additional support or therapy if they felt distressed.

All recorded data was kept on an encrypted memory stick, in password protected files, on a password protected laptop only used by the researcher, which was kept in a locked cabinet when not in use. The researchers' physical safety was considered at the planning, design and practise stage as the participants had complex mental health presentations and could be unpredictable.

Researcher Reflexivity

I am a 47-year-old white, female, wife, mother and trainee counselling psychologist; at the time of undertaking the research, I was employed to provide therapy and support within a registered mental health, nurse-led residential care home for adults with severe complex mental health needs. I have experience of working with both men and women who have presented with complex mental health needs. What interested me in this topic is the stories and histories that each individual present with. This helped me to make sense of the behaviours and challenges that each client can present. In contrast, I am aware of the resilience that each individual has and how fostering hope can potentially aid recovery. It is my experience that when clients are allowed space to be heard, a secure base can develop and establish a more person centred approach.

The significance of this professional experience must be recognised as an influencing factor in this study. Positively, it has allowed me to investigate a marginalised patient group that other researchers without this experience might not have gained consent for. It also allows me to understand potential risks and manage these effectively. However, I am aware that the influence of prior knowledge and beliefs about the group under investigation has potentially influenced the analysis and writing up of the thesis. Therefore, supervision was paramount in staying close to the data during the final stages of the work.

This is my first experience of carrying out qualitative research, and therefore the interviews conducted have been my first experiences in the researcher role of semi-structured qualitative interview. I am aware from listening to the recording that building rapport and trust may have been my priority and that it was difficult to sit back and not encourage the participants. As a researcher it is important to be able to understand that giving the participants an opportunity to talk about their experiences and be heard is reparative and should not be underestimated, despite not being able to offer the type of support as if I was in the role of therapist.

There was a tension which is the double hermeneutic and how I made sense of interviewing each participant. I was aware that as part of my technique I would metaphorically ‘tip toe’ alongside and gently nudge each participant when asking the questions. This group is a unique group and I used encouraging utterances which I may not have used if I was interviewing a different population. What I experienced was a richness from each interview. I think this is owing to how little these participants are asked to tell their story and hear their experiences.

I felt an anxiety about interviewing these clients as I was concerned that they may not engage with me. I was very aware that this population often find it difficult to engage or trust new people. I was pleasantly surprised that each participant gave a fantastic and rich interview. I had wondered if the participants felt confident to speak to me about recent care as honestly as past care. I got a sense because they felt safe and supported in each of the homes that they were able to speak honestly. However, I remained mindful that this population are vulnerable and this is an unusual piece of work.

Writing this thesis has been a process of reflection. Firstly, from how I was influenced to interview. Secondly, how this process has influenced my practise and continues to shape my work. During the write up I started to become aware of the terminology that is part of the culture of my work, especially when the work I do can be influenced strongly by the medical model. Terminology such as ‘acting out’ raised my awareness of how the things I say can put me in a position of power. Therefore, this changed the way I speak about another’s distress. This has also raised my awareness of how I speak to clients without treating them like children. I am much more aware when I slip into ‘motherease’ and how I model what I do for others. This can be difficult in a residential environment with a mix of support workers, nurses and managers all having opinions about a client without hearing what is actually going on for the client. When working as part of a multidisciplinary team there can be conflict when certain decisions are not influenced by the client and this can be difficult to manage psychologically which is another example of power operating.

I had strong reactions to the participants' diagnoses and their stories of how diagnosis had influenced their journey. Most of the participants would have been part of deinstitutionalisation and moving of vulnerable, distressed people back into the community. This research highlights that for some people society is not accepting or kind, and others are not brave enough to acknowledge that it is 'ok not to be normal'.

A couple of interviews touched on enforced or over medication and treatments such as ECT. This brought up powerful thoughts and feelings that I struggled to contain. I have strong views about ECT and this was difficult for me to stay on track when these subjects were broached. I felt powerless and had to sit with and listen to what had happened to each participant, often without consent.

Strong feelings were also brought up when participants spoke about ways that they actively sought to die; this was a strong communication of pain. Particularly, Fred who spoke about standing waiting for an articulated lorry to run him over, and Julie who jumped out of a top floor window to try and get her voice heard about abuse that was happening to her and others.

Interview 4 highlighted that I had not considered the importance of holidays. This then influenced the final two interviews in which both clients had experienced positive holidays whilst in residential care.

As I started the analysis I became acutely aware of how the content of each interview must be used sensitively. As I moved into the discussion it felt empowering for me to write honestly about invisible power and how when working in residential settings how important it is to not just do things because they have always been done that way. As I continue to write I am aware of how the participants may feel if they read the thesis.

Another awareness is as the themes generated they seem to have followed my own story of how I have changed over time, including my own search for 'care' or a place to care for others. Also, how I have grown in my awareness of the challenges of the work that I do. Lastly, as I have acquired new skills and how I have learnt to grow in my role which has not always been easy.

Covid-19 emerged in society when I was at the start of my analysis; I am aware this experience has shaped my discussion. I have experienced power operating negatively within my organisation and specifically against psychology. I am aware how this has affected my approach and how I feel about my research. The current climate has made me aware of how power is operating on so many levels within the work that I do. For example, how as society is emerging from lock down, opening up and restrictions are easing. For our client's lockdown remains. I question is this right? On one hand it is to protect the clients that live in residential care from Covid 19. However, some clients are more vulnerable than others but they all live together. This had meant that some clients have been stopped from seeing family, whilst for me living in the community this is my choice. However, to operate at the individual level means that some clients should be able to now have access to the community and family. This is difficult to facilitate owing to protecting clients that are still shielding.

The nursing team are operating in the best way they know how but each day new advice emerges. At this point psychology is becoming more necessary with more incidents of self-harm, readmission to hospital and increased anxiety owing to uncertainty and new ways of doing things. This has made me reflect on my own journey, as I continue to grow as a psychologist and this has raised questions about where I fit as a professional in the world.

Post Covid I feel relieved that my data had been collected and transcribed. If I had been approaching residential care homes now these participants would have been even more difficult to access.

Results

Participants; brief histories

Fred, aged 59, described difficulties of not being cared for and a physically abusive father when growing up; this resulted in an inability to relate to men. In the past Fred had been in trouble with the police. Fred shared that for periods of his life he had been homeless; this is a snap shot of what brought him to residential care.

Julie, aged 58, shared that she had suffered abuse as a child, social services had been involved and she spent periods of her childhood in care. Julie described running away from the family home, supported living, and hospital settings including residential homes she lived in. Julie says her life began aged ‘38’ and she is now ‘happy’.

Peter, aged 44, described the breakdown of his relationship with his wife. At this point he turned to alcohol and this led to his father becoming his main carer. Self-neglect led Peter to find himself in residential care.

Margaret, aged 69, described her story of trauma, family rupture and rejection that had never been repaired. Margaret described a need for connection, to be valued, have a sense of purpose and residential care as ‘rebalancing of the scales’.

Ray, aged 65, described an early psychological breakdown and he had been in a care setting since his early 20s (nearly 50 years).

Mike, aged 46, described his journey from secure hospitals to supported living and finally residential care.

Table 2 : Participant demographics

Participant	Age	Gender	Employment	Cluster	Diagnosis	Length of time in residential care	Sexuality	Race / Ethnicity	Social class	Disabled	Relationship status	Children	Rural or city
Fred	59	Male	Other	7/8	Schizophrenia with anti-social personality disorder traits.	1 year 30 years on and off	Heterosexual	White British	Middle class	Yes	Partner	No	Rural
Julie	58	Female	Other	8	Borderline Personality disorder. Sight problems Anxiety	21 years	Heterosexual	White British	Prefer not to say	No	Single	No	Rural
Peter	44	Male	Prefer not to say	17	Schizophrenia and alcoholism.	6months and 7 years on and off	Other	White British	Working Class	Yes	Separated	2	Rural
Margaret	69	Female	Other	8	Borderline personality disorder. Spondylosis of the neck.	5 years 14 years	Heterosexual	White British	Middle class	Yes	Divorced	2	Rural
Ray	65	Male	Other	17	Schizophrenia	27 years	Prefer not to say.	Prefer not to say.	No Class	Yes	Single	No	City
Mike	46	Male	Other	13	Paranoid Psychosis	6 years	Heterosexual	White	Working Class	Yes	Single	No	City

When researching the lived experience of living in residential care four superordinate themes were developed . These themes and subthemes are detailed in the table below and are discussed in detail with excerpts from the participants' narratives to exemplify the themes. The ideas that the participants subscribed to were unique and led to a personal and idiosyncratic experience; however there were convergent and divergent experiences. These were also explored.

Table: 3 of superordinate and subordinate themes with illustrative extracts

Superordinate theme	Subordinate themes	Examples of data
Stories of change over time ; an historical journey	Where I started.	My life began when I came here. And **** sometimes says he is sorry he ever came here but I say believe you me there's I've been in a lot of homes, I've been in fre... I've been in ******** All because of Dad! Um, cause I was at home then and I've been in a home I was in a home and I was a child and I was in care for 8 days and they were horrible places (Julie 10101) Cause of what was happening to me and this is the best home I have been in. This is the only home I haven't run, well now I don't run away cause I am settled. Cause even when I was living at home I was always running away" (Julie - 129).
	My past journey.	It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room (Julie 83) Now I've got a life, I can go out on my own. Do you know before I came here I'd never been shopping on my own (Julie 1083) I'm too frightened to look to, to close into the future because of what I've had in the past (Jean 1264)
	Where I am now.	Yeah, I had a lot of issues when I first came here because it was run differently it was run badly and I was always running away but I don't now because I am happy (Julie – 37)

		It's the only place I will be happy, I the, it's the only place. My life began at 38 (Julie - 531)
Superordinate theme	**Subordinate themes**	**Examples of data**
Searching for care	**Safer inside.**	It's safe um it's safe and it's my safe place (Julie-523) Well I can't get out in the community because I am too vulnerable at my age love (Margaret-377) Well yes I have to be cared for at my age (Margaret- 424) Well if I was to go out into the community I would be frightened to death by the spirits you know (Mike- 342)
	Scary outside.	The only pain I feel is being alive (Fred - 113). I took so many overdoses like paracetamol umm tablets I crumbled them up in the drink not through drinking, I was socialising in the pubs and that. I did not used to drink too much I just used to crush all the tablets in a drink it. I was took to hospital and pumped, pumped out. I was, I was, I was found on the side of the road sort of thing.
Superordinate theme	**Subordinate themes**	**Examples of data**
The challenges of living in residential care	**Powerlessness and infantilising.**	It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room (Julie – 83).
	I want to be treated as an individual.	And as I say it is the best home that I have been in. But I need to get out and keep occupied cause I don't want to just sit doing nothing like a lemon. I want to get motivated I want to keep doing things. And I like to help (Margaret – 268).
Superordinate theme	**Subordinate themes**	

Learning to grow as a resident in a residential care home.	Gaining control and learning new skills to live.	I had no life skills when I, I come to move over here and they helped me grow, because make me feel I do my own washing, I,I can use the dryer, I go out. and um just sensible rules there is not hard rules, just sensible rules which we, which you have in life (Julie – 292).
	Self-acceptance “It’s ok not to be normal”.	Cause here you can be a pig um you can be yourself. It doesn't matter if you are sometimes umm crazy you don' have to explain what you can just be what you want to be if you want to scream you can just scream, if you say something really outlandish like really crazy just for the sake of it, it's ok (Julie – 983)

Superordinate theme 1: Stories of change over time; an historical journey

A central way that participants wanted to talk about their care was in terms of a historical trajectory from considering where they started, the journey they had been on, and an opportunity to reflect on where they are now. More broadly there was a tendency to see past care as worse than their present experience. Included are concepts of past, present, good and bad care and some care is better than no care.

'Where I started'

Participants talked about the process by which they arrived in residential care mostly in a negative way. This brought up memories of engaging in risky behaviours including self-harm and suicide attempts to get their voices heard. Participants had experiences of police intervention such as being arrested, returned to a place that they felt unsafe or being incarcerated. All participants had experienced hospital care at some points before moving into residential care. Julie reflects on her troubled childhood as a starting point. Julie had been in care as a child and felt that she had always been running away:

> **"My life began when I came here. And **** sometimes says he is sorry he ever came here but I say believe you me there's I've been in a lot of homes, I've been in fre... I've been in ******** All because of Dad! Um, cause I was at home then and I've been in a home I was in a home and I was a child and I was in care for 8 days and they were horrible places" (Julie 10101)**

> "Cause of what was happening to me and this is the best home I have been in. This is the only home I haven't run, well now I don't run away cause I am settled. Cause even when I was living at home I was always running away" (Julie - 129).

Julie had found that she could not settle anywhere. When her mum and dad passed away, she found herself in supported living and finally residential care. All of her past care settings had broken down. This was owing to Julie harming herself, attempts to take her own life and running away as a way to communicate her difficulties. These actions were often met with a negative response such as medication and restrictive practices used to manage behaviours or strict punitive rules:

> “The worst I ever did was get out on the top floor and jump from the fire escape” (Julie – 74).

Fred had also found it difficult to settle or fit in anywhere in his past :

> “They thought that this would be the best place cause as I moved all around the xxxxxx area and I have been in a secure unit in xxxxxxxx, so I have been fighting all my life so. Cause what I got is Schizophrenic!” (Fred - 24-26)
>
> “Cause I was kicked out at an early age, yeah mum thought the world of me and I lived on the streets and different places.” (Fred - 95)

Fred found the world a difficult place to occupy, the word ‘fighting’ is exactly how he had approached each situation. This often led to the police becoming involved, leading to Fred ending up in a hospital, either for self-harm, attempted suicide or his mental health. The more Fred was pursued the more he fought and the less his voice was heard. More recently Fred experienced a residential care home as the ‘best place’ as he did not have to fight to have his voice heard. This theme of having one’s voice heard ran through each interview.

Margaret’s reflections on the first residential care home she experienced was that it was inappropriate owing to her need for independence. This meant she had stand up for herself to get her voice heard:

> “Well to be quite honest one of the other homes I was in. Wasn't suitable Well it was more they needed more in that home, they weren't so what do you call it ummm, ummm. They couldn't provide for themselves so well ….Uh hu in their care and things like that.”

> “I mean I am still do everything myself and as long as I can, I will” (Margaret - 3)

Margaret‘s past experience of residential care was around suitability of placement. Margaret used the word ‘suitable’ and sees herself as less in need than the other residents. This illuminates suitability and its importance and value when finding the right home for an individual that needs residential care.

Ray reflected on his past experience of electroconvulsive therapy (ECT). This also ties in with powerlessness and being done to. To receive effective treatments participants’ needs should be at the centre of decisions about their care:

> “I, I received some electrical treatment at ...., electrical treatment.”
>
> “They had to put you out you know, I didn't like it very much I had it about once or twice a year.”
>
> “Did that help you do you think?”
> “Nnnnnn not sure really, did not really know why I had to have it really (Ray - 1136).”

Fred acknowledges the influence of earlier family relationships had on how care is made sense of. Particularly how the gender of care giving staff plays out in how he acts within residential care. In this excerpt Fred reflects on his inability to relate to males and his preference for being around females:

> “My dad used to belt me, and I got no time, I can't relate to men. I talk to some of them here, but I don’t say too much” (Fred - 363)

Fred’s early experiences shape how he conducts himself within the residential home. This is an important reflection; to enable a secure base to develop a care giver needs to understand a person’s history and what has happened to bring them to this point in their life. It is well documented how a person’s attachment style will impact on how a person presents within different situations; in Fred’s example care being offered by a male.

'My past journey'

Another way in which participants made sense of residential experience was to think about the past journey of each client. This spoke to the need for practitioners to understand previous experiences; including potential trauma of the clients whom they work with in residential care homes as Julie and Jean have shared in the excerpts below :

> **"It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room "(Julie 83)**
>
> **"Now I've got a life, I can go out on my own. Do you know before I came here I'd never been shopping on my own" (Julie 1083)?**
>
> **"I'm too frightened to look to, to close into the future because of what I've had in the past" (Jean 1264)**

Opportunities for going on holiday were seen as important. In this excerpt Margaret talks about having her basic needs met:

> "But there again I am grateful as I have a roof over my head, that I am fed, it is a nice home the staff are all kind and I have got a nice room" (Margaret – 96).

Participants' reflected on maintaining or gaining independence within a safe environment, including having a space within the home such as own room, communal area or outside space such as a garden. Margaret reflects on 'kindness', having a 'nice room' and having her needs met. However, Fred found that even though he had a nice room, spending time in his room brought up past experiences of being in a 'cell'. Fred recognised the benefit of having communal areas with more space which he valued:

> "I got a room to go into like that. I can watch a bit of telly when want, sort of thing, yeah."
>
> "See I would rather be out in the communal, in the communal where, where, I watch telly sort of meeting. The trouble is if you lock yourself away to me it reminds me of a cell where you walk round and round, and round and round and round" (Fred - 144)

The phrase 'lock yourself away' connects with Fred's experience of the police and being locked in a cell. In Fred's experience having your own space can be threatening (a reminder of what was experienced in the past). This is important as it may be presumed that a place on your own might be what is needed but the participants are saying is what is important is choice about this. Alongside this Fred has a feeling of connectedness with other residents which helped to build up an environment of security and safety:

> "I like helping, I can speak to people."
>
> "Like yourself I can, I can speak to people that got yup I gonna do, what's it. Cause a lot of people go to these sorts of courses and they got that bad that they committed suicide."
>
> "They go to a train and they go in front of the train sort of thing, yeah."
>
> "And uh one, what was it? One of the social workers said to me what you going to council as you know what peoples going through. I can actually tell when peoples are putting it on and when it's real."
>
> "Cause, all I said there is one really bad at the moment and all I said was you gotta believe in yourself" (Fred – 1317)
>
> "Some of the patients, what I call patients you know. We are in the smoking area and yapping on about their blinking problem. I don't want to know; I just stay alone that's it "(Fred – 131)

Fred can sense when another is suffering, conversely, he also likes to keep himself to himself. He seems to have found a role for himself in supporting others, which has helped him start to feel connected to others. In contrast Mike states, ‘not too many residents’ as this can feel threatening. Mike experiences good care as people being nice and communicating with him. In his past he had not had such a good experience of other residents:

> “Lovely, lovely garden, lovely nice not so many residents. The residents were not so very nice at xxxxxx road. Some of the staff were nice but the residents were not very nice.
> Well they are really nice especially xxxx and no….especially xxxxxx and xxxxxx “(Mike – 89).

The participants needed their past to be understood and for staff to work in a trauma informed way. This links back to ‘PIE 2.0’ with the concept of developing more 'psychological awareness' of the needs of service users and valuing training to support practitioners to work effectively and compassionately.

‘Where I am now’

> “Yeah, I had a lot of issues when I first came here because it was run differently it was run badly and I was always running away but I don't now because I am happy” (Julie – 37).
>
> “It's the only place I will be happy, I the, it’s the only place. My life began at 38” (Julie 531)

This quote illustrates how for 38 years Julie had felt unsafe when living at home and for a large part of her life. Aged 38 her search for care ended, in her own words, ‘she began to grow’. In contrast Margaret sees residential care as a rebalancing the scales:

> “So much you know that I've had in life ummm I don't think I should of had
> And what I should have had and what I have given the scales weren't weighed up right” (Margaret – 1244).

The use of scales as a metaphor for illustrating how Margaret had been given a set of circumstances that are not weighed up in her opinion fairly as an explanation of her experience to where she is now. In contrast Fred reflected that he had been brought to the setting by his social worker; it is only by luck that this setting appears to have been a good experience.

> "What erm cus I have been all around the district I did not know this place existed see. I know xxxxxx cause I used to hang around about round xxxxxxxx and be um.......I been on section that many times and .....you know .... it's all social worker brought me yer, same brought me here. We had a meeting at xxxx House" (Fred – 9)

> "This is where I will be for the rest of my life now." (Fred- 1091)

Fred shares that he is here for the remainder of his life and either he has decided to settle, or the setting has enabled this. Mike reflects on what brought him to residential care and he quotes:

> "I don't know who done it. I just ended up out here. Somebody done it" (Mike – 79)

Mike's words are interesting as he is not clear how he ended up in the setting he is in, this brings up powerlessness and lack of choice, simply 'somebody done it'! Mike values' having the garden space and tends to the lawn. This links with the theoretical model 'PIE 2.0' and values the importance of creating and working with 'spaces of opportunity 'which incorporate both social and psychological spaces.

Julie spoke about the importance of having a pet to care for and how this gave her a sense of purpose. Julie explained how the guinea pigs are scared and how this has helped Julie to 'get over her fear':

> "But I would be alright to live on my own if it was daylight all the time, but it's just the dark, and thunder, I'd be scared of the thunderstorms. I sit with

> my guinea pigs cause their scared so, they've got me over that fear but if I was on my own I would be scared. Cause here I am not scared because we have got those lightening strips on the house. Yeah so, I feel safe here. “ (Julie – 858)

Mike was able to reflect on having a role and sense of purpose, it was his responsibility to care for and feed fish:

> “I feed the fish. Over in there. Yeah uh every day. But they belong to…. bbbbut me n xxx went out to get them.”

Mike and Ray both shared that the best experiences of residential care as the opportunity to go on holiday. Both reflected on these experiences with enthusiasm:

> “I have been on about 10 holidays since I have been here. Most, most, Newquay, Croyde no Newquay, Woolacombe and Poole. We went there last September for four days. It was nice we went to monkey world. Then we went to Bournemouth, we walked along the front of Bournemouth. Uhhh self-catering it's like a massive big house with bedrooms. Yeah there's is 4...5 days away. Four staff went some staff went for the first part of the week. Uh......... then another 4 staff went the other part of the week.” (Mike -664)

Mike and Ray spoke with enthusiasm about taking holidays, this enabled being part of the community, gaining independence and confidence whilst being supported by a team of carers.

To conclude the superordinate theme stories of change over time; a historical journey speaks to a need for practitioners to understand the previous experiences which include potential trauma of clients who live in residential care. This is important and links with ‘PIE 2.0’ to develop practitioner understanding and psychological awareness of the needs of service users through staff training and creating a service culture of learning and enquiry.

Superordinate theme 2: Searching for care

Julie, Margaret and Mike all talked about their experience of residential care as safer than in the community. Margaret and Mike both felt a sense of vulnerability in the community especially when experiencing poor mental health and disconnection from reality**.** This links back to Julie and Fred’s similar accounts of community as cruel, difficult to fit into and feelings of vulnerability that trigger care seeking behaviours to try to get help; below are the participants’ reflections:

> “It's safe um it's safe and it’s my safe place” (Julie 523)
>
> “Well I can't get out in the community because I am too vulnerable at my age love” (Margaret-377)
>
> “Well yes I have to be cared for at my age” (Margaret- 424)
>
> “Well if I was to go out into the community I would be frightened to death by the spirits you know” (Mike- 342)

Julie reflects on her past and her vulnerabilities and difficulties fitting in at school and when growing up as part of her experience of a search for care that ended in residential care :

> “Yeah mum and Dad wouldn't let me, they used to lock, my mum used to have to lock the door because even if she left the room for a minute I wouldn't be there” (Julie – 138)
>
> “I didn't have any friends of my own. Ummm school stopped when I was 14 because I started being disruptive in class, but I was unhappy” (149 - Julie).
>
> “And my mom was (pause) she controlling, if ever I wanted to do something, you wouldn't be able to do it you'd be scared, uh, she wouldn’t let me do anything without and if she went out I had to go with her. If she went to the supermarket, I had to go with her” (Julie -174).
>
> “Yeah. You know. I'm not scared. I'm too frightened to look to, to close into the future because of what I've had in the past” (Margaret – 1264).

Margaret’s story is one of grief and loss and she found herself in residential care. When asked her where she saw herself in 10 years the thought filled her with dread. The future feels uncertain to her as she is not in control of what might happen to her. This was a big part of the interview, fear that she may need to move on again:

‘Scary outside’

Some participants but not all described the world as scary; this was when the person was young or even as an adult they experienced difficulties such as early abuse, or significant relationship break down. They talked about finding themselves in a world that was seemingly ‘scary outside’ and their experience of residential care provided something that could be seen as ‘safer inside’ without it being a hospital or prison but not always.

> “I took so many overdoses like paracetamol umm tablets I crumbled them up in the drink not through drinking, I was socialising in the pubs and that. I did not used to drink too much I just used to crush all the tablets in a drink it. I was took to hospital and pumped, pumped out………I was trying to, I was trying to do away with myself “ (Fred – 183).

> “And when I went to….. the psychiatrist said I was not very well. He said take……so and so you will be alright, then I'll. When I was really bad I stood in the middle of the road waiting for an artic lorry to run me over “(Fred 1026 – 1028)

Evidenced in the above quotation Fred assumes that everyone in the world is ready for a fight! Outside of residential care he would communicate and seek care in challenging ways, such as employing shock tactics as a way of communicating with the world that he was unwell or feeling unsafe. He illustrated this with his experience of standing in the road waiting for an articulated lorry to run him over, leading him to being picked up by the police, or sectioned and confined to a secure hospital:

> “The only pain I feel is being alive “(Fred 113).

> "I was, I was, I was found on the side of the road sort of thing."
>
> "Yeah and they could not keep me warm, they had to wrap me in this sort of thing the thing, I had that" (Fred 183, 198 and 200).

Julie shared similar experiences of trying to ask for help using ways that put her life in danger. This illustrates how being in the outside world was scary and unpredictable leading Julie to embark in risky behaviours as part of her search for care :

> "So... I used to take loads of tablets. I used to, the result was that I was in and out of hospitals because I used to run away together cause I was unhappy. But I didn't know why I was doing it but it was only since I had counselling that I realised why I used to do it. Cause I didn't want to die I just wanted to say....help me" (Julie – 186, 188)

Julie is able to reflect on her unhappy past experiences of residential care and how she would overdose to communicate her unhappiness but at the time she was not aware of why she did the things she did. Julie experienced more recent residential care as being able to provide new opportunities including access to therapy.

Peter experienced past care as so painful that he almost disengaged with life; this quote highlights a sense of giving up:

> "My Dad uhhh was in the end, ended up being my registered carer in the end.
> He dealt with it. Whilst I sat there watching TV and listening to the radio"
> (Peter- 864)

This quote illustrates Peter's quest for care. He appears to have given up, by indicating he is just sat there watching TV being cared for by his dad. Whereas Mike believes that he needs residential care as his outside life has been difficult because of his past experiences of trauma but also when experiencing the disconnection with reality:

> "Well if I was to go out into the community I would be frightened to death by the spirits you know."
>
> "On my own. Like uhhhh....frightened me to death. I got frightened out with a ......my flat in xxxxxx I was only out there for a week. And there was knife levitating in the middle of the night. I left a knife there. Cause their weird people used to get in and it was knife and it was going like that in the middle of the night (waving his hand). Well I should have of all night, and I went out for a walk in the morning and went and seen the Police and they banged me up. Got assessed and they banged me up by the assessment" (Mike – 342).

Mike's immediate response is 'being frightened to death' how being outside in the community filled him with fear, pulling on his memories being sectioned, arrested and ending up in a secure unit of which he had very strong views about:

> "I don't know cause the hospital side of it I don't really agree with it you see. Cause people that are all mentally ill mixed up with people that are all mentally ill and they just make you, make you worse" (Mike – 1068).

What is interesting in Mike's quote is that he does not see himself as 'mentally ill and being mixed up with others who are mentally unwell'. He sees himself in a home with other people. This feels reparative as he sees himself as a person living at home and not as a mentally ill person in residential care.

Fred reflects on how when in the community he tried to get help from the crisis team. As you can see from Fred's quote he felt let down and reverted to escalated actions such as a visual way of showing his pain through severe self-harm. He describes feelings of powerlessness and infantalisation as he felt he was being 'baby sat' by the police:

> "Yeah, I used to tell um off and they said give me these emergency numbers when I am in the community. And ya know I told um that I had an emergency and oh they said I will come and see you today. I said what I said

> what is this f.....emergency number at night and when I phone you tell me I to busy papa ....Oh fu...um. Bang I put the phone down! And I get told take this tablet you be alright, and 2 coppers will come n baby sit me while I cut me blummin arm open and do ya know what I was in xxxxxxx right when I lived there for a bit and I said I gonna sort you blummin bills out. Ha, ha yeah" (Fred - 1712).

This subordinate theme leads us to 'safer inside'.

'Safer inside'

This excerpt sums up how Julie has survived and continues to survive the outside world. Safer inside does not just refer to residential care, but she is allowed her 'inside head friends' in this setting:

> "No, it's crazy but I have my friends in my head and they are not just in my head they are real to me, they are really there to me. That's just me crazy (colour) I've always done it" (Julie – 966).
>
> "Cause I was lonely when I was a kid but everybody thought I was lonely, but I weren't I had friends that liked me for me. That didn't, I didn't have to be anyone I carry them when I am out as they keep me safe" (Julie – 975).

This excerpt from Margaret is her response when asked why she felt she needed residential care. A theme that runs through each participant is a fear of homelessness that can be threatening:

> "Well I can't get out in the community because I am too vulnerable at my age love" (Margaret - 377).

Below is Fred's reflection on homelessness in a rural part of the world this was before he found the care he was seeking in a residential care home.

> "I lived on the streets and different places…… and when it was farm land around xxxxxxx I used to live in the woods in like a barn so …."(Fred – 98).

This leads to Ray’s reflection from his early 20s of being cared for, being safe on the inside may be a double-edged sword as it has not been given opportunities to develop independence, to expand and flourish:

> “In the 70s I went into saw a psychiatrist and she said you had a nervous breakdown” (Ray – 696)

The excerpt below highlights the ‘double edged sword’. Ray does not even consider going to the football alone; he immediately thinks about someone else sorting out another person to go with him. This is an example of not allowing or encouraging Ray to make his own plans and problem solve, effectively de-skilling him. As a service responding to each individual client in a way that gently allows independence, whilst being there to support them if they need it is ultimately a way of re-skilling instead of deskilling.

> “No. Ju Julie is taking me. She won't be able to take me anymore because she is retiring. They will have to get someone else to take me” (Ray - 558).

The researcher got a sense that a 50 year old diagnosis of a nervous breakdown shaped Ray’s life. He would have been in his early 20s and his search for care stopped there. He went from one hospital to another and sees himself as disabled finally finding peace, acceptance and safety in his recent experience of residential care. He values his own room surrounded by his parent’s old furniture, meeting his sister once a week for lunch and attending football in which he is always supported by staff. It seems that Ray’s biological susceptibility has maintained him in long term care; can safe care be too safe? Ray has few expectations; he is quite independent but relies on staff to facilitate things he needs to do.

Superordinate theme 3: The challenges of living in residential care

This theme articulates things that the participants found challenging in residential care and how power is at play in more subtle ways. The main subordinate themes that were developed were being treated as an individual and powerlessness and infantilisation. This theme gives insight into the factors that actively silence the voice of the resident. The researcher was able to reflect on this in her practise and this raised her awareness of how easy it is to slip into ‘motherese’ around clients, and how staff often stop treating clients as individual adults.

‘Treat me as an individual’

Margaret is grateful for the care that she has but she is not fulfilled in many ways. There is a sense of loss of independence and individuality:

> “And as I say it is the best home that I have been in. But I need to get out and keep occupied cause I don't want to just sit doing nothing like a lemon. I want to get motivated I want to keep doing things. And I like to help” (Margaret – 268).

Margaret felt very unstimulated. Her use of sat like a ‘lemon’ was something that came throughout her interview. The entire interview felt like a way to communicate that Margaret felt she deserves more. Margaret talks about being dependant on others to socialise and this sounds quite powerless or childlike. She suggests that she has experienced residential care as restrictive; having opportunities within the home was important to combat boredom and gives a sense of purpose:

> “We rarely go out to the pub. I wouldn't mind going. I mean I wouldn't mind going and helping the staff and taking one in the wheelchair. We have done it on the odd occasion, but it doesn't happen very often. Well that's all down to....... the staff being available un and everything else.
> Well who wants to go out. You know who's, who would look forward to going out and having a change” (Margaret – 954).

Margaret has to now rely on others, whereas in the past she had a family, drove a car and ran a home and cared for her mother. This is a quote that emphasises Margaret’s struggle of not being able to care for her mother:

> "And then she went straight downhill and I have always felt that was my fault because they said I was her carer. Her cook, her bottle washer, the gardener and her chauffer" (Margaret - 207).

There is a sense of loss of freedom to choose to do what she wants. Margaret living in care has to rely on others and conform with what is best for the group rather than for the individual. This is something that was systemic in the past institutions and often continues within residential care today. This invalidates independence and individual likes and dislikes and residents can be seen as trouble makers or non-conformers if they do not comply.

> "Yeah and I have driven all sorts of cars. Little minis, the old-fashioned Minis', not the pregnant ones as I call them" (Margaret – 228).

Margaret had not experienced a holiday and had a yearning for going as in her past she had been quite adventurous. I felt that Margaret was quite powerless and found the reliance on others frustrating. During the interview it felt as if Margaret was seeking outside help to get her needs met and acknowledged. It almost felt like an act against powerlessness:

> "Do holidays happen? You know and what is the experience of holidays and does this happen within this home?"
>
> "They have done but it has only been a very short break."
>
> "Well the fact that I am getting on now I need a nice long break. Laughter. From a Thursday morning to a Monday morning, something like that. So, I can" (Margaret - 1490).

In contrast Julie did not feel that activities were necessary. In real terms activity schedules were provoking and would force her to become 'resident evil'. Holidays and activities are not suitable for all residents and it is important to have choice and individual needs should be met as far as possible:

> “Yeah, that member of staff has long gone she used to make us do chores, she used to, we used to have activity diaries and I used to rebel then, I was really like resident evil the cause I really didn't get on with her. I thought she was the boss over the unit, but, she went she was just another team leader, I didn't know they are all team leaders, but she's long gone “(Julie 1019).

When a person is not treated as an individual then the person will not feel valued and rebel against being scheduled to do things. Participants valued carers that saw them as unique individuals treating them as unique human beings. However, this process needs collaboration of both client and staff to enable a sense of purpose, as Julie shares below:

> “Yeah, she used to plan your week for you, and I used to say 'I don't need my day planned, I can plan my own day but no. We had to have a timetable, we had to do, we still have our set washing days but that is practical” (Julie 1019).

Julie is able to understand practical solutions to living in a busy home but as an adult and clearly is able to plan her day without it being planned for her. This links with PIE 2.0 and as an organisation responding to client and staff feedback. This will be further deliberated in the discussion.

‘Powerlessness and infantalisation’

Julie shared how powerless she felt when she first came into residential care. She reflects on times of cruelty and infantalisation. It is important for practitioners to be aware that clients may have been subjected to stigma and restrictive practise in residential care homes in the past.

> “Matron she had lots of hard rules and she was very strict and also, we weren't allowed to, we had to ask for if we could have our pocket money on a Thursday. She, she kept our bank cards and we used to get £15 a week and we weren't allowed to have our own cigarettes she used to use to supply

> them. If we got caught with cigarettes, we would get grounded and our pocket money was slammed "(Julie – 43).

Julie's experience is of the same residential care home she is in now but how it was run very differently. The impact of this on Julie was detrimental and as reflected earlier she resorted to desperate behaviours such as attempts to take her own life. How matron ran the home felt more in line with a prison. Julie shared that clients were treated like prisoners or children without rights and privileges. Medication was used as a control, as Julie shares in the quote below:

> "It was horrible when she was here, she was cruel, and she was, and she used to take me she used to give me Haloperidol when I used to run away and then I couldn't walk properly, and I couldn't talk properly" (Julie – 93).

It was shocking to hear an account of how medication was used to control Julie. Julie talks about punishment and dehumanising her to force her to conform by taking away her independence:

> "It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room" (Julie – 83).

Julie's excerpt uses the word 'allowed' used in both of the quotes above and below. This throws up an image of a child, highlighting the infantilising of clients. Infantilisation is damaging and deprives an individual of their personhood and agency which is documented to lead to a decline in both psychological, physical symptoms and agency. Thus, Julie is raising awareness of how power operates between the staff and the client. Another way in which participants make sense of residential care is in terms of being powerless:

> "Matron was very strict, the only time she was happy was six o'clock, she used to send me to the cupboard in the kitchen, cause that is where the

> alcohol was kept and I used to have to go and get and get her. She used to have a big 'bucket'. What she used to call called a bucket was a big glass and I used to have to get her a big glass of wine and then she was, she was in a happy mood. Then we were allowed to drink but, still allowed to drink. But I only have one a night, it helps me to sleep” (Julie – 198).

When staff left, participants appeared confused or agitated and this had a big impact on Ray who reflected on how it feels to have staff not turn up for a shift:

> “xxxx used to work here but. But he left without saying anything. He just suddenly stopped coming” (Ray - 649)

Ray reflected on one of the members of staff retiring and he seemed to feel a real sense of loss. Ray talked about the strong relationships with members of staff and how they had common interests such as the football and could be relied upon to keep him safe.

> “No. xxxx is taking me. She won't be able to take me anymore because she is retiring. They will have to get someone else to take me” (Ray - 554).

Ray was able to say how he felt a ‘bit low’ and this is interesting to hold in mind that as a member of staff working in someone’s home endings need to be managed appropriately with opportunities to say goodbye.

Julie reflects on how powerless she felt in a mentally abusive relationship with a senior member of staff when in residential care. The phrase ‘Matron mum’ feels sinister and inappropriate, repeating the pattern of abuse Julie had experienced living with her controlling mum and abusive father:

> “Yeah, she told me she was my mum and she told me she adopted me. Cause, cause I kept running away so that if I was found the Police wouldn't take me to hospital they would bring me back here. So the Guardianship order, was here but she said she'd adopted me and that she was my mom

> and I used to call her Matron mum and she used to call herself my Matron mum” (Julie – 61).

Reflections of staff being in a position of power such as rationing out tea, coffee or milk with some staff seen as generous and others seen as mean brings up a sense of unfairness . This experience in residential care clearly emphasises unequal power balance and infantilisation:

> “After I ran out of coffee cause me n xxxx have these small things that they put so many....I am supposed to have 4 spoonfuls of coffee and 2 teabags. But xxxx has 6 spoonfuls of coffee and no tea bags.”
>
> “And some staff are generous, and some aren’t!” (Ray - 858)

Ray speaks about staff power and control over the time a person gets up or goes to bed at night. This emphasises invisible power at working with vulnerable persons. Ray’s quote shows his resilience at finding ways around things that are difficult when living in care:

> “But one nurse that works here she didn't let me get up till 7 o clock.”
>
> “Her names xxx she usually does Wednesdays and Saturdays, but she never did it last night!”
>
> “No. How did you experience that when you when you wanted to get up and have your cup of tea and…..”
>
> “I don't mind really just uh. When she is on I always go to bed early. But I went to bed early last night I went to bed a quarter past nine” (Ray-780).

Mike reflected on how different members of staff treated him and, in this case, this particular nurse made him feel angry. It is clear from the excerpt that he knows exactly when she is on shift and has managed to avoid her for a year. Mike highlights simply being ‘talked’ to helped create an environment of warmth. Not being spoken to felt threatening and cold and like being ‘blanked’:

> “All of them. Apart from one. Who I don't see anymore? She only works here once a week anyway.”
> “She blanks me.....”(Mike – 234).

Mike’s experience of residential care emphasises how invisible power operates, raising the issue of how as health professionals we need to be aware of social justice issues and question the work that is done and ensure that we treat residents as equals. This emphasises the importance of training and critical awareness of power imbalance.

Superordinate theme 4: Learning to grow as a resident in a residential care home.

This theme tracks how participants experienced residential care as a place to grow and develop new skills. However, it was interesting that most participants were not given a choice of where to live. For some participants this was not a problem. For other participants it felt restrictive, or that they were deserving of somewhere better.

The participants who experienced residential care as positive were supported to have freedom and control over their experiences, accessing a range of activities if they wanted them, which included holidays. The participants less satisfied were less focussed, bored, under stimulated, deskilled and restricted.

‘Gaining control and learning new skills for living’

Julie reflects on her journey and is able to remember that she did not have any life skills. The interesting phrase used in this theme is how the rules are not ‘hard’ but ‘just sensible’. This can be a tension when living in residential care and there is a tension around freedom and rules. The researcher was enlightened to how developmentally important it is when working with traumatised individuals to provide opportunities for individuals to experience pushing boundaries in a safe environment to test the rules and explore their identity, likes and dislikes:

> “I had no life skills when I, I come to move over here and they helped me grow, because make me feel I do my own washing, I,I can use the dryer, I go out. and um just sensible rules theirs not hard rules, just sensible rules which we, which you have in life” (Julie – 292).

Fred reflected on being looked after; he was able to share why he can do some things but not others. This helps Fred to be in control as well as a sense of being cared for:

> “Yeah, yeah, xxxxxx residential had people to look after him. He done the cooking and do things, but I don't want to be, do the cooking cause sharp knives or any knives temptation!”
>
> “That right, that's right that why cause at xxxxx house they used to do the cooking for us, and we used to sit in the dining room and have meals sort of thing.”
>
> “And they used to count the knives and all that” (Fred – 1128).

Fred reflected on how residential care had raised his awareness about being a danger to himself and others. In other residential settings Fred had experienced how staff counted the knives in and out.

‘Learning new skills to live’

Fred was proud of the skills he had learnt, and this is his way of communicating and bonding with the staff alongside rather than face to face. An example of his old way of communicating is in the subordinate theme ‘Scary outside’ and Fred’s incident with the ‘artic truck’.

> “yeah, yeah I talk to um we talk to staff and I help um clean the kitchen up sooo so it int dirty when they come on sort of thing. Actually, I like to be busy, I hardly sit down. I buy my own, buy me own washing powder. Black bags I buy. Cause they um got a washing machine like in the kitchen and a dryer. As they supply them but when they put them in, they used to leave black marks on ya trousers. So I have this special sort. Like a thing, it in a

> green box and you put one in and it's gets them clean. I put it in, then I put it in, put the machine on, put it in the dryer. Take it up and fold me trousers up. Fold up and, and put um into a drawer and, and I u put my t-shirts (Fred-886 – 1279)."

New skills are not easy to attain; residential care done well gives a platform to try out new things; and be there to gently catch the person if they fall, which is containing rather than restrictive :

> "Cause, we can go out, they said we can go out and we can get a lift to Tesco, but we had to make our own way back if we wanted to go further, and I was willing to do that. And I was the only one that really cooperated that day, so they were, they gave me a lot of praise about that"(Julie – 403).

Ray speaks about being part of the interview panel for the trust and he enjoys his experience but feels he needs a member of staff with him to do this and he stresses the importance of this being paid work. This is validating for Ray, giving him sense of purpose and value:

> "I do some interviewing for the trust centre. It's every couple of months that…..I haven't done any for a long time. Well the first time I interviewed about four years ago I had to go to the recreation hall. That was the first time I did it. It seemed to be all right. Someone helps me. I get paid for it you know" (Ray - 935).

Mike shares some of the skills that he has and how routine and structure has helped him to grow.

> "And that. Well I uh my cook days on Monday. I will cook for everyone once a week. Uhhhh room days on Tuesday. I take about 40, 40 to 45 minutes doing me room I a clean my room, do the washing, do my bedding, bedding n all that. I do me chores on Monday. I uhhhh clean the surfaces. In the utility room and I wash and clean them. And uhhh I mop the floor."(Mike - 505).

Mike also likes to support other residents and this enables him grow and connect with others.

> “No Monday is my cook day, but Tuesday is xxxxxx cook day. I help xxxxxxx do the washing up and that.” (Mike – 547)

Creating spaces of opportunity is vital for clients to learn skills for living.

‘Self-acceptance “It’s ok not to be normal”.’

Finally, a detailed examination of a passage from participant – Julie. This is placed here as it illustrates her experience of residential care and is articulated in other accounts with each participant using their own words. ‘It’s ok not to be normal’ has become the subordinate theme, showing that Julie has accepted who she is, whatever normality is. It does not matter, no on one is going to fail her, she is free not to have to pass any tests. She reflects on the cruelty of others and how hard it is ‘out there’:

> “Cause here you can be a pig um you can be yourself. It doesn't matter if you are sometimes umm crazy you don' have to explain what you can just be what you want to be if you want to scream you can just scream, if you say something really outlandish like really crazy just for the sake of it, it's ok” (Julie - 983)

There is so much being articulated in this passage, acceptance of self as well as acceptance by others to be who she is without judgement or cruelty which is what this participant and others have spoken about in their own experiences. Julie’s use of like a ‘pig’ as a metaphor, is interesting as it gives an image of Julie as a messy, greedy, smelly, pink animal and staff and residents acceptance of her. This leads on to ‘it’s ok not to be normal’ and the expectation of being out in the community when there are unwritten rules about what is ‘normal’ or socially acceptable:

> “If you say I' don't know why I said that it's ok to say it, it’s ok to not be normal sometimes cause you don't have to explain it” (Julie).

Julie reflects on her experiences of residential care as a place she can be herself. This appears to be a comparison to living out in the community, where there is pressure to conform to societies norms and values:

> “Yep, nothing is expected of you, nothing that is going to say you have failed. You haven't done it right you are safe here” (Julie)

In her experience she finds living in a residential care home ‘safe here’ no passing or failing which Julie goes onto articulate:

> “You haven't got to pass any tests. That is what life is out there it is a test and a lot of people don't pass it” (Julie).

Julie talks about ‘tests’ and her experience of life before a residential care home had been a test ‘out there’. Julie was able to express how inside a residential care home feels safe, to try things out without judgement or fear of failure.

> “I've been out there too often to have had some cruel people in my time, and it’s…. can be hard out there” (Julie - 983).

Julie reflects on the cruelty in society and how tough it has been living a life outside of care, and at times in residential care owing to restrictions and cruelty.

Fred also reflected on living and brings up trying to ‘fit in’ and lead a ‘normal life’. A lot of Fred’s experiences have been around feeling different and stigmatised within society and some residential care settings. Fred states he felt different from birth and this is illustrated by his dramatic entrance into the world in which he did not breathe for a bit:

> “No. Mum knew something cause when I was born, I was actually dead right I stopped breathing and years ago they put you in cold water”
>
> “Yeah! It brought me back. I was mum’s closest …..and part of his brain was like damaged, that is why I can't remember and um when I used to go out uuuh the psychiatrist used to think it was me drink because of speech. It's not that at all. I knew exactly what it was .”
>
> “And when I get stressed out my voice goes and all that and like ....And then I get angry then cause I cannot get my bleeding words out ,yeah, and I get frustrated!” (Fred).

This is Fred’s way of understanding his perceived difference. He speaks about how it is to hear voices and why he needs a residential care home not only to keep him safe, but others safe from him. He talks about the frustration of trying to fit in and leading a life without stigma:

> “I used to go out in the community and try and fit in, I would go out sort of drinking socialising. Aw he's a bit of this and a bit of Ohhhh… f….. off I used to say, yeah. They said go out in the community and be like try and lead a normal life” (Fred - 1073).

Mike has been in and out of secure units, hospitals, supported living and eventually settling in a residential care home six years ago. The excerpt describes a bad day, as he struggles with his thoughts about spirits and dates which can overwhelm him at times:

> “Um it gets to me, it got to me yesterday for uhhh couple of hours, two hours yesterday. I felt terrible. All you got to do is blank everything out and lay on me back on me bed. Close me eyes and wait for it to go away. Yeah, I just need to be completely on my own” (Mike – 711).

Residential care is a space in the world in which Mike finds peace and acceptance from other residents and staff. Space is facilitated and helps Mike to stay well and manage his difficult moments.

This superordinate theme sheds light on the resilience of this population despite the back stories that mostly included trauma, stigma, cruelty and restriction. Most participants experienced a form of bad residential care in their past as well as the present. Residential care needs to continue to evolve and grow to be able to offer a safe space that is reparative, containing, a place to try things out enabling residents take back control of their lives.

<u>Discussion</u>

At this point, a summary of the research findings will be provided, this will include a discussion about the contribution of this study to the literature, the implications for the discipline of counselling psychology, the limitations of the study and suggestions for future research. These themes and quotes are presented in Table 3 and described further within this section. Accounts from the participants' interpretive content is now presented below.

Summary of research findings

The findings of this study revealed how six clients with complex mental health needs experienced living in a residential care home. Four superordinate themes were developed from the analysis of the interview data. These were (1) Stories of change over time; an historical journey (2) Searching for care (3) The challenges of living in residential care; (4) Learning to grow as a resident in a residential care home. These themes will now be summarised.

Each participant had been part of the mental health system for many years and this is documented in the first theme in which residential care was understood as '**Stories of change over time; an historical journey'** which revealed that some care is better than no care. The interviews shed light on how early institutes and residential care homes could be very unhappy places, in which control operated on many levels. As discussed in the introduction there have been debates around the relationship between the medicalisation of emotional distress, psychiatry and social control (Foucault, 1989). This theme introduces how residential care has improved over time, whilst highlighting areas in which residential care may still need to change. Participants reflected on ‘**where I started’**, ‘**my past journey’** the experiences they had along the way and ‘**where I am now’**. Participants shared accounts of past care and being controlled in many ways, such as overly strict rules, over medication, non-consensual treatments and restrictive practices. This theme spoke to the need for practitioners to understand potential past trauma of the clients that they work with. This links with PIE 2.0 developing more ‘psychological awareness’ of the needs of service users.

The second superordinate theme ‘**searching for care’** documented memories of difficult backgrounds, relationship break ups and society as cruel and unkind. At times participants talked about engaging in risky and self-harming behaviours to get their voices heard. These methods were shocking to hear, such as attempted suicide, self-harm and the use of alcohol to cope.

This became the subordinate themes ‘**safer inside’** and ‘**scary outside**’. This overarching theme captured the participants’ responses to distress, how they experienced threat and how they responded in an attempt to regain a sense of power and control. Most participants said that they would use whatever resources that were available to them as a defence against the scary outside. Bacha, Hanley and Winter’s (2020) research presented a quote from a participant that stated ‘her body was the only thing she felt that she had control of’ which mirrors the experience of the participants in this research. In contrast, there was an instance in which one of the participants was unable to attend a football match without a carer present. This emphasised that residential care could be too safe, where clients could become deskilled, dependent on care and stuck. However, being ‘**safer inside’** provided evidence that residential can be a shield from the ‘**scary outside’.** Some care is better than no care and the participants experienced residential care as safer than in the community.

As the narrative unfolded participants shared the **‘The challenges of living in residential care’.** This felt important as the researcher was concerned that the participants would not be able to bring any negative experiences owing to their circumstances of being dependant on the care that they receive. However, this was not the case and participants' reflections indicated the subordinate themes '**powerlessness and infantilising'**, lack of control, boredom and **'I want to be treated as an individual'.** This theme gave insight into the factors that actively silence the voice of the participants.

The final superordinate theme became '**learning to grow; as a resident in a residential care home**'. Good residential care provided a safe enough environment to nurture, repair and allow space to grow. This included '**gaining control and learning new skills to live'**, and a space for '**self-acceptance; it's ok not to be normal'**. Participants who were less satisfied were less focussed, bored, under stimulated, deskilled and restricted. The next part of this paper will discuss the findings and examine real examples to illustrate how clients experience residential care and help me (the researcher) to make sense of their experience as a trainee counselling psychologist.

Reflection on the literature

As considered in the literature review care for people with complex mental health has undergone changes since the first mental health asylums in the 19th century (Fakhoury and Priebe, 2007). As illustrated there were big changes in the 1960s, when the intention was for people with mental health problems to be discharged from institutes back into community living. This was without consideration into how this specific population would cope. For these six participants community living felt unsafe. This was owing to feeling a sense of rejection from society, unable to 'fit' into community living. As Julie quoted in relation to residential care 'It's ok not to be normal'. This raises questions about society's norms and values which on reflection feel 'broken'; and raises questions about western society's assumptions about meaning and the value of humanity (Bacha et al., 2020).

According to this research residential care for these six participants has been a difficult journey. Each participant described past care as problematic and more recent care as safer than being in the community. Participants experienced residential care as a space in the world that is reparative, where they felt listened to enabling the nurturing of new skills. Moving onto the concept of psychologically informed environments (PIE 2.0), this psychological model fits well with this research and will now be discussed.

PIE 2.0

The basis of a PIE was born out of ‘Enabling Environments’ which was set up between 2007 and 2008 by the Royal College of Psychiatrists (Haigh et al., 2012) PIE has evolved since its conception and continues to evolve and is now referred to as PIE 2.0. PIE 2.0 is still in its exploratory stages and has the potential to consider more systemic issues, which lends itself to this research (Haigh et al., 2012).

PIE 2.0 identifies themes, dimensions, or areas to look at under five headings:

- Developing more 'psychological awareness' of the needs of service users
- Valuing training and support for staff, volunteers, as well as service users
- Creating a service culture of constant learning and enquiry
- Creating and or working with 'spaces of opportunity'
- Fine-tuning the 3 Rs - the rules, roles and responsiveness of the service.

These themes will now be discussed in turn in relation to the findings of this research. Firstly, let’s consider ‘psychological awareness’; this dimension is particularly relevant to this research as it is the foundation on which a PIE 2.0 is built. Psychological awareness is something that all humans possess. However, vulnerable and more at-risk individuals, such as the participants for this research often struggle to manage social and emotional life. This speaks to the need for practitioners to understand potential past trauma of the clients who they work with. This links with PIE 2.0 developing more ‘psychological awareness’ of the needs of service users. Within residential care, creating connection and trust is a vital part of the work for people that have suffered emotional trauma in their early life. This is evidenced by the participants’ comments about connecting to members of staff, particularly when they leave and what this may bring up for clients.

Secondly, the theme ‘staff training and support’ is vital in residential care to increase awareness for the staff to stay current and up to date with their practise. It allows for growth of not only staff, but PIE 2.0 advocates being inclusive of service users, equalising the power imbalance, thus, giving a platform for service users to raise awareness, giving valuable insight into the experiences of living in the residential care and questioning what works and what needs to be changed. This relates to what Mike and Ray shared about their experience of the night nurse. Thus, informing what training is needed, ultimately leading to a home that is pleasant to live and work in.

We now turn to ‘learning and enquiry’; this area aims to look at what helps and what constrains the progress of a PIE. This allows an assessment framework that is inclusive of commissioning as well as service delivery. This sets aside time to think about what is done well and what needs improving using an assessment framework ‘Pizazz’. Pizazz is intended to look at the effectiveness of particular aspects of a PIE’s approach, including front line staff, head office, funders and includes researchers. The aim is to give a wide range of providers, including residential care homes that work with people with complex psychological and emotional needs, a space to self-assess and think about progress management.

This brings us to ‘spaces of opportunity’ which are the pathways between services, and working with the gaps between, which is a more systemic approach and necessary feature when working with marginalised groups. As presented in the literature review, this area incorporates the social and psychological space and how it is used. The analysis discovered that each participant touched on how important the physical environment was, reflected on having outside space such as gardens or grounds to seek solace. Linking with recent research, Suto, Smith, Damiano and Channe (2021) found that participation in community gardening programmes developed a sense of belonging and positive feelings through doing.

Secondly, social spaces were important for meeting with others, even if this was being alongside another person. One of the participants found his bedroom oppressive, reminding him of a ‘cell’; he had also spent time living homeless. He particularly valued the communal areas and outside spaces.

Thirdly, having a pet, such as Julie’s guinea pigs and Mike’s fish, enabled a sense of purpose, routine and an anchor that helped participants to stay safe and allow new skills to develop linking with recent research (Fossey, Harvey and McDermott, 2020). PIE is trauma informed and is relevant to this population of service users who often find it easier to trust animals, or work with plants, than to trust people.

Finally, this leads into the 3Rs: rules, roles and responses to user involvement. Johnson and Boyle (2018) outline the rules and talk about having an ‘elastic tolerance’ which is defined as a flexible approach to dealing with issues which normally result in a warning or eviction (Haigh et al., 2012). This enables service users and staff to agree ways of working that set achievable boundaries and has an opportunity for a way back; such as de-escalation or cooling off spaces**.** This leads us to service user involvement opportunities, and considers roles that can be developed for individuals to gain confidence such as peer mentoring and key worker roles. This is specific to findings in the research in which Ray shared he had been involved in the recruitment of staff. This was a paid role and Ray was encouraged to give his views at the selection process.

The final ‘r’ is responsiveness which raises awareness of how the organisation responds. There are philosophical and ethical arguments for patient choice (Langharene and Priebe, 2006). To illustrate, Margaret spoke about being given choice to decide the activities that she would like to take part in. In contrast, Julie voiced she would become ‘resident evil’ if she was made to take part in a regular programme of events. There is a large body of research around collaboration and shared decision making and this research supports how decision making should not only be shared but based around an individual’s needs (Cooper, Dryden, Martin and Papayianni, 2016).

PIE 2.0 is based on psychological awareness (model) valuing a client centered approach. This research fits with some of the core PIE principles to help make sense of client experience, using this valuable insight to improve practice, which for this research is in residential care. PIE should be explored in the wider field of mental health and social exclusion. PIE has the potential to impact on client experience, gaining insight from the client perspective and counselling psychologists are well placed to take on projects to explore this concept further (Cockersell, 2016). We now turn to social justice.

Social Justice and Marginalised voices

Social justice is difficult to define; Cutts (2013) recognises this difficulty and argues that social justice in counselling psychology is a goal and a process. Kagan et al. (2011) reiterate this and go further, emphasising equity distinct from equality. Cutts (2013) describes how to differentiate between the two and argues that equal distribution is where each individual in society has the same set of resources. In contrast equitable distribution is the sharing of resources, which is fair, but, perhaps not equal using an example of a guide dog to illustrate (Cutts, 2013).

Cutts' (2013) paper considers the social justice agenda for counselling psychology. This paper speaks to this research as the paper emphasises working with and empowering marginalised groups, to address power imbalances and inequalities. The notion of equality is vital to reflect how to treat the 'other' as someone with equal and moral worth as a human being (Bacha et al., 2020). This paper described four main principles of social justice one of which includes equity – access to services, resources, power, knowledge and information; participation; and harmony. Principally, relevant to this research is the balancing of power across society. Bearing social justice in mind from the view of the 'other' and how the other may experience unequal power in a simple act such as counting out tea bags, or restrictions on times to get up, which many adults would not tolerate. This is interpreted in the research as unequal power balance and infantalisation.

Infantalisation is the act of treating an individual in a way that denies their level of maturity by age or experience (Gresham, 1976). Infantalisation can take many forms that include language, use of tone, actions, interactions and the environment (Brady et al. 2014). In the researcher's experience when working in adult mental health it is easy to slip into a way of soothing and comforting. Kittwood (1990) is a key figure in dementia, there are no references to his work outside of dementia, but his theory of malignant social psychology shines a light on infantalisation as potentially the most damaging aspect that deprives an individual of their personhood which leads to worsening of psychological and physical symptoms of illness. This is pertinent to this research and to counselling psychologists working in this area; as Cabiati and Raineri (2016) argue that Kittwood's thoughts about infantalisation give all healthcare professionals something to consider, when working in a residential care home.

Stigma

Sartorious (2007) argues that stigma and mental distress is what stands in the way of care for people with a mental health diagnosis. He defines stigma of mental distress as a negative attitude which is based on prejudice and misinformation, that emphasised when there are displays of odd behaviour or psychiatric treatment is disclosed. Thornicroft's book 'Shunned' argues that stigma is the start of a vicious cycle leading to discrimination in all classes of people (Thornicroft, 2006).

As mental health professionals we all have the potential to contribute to the development and reinforcement of stigma, for example, by using terms such as schizophrenics instead of speaking of the person who has mental illness. In Fred's interview he refers to himself as having 'schizophrenic'. Ray defined himself by his early diagnosis of a 'mental breakdown'. Both of these participants describe themselves as their diagnosis, not who they are as an individual.

The World Health Organisation has highlighted the need to combat stigma and foresee measures in mental health policy (Jané-Llopis, Katschnig, McDaid, D., and Wahlbeck, 2011). When a diagnosis such as PD or schizophrenia is put before the ‘face’ of the client, and the client is seen as their diagnosis this is called ‘thingification’ of the other (Levinas, 2006). Cooper (2009) argues that this is an attempt to reduce complex unknowable ‘otherness’ to the familiar and the ‘same’. This research argues that psychologists are able to welcome and work with the richness and vastness of clients beyond diagnosis. This is a particular skill of the counselling psychology profession.

Power

Power is defined as the ability to do or to act; the capability of doing something; strength; might; and force (Allen, 2006). Unfortunately, power quietly haunts health and social care (Cutcliffe and Happell, 2009). There are strong links between traditional psychiatry and coercion/power (Hannigan and Cutcliffe, 2002). A critique of historical and socio-political literature pertains that mental health and psychiatry often linked to social exclusion, control and incarceration over time in settings such as madhouses, workhouses, asylums, prisons and more recently hospitals (Cutcliffe and Happell, 2009). This has been evidenced throughout the results section ‘a story of change over time’ where participants spoke about the past and in some cases in the here and now in which power, control and exclusion featured prominently.

Power and powerlessness became underlying themes that punctuate the analysis. Interpersonal relationships are considered the anchor of therapeutic engagement. However, relationships within residential care are littered with issues of power. In a residential setting in which health care professionals work with highly vulnerable populations ‘invisible power’ can breed unnoticed by professionals who are seemingly unaware of the dynamic (Cutcliffe and Happell, 2009).

This research has flagged up how mental health nursing practise is not free from problems from the service user perspective. Cutcliffe and Happell (2009) argue there is an absence of empirical and theoretical literature that focusses explicitly on power and issues of power within this field. Finfgeld (2004) explicitly states that mental health nurses frequently speak about empowerment. However, Cutcliffe and Happell (2009) critique that this is fascinating scenario, where practitioners espouse theory and practise empowerment whilst being conceptually uncertain of the phenomenon called power. This research shines a light on how power has operated in the past as per Julie’s experience of ‘matron’ but more worryingly, still operates but is less visible, such as Ray’s example of ‘tea bags and Mike’s example of the ‘night nurse’.

The Power Threat Meaning framework advocates that understanding how power operates in the life of the client should be the starting point for understanding the distress or disturbing behaviour of another (Johnstone and Boyle, 2018). The participants were very clear about the lengths they would go to get their voices heard. The participants spoke about past coercive power in which medications or treatments were prescribed and enforced against their will. Unfortunately, restrictive practise still happens today using power such as community treatment order (CTO), or legal power such as arrest which was a large part of participants’ histories. Interpersonal power was also spoken about mostly in the past but also recently. Participant Julie gave a graphic description of a powerful matron who was controlling and cruel, and articulated how she was undermined, controlled and over medicated as a way of managing her. Unfortunately, mental health is unique to medicine as some patients have been in the past and continue to be treated against their will (Laugharne and Priebe, 2006).

Finally, there are more hidden forms of power operating for example within government, legal systems and health care professionals. This gives power to exercise over users of the system by imposing an ‘expert truth’ (Sapouna, 2012). These hidden forms of power need to be challenged and this research gives an opportunity to give a transformative platform to view this as ‘one truth amongst many’. This can only happen in the context that allows alternative views, most importantly, by understanding the clients’ explanations and views, empower the client offering meaning and potential solutions for a person’s distress (Cutcliffe and Happell, 2009). This is a significant development in the field of mental health where there is an increase in service user/ survivor movements to articulate different ‘truths’ by experts by experience. These are the perspectives that shape the voices of those directly affected by the mental health system and give opportunities to hear the unheard.

Empowerment

A precursor to empowerment is the lack of power or an imbalance of power (Finfgeld, 2004). The theme 'learning to grow' evidences relationships that have developed from the participants being communicated within a caring and respectful manner, thereby aiding that person to see their personal value and worth. Unfortunately, not all health care professionals are able to innately support empowerment, particularly in the past, as this research emphasised. To empower an individual, all health care professionals should be willing to allow themselves to co-operate, compromise and surrender control. Those that can do this well require an instinctive acceptance of the needs of others, empathy, tolerance and flexibility. This links back to social justice and needs great courage, respectful mutuality, power sharing and participatory decision making, and an abandoning of professional power. This requires everyone to be placed in a position to learn from each other (Finfgeld, 2004). Piat, Seida and Padgett (2019) argue that a person should be responsible for one's life, including choice to organise one's social life and choices in the residential care home to ensure they feel at home. This connects back with the ethos of a PIE, in particular developing psychological awareness as practitioners of the needs of the people we care for.

As discussed earlier, addressing power imbalances means breaking down professional boundaries and establishing more equitable relationships. The participants were able to describe what had enabled them to grow and one of the concepts was a sharing of responsibility between the health care professional and the participant in which both are open to new ways of learning (Finfgeld, 2004). These six participants have implicated and evidenced a loss of power in an oppressive health care system. The resilience they have displayed, to learn to trust once again in residential care, supported by health care professionals, willing to share power has been evidenced in these six interviews. These shared stories, do not have perfect endings but each participant has found a place where they have been empowered to grow, in a residential setting that is also continuing to grow. We now turn to policies.

Policies

NICE (2011) specifically state that there is a paucity of evidence about interventions that improve the experienced of people using mental health services (Deering, Pawson, Summer and Williams, 2019). Recent research by Killaspy and Priebe (2020:2021) state that there are 100,000 people who live in one of three types mental health supported accommodation that includes residential care homes. They argue that there is little evidence to guide investment in the most effective models. This research adds to the evidence base giving a qualitative view of experiences of life in residential care. NICE recommend “service user” informed research (Beresford et al., 2016; Langharne, 2004); however, it remains thin on the ground, often being marginalised and devalued in mental health research communities (Bacha et al., 2020; Beresford et al., 2016). In 2012 to 2017 a programme of research into mental health supported accommodation across England was conducted (Killaspy and Priebe, 2020:2021). This research highlighted unrealistic targets in which services are commissioned to ‘move people on’ within two years. To meet this performance indicator individuals with high level needs are moved on to other services that provide a similar level of support. This is unhelpful, unnecessary and inhumane in the light of this research.

Contribution of this study to the literature

This is a significant contribution to the mental health literature around experiences from client perspective of life in residential care gaining new knowledge to be added to the literature. Service users have historically had little opportunity to express their opinions about their experiences of mental health services (Shepherd, Boardman, and Slade, 2008). This research raises our awareness of the lack of meaningful community-based alternatives to hospitalisation, involuntary treatment, abuse of professional power and lack of information and choice in relation to ‘treatment’ options particularly in the past. This research aligns itself with the findings of Bacha et al., (2020) in which all eight participants talked about treatments such as ECT that were not effective in relieving symptoms of mental distress. Participant Ray shared that he had received ECT treatment but did not know why. His response to this was passivity to protect himself which is described as ‘patient’ defensive reaction’ (Bacha et al., 2020).

Shaping our knowing about mental health gives insight into there being not only two sides to acknowledge but many sides. Those that experience distress are entitled to be in charge of writing and interpreting their own story. This shaking up of certainty also provides opportunity for transformation towards a more democratic, person centred response to human distress, giving an opportunity to open up a new discourse with people whose voices have been habitually silenced and marginalised. This research raises awareness and supports the move away from the biomedical model of mental distress towards a more interpersonal and humanistic attitude to the experience of clients in residential care. Bacha et al. (2020) argue this kind of research has reliably revealed that clients value shared power, trust and empathy as humans in their relationships with mental health staff who work in residential care.

My place in the literature

The research fits well with psychiatric and mental health, nursing as well as counselling psychology literature as it gives voice to a marginalised group and raises awareness. It gives insight to health care professionals including psychologists of how it may feel to be the ‘other’. The Power Threat Meaning Framework ties in with this research of hearing client voice. Lastly, this research anchors itself in the evolving PIE 2.O theoretical framework and has the scope to add to evidence base of psychological awareness.

The implications for the discipline of counselling psychology

The results from this study have significant implications for the profession of counselling psychology. This research is a reflection on the experience of how it is as an adult to be taken into residential care, often against your will. As counselling psychologists, we are aware of our respect for client's autonomy, as trustworthy and a commitment to maintaining confidentiality are the heart of what we do (Cooper, 2009). Counselling psychologists are aware of prioritising clients' subjective and intersubjective experience and enabling growth and actualising potential. Therefore, having insight into a client's history, such as Fred's aversion to a male carer, helps psychologists and carers to be aware of past trauma and how the past continues to play out in the present. This offers a way of making sense of someone's distress and understand what is being communicated.

Counselling psychologists conceptualise people's problems in a humanistic way (Strawbridge et al, 2009). This is relevant to these participants as they all reported difficult relationships and experiences of living in a world that they felt they did not fit into. Counselling psychologists work relationally and are acutely aware that it is the therapeutic relationship that aids the process of healing (Kahn, 1997) . Therefore, this research raises counselling psychologists' understanding of a marginalised group. A large part of this work is saying loud and clear that the participant or client is appreciated for who they are, as a unique being, relationally embedded and this includes an awareness of how this individual may experience discrimination, prejudice, stigma and restrictive practise.

One of the ways the participants expressed discrimination and prejudice was that out of the six participants who had suffered distress for most of their lives, only one participant had access to therapy. One participant spoke about a drug and alcohol group that he belonged to but had found it difficult to engage at depth or attend weekly. The other participants had not engaged or been offered therapy. Counselling psychologists are well placed to ask the question 'why is this' and 'what can we do to change this'? This is the humanistic value of counselling psychology that observes a 'thing', takes a step back and questions why is this group of people not being included and what can I do about this, hearing the unheard.

Cooper’s (2009) paper on ‘welcoming the other’ examines how counselling psychology may advance in the future. He posits that professionals need to engage with people in a way that considers labels ‘lightly’ and meets people firstly as people, ensuring they are met as who they are not just their diagnosis. This research sheds light on how the journey from mental illness to mental health is to re-claim one’s obligations, responsibilities to and for the other. Psychologists need to consider how challenging the client may need to be reconsidered and instead think about welcoming the client. Cooper (2009) suggests that the gentleness of the word ‘welcoming’ has the potential to induce transformation in clients to enable the capacity for a life worth living.

Limitations and recommendations for future research

As a qualitative study generalisability of research findings are not sought due to the experiential nature of qualitative research. The sample chosen was a predominantly white British residential home in the south west of England. However, this research does not reflect the diverse multi-cultural society that residential care homes may be made up of. Therefore, there is room for this research to look at a cross cultural expansion of the work. For example, how would research look in the Polish, Somali or afro Caribbean communities?

A further issue was that this sample was made up of working age adults, mostly an older population. This research may also have scope to be explored within a younger population which would also shed light on a set of different experiences within a different time point.

It should also be understood that IPA recognises a double hermeneutic with the researcher aiming to make sense of the participants making sense of their experiences of living in residential care. This analysis presents one of many possible constructs of the phenomenon under study which was influenced by the researcher’s own subjectivity. Therefore, another researcher would have produced different themes dependant on their own set of experiences (Elliot et al., 1999).

If this research had fewer time limitations it would be have been advantageous to offer each participant an opportunity to review each transcript and review the quotes used in the write up of this work. This would have given the participants more power and control over the finished thesis. However, owing to time limitation of the professional doctorate and Covid restrictions this was not possible for the researcher to complete this in a timely manner. In Bacha et al.'s (2020) research, the participants interviewed were given an opportunity to review and report whether the findings were representative of their experiences. This would be a recommendation for future research in this area of client experience.

Conclusion

The findings in this study revealed four superordinate themes; Stories of change over time; an historical journey; Searching for care; the challenges of living in residential care and learning to grow as a resident in a residential care home. These themes developed from the interviews of the participants' who live in residential care.

Each participant experienced being part of the mental health system for many years and shared stories of significant change over time. The participants were able to reflect on power operating negatively in their lives inside and outside of residential care. There was a clear emphasis on a search for care from pre-existing emotional distress which had been exacerbated by living in a community in which they felt unsafe. Therefore, this research found residential care to be a safer space in the world with the potential to learn new skills to grow. This research documented how in the past residential care felt unsafe; this was articulated in the participants' interviews. More recently residential care has improved, participants suggest that having some care is better than no care.

This research explored people's experiences of being in residential care. Counselling psychologists are well placed to support people by understanding distress in a genuinely compassionate way. The research raises awareness of how vulnerable these participants feel when in the community and more recently how the participants' found residential care as a safer space in the world to begin to gain control, learn new skills and find acceptance. However, this was dependant on the practitioners who worked with them and how power was understood within the residential care home.

The concept of PIE 2.0 has been explored as a theoretical framework in which this research can be discussed. PIE 2.0 values a client centred approach. This research fits with some of the core PIE principles to help make sense of client experience, using this valuable insight to improve practice, which for this research is in residential care. PIE has the potential to impact on client experience, gaining insight from the client perspective. Counselling psychologists are well placed to take on projects to explore concepts such as how clients experience power operating in a residential care home and how this knowledge is disseminated and shared with other professionals (Cockersell, 2016).

Secondary to this, the researcher found that by undertaking this important research impacted on her in the following ways. The study provided insight into the experiences of people that need residential care, and raised questions about accepted ways of responding to human distress. The analysis provided suggestions directly from the participants for the researcher and other health care professionals around fostering relationships that are consistent, trusting and protective in a residential care context. This included providing opportunities to question professional boundaries such as personal experience of residential care homes kitchens being locked, denying basic human rights such as food and drink. This research gains insight into how denying basic needs stands in the way of establishing equitable relationships. The researcher found the themes mirrored a similar journey to her own. This enhanced the determination to present a piece of work that can raise questions of all professionals who work in the field of complex mental health. Undertaking this research has given the researcher the confidence to question what is sometimes considered 'the way we do it' and question 'why'? The study aims to raise awareness for all health care professionals including counselling psychologists around how to work with people that live in residential settings and consider interventions that support a person to live ‘their best life’.

> “I had no life skills when I, I come to move over here and they helped me grow. Because make me feel I do my own washing, I,I can use the dryer, I go out and um just sensible rules there’s no hard rules, just sensible rules which we, which you have in life” – Julie

Reference List

Adshead, G., Burn, W., Byrne, L., Goslar, D., James, A., Khan, M., Lovett, K., Morris, D., Wallace, V. (2018). *Person-centred care: Implications for training in psychiatry*. England: The Royal College of Psychiatrists.

Allen, R. E. (2006). *The concise oxford dictionary of current English* (10th ed.). London: BCA.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR* (4th ed.). Washington, D.C: American Psychiatric Association.

American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.) Washington. D.C: American Psychiatric Association.

Anfossi, A. (2017). The current state of recovery colleges in the UK: final report. Nottingham: ImROC.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.

Anthony, W. A. (2004). The principle of personhood: The field's transcendent principle. *Psychiatric Rehabilitation Journal, 27*(3), 205-205.

Bacha, K., Hanley, T., & Winter, L. A. (2019; 2020). 'Like a human being, I was an equal, I wasn't just a patient': Service users' perspectives on their experiences of relationships with staff in mental health services. *Psychology and Psychotherapy, 93*(2), 367-386.

Beresford, P. Perring, R. Nettle, Wallcraft, J. (2016). *From mental illness to a social model of madness and distress.* London: Shaping our lives.

Blackburn, P. J. (2012). Developing a psychological approach: The wellbeing service for homeless and vulnerably housed people in Bristol. *Housing, Care and Support, 15*(2), 66-70.

Boardman, J., Craig, T., Goddard, C., Henderson, C., McCarthy, J., McInerny, T., Whicher, E. (2010). *Social inclusion and recovery (SIR) strategy.* (). London: South London and Maudsley NHS Foundation Trust.

Brady, D., Clifton, A., Burr, V., and Curran, S. (2014). The infantilisation of older people: Is it a problem? *Mental Health Nursing (Online), 34*(5), 22.

Braun, V., and Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* London : Sage.

British Psychological Society. (2019). The Delphi method. Retrieved from https://thepsychologist.bps.org.uk/volume-22/edition-7/delphi-method

British Psychological Society. (2017). DCP psychosis and complex mental health faculty. Retrieved from www1/bps.org.uk

British Psychological Society. (2017). In Division of Counselling Psychology (Ed.), *Standards for the accreditation of doctoral programmes in counselling psychology*. Leicester: British Psychological Society.

Brocki, J. M., and Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87-108.

Bhui, K., Shanahan, L., & Harding, G. (2006). Homelessness and mental illness: A literature review and a qualitative study of perceptions of the adequacy of care. *International Journal of Social Psychiatry, 52*(2), 152-165.

Cabiati, E., and Raineri, M. L. (2016). Learning from service users' involvement: A research about changing stigmatizing attitudes in social work students. *Social Work Education, 35*(8), 982-996.

Chilvers, R., Macdonald, G. M., and Hayes, A. A. (2006). Supported housing for people with severe mental disorders. *The Cochrane Database of Systematic Reviews,* (4)

Clare, A. (1980). *PSYCHIATRY IN DISSENT*. New York: Routledge.

Clare, L., and Cox, S. (2003). Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability and Society, 18*(7), 935-953.

Cockersell, P. (2016). PIEs five years on. *Mental Health and Social Inclusion, 20*(4), 221-230.

Conrad, P. (1987). The experience of illness: Recent and new directions. *Research in the Sociology of Health Care,* (6), 1-31.

Cooper, M. (2009). Welcoming the other: Actualising the humanistic ethic at the core of counselling psychology practice. *Counselling Psychology Review, 24*(3).

Cooper, M.,Dryden, W., Martin, K., Papayianni, F. (2016). Metatherapeutic communication and shared decision-making. In M. Cooper and W. Dryden (Eds), H*andbook of pluralistic counselling and psychotherapy* (pp. 42-54). London: Sage.

Copeland, M.E. (2002) *Wellness Recovery Action Plan*. USA: Peach Press

Cromby, J., Harper, D., Reavey, P. (2013). *Psychology, mental health and distress*.

New York: Palgrave Macmillan.

Cullen, S. (2005) Shelter Involving user in supported housing A good practise guide.

London: Shelter

Cutcliffe, J., and Happell, B. (2009). Psychiatry, mental health nurses, and invisible power: Exploring a perturbed relationship within contemporary mental health care. *International Journal of Mental Health Nursing, 18*(2), 116-125.

Cutts, L. A. (2013). Considering a social justice agenda for counselling psychology in the UK. *Counselling Psychology Review, 28*(2), 8-16

Davidson, L., Bellamy, C., Guy, K., Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry, 11*(2), 123-128.

Davies, K., & Gray, M. (2017). The place of service-user expertise in evidence-based practice. *Journal of Social Work : JSW, 17*(1), 3-20

Deering, K., Pawson, C., Summers, N., Williams, J. (2019). Patient perspectives of helpful risk management practices within mental health services. A mixed studies systematic review of primary research. *Journal of Psychiatric and Mental Health Nursing, 26*(5-6), 185-197.

Deegan, P. E. (1988). The lived experience of rehabilitation. *Psychosocial Rehabilitation Journal, 9*(4), 11-19.

Deegan, P. E. (. (2001). Recovery as self ‘directed healing, and transformation. In C. Brown (Ed.), *Recovery and wellness: Models of hope and empowerment for people with mental illness.* (pp. 5-21). New York: Haworth Press.

Deegan, P. E., and Drake, R. E. (2009). Shared decision making is an ethical imperative. *Psychiatric Services, 60*(8), 1007-1007.

De Silva. D. (2014). *Helping measure person-centred care: A review of evidence about commonly used approaches and tools used to help measure person-centred care*. England: Health Foundation.

Department of Health. (2011). *No health without mental health*. London: Department of Health.

Eldal, K., Natvik, E., Veseth, M., Davidson, L., Skjølberg, Å., Gytri, D., & Moltu, C. (2019). Being recognised as a whole person: A qualitative study of inpatient experience in mental health. *Issues in Mental Health Nursing, 40*(2), 88-96.

Fairfax, H. (2016). The role of counselling psychology in secondary adult mental health care. In Douglas, B. Woolfe, R. Strawbridge, Kasket, E. Galbraith, V. (Ed.) *The handbook of counselling psychology* (4th ed., pp. 511 - 529). London: SAGE.

Fakhoury, W., and Priebe, S. (2007). Deinstitutionalization and reinstitutionalization: Major changes in the provision of mental healthcare. *Psychiatry (Abingdon, England), 6*(8), 313-316.

Faulkner, A. (2017). Survivor research and mad studies: The role and value of experiential knowledge in mental health research. *Disability and Society, 32*(4), 500-520.

Field, B., I., and Reed, K. (2016). The rise and fall of the mental health recovery model. *The International Journal of Psychosocial Rehabilitation, 20*(2), 86-95.

Finfgeld, D. L. (2004). Empowerment of individuals with enduring mental health problems: Results from concept analyses and qualitative investigations. *Advances in Nursing Science, 27*(1), 44-52.

Fossey, E., Harvey, C., & McDermott, F. (2019; 2020). Housing and support narratives of people experiencing mental health issues: Making my place, my home. *Frontiers in Psychiatry, 10*, 939-939.

Foucault, M. (1989). *Madness and civilization: A history of insanity in the age of reason*: Routledge.

Gillis, A. (2015). The rise of mad studies. Retrieved from https://www.universityaffairs.ca/features/feature-article/mad-studies/

Gould, D. (2012). *Service users' experiences of recovery under 2008 Care Programme Approach*. London: Mental Health Foundation.

Gresham, M.,. (2015). The infantilisation of the elderly: A developing concept. *Nursing Forum, 2*, 195-210.

Haigh, R., Harrison, T., Johnson, R., Paget, S., and Williams, S. (2012). Psychologically informed environments and the "Enabling environments" initiative. *Housing, Care and Support, 15*(1), 34-42.

Hannigan, B., and Cutcliffe, J. (2002). Challenging contemporary mental health policy: Time to assuage the coercion? *Journal of Advanced Nursing, 37*(5), 477-484.

Harrison, M., Singh Roy, A., Hultqvist, J., Pan, A., McCartney, D., McGuire, N., Forsyth, K. (2020). Quality of life outcomes for people with serious mental illness living in supported accommodation: Systematic review and meta-analysis. *Social Psychiatry and Psychiatric Epidemiology, 55*(8), 977-988

Johnstone, L., and Boyle, M. (2018). *The power threat meaning framework: Towards the identification of patterns in emotional distress, unusual experiences and troubled behaviour, as an alternative to functional diagnosis*. Leicester: British Psychological Society.

Jose, A. L., Harrison, M., Roy, A. S., Fitzpatrick, L. I., & Forsyth, K. (2021). The level of formal support received by people with severe mental illness living in supported accommodation and participation: A systematic review. *International Journal of Social Psychiatry*

Kahn, M., and NetLibrary, I. (1997). *Between therapist and client: The new relationship* (Rev. ed.). New York: W.H. Freeman and Co.

Kagan, C., Burton, M., Duckett, P., Lawthorn, R. and Siddiquee, A. (2011). *Critical community psychology*. West Sussex: BPS Blackwell.

Kennedy, B. A., and Arthur, N. (2014). Social Justice and Counselling Psychology: Recommitment Through Action. *Canadian Journal of Counselling and Psychotherapy*, *48*(3).

Kernberg, O. F. (1967). Borderline personality organisation. *Journal of American Psychotherapy, 15*, 641-645.

Killaspy, H., & Priebe, S. (2020; 2021). Research into mental health supported accommodation - desperately needed but challenging to deliver. *British Journal of Psychiatry, 218*(4), 1-181.

Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer's disease. *Ageing and Society, 10*(2), 177-196.

Krotofil, J., McPherson, P., and Killaspy, H. (2018). Service user experiences of specialist mental health supported accommodation: A systematic review of qualitative studies and narrative synthesis. *Health and Social Care in the Community, 26*(6), 787-800.

Larkin, M., Watts, S., and Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120.

Laugharne, R., and Priebe, S. (2006). Trust, choice and power in mental health: A literature review. *Social Psychiatry and Psychiatric Epidemiology, 41*(11), 843-852.

Law, H., and Morrison, A. P. (2014). Recovery in psychosis: A Delphi study with experts by experience. *Schizophrenia Bulletin, 40*(6), 1347-1355.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., and Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systemic review and narrative synthesis. *The British Journal of Psychiatry,* (199), 445-452.

Levinas, E. (2006). *Humanism of the other*. Urbana, [Ill.]: University of Illinois Press.

Martindale, K., and Philips, R. (2010). Applying quality of life in mental health social work practise. *Social Work, 22*(1)

McAdams, D. P. (2015). *The art of science and personality development*. England: Guilford Press.

McPherson, P., Krotofil, J., Killaspy, H., Joanna Krotofil, (2018). What works? toward a new classification system for mental health supported accommodation services: The simple taxonomy for supported accommodation (STAX-SA). *International Journal of Environmental Research and Public Health, 15*(2)

Mead, S. and Filson, (2016) Becoming part of each other's narratives. In Russo, J and Sweeney A Eds (Ed.), *Searching for a rose garden.* (2016). Ross-on-Wye: PCCS Books.

Mental Health Taskforce. (2016). *The five-year forward view for mental health*. England: Mental Health Taskforce to the NHS England.

NHS England. (2019). *The next steps on the NHS five- year forward view. A report from the independent mental health taskforce to the NHS in England*. London: NHS England.

NICE. (2009). *Borderline personality disorder: Recognition and management*. England: NICE.

NICE. (2011). *Service user experience in adult mental health: Improving the experience of care for people using adult NHS mental health services*. England: NICE.

NICE. (2012). *Antisocial personality disorder: Prevention and management*. England: NICE.

NICE. (2014). *Psychosis and schizophrenia in adults: Prevention and management*. England: NICE.

O'Hagan, M. (2016*). International mental health leader with lived experience*. Retrieved from http://www.maryohagan.com/about-mary.php

Open Dialogue. (2018). *Developing open dialogue*. Retrieved from http://developingopendialogue.com/

Parker, S., Hopkins, G., Siskind, D., Harris, M., McKeon, G., Dark, F., and Whiteford, H. (2019). A systematic review of service models and evidence relating to the clinically operated community-based residential mental health rehabilitation for adults with severe and persisting mental illness in Australia. *BMC Psychiatry, 19*(1), 55-55.

Perkins, R., and Slade, M. (2012). Recovery in England: Transforming statutory services? *International Review of Psychiatry, 24*(1), 29-39.

Piat, M., Seida, K., & Padgett, D. (2020). Choice and personal recovery for people with serious mental illness living in supported housing. *Journal of Mental Health (Abingdon, England), 29*(3), 306-313.

Pitt, L., Kilbride, M., Nothard, S., Welford, M., and Morrison, A. P. (2007). Researching recovery from psychosis: A user-led project. *Psychiatric Bulletin, 31*(2), 55-60.

Poloni, N, Zizolfi, D., Ielmini, M., Pagani, R., Caselli, I., Diurni, M., Callegari, C. (2018). A naturalistic study on the relationship among resilient factors, psychiatric symptoms, and psychosocial functioning in a sample of residential patients with psychosis. *Psychology Research and Behaviour Management, 11.*

Raanaas, R. K., Patil, G., and Alve, G. (2015). Patients' recovery experiences of indoor plants and views of nature in a rehabilitation centre. *Work (Reading, Mass.), 53*(1), 45-55.

Rayner, V. (2012). Psychologically informed services: A response from the housing, care and support sector. *Housing, Care and Support, 15*(2), 71-73.

Recovery in the Bin. (2017). *UBI: The good, the bad and the ugly*. Retrieved from https://recoveryinthebin.org/2017/09/04/ubi-the-good-the-bad-and-the-ugly/

Reid, K., Flowers, P., and Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*, 20-23.

Repper, J., and Perkins, R. (2003). *Social inclusion and recovery: A model for mental health practice*. Edinburgh: Baillière Tindall.

Roberts, G., and Wolfsen, P. (2004). The rediscovery of recovery: Open to all. *Advance in Psychiatric Treatment, 10*, 37-49.

Roberts, G., Good, J., Wooldridge, J., and Baker, E. (2011). Steps towards “putting recovery at the heart of all we do”: Workforce development and the contribution of “lived experience”. *Journal of Mental Health Training, Education and Practice, 6*(1), 17-28.

Roos, E., Bjerkeset, O., Svavarsdóttir, M. H., and Steinsbekk, A. (2017). Like a hotel, but boring: Users' experience with short-time community-based residential aftercare. *BMC Health Services Research, 17*(1), 832-10.

Royal College of Psychiatrists. (2019). *The health of the nation outcome scale (HoNOS).* Retrieved from https://www.rcpsych.ac.uk

Sapouna, L. (2012). Foucault, Michel. Madness and Civilization: A History of Insanity (2001). *Community Development Journal, 47*(4), 612-617.

Sartorius, N. (2007). Stigmatized illnesses and health care. *Croatian Medical Journal, 48*(3), 396-397.

Seikhula, J. (2015). *Open dialogues with clients with mental health problems and their families*. Retrieved from http://developingopendialogue.com/

Shah, P., and Mountain, D. (2007). The medical model is dead long live the medical model. *The British Journal of Psychiatry, 191*(5), 375-377.

Shepherd, G., Boardman, J., and Slade, M. (2008). *Making recovery a reality.* London, UK: Sainsbury Centre for Mental Health.

Sibbald, S. E. A. (2016). *The consensus statement for people with complex mental health difficulties who are diagnosed with a personality disorder: 'shining lights in dark corners of people's lives'.* Faculty of Psychosis and Complex Mental Health, Division of Clinical Psychology, British Psychological Society. London

Slade, M. Longdon., E. (2015). *The empirical evidence about mental health and recovery: How likely , how long, what helps?* Victoria: MI Fellowship.

Slade, M., Adams, N., and O'Hagan, M. (2012). Recovery: Past progress and future challenges. *International Review of Psychiatry, 24*(1), 1-4.

Smith, A., J., Flowers, P., and Larkin, M. (2009). *Interpretative phonological analysis*. London: Sage.

Smith, J.A. and Dunworth, F. (2003) *Qualitative Methodology*. In: Valsiner, J., Ed., *Handbook of Development Psychology*, London: Sage. , 603-621.

Smith, J., A. (2007). *Qualitative psychology: A practical guide to research methods*. London: Sage.

Smith, J. A., and Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health, 22*(5), 517-534.

South London and Maudsley NHS Foundation Trust and South West London and St George’s Mental Health NHS Trust (2010) R*ecovery is for All. Hope, Agency and Opportunity in Psychiatry.* A Position Statement by Consultant Psychiatrists. London: SLAM/SWLSTG.

Suto, M. J., Smith, S., Damiano, N., & Channe, S. (2021). Participation in community gardening: Sowing the seeds of well-being. *Canadian Journal of Occupational Therapy,* 1-11

The Kings Fund. (2018). *Case study 1: Deinstitutionalisation in UK mental health services*. Retrieved from https://www.kingsfund.org.uk/publications/making-change-possible/mental-health-services

Thornicroft, G. (2006). *Shunned: Discrimination against people with mental illness*. Oxford: Oxford University Press.

TurningPoint. (2014). *Factsheet 1- complex needs and dual diagnosis*. Retrieved from http://www.turning-point.co.uk/media/636823/appg_factsheet_1_-_june_2014.pdf

Valuing people now: A new three-year strategy for people with learning disabilities making it happen for everyone. (2014). Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf

Waldemar, A. K., Arnfred, S. M., Petersen, L., & Korsbek, L. (2016). Recovery-oriented practice in mental health inpatient settings: A literature review. *Psychiatric Services (Washington, D.C.), 67*(6), 596-602.

Watson, J., Fossey, E., and Harvey, C. (2018). A home but how to connect with others? A qualitative meta-synthesis of experiences of people with mental illness living in supported housing. *Health and Social Care in the Community, 0*(0)

Jané-Llopis, E., Katschnig, H., McDaid, D., and Wahlbeck, K. (2011). Supporting decision-making processes for evidence-based mental health promotion. *Health Promotion International, 26*

Willig, C. (2008). *Qualitative research in psychology* (2nd ed.). Berkshire: McGraw-Hill.

Winter, L. A. (2019). Social justice and remembering “the personal is political” in counselling and psychotherapy: So, what can therapists do? *Counselling and Psychotherapy Research, 19*(3), 179-181.

Wolfsen, P., Holloway, F., Killaspy, H. (2009). *Enabling recovery for people with complex mental health needs. A template for rehabilitation service.* England: The Royal College of Psychiatrists

Woolfe, R., Dryden, W., and Strawbridge, S. (2003). *Handbook of counselling psychology* (2nd ed.). London: Sage.

Wusinich, C., Lindy, D. C., Russell, D., Pessin, N., & Friesen, P. (2020). Experiences of parachute NYC: An integration of open dialogue and intentional peer support. *Community Mental Health Journal, 56*(6),

Appendices

Appendix 1 – The Mental Health Clustering Tool

Mental Health Clustering Booklet

(V5.0)

(2016/17)

NHS England Publications Gateway Reference: 04421

Contents

Introduction

The Mental Health currencies have been mandated for use since April 2012. For most provider and commissioning organisations completeness and accuracy of cluster allocations is now a key concern and a great deal of audit/assurance work is being undertaken. This manual is not intended to replace face-to-face training sessions, but to provide clinicians with all the information needed to accurately use the model.

What is a Cluster?

In this context a cluster is a global description of a group of people with similar characteristics as identified from a holistic assessment and then rated using the Mental Health Clustering Tool (MHCT). The clusters allow for a degree of variation in the combination and severity of rated needs. However, as the clusters are statistically underpinned, definite patterns in the MHCT ratings exist for each of them. These ranges are indicated by the colour coded grids (Appendix 3) and are supplemented by the contextual information on the left hand side of each page, which is particularly useful when reviewing the appropriateness of previous cluster allocations.

When should I cluster someone?

People's needs change over time, and over the course of their treatment. A payment system for mental healthcare must reflect the differing levels of input that are provided throughout changing and unpredictable episodes of care. In order to achieve this, it is essential that people are not only assessed and clustered at the point of referral, but also re-assessed and re-clustered periodically. In practice this will equate to assessing and clustering people at:

- The end of the initial assessment (typically within 2 contacts).
- All planned CPA or other formal care reviews.
- Any other point where a significant change in planned care is deemed necessary (e.g. unplanned reviews, urgent admissions etc.)

Organisations should ensure there is clarity about who is responsible for clustering, particularly when more than one professional is involved.

How do I Cluster someone who is newly referred?

As organisations use different IT systems, the exact procedures will vary from provider to provider. However all providers will follow these basic steps:

Step 1: Based on the information you have gathered during your routine screening/assessment process, rate the individual's identified needs using the Mental Health Clustering Tool - Version 5.0 (Appendix 1).

Step 2: Use the Decision Tree (Appendix 2) to decide if the presenting needs are non-psychotic, psychotic or organic in origin. Then decide which of the next level of headings is most accurate. This will have narrowed down the list of clusters that are likely to describe the person's needs.

Step 3: Look at the rating grids (Appendix 3) to decide which one is the most appropriate by using the colour-coded key.

- Start with the Red ratings. These indicate the type and level of need which must be apparent in order to be a member of this cluster. If the ratings do not match, try another cluster.
- Next, consider the Orange ratings. These represent expected ratings. You may allocate a person to a cluster if the orange ratings do not exactly match the coloured grids. However, this reflects a "weaker fit" to that cluster.

Finally review the Yellow ratings. These represent ratings that may occur. These scales have significantly less bearing on cluster allocation but may indicate the need for additional care plan interventions.

Remember, the final clustering decision is yours, based on your assessment results and your clinical judgement in applying this guidance.

Care Review and the clustering process

Every day practitioners make decisions about starting, stopping, increasing and decreasing interventions. These decisions are made according to a range of complex and inter-related factors, but primarily in response to individual service user need. The Care Pathways and Packages model describes these individually assessed needs in a consistent way, using a combination of the Mental Health Clustering Tool (MHCT) and the resulting set of needs-based clusters.

The clusters, therefore, describe groups of service users with similar types of characteristics. These groups/clusters can be compared to each other in a variety of ways including: severity of need; complexity of need; acuity; intensity of likely treatment response; anticipated course of illness etc.

Whilst some comparisons will be either leads to the term **‘step-up’**	more useful than others in different situations, in this booklet a global judgement is made which combines all these factors and or **‘step-down’** being used to describe movement between any given clusters.

Care Transition Protocols

The points at which the appropriateness of the current cluster allocation is reconsidered should not be arbitrary. It should occur at natural and appropriate points in the individual's care pathway. Typically these are termed as reviews but it is important to note that reviews can be relatively informal as well as formal, and can be in response to unforeseen changes in need i.e. unplanned as well as pre-planned.

Consider the following clinical scenarios:

- The planned review of a service user halfway through a course of 16 sessions of CBT for depression will often reveal significant improvements and a corresponding reduction in MHCT ratings for anxiety and low mood. This is rarely seen as a sustainable change in the user's presentation and thus the original treatment plan continues until the intervention is completed, rather than be reduced to a lower intensity intervention (e.g. computerised CBT).

- Some months after treatment from an Assertive Outreach Team begins, improvements in presentation (particularly patterns of engagement) are not uncommon. These are unlikely to trigger a significant reduction in the overall level of intervention provided until the improvements have been maintained for some time. Thus the cluster allocation that originally triggered an assertive and intensive service response remains valid, as it is still seen as a truer reflection of the individual's overall needs.

- Service Users diagnosed with borderline personality disorder are well known to exhibit erratic patterns of behaviour, with fluctuations in distress and risk commonplace. Despite increases in risk, decisions are often made to take therapeutic risks rather than immediately increasing the overall level of intervention in response to what may turn out to be transient and self-limiting increases in perceived need.

From these examples it is clear that individuals only fit the needs profiles for the appropriate cluster at certain key points in their journey (i.e. the start of a period of care) and that, at clinical reviews additional factors must also be taken into account before an alternative cluster allocation is made and care is changed significantly.

These factors are described in this booklet as care transition protocols and include the step-up and step-down criteria for each cluster. **Only when a set of criteria have been met should the allocated cluster be changed to that suggested by the clustering tool ratings.** The protocols also include examples of local discharge criteria which outline the circumstances when service users could be discharged from in-scope Mental Health Services completely.
N.B. Providers and commissioners will need to agree their own local discharge criteria; hence this section of the booklet is editable.

The care transition pages in this booklet describe, for each cluster: the length of time service users are likely to remain in MH Services; a frequency for re-assessing the appropriateness of the cluster; and the likelihood of each possible cluster transition. It also attempts to visually represent the relationship between each cluster in terms of intensity, acuity and complexity etc.
N.B. In general cluster reviews should be aligned to care reviews. The review frequencies quoted are outer limits, not absolute frequencies.

As most practitioners work with specific groups of service users and will only routinely encounter a small number of clusters, they will become familiar with their own 'portion' of the booklet. In addition, the 6 steps described below will guide practitioners through the process.

Step-by-step guide to the use of MHCT ratings, cluster profiles and care transition protocols at care reviews

1. Select the page containing care transition protocols that correspond to the individual's current cluster.

2. After completing an appropriate re-assessment of risks and needs complete a new MHCT.

3. Consider the **step-up criteria**. If any one of these is met, this suggests the current cluster allocation needs to change and, with reference to the clustering booklet; the latest MHCT ratings should be used to decide on the new cluster. If the step-up criteria are not met…

4. Consider the **discharge criteria**. If all of these are met, this indicates the need to explore discharge from in-scope Mental Health Services back to GP-led (Primary) Care. If the discharge criteria are not met…

5. Consider the **step-down criteria**. If all of these are met, this suggests the current cluster allocation needs to change and, with reference to the clustering booklet, the MHCT ratings should be used to decide on the new cluster. If the step-down criteria are not met …

6. This indicates that the existing cluster allocation remains valid, as any differences in the user's needs that have occurred do not warrant the changes in service response that allocation to a different cluster would trigger.

Patient Safety

Any issues relating to service User safety that arise through the use of the Mental Health Clustering Tool and the Mental Health Care Clusters should be raised through your organisation’s own patient safety reporting routes. Any urgent Service User safety issues that directly relate to the clustering tool or the clusters should also be reported via pricing@monitor.gov.uk.

Brief note on changes made for 2016/17:

Each year the clustering booklet is reviewed. There are no major changes to the booklet for 2016/17 but we are repeating the changes included for 2015/16. We may, however issue a further version of the booklet later in the year as the Royal College of Psychiatrists will be publishing an updated version of HoNOS. This does not change the number of scales or the rating of the scales, but some of the language will be updated.

Changes were made last year in response to some difficulties reported when allocating some patients diagnosed with Bipolar Affective Disorder to a cluster. A specific guidance note on this issue is appended to the booklet. The main aim has been to legitimise the allocation of patients with Bipolar disorder to the complex non-psychotic clusters where psychosis has never been apparent, or where its occurrence was so long ago that the patient’s well-established pattern of needs does not fit well with the psychosis superclass.

Bipolar advice

All patients, including those with a diagnosis of bipolar disorder should be allocated to the cluster **which best describes the combination and severity of their primary presenting needs**. Patients with the same diagnosis can therefore be accurately allocated to different clusters within a superclass (non-psychotic, psychotic / organic). As a diagnosis of bipolar disorder covers a particularly wide variety of presentations these patients may be allocated to either a psychotic or a non-psychotic cluster depending on your clinical judgement, though consideration of the likely and unlikely diagnoses sections of the clustering booklet should be carefully considered.

Please see annex four of this document for further practice guidance regarding allocating patients with bipolar diagnosis to a cluster.

Advice concerning the transition of patients into and out of clusters 14 and 15 (psychotic crisis and psychotic depression)

Patients’ needs change over time. The clusters are relatively broad in nature and hence there will be a range of presentations (more – less well) within each. It is not unusual for patients in clusters 10, 13, 16 and 17 to relapse and be better described by cluster 14 i.e. be experiencing a psychotic crisis.
In this case, assuming the change in presentation warrants a significant change in the intensity of their treatment package, they should be re-clustered accordingly (i.e. to cluster 14).

Whilst not universally followed, this process is reasonably well recognised. Upon recovery however it is important to **take account of the patient's previous presentation** when stepping the patient down from cluster 14 post crisis.

So, if for example the patient has been in cluster 17 prior to their psychotic crisis, even if their symptoms are well controlled, at the point of stepping down from 14 it is unlikely that anything other than cluster 17 will meet their needs.

Similarly, if a patient in cluster 10 (first episode psychosis) becomes acutely unwell and warrants allocation to cluster 14, upon stepping-down, if they are within three years of initial presentation they should be re-allocated to cluster 10 for the remainder of their three year treatment package.

For the purposes of payment, where providers are being paid for an episode of care, it should be noted that a separate payment for cluster 14 will only be made when this is the first presentation of a patient into secondary mental health services. For other patients in receipt of on-going treatment, although the crisis should be recorded and captured using the clustering tool and reported via the Mental Health Dataset, the episodic payment should continue.

Appendix 1

Mental Health
Clustering Tool
Version 5.0

Mental Health Clustering Tool (MHCT) version 5.0 (2016)

The MHCT incorporates items from the Health of the Nations Outcome Scales (HoNOS), (Wing et al. 1999[1]) and the Summary of Assessments of Risk and Need (SARN), (Self et al 2008[2]) in order to provide all the information necessary to allocate individuals to clusters.

HoNOS is an internationally recognised outcome measure developed by the Royal College of Psychiatrists Research Unit (CRU) to measure health and social functioning outcomes in Mental Health Services. The aim of the HoNOS was to produce a brief measure capable of being completed routinely by clinicians and recorded as part of a minimum mental health dataset. The first twelve items of the MHCT are HoNOS items. The HoNOS items are used here with the permission of the Royal College of Psychiatrists, who hold the copyright. Readers will want to note that the Royal College will be publishing an updated version of HoNOS in early 2016 following an international review. Although some of the words will change the items and the scales will remain the same. The tool will be updated to reflect the new wording when it is available

SARN

The Summary of Assessments of Risk and Need (SARN) was developed by the Care Pathways and Packages Project[1] to aid in the process of establishing a classification of Service Users based on their needs so that appropriate service responses could be developed both at the individual and service level. It provides a brief description of the needs of people entering into Mental Health Services for the first time or presenting with a possible need for change in their care or treatment. It allows professionals from a range of backgrounds to summarise their assessments in a shared format. Thus it provides a common language for describing health states and related social conditions and improves communication between different users of the tool including health and social care professionals, Service Users themselves, commissioners and researchers.

Mental Health Clustering Tool (MHCT)

Part 1 contains scales relating to the severity of problems experienced by the individual during the 2 weeks prior to the date of the rating.

Part 2 contains scales that consider problems from a ‘historical’ perspective. These will be problems that occur in episodic or unpredictable ways. Whilst they may not have been experienced by the individual during the two weeks prior to the rating date, clinical judgement would suggest that there is still a cause for concern that cannot be disregarded (i.e. no evidence to suggest that the person has changed since the last occurrence either as a result of time, therapy, medication or environment etc.). In these circumstances, any event that remains relevant to the cluster allocation (and hence the interventions offered) should be included.

Summary of rating information

- **Rate each scale in order from 1 to 13 (Part 1), followed by A to E (Part 2).**
- **For the first 12 scales, do not include information rated in an earlier scale except for scale 10 which is an overall rating.**
- **Rate the MOST SEVERE problem that occurred in the rating period**
- **All scales follow the format:**

0 = no problem
1 = minor problem requiring no action
2 = mild problem but definitely present
3 = moderately severe problem
4 = severe to very severe problem
Rate 9 if Not Known but be aware that this is likely to make accurate clustering impractical and indicate that further assessment is required.

---

[1] CPPP was a consortium of providers and commissioners in Yorkshire and the North East that undertook the initial development work on mental health currencies.

References

[1] Wing, J. K., Curtis, R. H. & Beevor, A. S. (1999) Health of the Nation Outcome Scales (HoNOS). *British Journal of Psychiatry, 174 (5), 432-434***.**

[2] Self R; Rigby A; Leggett C and Paxton R (2008) Clinical Decision Support Tool: A rational needs-based approach to making clinical decisions. *Journal of Mental Health*, 17(1): 33-48.

PART 1: Current Ratings

For scales 1-13, rate the most severe occurrence in the previous two weeks

1. Overactive, aggressive, disruptive or agitated behaviour (current)

	0	1	2	3	4
• *Include such behaviour due to any cause (e.g. drugs, alcohol, dementia, psychosis, depression, etc.)* • *Do not include bizarre behaviour rated at Scale 6.*	No problem of this kind during the period rated.	Irritability, quarrels, restlessness etc. not requiring action.	Includes aggressive gestures, pushing or pestering others; threats or verbal aggression; lesser damage to property (e.g. broken cup, window); marked over-activity or agitation.	Physically aggressive to others or animals (short of rating 4); threatening manner; more serious over-activity or destruction of property.	At least one serious physical attack on others or on animals; destructive of property (e.g. fire-setting); serious intimidation or obscene behaviour. ***Rate 9 if not known***

2. Non-accidental self-injury (current)

	0	1	2	3	4
• *Do not include accidental self-injury (due e.g. to dementia or severe learning disability); the cognitive problem is rated at Scale 4 and the injury at Scale 5.* • *Do not include illness or injury as a direct consequence of drug/alcohol use rated at Scale 3 (e.g. cirrhosis of the liver) or injury resulting from drink driving which are rated at Scale 5).*	No problem of this kind during the period rated.	Fleeting thoughts about ending it all but little risk during the period rated; no self-harm.	Mild risk during the period rated; includes non-hazardous self-harm (e.g. wrist-scratching).	Moderate to serious risk of deliberate self-harm during the period rated; includes preparatory acts (e.g. collecting tablets).	Serious suicidal attempt and/or serious deliberate self-injury during the period rated. ***Rate 9 if Not Known***

3. Problem-drinking or drug-taking (current)

	0	1	2	3	4
• *Do not include aggressive/destructive behaviour due to alcohol or drug use, rated at Scale 1.* • *Do not include Physical Illness or disability problems or disability due to alcohol or drug use, rated at Scale 5.*	No problem of this kind during the period rated.	Some over-indulgence but within social norm.	Loss of control of drinking or drug-taking, but not seriously addicted.	Marked craving or dependence on alcohol or drugs with frequent loss of control; risk taking under the influence.	Incapacitated by alcohol/drug problem. ***Rate 9 if Not Known***

4. Cognitive problems (current)

	0	1	2	3	4
• *Include problems of memory, orientation and understanding associated with any disorder: learning disability, dementia, schizophrenia, etc.* • *Do not include temporary problems (e.g. hangovers) resulting from drug/alcohol use, rated at Scale 3.*	No problem of this kind during the period rated.	Minor problems with memory or understanding (e.g. forgets names occasionally).	Mild but definite problems (e.g. has lost the way in a familiar place or failed to recognise a familiar person); sometimes mixed up about simple decisions.	Marked disorientation in time, place or person; bewildered by everyday events; speech is sometimes incoherent; mental slowing.	Severe disorientation (e.g. unable to recognise relatives); at risk of accidents; speech incomprehensible; clouding or stupor. ***Rate 9 if Not Known***

5. Physical Illness or disability problems (current)

	0	1	2	3	4
• *Include illness or disability from any cause that limits or prevents movement, or impairs sight or hearing, or otherwise interferes with personal functioning.* • *Include side-effects from medication; effects of drug/alcohol use; physical disabilities resulting from accidents or self-harm associated with cognitive problems, drink-driving, etc.* • *Do not include mental/behavioural problems rated at Scale 4.*	No physical health problem during the period rated.	Minor health problems during the period (e.g. cold, non-serious fall, etc.)	Physical health problem imposes mild restriction on mobility and activity.	Moderate degree of restriction on activity due to physical health problem.	Severe or complete incapacity due to physical health problem. ***Rate 9 if Not Known***

6. Problems associated with hallucinations and delusions (current)

	0	1	2	3	4
• *Include hallucinations and delusions irrespective of diagnosis.* • *Include odd and bizarre behaviour associated with hallucinations or delusions.* • *Do not include aggressive, destructive or overactive behaviours attributed to hallucinations or delusions, rated at Scale 1.*	No evidence of hallucinations or delusions during the period rated.	Somewhat odd or eccentric beliefs not in keeping with cultural norms.	Delusions or hallucinations (e.g. voices, visions) are present, but there is little distress to patient or manifestation in bizarre behaviour, i.e. clinically present but mild.	Marked preoccupation with delusions or hallucinations, causing much distress and/or manifested in obviously bizarre behaviour, i.e. moderately severe clinical problem.	Mental state and behaviour is seriously and adversely affected by delusions or hallucinations, with severe impact on patient. ***Rate 9 if Not Known***

7. Problems with depressed mood (current)

	0	1	2	3	4
• *Do not include over-activity or agitation, rated at Scale 1.* • *Do not include suicidal ideation or attempts, rated at Scale 2.* • *Do not include delusions or hallucinations, rated at Scale 6.*	No problem associated with depressed mood during the period rated.	Gloomy; or minor changes in mood.	Mild but definite depression and distress (e.g. feelings of guilt; loss of self-esteem).	Depression with inappropriate self-blame; preoccupied with feelings of guilt.	Severe or very severe depression, with guilt or self-accusation. ***Rate 9 if Not Known***

8. Other mental and behavioural problems (current)

	0	1	2	3	4
• *Rate only the most severe clinical problem not considered at scales 6 and 7 as follows.* • *Specify the type of problem by entering the appropriate letter: A phobic; B anxiety; C obsessive-compulsive; D mental strain/tension; E dissociative; F somatoform; G eating; H sleep; I sexual; J other, specify.*	No evidence of any of these problems during period rated.	Minor problems only.	A problem is clinically present at a mild level (e.g. patient has a degree of control).	Occasional severe attack or distress, with loss of control (e.g. has to avoid anxiety provoking situations altogether, call in a neighbour to help, etc.) i.e. moderately severe level of problem.	Severe problem dominates most activities. ***Rate 9 if Not Known***

9. Problems with relationships (current)

	0	1	2	3	4
• *Rate the patient's most severe problem associated with active or passive withdrawal from social relationships, and/or non-supportive, destructive or self-damaging relationships.*	No significant problem during the period.	Minor non-clinical problems.	Definite problem in making or sustaining supportive relationships; patient complains and/or problems are evident to others.	Persisting major problem due to active or passive withdrawal from social relationships and/or to relationships that provide little or no comfort or support.	Severe and distressing social isolation due to inability to communicate socially and/or withdrawal from social relationships. ***Rate 9 if Not Known***

10. Problems with activities of daily living (current)

	0	1	2	3	4
• *Rate the overall level of functioning in activities of daily living (ADL) (e.g. problems with basic activities of self-care such as eating, washing, dressing, toilet; also complex skills such as budgeting, organising where to live, occupation and recreation, mobility and use of transport, shopping, self-development, etc.).* • *Include any lack of motivation for using self-help opportunities, since this contributes to a lower overall level of functioning.* • *Do not include lack of opportunities for exercising intact abilities and skills, rated at Scales 11-12.*	No problem during period rated; good ability to function in all areas.	Minor problems only (e.g. untidy, disorganised).	Self-care adequate, but major lack of performance of one or more complex skills (see above).	Major problem in one or more areas of self-care (eating, washing, dressing, toilet) as well as major inability to perform several complex skills.	Severe disability or incapacity in all or nearly all areas of self-care and complex skills. ***Rate 9 if Not Known***

11. Problems with living conditions (current)

	0	1	2	3	4
• *Rate the overall severity of problems with the quality of living conditions and daily domestic routine. Are the basic necessities met (heat, light, hygiene)? If so, is there help to cope with disabilities and a choice of opportunities to use skills and develop new ones?* • *Do not rate the level of functional disability itself, rated at Scale 10.* **NB: Rate patient's usual situation. If in acute ward, rate activities during period before admission. If information not available, rate 9.**	Accommodation and living conditions are acceptable; helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.	Accommodation is reasonably acceptable although there are minor or transient problems (e.g. not ideal location, not preferred option, doesn't like the food, etc.)	Significant problem with one or more aspects of the accommodation and/or regime (e.g. restricted choice; staff or household have little understanding of how to limit disability or how to help use or develop new or intact skills).	Distressing multiple problems with accommodation (e.g. some basic necessities absent); housing environment has minimal or no facilities to improve patient's independence.	Accommodation is unacceptable (e.g. lack of basic necessities, patient is at risk of eviction, or 'roofless', or living conditions are otherwise intolerable) making patient's problems worse. ***Rate 9 if Not Known***

12. Problems with occupation and activities (current)

	0	1	2	3	4
• *Rate the overall level of problems with quality of day-time environment. Is there help to cope with disabilities, and opportunities for maintaining or improving occupational and recreational skills and activities? Consider factors such as stigma, lack of qualified staff, access to supportive facilities e.g. staffing and equipment of day centres, workshops, social clubs, etc.* • *Do not rate the level of functional disability itself, rated at Scale 10.* **NB: Rate patient's usual situation. If in acute ward, rate activities during period before admission. If information not available, rate 9.**	Patient's day-time environment is acceptable: helpful in keeping any disability rated at Scale 10 to the lowest level possible, and supportive of self-help.	Minor or temporary problems (e.g. late giro cheques): reasonable facilities available but not always at desired times, etc.	Limited choice of activities; lack of reasonable tolerance (e.g. unfairly refused entry to public library or baths, etc.); handicapped by lack of a permanent address; insufficient carer or professional support; helpful day setting available but for very limited hours.	Marked deficiency in skilled services available to help minimise level of existing disability; no opportunities to use intact skills or add new ones; unskilled care difficult to access.	Lack of any opportunity for daytime activities makes patient's problems worse. ***Rate 9 if Not Known***

13. Strong unreasonable beliefs that are not psychotic in origin (current)

	0	1	2	3	4
• *Rate any apparent strong unreasonable beliefs (found in* ***some*** *people with disorders such as Obsessive Compulsive Disorder, Anorexia Nervosa, personality disorder, morbid jealousy etc.)* • *Do not include Delusions rated at scale 6.* • *Do not include Severity of disorders listed above where strong unreasonable beliefs are not present – rated at Scale 8.* • *Do not include Beliefs/behaviours consistent with a person's culture.*	No Strong unreasonable beliefs evident.	Holds illogical or unreasonable belief(s) but has insight into their lack of logic or reasonableness and can challenge them most of the time and they have only a minor impact on the individual's life.	Holds illogical or unreasonable belief(s) but individual has insight into their lack of logic or reasonableness. Belief(s) can be successfully challenged by individual on occasions. Beliefs have a mild impact on the person's life.	Holds strong illogical and unreasonable belief(s) but has some insight into the relationship between the beliefs and the disorder. Belief(s) can be 'shaken' by rational argument. Tries to resist belief but with little effect. Has a significant negative impact on person's life. The disorder makes treatment more difficult than usual.	Holds strong illogical or unreasonable belief(s) with little or no insight in the relationship between the belief and the disorder. Belief(s) cannot be 'shaken' by rational argument. Does not attempt to resist belief(s). Has a significant negative impact on the person's life or other people's lives and the disorder is very resistant to treatment. ***Rate 9 if not known***

PART 2: Historical Ratings

Scales A-E, rate problems that occur in an episodic or unpredictable way. Include any event that remains relevant to the current plan of care.

Whilst there may or may not be any direct observation or report of a manifestation during the last two weeks, the evidence and clinical judgement would suggest that there is still a cause for concern that cannot be disregarded (i.e. no evidence to suggest that the person has changed since the last occurrence either as a result of time, therapy, medication or environment etc.)

A. Agitated behaviour/expansive mood (historical)

	0	1	2	3	4
• *Rate agitation and overactive behaviour causing disruption to social role functioning. Behaviour causing concern or harm to others.* • *Elevated mood that is out of proportion to circumstances.* • *Include such behaviour due to any cause (e.g. drugs, alcohol, dementia, psychosis, depression etc.)* • *Excessive irritability, restlessness, intimidation, obscene behaviour and aggression to people animals or property.* • *Do not include odd or bizarre behaviour to be rated at Scale 6.*	No needs in this area.	Presents as irritable, argumentative with some agitation. Some signs of elevated mood or agitation not causing disruption to functioning.	Makes verbal/gestural threats. Pushes/pesters but no evidence of intent to cause serious harm. Causes minor damage to property (e.g. glass or crockery). Is obviously over-active or agitated.	Agitation or threatening manner causing fear in others. Physical aggression to people or animals. Property destruction. Serious levels of elevated mood, agitation, restlessness causing significant disruption to functioning.	Serious physical harm caused to persons/animals. Major destruction of property. Seriously intimidating others or exhibiting highly obscene behaviour. Elevated mood, agitation, restlessness causing complete disruption. ***Rate 9 if not known***

B. Repeat self-harm (historical)

	0	1	2	3	4
• *Rate repeat acts of self-harm with the intention of managing people, stressful situations, emotions or to produce mutilation for any reason.* • *Include self-cutting, biting, striking, burning, breaking bones or taking poisonous substances etc.* • *Do not include accidental self-injury (due e.g. to learning disability or cognitive impairment); the cognitive problem is rated at Scale 4 and the injury at Scale 5.* • *Do not include harm as a direct consequence of drug/alcohol use (e.g. liver damage) to be rated at Scale 3. Injury sustained whilst intoxicated to be rated at Scale 5.* • *Do not include harm with intention of killing self (rated at Scale 2).*	No problem of this kind.	Superficial scratching or non-hazardous doses of drugs.	Superficial cutting, biting, bruising etc. or small ingestions of hazardous substances unlikely to lead to significant harm even if hospital treatment not sought.	Repeat self-injury requiring hospital treatment. Possible dangers if hospital treatment not sought. However, unlikely to leave lasting severe damage even if behaviour continues providing hospital treatment sought.	Repeat serious self-injury requiring hospital treatment and likely to leave lasting severe damage if behaviour continues (i.e. severe scarring, crippling or damage to internal organ) and possibly to death. ***Rate 9 if not known***

C. Safeguarding other children & vulnerable adults (historical)

	0	1	2	3	4
• *Rate the potential or actual impact of the patient's mental illness, or behaviour, on the safety and well-being of vulnerable people of any age.* • *Include any patient who has substantial access and contact with children or other vulnerable persons.* • *Do not include risk to wider population covered at scale A.* • *Do not include challenge to relationships covered in scale 9.*	No obvious impact of the individual's illness or behaviour on the safety or well-being of vulnerable persons.	Mild concerns about the impact of the individual's illness or behaviour on the safety or well-being of vulnerable persons.	Illness or behaviour has an impact on the safety or well-being of vulnerable persons. The individual is aware of the potential impact but is supported and is able to make adequate arrangements.	Illness or behaviour has an impact on the safety or well-being of vulnerable persons but does not meet the criteria to rate 4. There may be delusions, non-accidental self-injury risk or self-harm. However, the individual has insight, can take action to significantly reduce the impact of their behaviour on the children and is adequately supported.	Without action the illness or behaviour is likely to have direct or indirect significant impact on the safety or well-being of vulnerable persons. Problems such as delusions, severe non-accidental self-injury risk or problems of impulse control may be present. There may be lack of insight, an inability or unwillingness to take precautions to protect vulnerable persons and/or lack of adequate support and protection for vulnerable persons. ***Rate 9 if not known***

D. Engagement (historical)

	0	1	2	3	4
• *Rate the individual's motivation and understanding of their problems, acceptance of their care/treatment and ability to relate to care staff.* • *Include the ability, willingness or motivation to engage in their care/ treatment appropriately, agreeing personal goals, attending appointments. Dependency issues.* • *Do not include Cognitive issues as in scale 4, severity of illness or failure to comply due to practical reasons.*	Has ability to engage/disengage appropriately with services. Has good understanding of problems and care plan.	Some reluctance to engage or slight risk of dependency. Has understanding of own problems.	Occasional difficulties in engagement, i.e. missed appointments or contacting services between appointments inappropriately. Some understanding of own problems.	Contacts services inappropriately. Has little understanding of own problems. Unreliable attendance at appointments. Or attendance depends on prompting or support.	Contacts multiple agencies, i.e. GP, A & E etc. constantly. Little or no understanding of own problems. Fails to comply with planned care. Rarely attends appointments. Refuses service input. Or Attendance and compliance dependent on intensive prompting and support. ***Rate 9 if not known***

E. Vulnerability (historical)

	0	1	2	3	4
• *Rate failure of an individual to protect themselves from risk of harm to their health and safety or well-being.* • *Include physical, sexual, emotional and financial exploitation or harm/harassment* • *Do not include problems of engagement rated at scale D.*	No vulnerability evident.	No significant impact on person's health, safety or well-being.	Concern about the individual's ability to protect their health, safety or well-being requiring support or removal of existing support would increase concern.	Clear evidence of significant vulnerability affecting the individual's ability to protect their health and safety or well-being that requires support (but not as severe as a rating of 4). Or removal of existing support would increase risk.	Severe vulnerability – total breakdown in individual's ability to protect themselves resulting in major risk to the individual's health, safety or well-being. ***Rate 9 if not known***

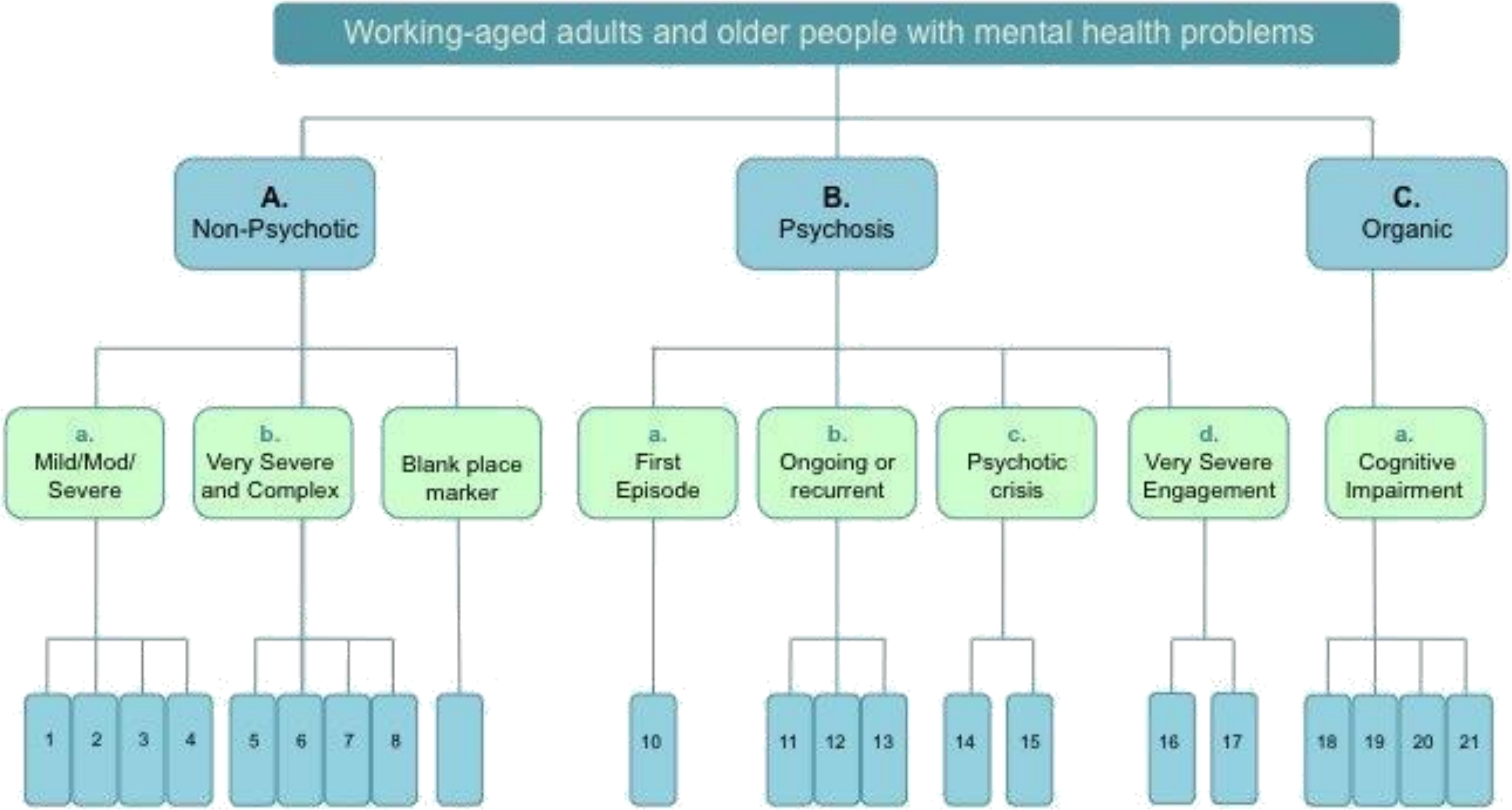
Item	**Rating**	**Item**	**Rating**
Part 1 (Current)		Part 2 (Historical)	
1		**A**	
2		**B**	
3		**C**	
4		**D**	
5		**E**	
6			
7			
8			
Please Circle	A B C D E F G H I J		
N.B. If J – (other) please specify			
9			
10			
11			
12			
13			

Appendix 2

Decision Tree

DECISION TREE

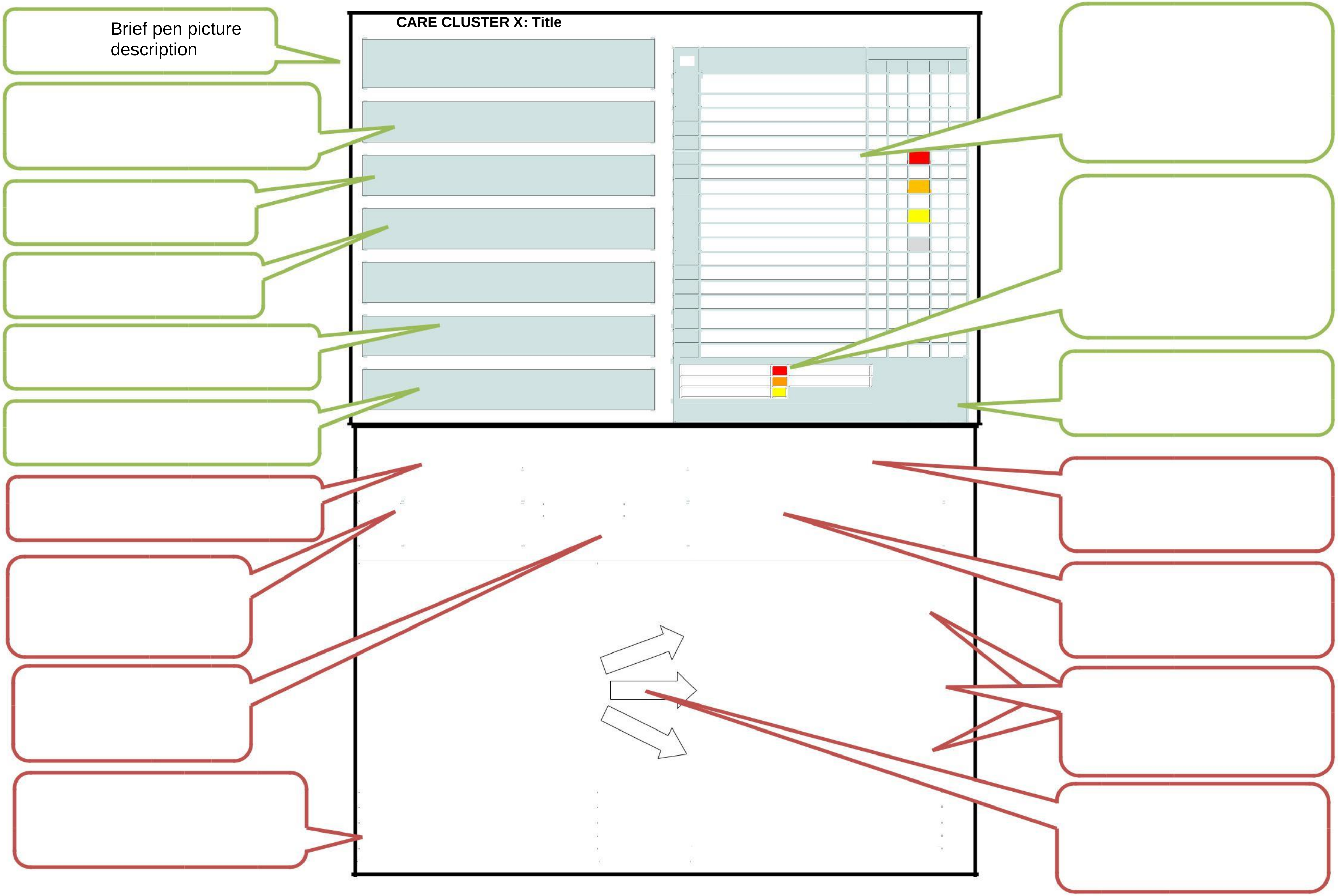
(RELATIONSHIP OF CARE CLUSTERS TO EACH OTHER)



Appendix 3

Cluster Descriptions
& Care Transition Protocols

Guide to appendix 3


Brief pen picture description
CARE CLUSTER X: Title

CARE CLUSTER 7: Enduring Non-Psychotic Disorders (High Disability)

(longer-term management) CG 133, Depression with Chronic health Problems CG91

Description:
This group suffers from moderate to severe disorders that are very disabling. They will have received treatment for a number of years and although they may have improvement in positive symptoms considerable disability remains that is likely to affect role functioning in many ways.

Likely primary diagnosis:
Likely to include: F32 Depressive Episode (Non-Psychotic), F33 Recurrent Depressive Episode (Non-Psychotic), F40 Phobic Anxiety Disorders, F41 Other Anxiety Disorders, F42 Obsessive-Compulsive Disorder, F43 Stress Reaction/Adjustment Disorder, F44 Dissociative Disorder, F45 Somatoform Disorder, F48 Other Neurotic Disorders, F50 Eating Disorder and some F60.

Unlikely primary diagnosis:
F00-03 Dementias, F20-29 Schizophrenia, schizotypal and delusional disorders , F30 Manic Episode, F31.2&31.5 Bipolar Disorder with psychosis

Impairment:
Likely to seriously affect activity and role functioning in many ways.

Risk:
Unlikely to be a major feature but safeguarding may be an issue if any responsibility for young children or vulnerable dependant adults.

Course:
The problems will be enduring.

Likely NICE Guidance:
Service user experience in adult mental health CG136, Eating Disorders CG9, OCD CG31, Anxiety CG113, Depression in adults CG90, Medicines adherence CG76, Post-traumatic stress-disorder (PTSD) CG26, Antisocial personality Disorder CG77, Borderline Personality Disorder CG78, Self-harm

No	Item Description	Rating				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	🟨	🟨	🟨	⬜	⬜
2	Non-accidental self-injury	🟧	🟧	🟧	⬜	⬜
3	Problem drinking or drug taking	⬜	🟨	🟨	⬜	⬜
4	Cognitive Problems	🟨	🟨	🟨	⬜	⬜
5	Physical Illness or disability problems	🟨	🟨	🟨	⬜	⬜
6	Hallucinations and Delusions	🟨	🟨	🟨	⬜	⬜
7	Depressed mood *	⬜	⬜	🟥	🟥	⬜
8	Other mental and behavioural problems *	⬜	⬜	🟥	🟥	⬜
9	Relationships	⬜	🟧	🟧	🟧	⬜
10	Activities of daily living	⬜	🟨	🟨	🟨	⬜
11	Living conditions	⬜	🟨	🟨	🟨	⬜
12	Occupation & Activities	⬜	🟨	🟨	🟨	⬜
13	Strong Unreasonable Beliefs	⬜	⬜	🟧	🟧	🟧
		⬜	⬜	⬜	⬜	⬜
A	Agitated behaviour/expansive mood	🟨	🟨	🟨	⬜	⬜
B	Repeat Self-Harm	🟧	🟧	🟧	⬜	⬜
C	Safeguarding other children & vulnerable dependant adults	🟨	🟨	🟨	⬜	⬜
D	Engagement	🟧	🟧	🟧	🟧	⬜
E	Vulnerability	⬜	🟨	🟨	🟨	⬜

Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▒
May score	🟨		

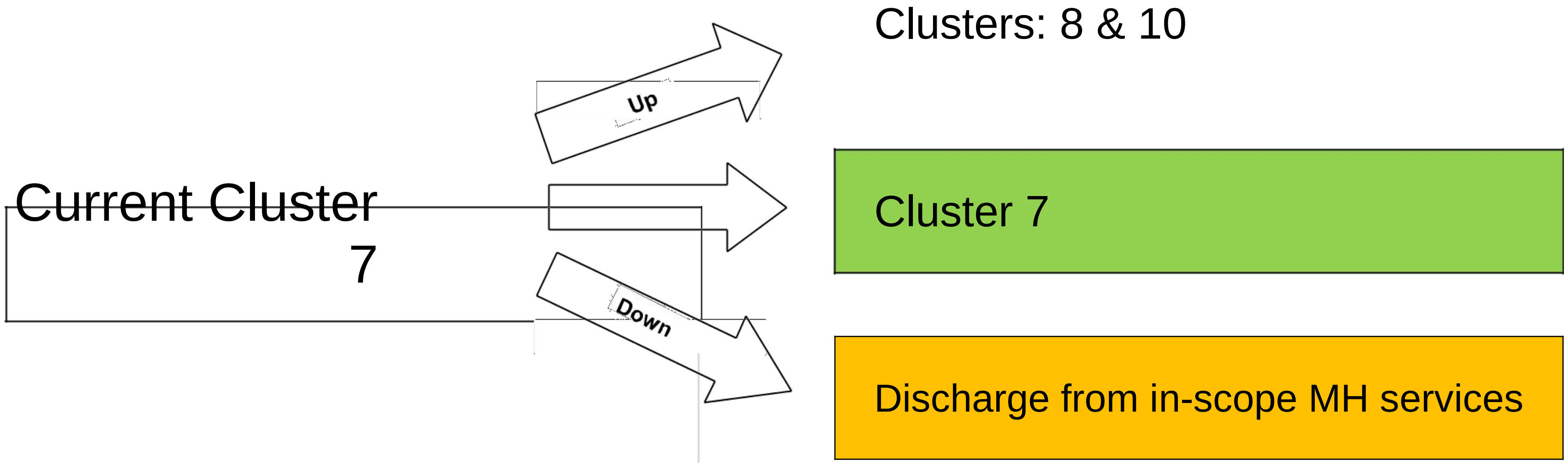
***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

CARE TRANSITION PROTOCOLS - Cluster 7: Enduring Non-Psychotic Disorders (high disability)

Indicative episode of care: 3 years +

Cluster reviews at least: Annually

Cluster	Step-up Criteria (The following criterion is met)	Example local discharge Criteria for MH services (All of the following criteria are met)	Step-down Criteria (The following criterion is met)
7	• Service User fits description and scoring profile of any likely/ possible 'step-up' cluster.	• MHCT V1 item 2 (Non-accidental self-injury) = 1 or less • MHCT V1 item 7 (Depression) = 1 or less • MHCT V1 item 8 (Other) = 1 or less N/A	• Service User fits description and scoring profile of any likely/ possible 'step-down' cluster.



Clusters: 8 & 10

Current Cluster 7

Cluster 7

Discharge from in-scope MH services

Key:

🟩 Most likely transition(s)

🟧 Possible transition

🟥 Rare Transition

Clusters: 1-6 11-17 & 18-21

CARE CLUSTER 8: Non-Psychotic Chaotic and Challenging Disorders

Description:
This group will have a wide range of symptoms and chaotic and challenging lifestyles. They are characterised by moderate to very severe repeat deliberate self-harm and/or other impulsive behaviour and chaotic, over dependent engagement and often hostile with services.

Likely primary diagnosis:
Likely to include F60 Personality disorder.

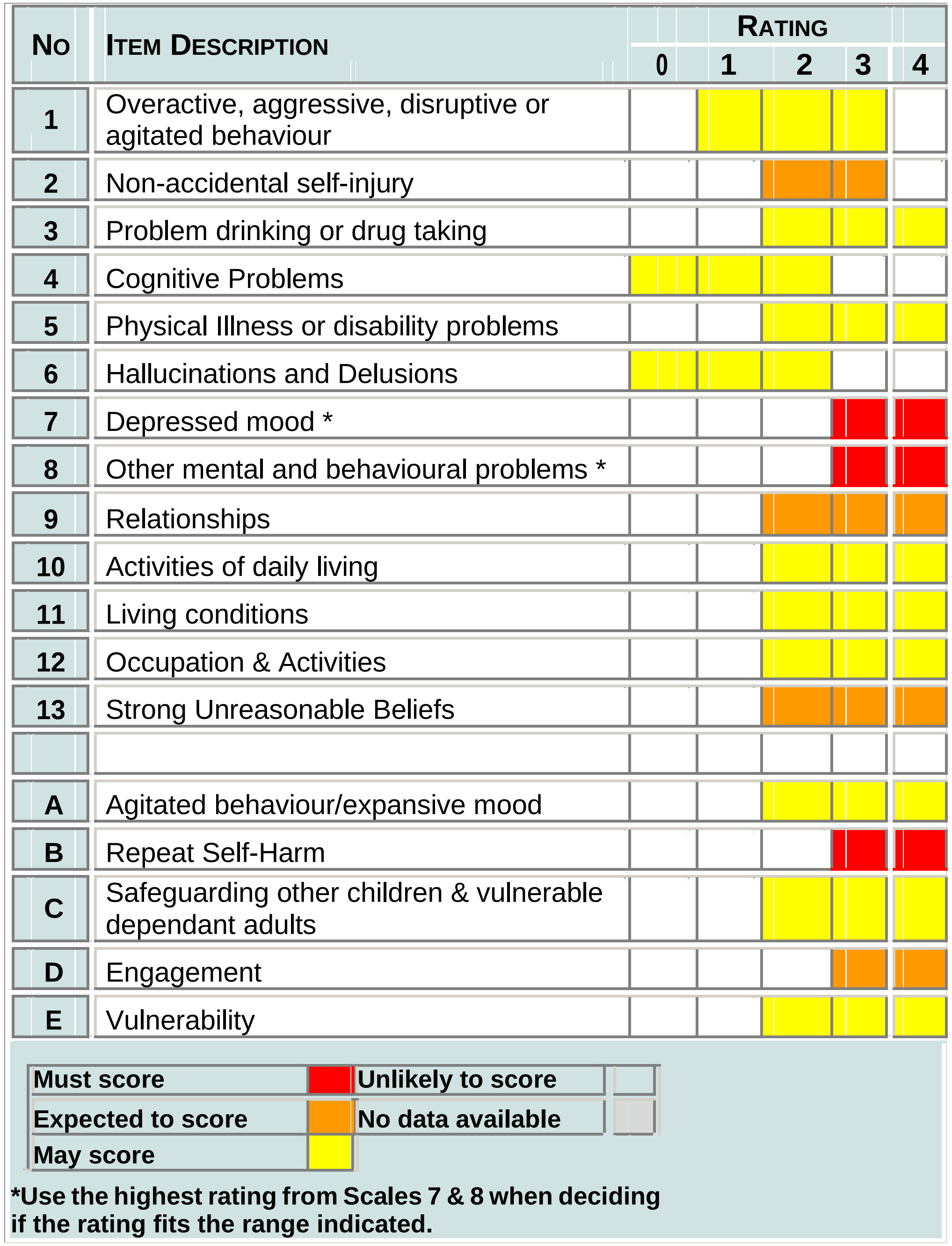
Unlikely primary diagnosis:
F00-03 Dementias, F20-29 Schizophrenia, schizotypal and delusional disorders , F30 Manic Episode, F31 Bipolar Disorder.

Impairment:
Poor role functioning with severe problems in relationships.

Risk:
Moderate to very severe repeat deliberate self-harm, with chaotic, over dependent and often hostile engagement with service. Non-accidental self-injury risks likely to be present. Safeguarding may be an issue.

Course:
The problems will be enduring.

Likely NICE Guidance:
Service user experience in adult mental health CG136, Borderline Personality Disorder CG78, Self-harm CG16, Self-harm (longer-term management) CG 133, Post-traumatic stress-disorder (PTSD) CG 26 Depression in adults CG90, Anxiety CG113, Alcohol dependence and harmful alcohol misuse CG115, Antisocial personality disorder CG77.



No	Item Description	Rating				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour		🟨	🟨	🟨	
2	Non-accidental self-injury			🟧	🟧	
3	Problem drinking or drug taking			🟨	🟨	🟨
4	Cognitive Problems	🟨	🟨	🟨		
5	Physical Illness or disability problems			🟨	🟨	🟨
6	Hallucinations and Delusions	🟨	🟨	🟨		
7	Depressed mood *				🟥	🟥
8	Other mental and behavioural problems *				🟥	🟥
9	Relationships			🟧	🟧	🟧
10	Activities of daily living			🟨	🟨	🟨
11	Living conditions			🟨	🟨	🟨
12	Occupation & Activities			🟨	🟨	🟨
13	Strong Unreasonable Beliefs			🟧	🟧	🟧
A	Agitated behaviour/expansive mood			🟨	🟨	🟨
B	Repeat Self-Harm				🟥	🟥
C	Safeguarding other children & vulnerable dependant adults			🟨	🟨	🟨
D	Engagement				🟧	🟧
E	Vulnerability			🟨	🟨	🟨

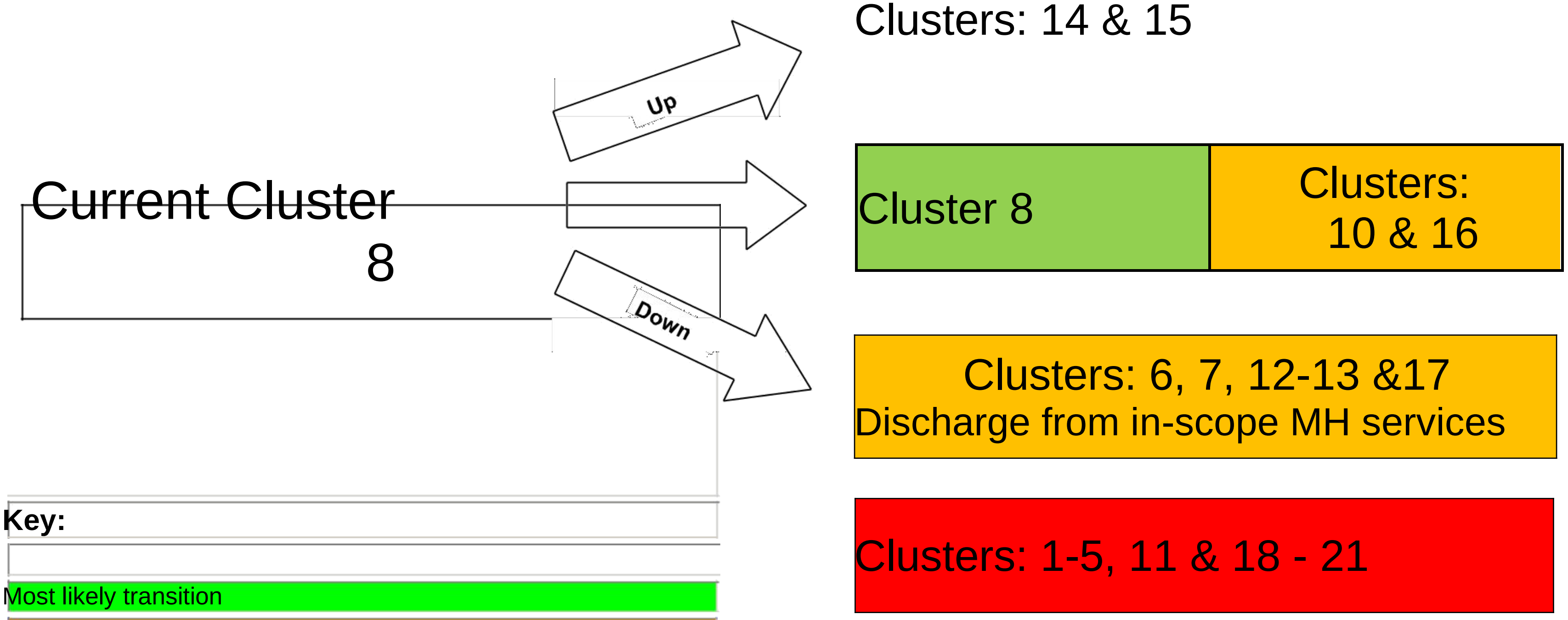
Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▨
May score	🟨		

***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

CARE TRANSITION PROTOCOLS - Cluster 8: Non-Psychotic Chaotic and Challenging Disorders

Indicative episode of care: 3 years + **Cluster reviews at least:** Annually

Cluster	Step-up Criteria (The following criterion is met)	Example local discharge Criteria for MH services (All of the following criteria are met)	Step-down Criteria (The following criterion is met)
8	• Service User fits description and scoring profile of any likely/ possible 'step-up' cluster.	• MHCT V1 item 2 (Non-accidental self-injury) = 1 or less • MHCT V1 item B (self-harm) = 1 or less • MHCT V1 item 7 (Depression) = 1 or less • MHCT V1 Item 8 (Other) = 1 or less	• Service User fits description and scoring profile of any likely/ possible 'step-down' cluster consistently for the past 12 months.



Current Cluster 8

Up

Down

Clusters: 14 & 15

Cluster 8

Clusters: 10 & 16

Clusters: 6, 7, 12-13 &17
Discharge from in-scope MH services

Clusters: 1-5, 11 & 18 - 21

Key:

🟩 Most likely transition

🟧 Possible transition

🟥 Rare Transition

CARE CLUSTER 12: Ongoing or Recurrent Psychosis (High Disability)

Description:
This group has a history of psychotic symptoms with a significant disability with major impact on role functioning. They are likely to be vulnerable to abuse or exploitation.

Likely primary diagnosis:
Likely to include (F20-F29) Schizophrenia, schizotypal and delusional disorders F30 Manic Episode, F31 Bipolar Affective Disorder.

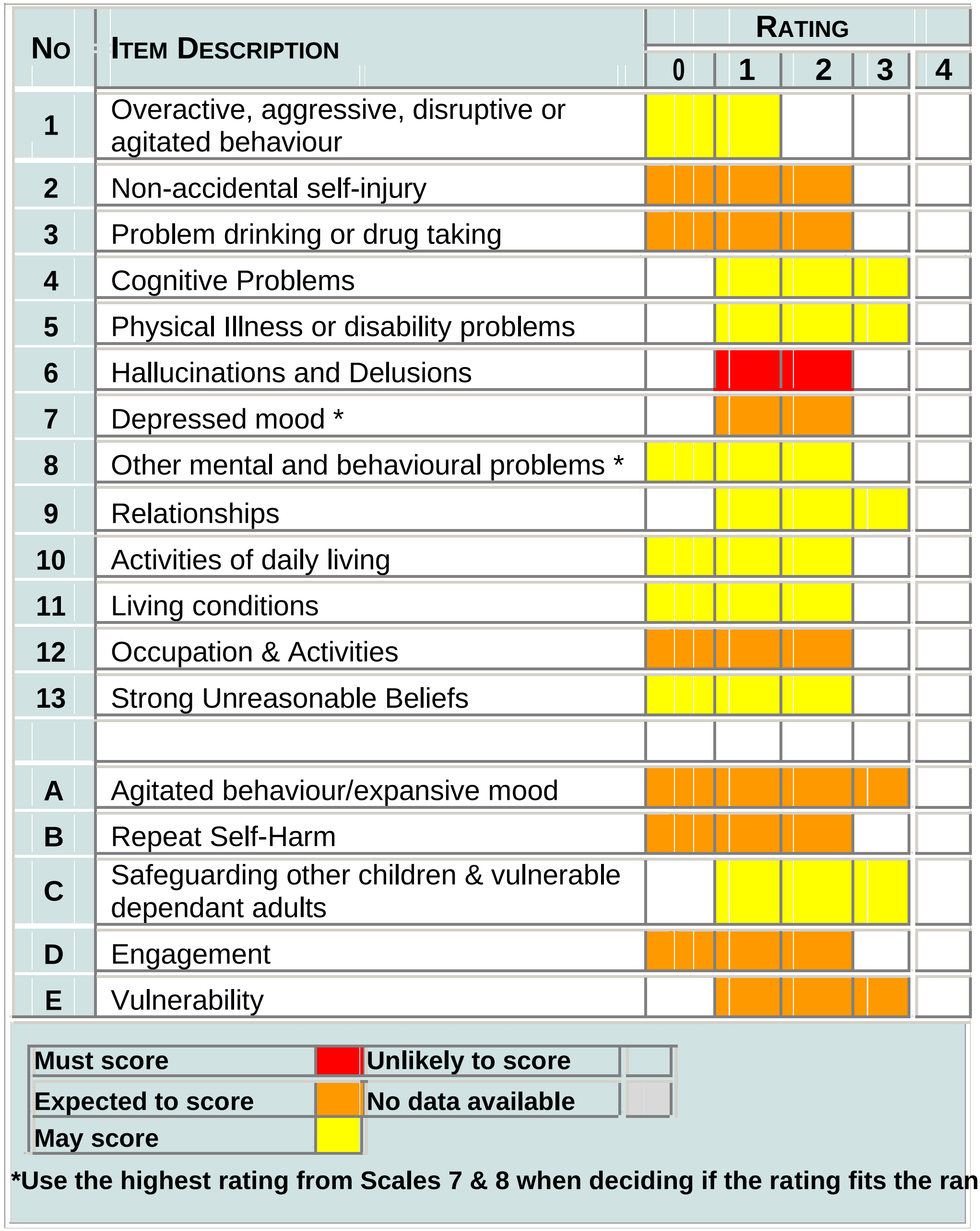
Unlikely primary diagnosis:
F00-03 Dementias, F32 Depressive episode, F33 Recurrent depressive disorder, F40-48 Neurotic, stress-related and somatoform disorders, F50 Eating disorders, F60 Specific personality disorders.

Impairment:
Possible cognitive and physical problems linked with long-term illness and medication. May have limited survival skills and be lacking basic life skills and poor role functioning in all areas.

Risk:
Vulnerable to abuse or exploitation.

Course:
Long term.

Likely NICE Guidance:
Service user experience in adult mental health CG136, Schizophrenia (update) CG82, Bipolar disorder CG38, Self-Harm CG16 , Self-harm (longer-term management) CG 133, Medicines adherence CG76.



NO	ITEM DESCRIPTION	RATING				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	🟨	🟨			
2	Non-accidental self-injury	🟧	🟧	🟧		
3	Problem drinking or drug taking	🟧	🟧	🟧		
4	Cognitive Problems		🟨	🟨	🟨	
5	Physical Illness or disability problems		🟨	🟨	🟨	
6	Hallucinations and Delusions		🟥	🟥		
7	Depressed mood *		🟧	🟧		
8	Other mental and behavioural problems *	🟨	🟨	🟨		
9	Relationships		🟨	🟨	🟨	
10	Activities of daily living	🟨	🟨	🟨		
11	Living conditions	🟨	🟨	🟨		
12	Occupation & Activities	🟧	🟧	🟧		
13	Strong Unreasonable Beliefs	🟨	🟨	🟨		
A	Agitated behaviour/expansive mood	🟧	🟧	🟧	🟧	
B	Repeat Self-Harm	🟧	🟧	🟧		
C	Safeguarding other children & vulnerable dependant adults		🟨	🟨	🟨	
D	Engagement	🟧	🟧	🟧		
E	Vulnerability		🟧	🟧	🟧	

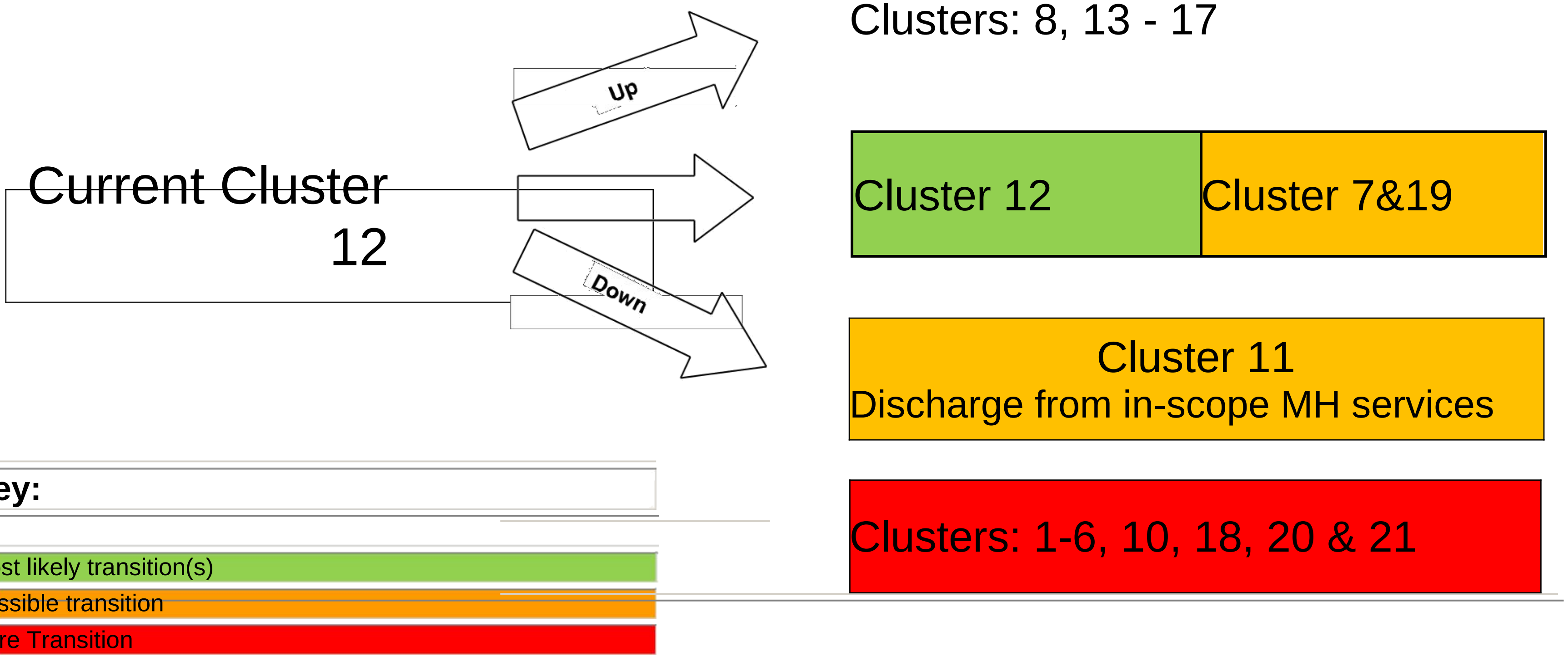
Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▨
May score	🟨		

***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

ARE TRANSITION PROTOCOLS - Cluster 12: Ongoing or Recurrent Psychosis (high disability)

Indicative episode of care: 3 years + **Cluster reviews at least:** Annually

Cluster	Step-up Criteria (The following criterion is met)	<u>Example local discharge Criteria</u> for MH services (<u>All</u> of the following criteria are met)	Step-down Criteria (The following criterion is met)
12	• Service User fits description and scoring profile of any likely/ possible 'step-up' cluster.	• Fits profile of cluster 12 at the point of the planned CPA review, and has done so consistently for the past 12 months. • Requires no psychotropic medication or has been on a stable dose for the past year. • Not currently detained under the Mental Health Act. • Has required no inpatient / IHT packages for the past year. • Any residual risks can be managed by primary care. • Scores 0-1 on MHCT V1 item 12 (Occupation and Activities). • Level of social inclusion meets service user's expectations.	• Service User fits description and scoring profile of any likely/ possible 'step-down' cluster consistently for the past 12 months.



Current Cluster 12

Up

Down

Clusters: 8, 13 - 17

Cluster 12

Cluster 7&19

Cluster 11

Discharge from in-scope MH services

Clusters: 1-6, 10, 18, 20 & 21

Key:

- 🟩 Most likely transition(s)
- 🟧 Possible transition
- 🟥 Rare Transition

CARE CLUSTER 13: Ongoing or Recurrent Psychosis (High Symptom & Disability)

Description:
This group will have a history of psychotic symptoms which are not controlled. They will present with severe to very severe psychotic symptoms and some anxiety or depression. They have a significant disability with major impact on role functioning.

Likely primary diagnosis:
Likely to include (F20-F29) Schizophrenia, schizotypal and delusional disorders F30 Manic Episode, F31 Bipolar Affective Disorder.

Unlikely primary diagnosis:
F00-03 Dementias, F32 Depressive episode, F33 Recurrent depressive disorder, F40-48 Neurotic, stress-related and somatoform disorders, F50 Eating disorders, F60 Specific personality disorders

Impairment:
Possible cognitive and physical problems linked with long-term illness and medication. May be lacking basic life skills and poor role functioning in all areas.

Risk:
Vulnerability to abuse or exploitation.

Course:
Long term.

Likely NICE Guidance:
Service user experience in adult mental health CG136, Schizophrenia (update) CG82, Bipolar disorder CG38, Medicines adherence CG76 Self-Harm CG16, Self-harm (longer-term management) CG 133.

No	Item Description	Rating				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	🟨	🟨	🟨		
2	Non-accidental self-injury	🟧	🟧	🟧		
3	Problem drinking or drug taking	🟧	🟧	🟧		
4	Cognitive Problems		🟨	🟨	🟨	
5	Physical Illness or disability problems		🟨	🟨	🟨	
6	Hallucinations and Delusions				🟥	🟥
7	Depressed mood *		🟧	🟧	🟧	
8	Other mental and behavioural problems *		🟨	🟨	🟨	
9	Relationships		🟨	🟨	🟨	
10	Activities of daily living		🟨	🟨	🟨	
11	Living conditions		🟨	🟨	🟨	
12	Occupation & Activities		🟧	🟧	🟧	
13	Strong Unreasonable Beliefs	🟨	🟨	🟨	🟨	
A	Agitated behaviour/expansive mood		🟧	🟧	🟧	
B	Repeat Self-Harm	🟧	🟧	🟧		
C	Safeguarding other children & vulnerable dependant adults		🟨	🟨	🟨	
D	Engagement	🟧	🟧	🟧		
E	Vulnerability		🟧	🟧	🟧	

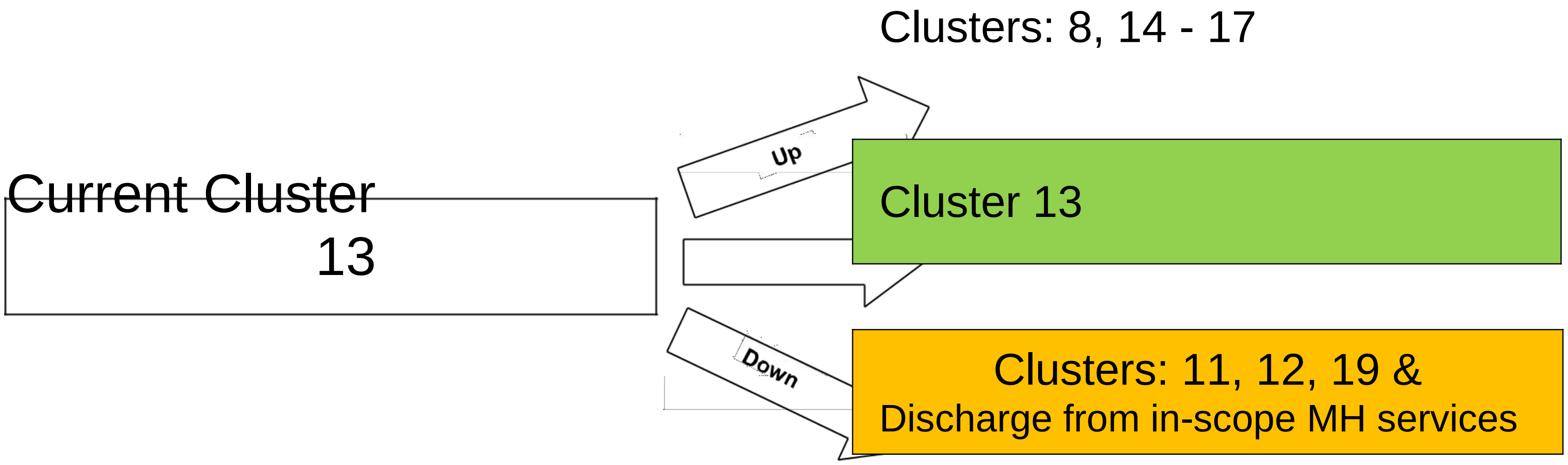
Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▨
May score	🟨		

***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

CARE TRANSITION PROTOCOLS - Cluster 13: Ongoing or Recurrent Psychosis (high symptom and disability)

Indicative episode of care: 3 years + **Cluster reviews at least:** Annually

Cluster	Step-up Criteria (The following criterion is met)	**<u>Example local discharge Criteria</u> for MH services (<u>All</u> of the following criteria are met)**	**Step-down Criteria (The following criterion is met)**
13	• Service User fits description and scoring profile of any likely/ possible ‘step-up’ cluster.	• Has received 2 years of specialist MH intervention. • Requires no psychotropic medication or has been on a stable dose for the past year. • Scores 0-1 on MHCT V1 item 6 (Hallucinations and Delusions) • Not currently detained under the Mental Health Act. • Has required no inpatient / IHT packages for the past year. • Any residual risks can be managed by primary care. • Scores 0-1 on MHCT V1 item 12 (Occupation and Activities). • Level of social inclusion meets service user’s expectations.	• Service User fits description and scoring profile of any likely/ possible ‘step-down’ cluster consistently for the past 12 months.



Clusters: 8, 14 - 17

Current Cluster 13

Up

Cluster 13

Down

Clusters: 11, 12, 19 &
Discharge from in-scope MH services

Key:

Most likely transition(s)

Possible transition

Rare Transition

Clusters: 1-7, 10, 18, 20 & 21

CARE CLUSTER 15: Severe Psychotic Depression

Description:
This group will be suffering from an acute episode of moderate to severe depressive symptoms. Hallucinations and delusions will be present. It is likely that this group will present a risk of Non-accidental self-injury and have disruption in many areas of their lives.

Likely primary diagnosis:
Likely to include, F32.3 Severe depressive episode with psychotic symptoms

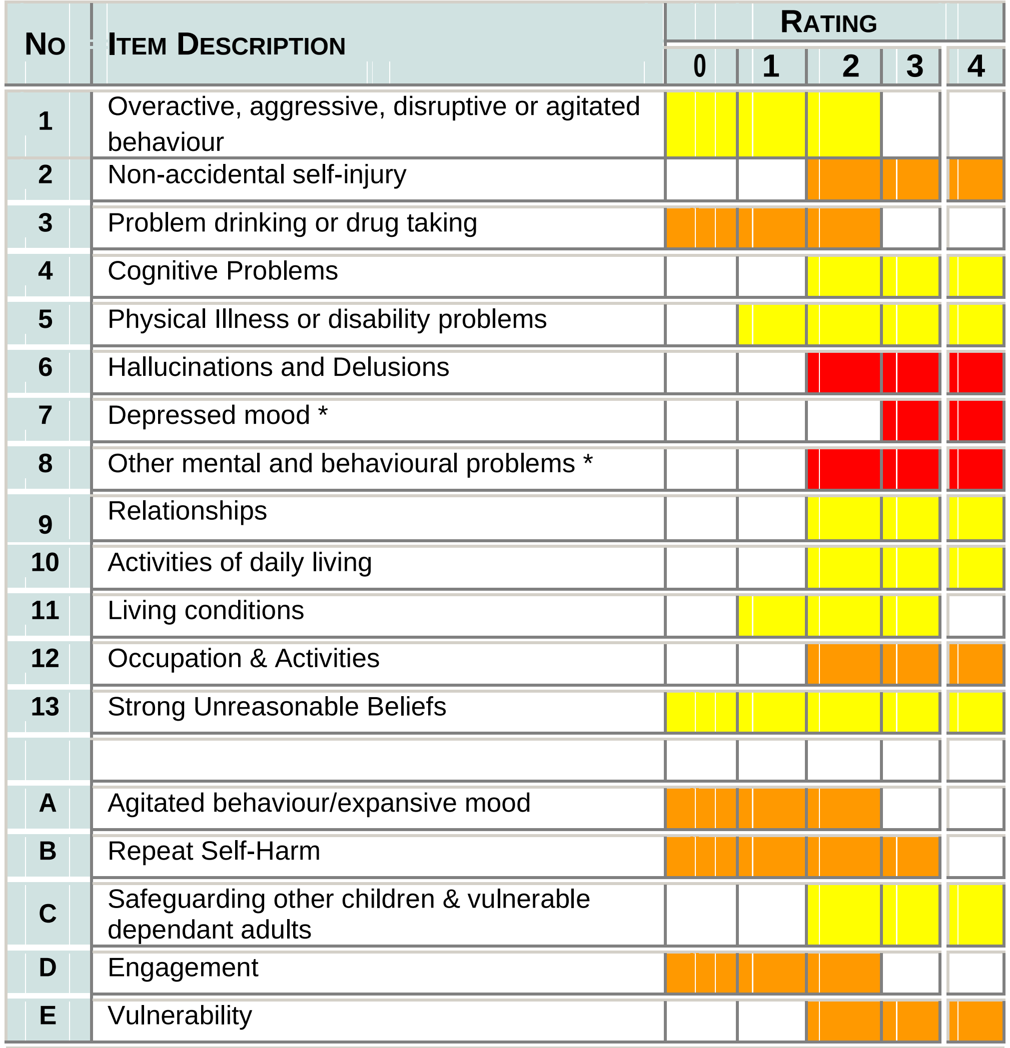
Unlikely primary diagnosis:
F00-03 Dementias, F40-48 Neurotic, stress-related and somatoform disorders, F50 Eating disorders,

Impairment:
Cognitive problems may present. Activities will be severely disrupted in most areas. Role functioning is severely disrupted in most areas

Risk:
Risk of Non-accidental self-injury and vulnerability likely to be present with other risks variable. Consider safeguarding risks if parent or carer.

Course:
Acute

Likely NICE Guidance:
Service user experience in adult mental health CG136, Medicines adherence CG76, Depression in adults CG90, OCD CG31, Schizophrenia (update) CG82, Bipolar disorder CG38, Self-Harm CG16.



No	Item Description	Rating 0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour	🟨	🟨	🟨		
2	Non-accidental self-injury			🟧	🟧	🟧
3	Problem drinking or drug taking	🟧	🟧	🟧		
4	Cognitive Problems			🟨	🟨	🟨
5	Physical Illness or disability problems		🟨	🟨	🟨	🟨
6	Hallucinations and Delusions			🟥	🟥	🟥
7	Depressed mood *				🟥	🟥
8	Other mental and behavioural problems *			🟥	🟥	🟥
9	Relationships			🟨	🟨	🟨
10	Activities of daily living			🟨	🟨	🟨
11	Living conditions		🟨	🟨	🟨	
12	Occupation & Activities			🟧	🟧	🟧
13	Strong Unreasonable Beliefs	🟨	🟨	🟨	🟨	🟨
A	Agitated behaviour/expansive mood	🟧	🟧	🟧		
B	Repeat Self-Harm	🟧	🟧	🟧	🟧	
C	Safeguarding other children & vulnerable dependant adults			🟨	🟨	🟨
D	Engagement	🟧	🟧	🟧		
E	Vulnerability			🟧	🟧	🟧

Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▨
May score	🟨		

***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

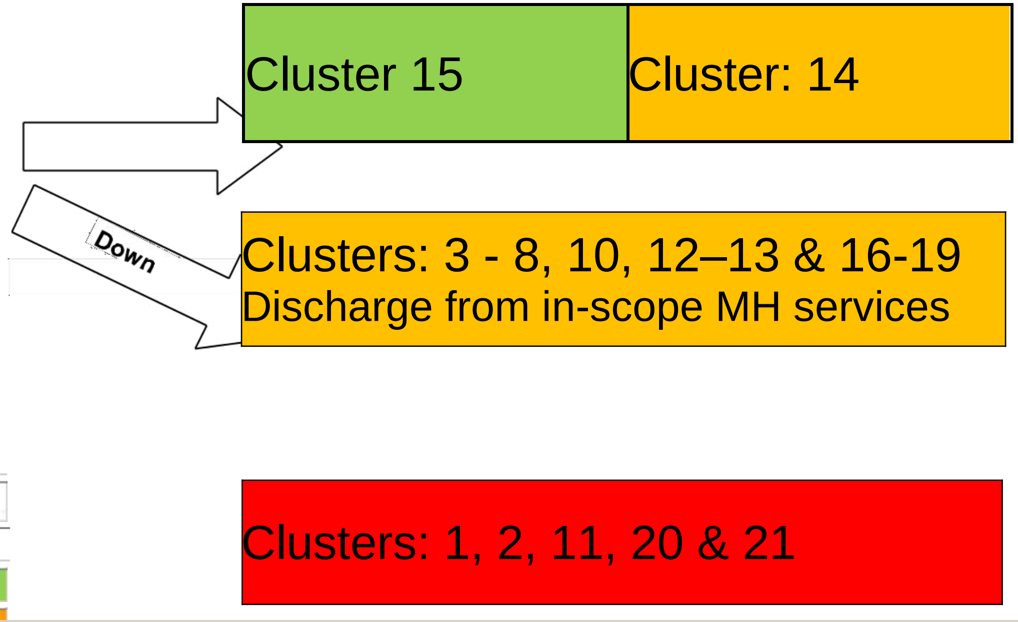
CARE TRANSITION PROTOCOLS - Cluster 15: Severe Psychotic Depression

Indicative episode of care: 8 – 12 weeks **Cluster reviews at least every:** 4 weeks

Cluster	**Step-up Criteria** **(The following criterion is met)**	**Example local discharge Criteria for MH services** **(All of the following criteria are met)**	**Step-down Criteria** **(The following criterion is met)**

15	N/A	• Requires no psychotropic medication or has been on a stable dose and is adherent. • Scores 0-1 on MHCT V1 item 6 (Hallucinations and Delusions). • Any residual risks can be managed by Primary Care • Scores 0-2 on MHCT V1 item 12 (Occupation and Activities). • Level of social inclusion meets service user's expectations	• Service User fits description and scoring profile of any likely/ possible 'step-down' cluster.

Current Cluster 15



Cluster 15 | Cluster: 14

Clusters: 3 - 8, 10, 12–13 & 16-19
Discharge from in-scope MH services

Clusters: 1, 2, 11, 20 & 21

Key:

🟩 Most likely transition(s)
🟧 Possible transition
🟥 Rare Transition

CARE CLUSTER 17: Psychosis and Affective Disorder – Difficult to Engage

Harm CG16, Self-harm (longer-term management) CG 133.

Description:

This group has moderate to severe psychotic symptoms with unstable, chaotic lifestyles. There may be some problems with drugs or alcohol not severe enough to warrant care associated with cluster 16. This group have a history of non-concordance, are vulnerable & engage poorly with services.

Likely primary diagnosis:

Likely to include, (F20-F29) Schizophrenia, schizotypal and delusional disorders, Bi-Polar

Unlikely primary diagnosis:

F00-03 Dementias, F32 Depressive episode, F33 Recurrent depressive disorder, F40-48 Neurotic, stress-related and somatoform disorders, F50 Eating disorders, F60 Specific personality disorders

Impairment:

Possibly cognitively impaired as a consequence of psychotic features or Problem drinking or drug taking including prescribed medication. Likely severe problems with relationships and one or more other area of functioning

Risk:

Moderate to severe risk of harm to others due to aggressive or violent behaviour. Risk of Non-accidental self-injury. Likely to be non-compliant, vulnerable and engage poorly with service.

Course:

Long term.

Likely NICE Guidance:

Service user experience in adult mental health CG136, Schizophrenia (update) CG82, Bipolar Disorder CG38, Medicines adherence CG76 Alcohol Use Disorders CG100, Drug misuse-psychosocial interventions CG51, Psychosis with coexisting substance misuse CG120 Self-

No	Item Description	Rating				
		0	1	2	3	4
1	Overactive, aggressive, disruptive or agitated behaviour		🟨	🟨	🟨	
2	Non-accidental self-injury			🟧	🟧	🟧
3	Problem drinking or drug taking		🟧	🟧		
4	Cognitive Problems			🟨	🟨	🟨
5	Physical Illness or disability problems			🟨	🟨	🟨
6	Hallucinations and Delusions		🟥	🟥	🟥	🟥
7	Depressed mood *			🟧	🟧	🟧
8	Other mental and behavioural problems *		🟨	🟨	🟨	
9	Relationships				🟨	🟨
10	Activities of daily living				🟨	🟨
11	Living conditions			🟨	🟨	🟨
12	Occupation & Activities				🟧	🟧
13	Strong Unreasonable Beliefs		🟨	🟨	🟨	🟨
A	Agitated behaviour/expansive mood				🟧	🟧
B	Repeat Self-Harm	🟧	🟧	🟧		
C	Safeguarding other children & vulnerable dependant adults			🟨	🟨	🟨
D	Engagement				🟧	🟧
E	Vulnerability			🟧	🟧	🟧

Must score	🟥	**Unlikely to score**	⬜
Expected to score	🟧	**No data available**	▨
May score	🟨		

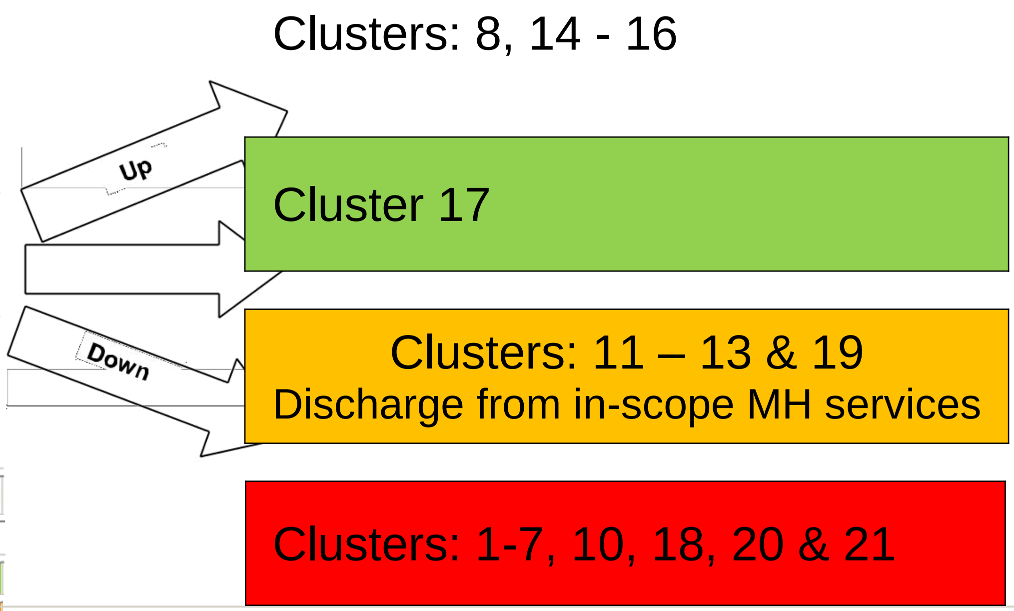
***Use the highest rating from Scales 7 & 8 when deciding if the rating fits the range indicated.**

CARE TRANSITION PROTOCOLS - Cluster 17: Psychosis and Affective Disorder Difficult to Engage

Indicative episode of care: 3 years + **Cluster reviews at least every:** 6 months

Cluster	Step-up Criteria (**Any** of the following criteria are met)	**Example local discharge Criteria** for MH services (**All** of the following criteria are met)	Step-down Criteria (**All** of the following criteria are met)
17	• Patient fits profile for clusters 14 or 15. • Patient scores above 2 on Problem drinking or drug taking item and this results in an inability to deliver the care typically provided to cluster 17 patients without a significant increase in resources.	• Has received 2 years of specialist MH intervention. • Requires no psychotropic medication or has been on a stable dose for the past year. • Scores 0-1 on MHCT V1 item 6 (Hallucinations and Delusions) • Has required no inpatient / IHT packages for the past year. • Any residual risks can be managed by primary care • Scores 0-1 on MHCT V1 item 12 (Occupation and Activities). • Level of social inclusion meets service user's expectations. • Scores 0-1 MHCT V1 item D (Engagement)	• Service User has fitted description and scoring profile of any likely/ possible 'step-down' cluster consistently for the past 12 months. • Has required no inpatient / IHT packages for the past year. • Scores 0-1 MHCT V1 item D (Engagement). • Level of support (frequency of visits etc.) has been reduced to a level that can be provided by a less intensive care package for the past 6 months.

Current Cluster
17



Clusters: 8, 14 - 16

Cluster 17

Clusters: 11 – 13 & 19
Discharge from in-scope MH services

Clusters: 1-7, 10, 18, 20 & 21

Key:

- 🟩 Most likely transition(s)
- 🟧 Possible transition
- 🟥 Rare Transition

Appendix -2 Letter to participants and residential care homes.

UWE Bristol | University of the West of England

Date

To

I am a Trainee Counselling Psychologist at the University of the West of England and I am writing to introduce my research. I have five years' experience working in a residential care home with clients with complex needs as an Assistant Psychologist, therapist and trainee. I am supported by my Director of Studies Dr Toni DiCaccavo who is a Chartered Psychologist, Practitioner Counselling Psychologist. Secondly, Dr Zoe Thomas who is a Chartered Counselling Psychologist and the lead for the Professional Doctorate in Counselling Psychology. I am privileged that both have a wealth of experience working in an applied context with complex clients.

My own experience has made me aware that clients with complex needs have difficulty having their voices heard. Therefore, I am interested in hearing about the experience of living with complex needs in residential care. Therefore, I would like to find out if the clients you support would be interested in being part of the research.

The criteria would be that the client has complex mental health needs and reside in a residential care for more than 3 months. I would be happy to meet with yourself and your clients to talk further about the research. The participants will need to consent and engage in a recorded interview in which I would ask about their experiences. This research will be valuable for my practise, to inform other professionals as well as other trainees and add to literature of lived experience, giving voice to often unheard clients.

Please contact me if you have any questions, I look forward to hearing from you.

Yours sincerely

Alison Chivers BSc (Hons) Psychology MBPsS - Counselling Psychologist in Training

Dr Zoe Thomas CPsychol, AFBPsS, HCPC Reg. Counselling Psychologist
Programme Leader Professional Doctorate in Counselling Psychology
Health and Social Sciences
University of the West of England
Coldharbour Road
Frenchay Campus,
Bristol,
BS16 1QY
zoe2.thomas@uwe.ac.uk
0117 32 83794

Dr Toni DiCaccavo MSc., PHD, HCPC Reg. Chartered Psychologist, Practitioner Counselling Psychologist
BABCP Accredited CBT Psychotherapist
Department of Health & Social Sciences
University of the West of England
Cold Harbour Lane
Frenchay, Campus
Bristol, BS161QY Toni.DiCaccavo@uwe.ac.uk

Appendix – 3 Participant information sheet

An IPA study exploring client experience of living with complex needs in a residential care home: some voices are harder to hear!

Participant Information Sheet

Who are the researchers and what is the research about?

Thank you for your interest in this research I am interested in your experiences of living with complex needs in residential care. The data will support my practise and influence the direction of research in this area. My name is Alison Chivers and I am a psychology postgraduate student in the Department of Health and Social Sciences, University of the West of England, Bristol. I am completing this research for my Professional Doctorate in Counselling Psychology thesis. My research is supervised by DR Toni DiCaccavo (see below for her contact details).

What does participation involve?

You are invited to participate in a qualitative interview – a qualitative interview is a 'conversation with a purpose'; you will be asked to answer questions in your own words. The questions will cover your experiences of living in residential care and having complex needs. The interview questions will be guided by me but mostly led by your own unique experience of living with complex needs in residential care. The interview will be audio recorded and I will transcribe (type-up) the interview for the purposes of analysis. On the day of the interview, I will ask you to read and sign a consent form. You will also be asked to complete a short demographic questionnaire. This is for me to gain a sense of who is taking part in the research. I will discuss what is going to happen in the interview and you will be given an opportunity to ask any questions that you might have. You will be given another opportunity to ask questions at the end of the interview.

Who can participate?

Anyone over the age of 18 who lives in a residential care home and have complex mental health needs.

How will the data be used?

Your interview data will be anonymised (i.e., any information that can identify you will be removed) and analysed for my research project. This means extracts from your interview may be quoted in my thesis and in any publications and presentations arising from the research. The demographic data for all of the participants will be compiled into a table and

included in my thesis and in any publications or presentations arising from the research. The information you provide will be treated confidentially and personally identifiable details will be stored separately from the data.

The personal information collected in this research project (e.g., the interview audio recording, transcript and the demographic form) will be processed by the University (data controller) in accordance with the terms and conditions of the General Data Protection Regulation (GDPR) as applied, enacted and amended in the UK law. We will hold your data securely and not make it available to any third party unless permitted or required to do so by law. Your personal information will be used/processed as described on this participant information sheet. You have a number of rights in relation to your personal data. For data protection queries, please write to the DataProtection Officer, UWE Frenchay Campus, Coldharbour Lane, Bristol, BS16 1QY, or dataprotection@uwe.ac.uk

- **What are the benefits of taking part?**

You will get the opportunity to participate in a research project on an important social and psychological issue. Helping others to make sense of and understand your lived experience. This will support the researcher to shape her practise when working with other clients who have similar experiences to you.

How do I withdraw from the research?

If you decide you want to withdraw from the research, please contact me via email Alison2.Chivers@uwe.ac.uk. Please note that there are certain points beyond which it will be impossible to withdraw from the research – for instance, when I have submitted my thesis. Therefore, you will need to contact me via email within a month of the date of participation in the interview if you wish to withdraw your data. I’d like to emphasise that participation in this research is voluntary and all information provided is anonymous but may need to be shared with supervisors and examiners. Participants can contact the researcher if they wish to be sent a summary of the finding.

Are there any risks involved?

We don’t anticipate any particular risks to you with participating in this research; however, there is always the potential for research participation to raise uncomfortable and distressing issues. For this reason, we have provided information about some of the different resources which are available to you. The following website lists free or low cost counselling services in the local area: http://www.bristolmind.org.uk/bsn/counselling. Alternatively, your house manager, Community Psychiatric Nurse or Social Worker will be able to support you if you have any further questions or need to talk through anything the interview has brought up for you.

UWE Bristol | University of the West of England

If you have any questions about this research please contact my research supervisor: Dr Toni DiCaccavo, Department of Health and Social Sciences, Frenchay Campus, Coldharbour Lane, Bristol BS16 1QY.

Email: toni.dicaccavo@uwe.ac.uk

This research has been approved by the Health and Applied Sciences Faculty Research Ethics Committee (FREC).

Appendix 4 – Interview schedule

Pilot Interview schedule

1. How did you come to live her?

Prompt - (Did you have any choice in leaving, did you choose to come to this home)

2. Who made the decision?

Prompt – (Was this you or someone else)?

3. Can you tell me about your experiences of living in residential care?

Prompt (What experiences have been valuable for you? What experiences have been unhelpful for you)?

4. Why do you think you need a residential setting?

Prompt - (Do you have a choice?)

5. Can you describe a typical day at the residential care home?

Prompt - (Think about when you first wake, during the day and when you retire to bed)

6. How do you think it might be if you did not live here?

Prompt – (Have you ever lived alone, was this a good experience, where do you see yourself 10 years from now. can you share your hopes for the future)?

7. How do you think others view you living in residential care?

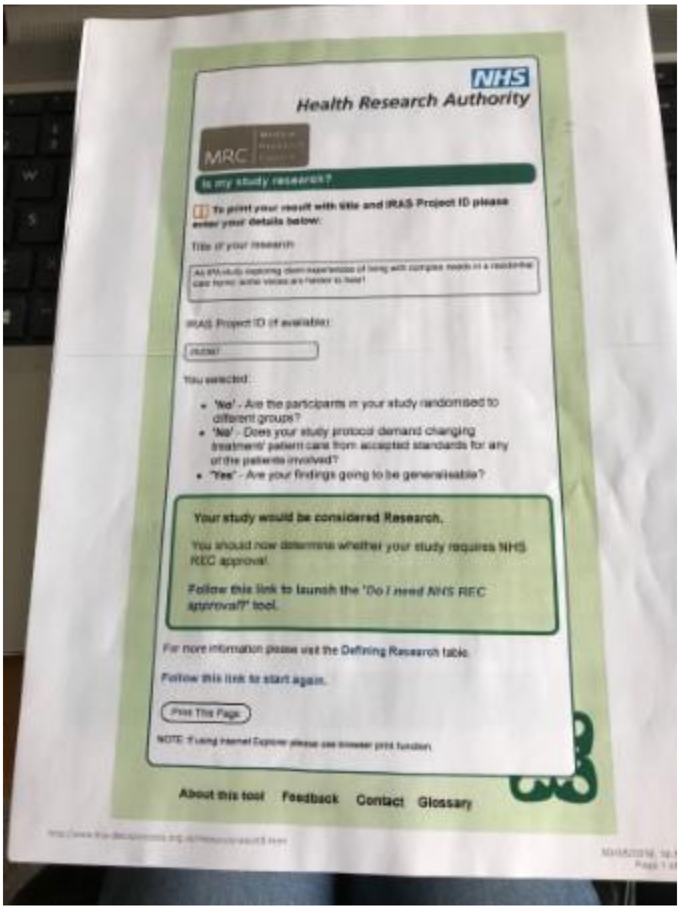
(Prompt – Is it acceptable? Stigmatised? What do you think it says about you?)

8. How do you think living in Residential Care affects your mental health?

(Prompt – negative impact, positive impact)?

9. Can you tell me what ‘Recovery means to you’?
10. Is there anything I have not asked you that you would like to say?
11. Do you feel your voice has been heard?

Appendix - 5 – NHS tool detailing do I need NHS approval.



NHS
Health Research Authority

MRC

Is my study research?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

IRAS Project ID (if available):

You selected:

- **'No'** - Are the participants in your study randomised to different groups?
- **'No'** - Does your study protocol demand changing treatment/ patient care from accepted standards for any of the patients involved?
- **'Yes'** - Are your findings going to be generalisable?

Your study would be considered Research.

You should now determine whether your study requires NHS REC approval.

Follow this link to launch the '*Do I need NHS REC approval?*' tool.

For more information please visit the Defining Research table.

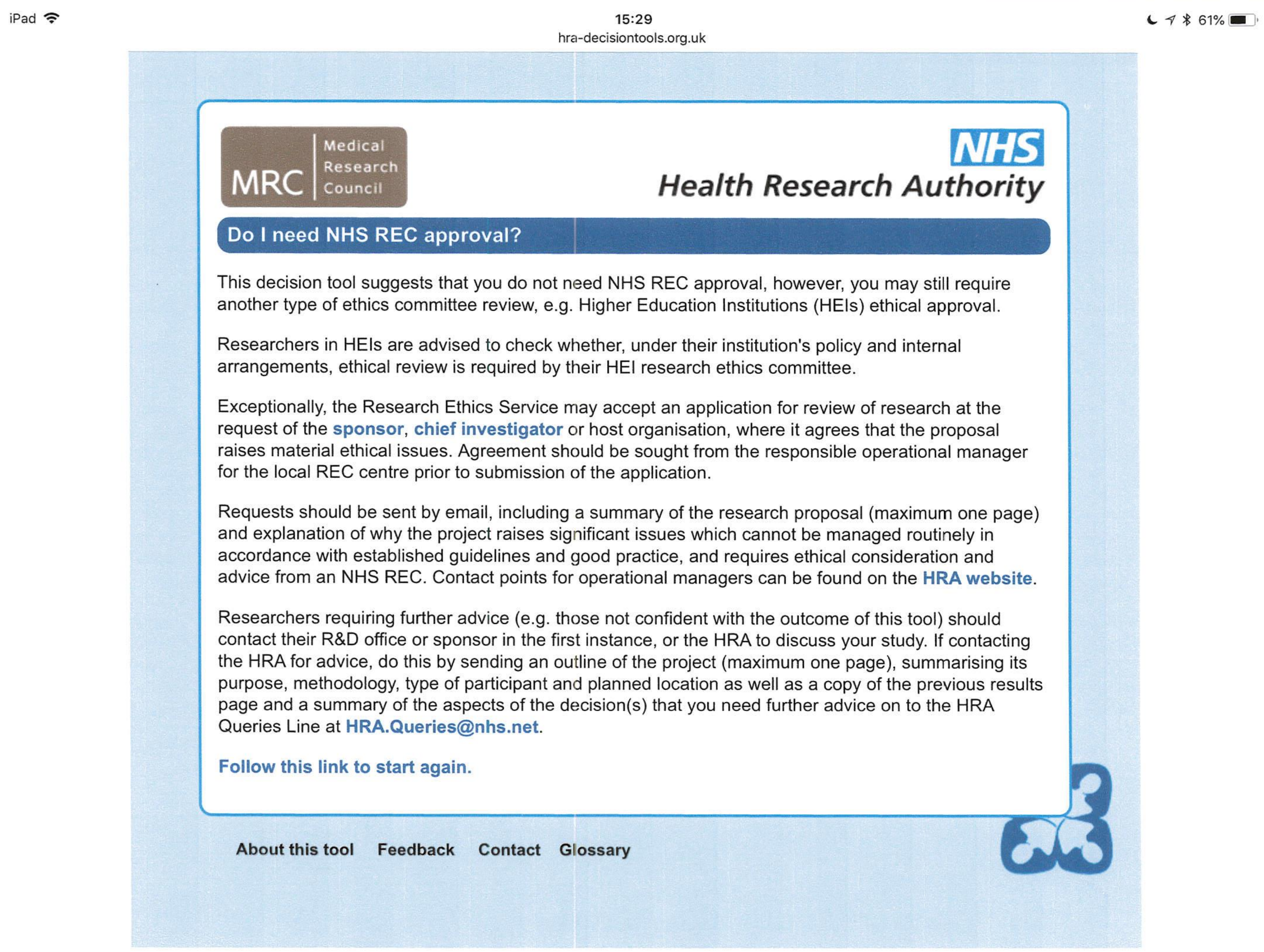
Follow this link to start again.

Print This Page

NOTE: If using Internet Explorer please use browser print function.

About this tool **Feedback** **Contact** **Glossary**

Appendix - 5 cont.– NHS tool detailing do I need NHS approval.



Do I need NHS REC approval?

This decision tool suggests that you do not need NHS REC approval, however, you may still require another type of ethics committee review, e.g. Higher Education Institutions (HEIs) ethical approval.

Researchers in HEIs are advised to check whether, under their institution's policy and internal arrangements, ethical review is required by their HEI research ethics committee.

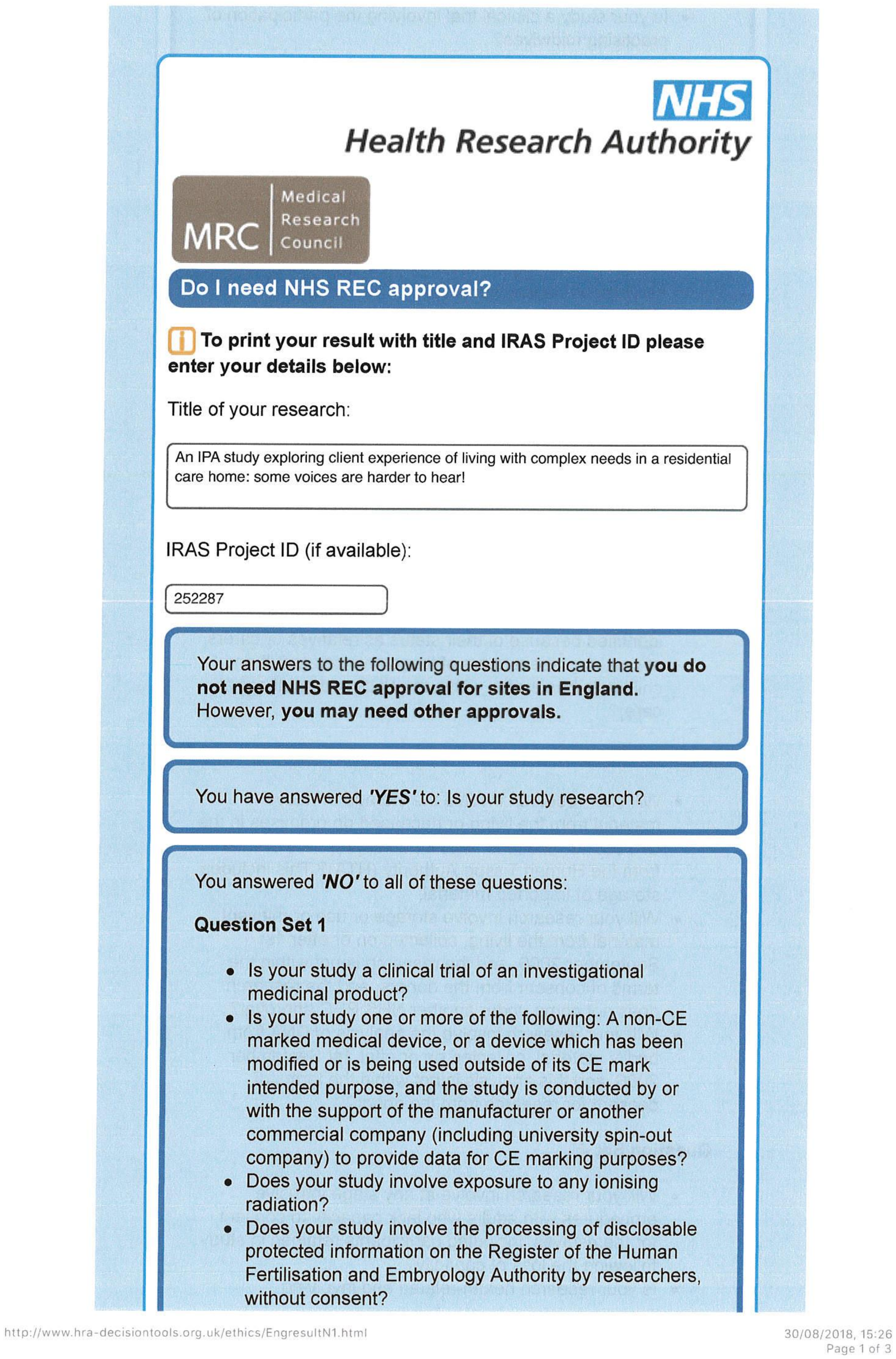
Exceptionally, the Research Ethics Service may accept an application for review of research at the request of the **sponsor**, **chief investigator** or host organisation, where it agrees that the proposal raises material ethical issues. Agreement should be sought from the responsible operational manager for the local REC centre prior to submission of the application.

Requests should be sent by email, including a summary of the research proposal (maximum one page) and explanation of why the project raises significant issues which cannot be managed routinely in accordance with established guidelines and good practice, and requires ethical consideration and advice from an NHS REC. Contact points for operational managers can be found on the **HRA website**.

Researchers requiring further advice (e.g. those not confident with the outcome of this tool) should contact their R&D office or sponsor in the first instance, or the HRA to discuss your study. If contacting the HRA for advice, do this by sending an outline of the project (maximum one page), summarising its purpose, methodology, type of participant and planned location as well as a copy of the previous results page and a summary of the aspects of the decision(s) that you need further advice on to the HRA Queries Line at **HRA.Queries@nhs.net**.

Follow this link to start again.

Appendix - 5 cont. – NHS tool detailing do I need NHS approval.



NHS
Health Research Authority

MRC Medical Research Council

Do I need NHS REC approval?

To print your result with title and IRAS Project ID please enter your details below:

Title of your research:

An IPA study exploring client experience of living with complex needs in a residential care home: some voices are harder to hear!

IRAS Project ID (if available):

252287

Your answers to the following questions indicate that **you do not need NHS REC approval for sites in England.** However, **you may need other approvals.**

You have answered ***'YES'*** to: Is your study research?

You answered ***'NO'*** to all of these questions:

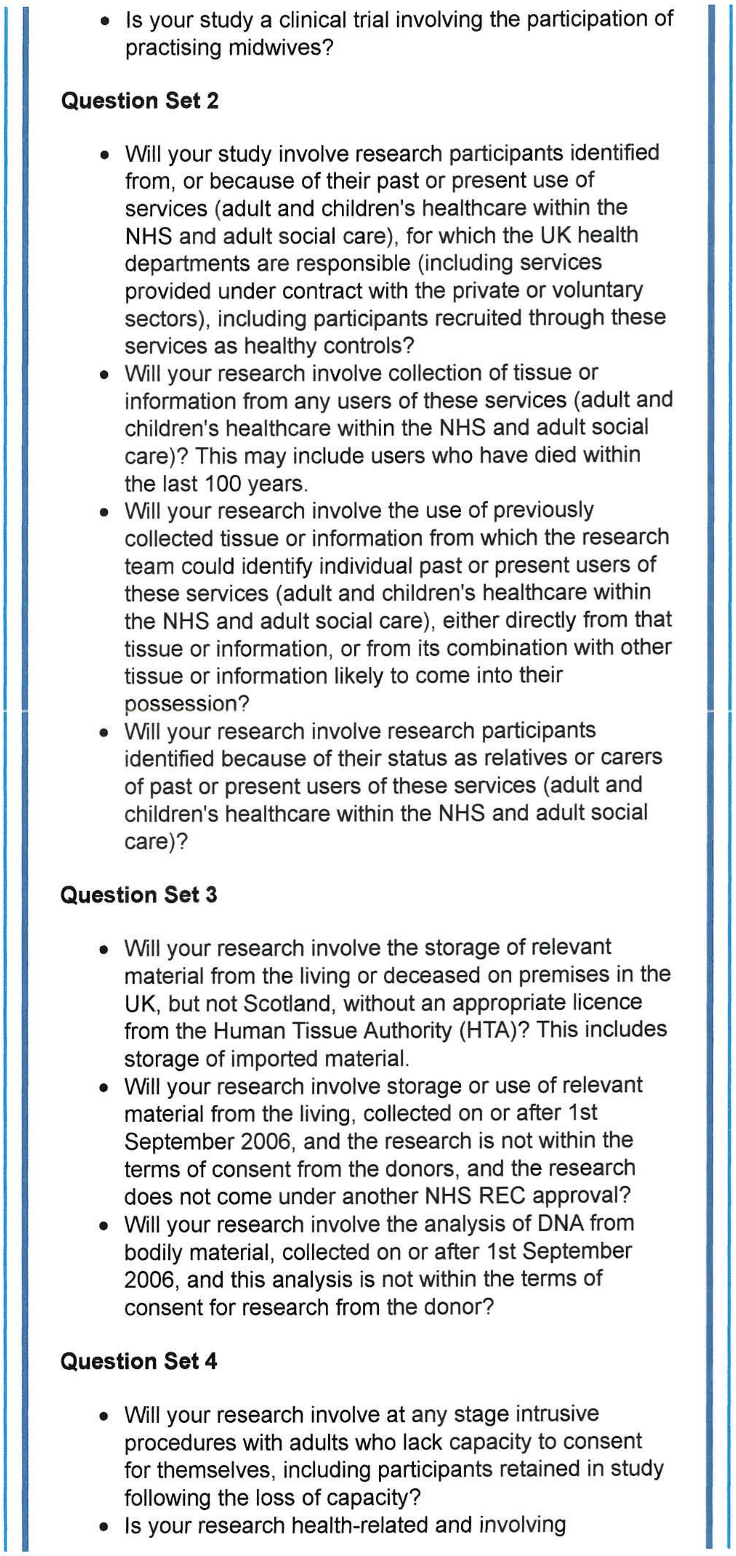
Question Set 1

- Is your study a clinical trial of an investigational medicinal product?
- Is your study one or more of the following: A non-CE marked medical device, or a device which has been modified or is being used outside of its CE mark intended purpose, and the study is conducted by or with the support of the manufacturer or another commercial company (including university spin-out company) to provide data for CE marking purposes?
- Does your study involve exposure to any ionising radiation?
- Does your study involve the processing of disclosable protected information on the Register of the Human Fertilisation and Embryology Authority by researchers, without consent?

http://www.hra-decisiontools.org.uk/ethics/EngresultN1.html

30/08/2018, 15:26
Page 1 of 3

Appendix - 5 cont. – NHS tool detailing do I need NHS approval.



- Is your study a clinical trial involving the participation of practising midwives?

Question Set 2

- Will your study involve research participants identified from, or because of their past or present use of services (adult and children's healthcare within the NHS and adult social care), for which the UK health departments are responsible (including services provided under contract with the private or voluntary sectors), including participants recruited through these services as healthy controls?
- Will your research involve collection of tissue or information from any users of these services (adult and children's healthcare within the NHS and adult social care)? This may include users who have died within the last 100 years.
- Will your research involve the use of previously collected tissue or information from which the research team could identify individual past or present users of these services (adult and children's healthcare within the NHS and adult social care), either directly from that tissue or information, or from its combination with other tissue or information likely to come into their possession?
- Will your research involve research participants identified because of their status as relatives or carers of past or present users of these services (adult and children's healthcare within the NHS and adult social care)?

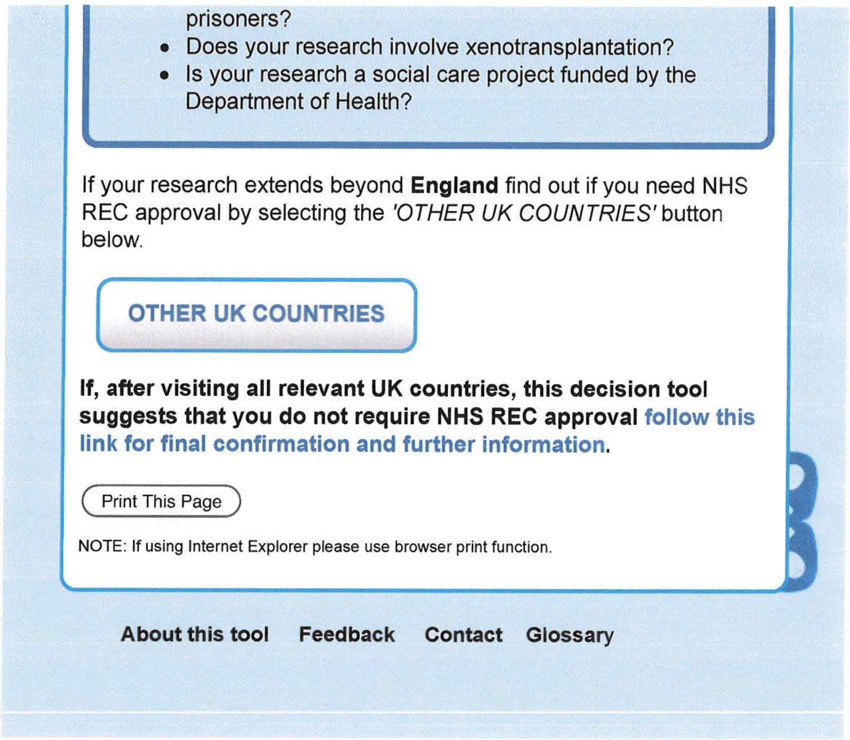
Question Set 3

- Will your research involve the storage of relevant material from the living or deceased on premises in the UK, but not Scotland, without an appropriate licence from the Human Tissue Authority (HTA)? This includes storage of imported material.
- Will your research involve storage or use of relevant material from the living, collected on or after 1st September 2006, and the research is not within the terms of consent from the donors, and the research does not come under another NHS REC approval?
- Will your research involve the analysis of DNA from bodily material, collected on or after 1st September 2006, and this analysis is not within the terms of consent for research from the donor?

Question Set 4

- Will your research involve at any stage intrusive procedures with adults who lack capacity to consent for themselves, including participants retained in study following the loss of capacity?
- Is your research health-related and involving

Appendix - 5 cont. – NHS tool detailing do I need NHS approval.



prisoners?

- Does your research involve xenotransplantation?
- Is your research a social care project funded by the Department of Health?

If your research extends beyond **England** find out if you need NHS REC approval by selecting the *'OTHER UK COUNTRIES'* button below.

If, after visiting all relevant UK countries, this decision tool suggests that you do not require NHS REC approval follow this link for final confirmation and further information.

NOTE: If using Internet Explorer please use browser print function.

Appendix - 6 – Confirmation email from Mark Walker regarding NHS ethics

Appendix - 7 RD1

Graduate School

Alison Chivers

Department of Health & Social Sciences

Faculty of Health & Applied Sciences

13 March 2018

Dear Alison,

RESEARCH PROJECT REGISTRATION (RD1):

An IPA study exploring client experience of living with complex needs in a residential care home: some voices are harder to hear!

Following a meeting of the Faculty Research Degrees Committee (FRDC) on 7th March 2018 I am pleased to inform you that your application for part time Professional Doctorate registration within the Faculty of Health & Applied Sciences has been approved. The Committee noted that your research degree registration started on 12th September 2016.

The FRDC has confirmed your supervision team as follows:

Director of Studies (DoS)

Dr Hamilton Fairfax

Second Supervisor 1

Dr Zoe Thomas

The Committee noted that this is a considered and well informed RD1 and the research idea and stance adopted fits well with counselling psychology philosophy which emphasizes individual meaning of psychological health rather than a solely diagnostic approach. The FRDC agreed that the following points should be fed back to you for consideration in the development of the project and at Progression stage:

- Participant selection needs more thought. As it stands there is a danger of being too broad which runs the risk of diluting the homogeneity of the sample needed for IPA. More specific criteria for selection need to be developed. Otherwise you are likely to get a very diverse sample which would make coding and synthesis of results difficult.

- Exclusion criteria need more specification. With complex needs comes issues of risk. How will more vulnerable participants be identified and possibly excluded?

- There is some confusion as to whether NHS samples will be used or not? The team needs to make decisions about this now as if NHS ethics are needed this is likely to have a significant impact on the schedule of research. If this is the case the FRDC requires that an amended timetable is forwarded for consideration.

- If, as the form indicates, you are sponsored for this research, what is the agreement with the sponsor with regard to arrangements for research and dissemination of results?

- You have clearly engaged in a review of the literature which sets the scene for your research. Nonetheless, there is still scope for the critical element of your work to develop further and to ensure that an over-optimistic version of history leading to inevitable improvement is not presented, without some consideration of the limitations of more recent recovery approaches. The discussion of our existing knowledge of complex care needs lacks a little depth and detail and would benefit from considerable development as you complete your research project.

Please note that there are additional resources available for the development of your skills as a postgraduate researcher in addition to taught modules. Please see the Graduate School website for more information about skills development workshops.

The FRDC considered your project proposal carefully, including a consideration of ethics and research governance. If you have answered "yes" to any of the questions in Section 5 of the RD1 relating to ethics then please note that it is your responsibility to ensure that your proposal is considered by the Faculty Research Ethics Committee (FREC) before you begin your data collection.

Please get in touch with the Research Ethics Committee Secretary by emailing researchethics@uwe.ac.uk stating that you are a postgraduate researcher who is required to submit an application for approval. Please also give the name of your Director of Studies.

As part of your research degree you will be required to complete a Progression Examination. This is a mandatory assessment involving two independent examiners (outside of your supervision team) who will review your written work and performance under viva voce exam conditions. You and your DoS share responsibility for ensuring that the following sequence of deadlines is met:

Examiner Nomination (RD2a form):

1st January 2019

Progression Report Due:

1st February 2019

Progression Exam Due:

1st March 2019

Exam outcome (RD2c form) Due:

1st April 2019

Please note that if your examiners conclude that your progress has been unsatisfactory on the basis of your report and viva voce examination, it may be recommended that your registration be withdrawn. You and your supervisors can find out more about the progression exam from the Graduate School Handbook.

Following successful progression onto stage two of your research degree you will be required to demonstrate satisfactory progression at each subsequent stage of your registration. You will be required to submit further reports and evidence as part of Progress Review (PR). The deadlines for completion of these milestones are:

PR Stage 2/3 :

1st April 2020

Expected thesis submission :

1st October 2020

It is important to note that both you and your supervision team share joint responsibility for the timely completion of each milestone and engaging with the administrative requirements as set out by the Graduate School. If you do not successfully complete any of the Progress Review points your registration will be at risk and you may be withdrawn from your research degree. You are advised to familiarise yourself with the contents of the Graduate School Handbook, Code of Practice and Academic Regulations, all of which can be found the Graduate School webpages.

Please note that the above stated milestone dates do not necessarily correspond with your visa end date (if applicable), nor with the end dates of any funding arrangements you may have in place. It is your responsibility to be aware of any funding and/or visa arrangements, and to action these accordingly at the appropriate times.

If you experience any issues affecting your ability to continue with your research as expected, please get in touch with the Graduate School as early as possible so that they can advise you accordingly.

Yours sincerely

Dr Tim Moss

Director of Research

Chair of the Faculty Research Degrees Committee

Faculty of Health & Applied Sciences

cc: Dr Hamilton Fairfax

Dr Zoe Thomas

(It is the responsibility of the DoS to ensure that this notification is communicated to the whole team)

Appendix – 8 Ethics application

UWE Bristol | University of the West of England

Appendix – 9 Letter in response to ethics conditions

Appendix – 10 Ethics approval

UWE Bristol
University of the West of England

Appendix 11 – Risk Assessment

UWE
University of the
West of England
BRISTOL

GENERAL RISK ASSESSMENT FORM

Ref:

Describe the activity being assessed: Conducting face-to-face interview about experiences of having complex mental health needs and living in residential care.	**Assessed by:** Hamilton Fairfax	**Endorsed by:** Zoe Thomas
Who might be harmed: Conducting face-to-face interviews 'off site' (off campus) involves risks for the researcher. For the participants emotional feelings may be brought up **How many exposed to risk:** Write the **11** number of participants + the researcher if relevant (can be a range)	**Date of Assessment:** **8th September2018.**	**Review date(s):** 8th September 2019

Hazards Identified ***(state the potential harm)***	**Existing Control Measures**	**S**	**L**	**Risk Level**	**Additional Control Measures**	**S**	**L**	**Risk Level**	**By whom a by when**
One hazard per box. Describe the hazards that are specifically generated as part of the research process. Only assess everyday activities (using a computer, travelling on a bus, handling paper) if they are outside their normal context (e.g. travelling on a bus in a gorilla suit to assess people's reactions to someone getting on a bus in a gorilla suit). Examples include participant distress…	List the measures that are part of your study design that manage the risks involved (examples include, informed consent/participant information sheets, debriefing in quant designs, providing sources of supporting, the researcher using the safety buddy procedure, allowing the participants to withdraw from the research without giving and reason and with no penalty)…				You only need these if your risk level is 6 or higher; in most instances, in a well-designed student project we would expect the risk to be 5 or lower. Additional control measures and measures that aren't part of the original study design (so you generate them now after completing this form) that brings the risk to an acceptable level (5 or lower).				

Managing client distress.	The research is aimed at a vulnerable group and the researcher will use professional experience and supervision to ensure that participants are not open to manipulation and exploitation (Braun and Clarke, 2013).	3	3	9	Participants will not be subjected to known risk and the researcher will be honest and accurate in reporting results. The researcher will use reflection, supervision and professional experience to consider the implications of consent or communication difficulties. Therefore, flexibility of extra or shorter interview time, debrief and signposting to additional support or therapy if participants become distressed. All recorded data will be kept in password protected files and will be destroyed a year after the VIVA. The interviews are not intended to cause distress to participants however clients with complex mental health needs are often unpredictable in their emotional response. Therefore any distress will be managed by informing the key worker and the clients Care Co-ordinator or Social Worker and the client will be sign posted to extra support if necessary.	3	1	3	
Managing capacity.	I will work closely with Care Co-coordinators,Mental health nurses and Social Workers that will have the training to assess capacity. .	3	2	6	Health professionals will be able to assess their mental state on the day of the interview and if they are unwell then the interview can be postponed. This is a very real reflection of this client group and one of the reasons that research has been difficult in the past. All identified participants that fit the criteria will be asked to consent in writing. As per the Mental Capacity Act 2005, capacity will be assumed unless it has been established otherwise. Other health care professionals including the residential manager and other	3	1	3	

					members of the participants team will ensure that each participant has capacity to consent on the day of the interview in accordance with the Mental Capcity Act 2005. As long as capacity is assumed then a person is not to be treated as unable to make a decision and the consent form is a tool to support the participant to make a decision to take part in the interview.				
Potential risk of client accusations.	The research will be conducted in the clients residential settings the researcher will have access to care plans and risk assessments around safe working with each client on an individual basis.	3	2	6	The researcher will inform the manager of the care home when the interview will take place and how long the interview will take. If the interview over runs the researcher will ask the manager / key worker to check in after a certain time to check all is well. If I am concerned about the participant I will work with the keyworker to understand the organisation risk process if clients become distressed The researcher is at risk if the client makes and accusation. However as the interviews will be recorded the risk is diminished as all interaction will be captured and if necessary could be used as evidence to ensure best practice. I have a DBS and training Studio 3 Training in low arousal to support my research approach.	3	1	3	
Researcher safety	The research will be conducted in the clients residential settings the researcher will have access to care plans and risk assessments around safe working with each client on an individual basis. The researcher will inform the manager of the care home when the interview will take place	2	1	2					

	and how long the interview will take. If the interview over runs the researcher will ask the manager / key worker to check in after a certain time to check all is well. If appropriate the researcher could be provided with a personal alarm or aware of the procedure if there is an alarm in the room. If I am concerned about the participant I will work with the keyworker to understand the organisation risk process if clients become distressed The researcher will follow the safety buddy interview protocol and the researcher will check in with the supervisors immediately before and after each interview. As the interview will be within a Residential care home, contact with a member of staff who is aware of what is happening, and the researcher will check out with the same member of staff after the interview has finished . Signing in and out of an organisation will evidence arrival and leaving time. Prior to the meeting the participant a discussion about risk can be had with the participants care co-ordinator which will ensure the researcher is aware of any triggers and if appropriate the care co-ordinator could be invited to sit in on the interview.								
Managing client expectation of the study / my work.	The information sheet will be used to explain the potential of the research and manage clients expectation.	3	1	1					
Researcher fatigue after interview.	The researcher will take a 30 – 60 minute break after each interview away from the interview setting before driving home.	3	1	3					

Participant disclosure.	The researcher will be transparent with the client from the start. and if any disclosures occur.	3	2	6	The appropriate action will be taken, for example safeguarding or informing the manager adhering to the policies and procedures for each particular Residential Care home as well as the BPS ethics code on the management of disclosures.	3	1	3	

RISK MATRIX: (To generate the risk level).

Very likely **5**	**5**	**10**	**15**	**20**	**25**
Likely **4**	**4**	**8**	**12**	**16**	**20**
Possible **3**	**3**	**6**	**9**	**12**	**15**
Unlikely **2**	**2**	**4**	**6**	**8**	**10**
Extremely unlikely **1**	**1**	**2**	**3**	**4**	**5**
Likelihood (L) ↑ **Severity (S)** →	**Minor injury – No first aid treatment required** **1**	**Minor injury – Requires First Aid Treatment** **2**	**Injury - requires GP treatment or Hospital attendance** **3**	**Major Injury** **4**	**Fatality** **5**

ACTION LEVEL: (To identify what action needs to be taken).

POINTS:	**RISK LEVEL:**	**ACTION:**
1 – 2	NEGLIGIBLE	No further action is necessary.
3 – 5	TOLERABLE	Where possible, reduce the risk further

6 - 12	MODERATE	Additional control measures are required
15 – 16	HIGH	Immediate action is necessary
20 - 25	INTOLERABLE	Stop the activity/ do not start the activity

Journal Article updated – May 2021

An IPA study exploring client experience of living with complex mental health needs in a residential care home: some voices are harder to hear!

Alison Chivers and Antionetta Dicaccavo, 2021 University of the West of England

Abstract

Objectives. The aim of the research was to hear the voices of participants with complex mental health needs, gaining insight into the experience of living in residential care homes. These voices often get lost; as people with complex mental health needs are often seen as difficult to engage and consequently have been excluded from opportunities to influence services.

Design. The research engaged in a qualitative inquiry to explore the lived experience of six people with complex mental health needs who live in residential care.

Methods. The participants were required to engage in semi-structured interviews of up to sixty minutes. Interpretive Phenomenological Analysis (IPA) which was considered the most appropriate methodological approach (Smith, Flowers & Larkin, 2009) was used to analyse the data.

Findings. Four superordinate themes were developed from the analysis (1) Stories of change over time; an historical journey (2) Searching for care; (3) The challenges of living in residential care; (4) Learning to grow as a resident in a residential care home. Subordinate themes were developed for each of these Superordinate themes.

Conclusion. The research outcomes suggest that concepts of power, infantilisation and social justice operate in residential care and are important aspects to consider in people's experiences of long-term residential care. The concept of Psychologically Informed Environments (PIE 2.0) is put forward as a possible theoretical framework to which this research may contribute with the aim of developing greater psychological awareness, creating cultures of learning and enquiry and fostering more responsiveness of services.

Introduction

Researching service user experience of residential care has been limited (Chilvers et al., 2006; Krotofil et al., 2018; Parker et al., 2019; Watson et al., 2018; Deering, Pawson, Summer and Williams, 2019, Killaspy and Priebe 2020:2021). The application of psychological perspective can attempt to understand the experiences of having complex mental health needs and living in residential care.

Lit review, background rationale

This review has defined people with complex mental health needs living in residential care as a homogenous sample, to give clients that have often been marginalised an opportunity to get their voices heard about their experiences of residential care. The researcher acknowledges that this group is made up of individuals who have their own experiences and needs. This research provides an opportunity to hear the voice of clients that often get lost; as people with complex mental health needs who are often seen as difficult to engage and are found in settings that are difficult to define and access for research purposes (Clare and Cox, 2003). However, Killaspy and Priebe (2020:2021) argue that by leaving out the important field of housing services for people with mental health illness just because they are difficult to study is ethically and practically unacceptable.

The researcher’s own experience of working in adult mental health has raised her awareness of the tension between clients’ dependency on psychiatric diagnoses from the past, and the fact that this frequently conflicts with newer ways of thinking about recovery. Therefore, this research aims to give voice to complex client’s experience of living in care within an ever-evolving mental health system. This research challenges the concept of parity of esteem, as the age group that is being researched will have lived through and experienced a time that did not value mental health equally with physical health.

This research is current and necessary as the NHS 2019 long-term plan states that by 2023/24, 370,000 adults and older adults with severe mental illnesses will have greater choice and control over their care; this includes groups with specific needs, such as adults with eating disorders or a personality disorder diagnosis (NHS, 2019). Therefore, this research has the potential to inform the researcher’s own practice and aims to hear unheard voices. Complex mental health clients often carry with them traumatic and painful stories that have the potential to be explored qualitatively and told from clients' unique perspective in their own words (Blackburn, 2012; Walton and Walton, 2012). Having a safe and secure home is regarded as essential for an individual's health. However, this right is not implemented universally and people with mental health illness are among the vulnerable group at particular risk of potentially inadequate housing (Killaspy and Priebe (2020:2021).

This research needs to be undertaken sensitively, with rigour, respect and transparency, as research methods including qualitative used inappropriately can be disempowering (Faulkner, 2017). Therefore, the researcher aimed to capture experience and genuinely involve people with complex mental health needs, making an original contribution to enable new knowledge of client-centered practice guided by the client (Rayner, 2012; Roberts and Wolfsen, 2004; Gerrard, 2010).

Method / Design

Given the limited research from service user experience perspective (Deering, Pawson, Summer and Williams, 2019). The study uses an experiential qualitative approach with the aim of exploring how participants make sense of their personal and social worlds (Smith and Osborne, 2007). Analysis has been guided by a critical realist position which adopts a philosophical stance that human knowledge is contextualized and best defined as a set of procedures, rather than as a phenomenon that can be constrained. This gives freedom to explore and involve participants whose voices are often unrepresented to give meaning to their experience of life in residential care (Reid, Flowers and Larkin, 2005).

This research is driven by a desire to give precedence to client experience, collecting the information and organising an interpretative framework around what is articulated in the data (Smith, 2007). IPA accepts that it is impossible to gain direct access to the research participant's direct world but will explore participant's lived experience from the client perspective. Yet, it is acknowledged that such an exploration will implicate the researcher’s own view of the world and the nature of the interaction between researcher and participant. This will result in an interpretation of the participant’s experience (Willig, 2008).

Participants and sampling

The participants’ were a purposive homogeneous sample of clients with complex mental health needs and were working age adults. The researchers training and experience gives her the skills to pay close attention to the power and the exploitative potential of interviews regarding the relationship between the participants and researcher (Braun and Clarke, 2013). The researcher’s professional experience increased her ability to build rapport with participants who are often difficult to engage. As the participants were vulnerable adults, skills of empathy and gentle pace were used to facilitate one to one interviews and manage potential client distress (Braun and Clarke, 2013). The researcher also utilised other skills such as the use of appropriate language, shorter interviews, appropriate prompts and enough time for participants to think, speak and be heard. Participant demographics have been outlined in (Table 1).

Inclusion criteria

The inclusion criteria for participating in the research were that participants were working age adults in cluster seven, eight, and possibly twelve, thirteen, fifteen and seventeen of the HoNOS, presenting with complex mental health needs, and living in a residential care home for at least three months prior to interview, had capacity, were able to consent and engage in a forty-five-minute interview (Reid et al., 2005).

Exclusion criteria

Owing to ethical concerns and lack of clinical expertise in the following areas, participants who had a co-morbid learning disability of cognitive impairment, experienced florid psychosis, had a significant organic impairment, that were in acute crisis, lacked capacity at the time of the interview and had a significant history of sexual offences were excluded from the research. It was agreed in supervision that if the interview did not exceed twenty minutes then it was to be excluded owing to inadequate depth of interview.

Six interviews in total were conducted. The length of these interviews ranged from 34 minutes and 16 seconds to 60 minutes and one second (the average length was 46 minutes and 42 seconds). These interviews took place in participants' homes (six face-to-face,) in a private space within residential homes. Participants described their ethnicity as white British (5) and prefer not to say (1). Participants described their social class as working class (2), middle class (2) and prefer not to say (1) and no class (1). The age of the participants ranged from 44 – 69 years of age (mean was 57.5 years). All interviews were then transcribed by the researcher.

Data collection

Data were collected via semi-structured, recorded interviews; the flexibility of the semi-structured interview means that it was possible to access more comprehensive responses from participants initially reported (Smith et al., 2009). Dependant on the participants wishes, the option of the interview being divided into twenty to twenty-five-minute segments with a comfort break in the middle was offered. Typed transcripts were read whilst re-listening to audio recordings to improve accuracy of transcribing. This formed the data corpus which has been analysed using the procedure below.

Interview schedule

Turning now to the interview schedule, semi-structured interviews require a sensitive and ethical negotiation of rapport between interviewer and interviewee consisting of a relatively small number of open-ended questions (Willig, 2008). Smith et al., (2009) suggest that questions are open and expansive in which participants are encouraged to move between answers that are primarily narrative or descriptive and those that are more analytic or evaluative. As the researcher is required to enter the world of the participants it is imperative that the questions are open-ended and not directive (Willig, 2008). An interview guide was designed following discussions with the residential clients that the researcher works with and was then piloted (Appendix 4). This supported the researcher to test out that the schedule was fit for purpose and enable the researcher to practice building trust and rapport with participants. Therefore, six to 10 open questions, with prompts, occupied 34 to 60 minutes of conversation which is recommended for qualitative interviews (Smith et al., 2009). However, this was adapted for participants with complex mental health needs; for example, questions were asked sensitively, language was appropriate, and participants were given extra time and prompts.

Analysis

The aim of IPA is to explore how participants make sense of their personal and social world (Smith and Osborn, 2003). Good quality IPA will be sensitive to context in which it is situated. Therefore, in the early stages of the research, methodology and rationale were centred around the need for sensitivity of context (Smith et al., 2007). Consequently, good IPA tells us something important about an individual and something about themes that are shared within a homogenous sample (Smith et al., 2007). Interpretative hermeneutic tradition argues that the researcher is central to the analysis and acknowledges interpretations bound by participants' abilities to articulate thoughts and experiences and the researcher's ability to reflect (Brocki and Wearden, 2007).

The interviews were audio recorded and all six interviews were then transcribed and anonymised. IPA begins with a process whereby researchers comment on their early analytic observations about each data section; this is called 'initial' commenting' (Smith et al., 2009). The researcher notes any observations, reflections and thoughts that come about whilst reading the text as part of the six stages described by Smith et al. (2009). The first transcription was closely read, and the initial response noted about what is interesting and significant. This was followed by noticing patterns within the material, which were identified emphasising convergence, divergence, commonality, and nuance. The coding process in IPA starts by coding the first data section and goes on to develop themes for consecutive data sections (Smith et al., 2009). IPA has two types of codes that are referred to as 'conceptual' and 'descriptive'. Furthermore Smith et al. (2009) describes two levels of themes known as 'superordinate' a theme that identifies patterns of related themes more broadly and 'subordinate themes ' the themes that are more specific and inform the superordinate themes.

As a result, a table of superordinate and subordinate themes have been made for the first case and will be repeated for each case. Following analysis on each case, patterns were established across-cases and put into a table of master themes (Smith and Osborn, 2007). This was organised into a format allowing analysed data to be traced throughout the process. The research supervisor was consulted to test out the interpretation and inform the full narrative. Reflection on the researcher's own perceptions, conceptions and processes were acknowledged as part of the research process and recorded in a research journal (Braun and Clarke, 2013; Willig, 2008).

Trustworthiness and Rigour of the analytic process

Smith, Flowers and Larkin (2009) emphasise the importance of assessing the quality of qualitative research. However, there has been much debate on how this achieved. Smith et al. (2009) highlight the relevance of four broad principles proposed by Yardley (2000) who evaluates qualitative research that used IPA methodology. Each principle will be discussed in turn and related to this research project.

Sensitivity to Context: Smith et al. (2009) suggest sensitivity to context is demonstrated throughout the research process. In particular this can be determined by the researcher's appreciation and interactional nature of the data collection, the interview situation and how access was established with gate keepers bearing in mind how this may be experienced by each participant. The researcher had spent many years working in a residential unit providing therapeutic support individuals with complex mental health. She had developed a heightened awareness of how sensitive the participants may be to new people and how difficult it may be for participants to trust. Firstly, the researcher contacted the service manager by letter then by phone to arrange an appointment to present the research. The managers were asked to consider if any clients met the inclusion criteria. If appropriate the participant was given a participant information sheet and the researcher was **introduced to them in person to individually invite them to interview. An interview time was arranged at a time that was convenient to the participant in a safe space within the residential unit. Great time and care were taken in the analysis process to ensure that claims and interpretations were grounded in the narrative of participants and verbatim extracts were used to emphasise salient points. The researcher conducted an in-depth literature review in order to orient the study and place it in context.**

1) *Commitment and Rigour:* The interviews were conducted within each residential unit, in a space that was private but familiar to each participant. The researcher took care to ensure that each participant understood that they did not have to take part, that they could ask for their data not to be used in the final write up to 1 month after the interview. The researcher was sensitive to the participants' needs and measures such as short breaks and time for each participant to think and be heard to communicate their experiences with relative ease. The researcher's attentiveness to detail at every stage of the process demonstrates the researcher's personal commitment and investment in the project. Rigour can be considered as relating to the thoroughness of the study. The researcher took great care in selecting the sample by visiting each residential home and meeting each participant before asking them to commit to an interview. A hand written letter was sent to each participant thanking them for their time after each interview. The researcher's skills as a therapist were utilised to know when to be probe and when to offer time and space during the interview. The researcher utilised her Director of Studies to guide the analysis and

when moving beyond the purely descriptive sense of experience to include interpretations.

2) *Transparency and Coherence:* The former refers to how clearly the stages of the research process are described in the write-up of the study. The researcher enhanced transparency by describing in detail how each participant was recruited and was clear that each participant was working age adults. The interview schedule was constructed and tested out in the field of residential care. This was achieved by asking clients what they would like to be asked about their own experiences of living in residential care. A research journal was kept documenting each step in the research process. The completed write up presents a coherent argument with links between themes highlighted. The researcher made it clear that they were positioned as attempting to make sense of the researcher trying to make sense of the participants experience according to the principles of IPA and the personal values of the researcher.
3) *Impact and importance:* Yardley (2000) suggest that the test of real validity lies in whether it tells the reader something interesting, important and useful. This project has contributed to hearing unheard voices that have previously been overlooked in the past. It is proposed that the important messages this research has raised will be utilised in the researchers work to raise awareness using platforms such as workshops and presentations within a recovery complex needs NHS service.

Ethical considerations

The researcher had Ethical Approval clearance from the University of the West of England (Appendix 5,6, 7, 8, 9, 10 and 11), and agreement from my participant organisations. The research was aimed at a vulnerable group and the researcher used professional experience and supervision to ensure that participants were not open to manipulation and exploitation (Braun and Clarke, 2013). Participants were not subjected to known risk and the researcher has been honest and accurate in reporting results. The researcher used reflection, supervision and professional experience to consider the implications of consent or communication difficulties. Therefore, the researcher was flexible and offered a break in the middle of each interview and, dependant on each individual, extra or shorter interview time. Each interview was followed by a debrief, and each participant was signposted to additional support or therapy if they felt distressed.

All recorded data was kept on an encrypted memory stick, in password protected files, on a password protected laptop only used by the researcher, which was kept in a locked cabinet when not in use. The researchers' physical safety was considered at the planning, design and practise stage as the participants had complex mental health presentations and could be unpredictable.

Table 1 - Participant demographics

Participant	Age	Gender	Employment	Cluster	Diagnosis	Length of time in residential care	Sexuality	Race / Ethnicity	Social class	Disabled	Relationship status	Children	Rural or city
Fred	59	Male	Other	7/8	Schizophrenia with anti-social personality disorder traits.	1 year 30 years on and off	Heterosexual	White British	Middle class	Yes	Partner	No	Rural
Julie	58	Female	Other	8	Borderline Personality disorder. Sight problems Anxiety	21 years	Heterosexual	White British	Prefer not to say	No	Single	No	Rural
Peter	44	Male	Prefer not to say	17	Schizophrenia and alcoholism.	6months and 7 years on and off	Other	White British	Working Class	Yes	Separated	2	Rural
Margaret	69	Female	Other	8	Borderline personality disorder. Spondylosis of the neck.	5 years 14 years	Heterosexual	White British	Middle class	Yes	Divorced	2	Rural
Ray	65	Male	Other	17	Schizophrenia	27 years	Prefer not to say.	Prefer not to say.	No Class	Yes	Single	No	City
Mike	46	Male	Other	13	Paranoid Psychosis	6 years	Heterosexual	White	Working Class	Yes	Single	No	City

Table 2 of superordinate and subordinate themes with illustrative extracts

Superordinate theme	Subordinate themes	Examples of data
Stories of change over time ; an historical journey	Where I started.	My life began when I came here. And **** sometimes says he is sorry he ever came here but I say believe you me there's I've been in a lot of homes, I've been in fre... I've been in ******** All because of Dad! Um, cause I was at home then and I've been in a home I was in a home and I was a child and I was in care for 8 days and they were horrible places (Julie 10101) Cause of what was happening to me and this is the best home I have been in. This is the only home I haven't run, well now I don't run away cause I am settled. Cause even when I was living at home I was always running away" (Julie - 129).
	My past journey.	It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room (Julie 83) Now I've got a life, I can go out on my own. Do you know before I came here I'd never been shopping on my own (Julie 1083) I'm too frightened to look to, to close into the future because of what I've had in the past (Jean 1264)
	Where I am now.	Yeah, I had a lot of issues when I first came here because it was run differently it was run badly and I was always running away but I don't now because I am happy (Julie – 37) It's the only place I will be happy, I the, it's the only place. My life began at 38 (Julie - 531)
Superordinate theme	**Subordinate themes**	**Examples of data**
Searching for care	Safer inside.	It's safe um it's safe and it's my safe place (Julie-523) Well I can't get out in the community because I am too vulnerable at my age love (Margaret-377) Well yes I have to be cared for at my age (Margaret- 424)

		Well if I was to go out into the community I would be frightened to death by the spirits you know (Mike- 342)
	Scary outside.	The only pain I feel is being alive (Fred - 113). I took so many overdoses like paracetamol umm tablets I crumbled them up in the drink not through drinking, I was socialising in the pubs and that. I did not used to drink too much I just used to crush all the tablets in a drink it. I was took to hospital and pumped, pumped out. I was, I was, I was found on the side of the road sort of thing.
Superordinate theme	Subordinate themes	Examples of data
The challenges of living in residential care	Powerlessness and infantilising.	It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room (Julie – 83).
	I want to be treated as an individual.	And as I say it is the best home that I have been in. But I need to get out and keep occupied cause I don't want to just sit doing nothing like a lemon. I want to get motivated I want to keep doing things. And I like to help (Margaret – 268).
Superordinate theme	Subordinate themes	
Learning to grow as a resident in a residential care home.	Gaining control and learning new skills to live.	I had no life skills when I, I come to move over here and they helped me grow, because make me feel I do my own washing, I,I can use the dryer, I go out. and um just sensible rules there is not hard rules, just sensible rules which we, which you have in life (Julie – 292).
	Self-acceptance "It's ok not to be normal".	Cause here you can be a pig um you can be yourself. It doesn't matter if you are sometimes umm crazy you don' have to explain what you can just be what you want to be if you want to scream you can just scream, if you say something really outlandish like really crazy just for the sake of it, it's ok (Julie – 983)

Analysis

Superordinate theme 3: The challenges of living in residential care

This theme articulates things that the participants found challenging in residential care and how power is at play in more subtle ways. The main subordinate themes that were developed were being treated as an individual and powerlessness and infantilisation. This theme gives insight into the factors that actively silence the voice of the resident. The researcher was able to reflect on this in her practise and this raised her awareness of how easy it is to slip into 'motherese' around clients, and how staff often stop treating clients as individual adults.

'Treat me as an individual'

Margaret is grateful for the care that she has but she is not fulfilled in many ways. There is a sense of loss of independence and individuality:

> "And as I say it is the best home that I have been in. But I need to get out and keep occupied cause I don't want to just sit doing nothing like a lemon. I want to get motivated I want to keep doing things. And I like to help" (Margaret – 268).

Margaret felt very unstimulated. Her use of sat like a 'lemon' was something that came throughout her interview. The entire interview felt like a way to communicate that Margaret felt she deserves more. Margaret talks about being dependant on others to socialise and this sounds quite powerless or childlike. She suggests that she has experienced residential care as restrictive; having opportunities within the home was important to combat boredom and gives a sense of purpose:

> "We rarely go out to the pub. I wouldn't mind going. I mean I wouldn't mind going and helping the staff and taking one in the wheelchair. We have done it on the odd occasion, but it doesn't happen very often. Well that's all down to....... the staff being available un and everything else.
> Well who wants to go out. You know who's, who would look forward to going out and having a change" (Margaret – 954).

Margaret has to now rely on others, whereas in the past she had a family, drove a car and ran a home and cared for her mother. This is a quote that emphasises Margaret’s struggle of not being able to care for her mother:

> “And then she went straight downhill and I have always felt that was my fault because they said I was her carer. Her cook, her bottle washer, the gardener and her chauffer” (Margaret - 207).

There is a sense of loss of freedom to choose to do what she wants. Margaret living in care has to rely on others and conform with what is best for the group rather than for the individual. This is something that was systemic in the past institutions and often continues within residential care today. This invalidates independence and individual likes and dislikes and residents can be seen as trouble makers or non-conformers if they do not comply.

> “Yeah and I have driven all sorts of cars. Little minis, the old-fashioned Minis’, not the pregnant ones as I call them” (Margaret – 228).

Margaret had not experienced a holiday and had a yearning for going as in her past she had been quite adventurous. I felt that Margaret was quite powerless and found the reliance on others frustrating. During the interview it felt as if Margaret was seeking outside help to get her needs met and acknowledged. It almost felt like an act against powerlessness:

> “Do holidays happen? You know and what is the experience of holidays and does this happen within this home?”
>
> “They have done but it has only been a very short break.”
>
> “Well the fact that I am getting on now I need a nice long break. Laughter. From a Thursday morning to a Monday morning, something like that. So, I can” (Margaret - 1490).

In contrast Julie did not feel that activities were necessary. In real terms activity schedules were provoking and would force her to become ‘resident evil’. Holidays and activities are not suitable for all residents and it is important to have choice and individual needs should be met as far as possible:

> “Yeah, that member of staff has long gone she used to make us do chores, she used to, we used to have activity diaries and I used to rebel then, I was really like resident evil the cause I really didn't get on with her. I thought she was the boss over the unit, but, she went she was just another team leader, I didn't know they are all team leaders, but she's long gone “(Julie 1019).

When a person is not treated as an individual then the person will not feel valued and rebel against being scheduled to do things. Participants valued carers that saw them as unique individuals treating them as unique human beings. However, this process needs collaboration of both client and staff to enable a sense of purpose, as Julie shares below:

> “Yeah, she used to plan your week for you, and I used to say 'I don't need my day planned, I can plan my own day but no. We had to have a timetable, we had to do, we still have our set washing days but that is practical” (Julie 1019).

Julie is able to understand practical solutions to living in a busy home but as an adult and clearly is able to plan her day without it being planned for her. This links with PIE 2.0 and as an organisation responding to client and staff feedback. This will be further deliberated in the discussion.

‘Powerlessness and infantalisation’

Julie shared how powerless she felt when she first came into residential care. She reflects on times of cruelty and infantalisation. It is important for practitioners to be aware that clients may have been subjected to stigma and restrictive practise in residential care homes in the past.

> "Matron she had lots of hard rules and she was very strict and also, we weren't allowed to, we had to ask for if we could have our pocket money on a Thursday. She, she kept our bank cards and we used to get £15 a week and we weren't allowed to have our own cigarettes she used to use to supply them. If we got caught with cigarettes, we would get grounded and our pocket money was slammed "(Julie – 43).

Julie's experience is of the same residential care home she is in now but how it was run very differently. The impact of this on Julie was detrimental and as reflected earlier she resorted to desperate behaviours such as attempts to take her own life. How matron ran the home felt more in line with a prison. Julie shared that clients were treated like prisoners or children without rights and privileges. Medication was used as a control, as Julie shares in the quote below:

> "It was horrible when she was here, she was cruel, and she was, and she used to take me she used to give me Haloperidol when I used to run away and then I couldn't walk properly, and I couldn't talk properly" (Julie – 93).

It was shocking to hear an account of how medication was used to control Julie. Julie talks about punishment and dehumanising her to force her to conform by taking away her independence:

> "It was very....when I used to run away I used to have a door alarm on my door she used to alarm my door and lock me in my room. So, as a punishment that was. I was allowed down for a cigarette and I was then taken for a shower in the morning, then taken back to my room and my alarm was put on so I could not come out of my room" (Julie – 83).

Julie's excerpt uses the word 'allowed' used in both of the quotes above and below. This throws up an image of a child, highlighting the infantilising of clients. Infantilisation is damaging and deprives an individual of their personhood and agency which is documented to lead to a decline in both psychological and physical symptoms. Thus, Julie is raising awareness of how power operates between the staff and the client. Another way in which participants make sense of residential care is in terms of being powerless:

> “Matron was very strict, the only time she was happy was six o'clock, she used to send me to the cupboard in the kitchen, cause that is where the alcohol was kept and I used to have to go and get and get her. She used to have a big 'bucket'. What she used to call called a bucket was a big glass and I used to have to get her a big glass of wine and then she was, she was in a happy mood. Then we were allowed to drink but, still allowed to drink. But I only have one a night, it helps me to sleep” (Julie – 198).

When staff left, participants appeared confused or agitated and this had a big impact on Ray who reflected on how it feels to have staff not turn up for a shift:

> “xxxx used to work here but. But he left without saying anything. He just suddenly stopped coming” (Ray - 649)

Ray reflected on one of the members of staff retiring and he seemed to feel a real sense of loss. Ray talked about the strong relationships with members of staff and how they had common interests such as the football and could be relied upon to keep him safe.

> “No. xxxx is taking me. She won't be able to take me anymore because she is retiring. They will have to get someone else to take me” (Ray - 554).

Ray was able to say how he felt a ‘bit low’ and this is interesting to hold in mind that as a member of staff working in someone’s home endings need to be managed appropriately with opportunities to say goodbye.

Julie reflects on how powerless she felt in a mentally abusive relationship with a senior member of staff when in residential care. The phrase ‘Matron mum’ feels sinister and inappropriate, repeating the pattern of abuse Julie had experienced living with her controlling mum and abusive father:

> “Yeah, she told me she was my mum and she told me she adopted me. Cause, cause I kept running away so that if I was found the Police wouldn't take me to hospital they would bring me back here. So the Guardianship order, was here but she said she'd adopted me and that she was my mom and I used to call her Matron mum and she used to call herself my Matron mum” (Julie – 61).

Reflections of staff being in a position of power such as rationing out tea, coffee or milk with some staff seen as generous and others seen as mean brings up a sense of unfairness . This experience in residential care clearly emphasises unequal power balance and infantilisation:

> “After I ran out of coffee cause me n xxxx have these small things that they put so many....I am supposed to have 4 spoonfuls of coffee and 2 teabags. But xxxx has 6 spoonfuls of coffee and no tea bags.”
>
> “And some staff are generous, and some aren’t!” (Ray - 858)

Ray speaks about staff power and control over the time a person gets up or goes to bed at night. This emphasises invisible power at working with vulnerable persons. Ray’s quote shows his resilience at finding ways around things that are difficult when living in care:

> “But one nurse that works here she didn't let me get up till 7 o clock.”
>
> “Her names xxx she usually does Wednesdays and Saturdays, but she never did it last night!”
>
> “No. How did you experience that when you when you wanted to get up and have your cup of tea and…..”
>
> “I don't mind really just uh. When she is on I always go to bed early. But I went to bed early last night I went to bed a quarter past nine” (Ray-780).

Mike reflected on how different members of staff treated him and, in this case, this particular nurse made him feel angry. It is clear from the excerpt that he knows exactly when she is on shift and has managed to avoid her for a year. Mike highlights simply being ‘talked’ to helped create an environment of warmth. Not being spoken to felt threatening and cold and like being ‘blanked’:

> “All of them. Apart from one. Who I don't see anymore? She only works here once a week anyway.”
> “She blanks me.....”(Mike – 234).

Mike’s experience of residential care emphasises how invisible power operates, raising the issue of how as health professionals we need to be aware of social justice issues and question the work that is done and ensure that we treat residents as equals. This emphasises the importance of training and critical awareness of power imbalance.

Discussion

At this point, a summary of the research findings will be provided, this will include a discussion about the contribution of this study to the literature, the implications for the discipline of counselling psychology, the limitations of the study and suggestions for future research. These themes and quotes are presented in Table 2 and described further within this section is the theme ‘the challenges of living in residential care. Accounts from the participants’ interpretive content is now presented below.

Summary of research findings

The findings of this study revealed how six clients with complex mental health needs experienced living in a residential care home. Four superordinate themes were developed from the analysis of the interview data. These were (1) Stories of change over time; an historical journey (2) Searching for care; (3) The challenges of living in residential care; (4) Learning to grow as a resident in a residential care home. The theme ‘the challenges of living in residential care’ will now be summarised.

The superordinate theme ‘the challenges of living in residential care’ This felt important as the researcher was concerned that the participants would not be able to bring any negative experiences owing to their circumstances of being dependant on the care that they receive. However, this was not the case and participants' reflections indicated the subordinate themes '**powerlessness and infantilising'**, lack of control, boredom and **'I want to be treated as an individual'.** This theme gave insight into the factors that actively silence the voice of the participants', to destigmatise and hear the unheard. As a counselling psychologist in training and a researcher, the knowledge that evolved from this project raised the researcher's awareness and shaped her practise. Particularly understanding how power can operate seen and unseen within a residential care context.

Power

Power is defined as the ability to do or to act; the capability of doing something; strength; might; and force (Allen, 2006). Unfortunately, power quietly haunts health and social care (Cutcliffe and Happell, 2009). There are strong links between traditional psychiatry and coercion/power (Hannigan and Cutcliffe, 2002). A critique of historical and socio-political literature pertains that mental health and psychiatry often linked to social exclusion, control and incarceration over time in settings such as madhouses, workhouses, asylums, prisons and more recently hospitals (Cutcliffe and Happell, 2009). This has been evidenced throughout the results section 'a story of change over time' where participants spoke about the past and in some cases in the here and now in which power, control and exclusion featured prominently.

Power and powerlessness became underlying themes that punctuate the analysis. Interpersonal relationships are considered the anchor of therapeutic engagement. However, relationships within residential care are littered with issues of power. In a residential setting in which health care professionals work with highly vulnerable populations 'invisible power' can breed unnoticed by professionals who are seemingly unaware of the dynamic (Cutcliffe and Happell, 2009).

This research has flagged up how mental health nursing practise is not free from problems from the service user perspective. Cutcliffe and Happell (2009) argue there is an absence of empirical and theoretical literature that focusses explicitly on power and issues of power within this field. Finfgeld (2004) explicitly states that mental health nurses frequently speak about empowerment. However, Cutcliffe and Happell (2009) critique that this is fascinating scenario, where practitioners espouse theory and practise empowerment whilst being conceptually uncertain of the phenomenon called power. This research shines a light on how power has operated in the past as per Julie's experience of 'matron' but more worryingly, still operates but is less visible, such as Ray's example of 'tea bags' and Mike's example of the 'night nurse'.

The Power Threat Meaning framework advocates that understanding how power operates in the life of the client should be the starting point for understanding the distress or disturbing behaviour of another (Johnstone and Boyle, 2018). The participants were very clear about the lengths they would go to get their voices heard. The participants spoke about past coercive power in which medications or treatments were prescribed and enforced against their will. Unfortunately, this still happens today using power such as community treatment order (CTO), or legal power such as arrest which was a large part of participants' histories. Interpersonal power was also spoken about mostly in the past but also recently. Participant Julie gave a graphic description of a powerful matron who was controlling and cruel, and articulated how she was undermined, controlled and over medicated as a way of managing her. Unfortunately, mental health is unique to medicine as some patients have been in the past and continue to be treated against their will (Laugharne and Priebe, 2006).

Finally, there are more hidden forms of power operating for example within government, legal systems and health care professionals. This gives power to exercise over users of the system by imposing an 'expert truth' (Sapouna, 2012). These hidden forms of power need to be challenged and this research gives an opportunity to give a transformative platform to view this as 'one truth amongst many'. This can only happen in the context that allows alternative views, most importantly the clients explanations and views as a way to empower the client offering meaning and potential solutions for a person's distress (Cutcliffe and Happell, 2009). This is significant development in the field of mental health where there is an increase in service user/ survivor movements to articulate different 'truths' by experts by experience. These are the perspectives that shape the voices of those directly affected by the mental health system and give opportunities to hear the unheard.

Empowerment

A precursor to empowerment is the lack of power or an imbalance of power (Finfgeld, 2004). The theme 'learning to grow' evidences relationships that have developed from the participants' being communicated with in a caring and respectful manner, thereby aiding that person to see their personal value and worth. Unfortunately, not all health care professionals are able to innately support empowerment, particularly in the past, as this research emphasised. To empower an individual, all health care professionals should be willing to allow themselves to co-operate, compromise and surrender control. Those that can do this well require an instinctive acceptance of the needs of others, empathy, tolerance and flexibility. This links back to social justice and needs great courage, respectful mutuality, power sharing and participatory decision making, and an abandoning of professional power. This requires everyone to be placed in a position to learn from each other (Finfgeld, 2004). Piat, Seida and Padgett (2019) argue that a person should be responsible for one's life, including choice to organise one's social life and choices in the residential care home to ensure they feel at home in particular developing psychological awareness as practitioners of the needs of the people we care for.

As discussed earlier, addressing power imbalances means breaking down professional boundaries and establishing more equitable relationships. The participants were able to describe what had enabled them to grow and one of the concepts was a sharing of responsibility between the health care professional and the participant in which both are open to new ways of learning (Finfgeld, 2004). These six participants have implicated and evidenced a loss of power in an oppressive health care system. The resilience they have displayed, to learn to trust once again in residential care, supported by health care professionals, willing to share power has been evidenced in these six interviews. These shared stories, do not have perfect endings but each participant has found a place where they have been empowered to grow, in a residential settings that are also continuing to grow.

Implications for Counselling Psychology

The results from this study have significant implications for the profession of counselling psychology. This research is a reflection on the experience of how it is as an adult to be taken into residential care, often against your will. As counselling psychologists, we are aware of our respect for client's autonomy, as trustworthy and a commitment to maintaining confidentiality are the heart of what we do (Cooper, 2009). Counselling psychologists are aware of prioritising clients' subjective and intersubjective experience and enabling growth and actualising potential. Therefore, having insight into a client's history, such as Fred's aversion to a male carer, helps psychologists and carers to be aware of past trauma and how the past continues to play out in the present. This offers a way of making sense of someone's distress and understand what is being communicated.

Counselling psychologists conceptualise people's problems in a humanistic way (Strawbridge et al, 2009). This is relevant to these participants as they all reported difficult relationships and experiences of living in a world that they felt they did not fit into. Counselling psychologists work relationally and are acutely aware that it is the therapeutic relationship that aids the process of healing (Kahn, 1997) . Therefore, this research raises counselling psychologists' understanding of a marginalised group. A large part of this work is saying loud and clear that participant or client is appreciated for who they are, as a unique being, relationally embedded and this includes an awareness of how this individual may experience discrimination, prejudice, stigma and restrictive practise.

One of the ways the participants expressed discrimination and prejudice was that out of the six participants who had suffered distress for most of their lives, only one participant had access to therapy. One participant spoke about a drug and alcohol group that he belonged to but had found it difficult to engage at depth or attend weekly. The other participants had not engaged or been offered therapy. Counselling psychologists are well placed to ask the question ‘why is this’ and ‘what can we do to change this’? This is the humanistic value of counselling psychology that observes a ‘thing’, takes a step back and questions why is this group of people not being included and what can I do about this, hearing the unheard.

Cooper’s (2009) paper on ‘welcoming the other’ examines how counselling psychology may advance in the future. He posits that professionals need to engage with people in a way that considers labels ‘lightly’ and meets people firstly as people, ensuring they are met as who they are not just their diagnosis. This research sheds light on how the journey from mental illness to mental health is to re-claim one’s obligations, responsibilities to and for the other. Psychologists need to consider how challenging the client may need to be reconsidered and instead think about welcoming the client. Cooper (2009) suggests that the gentleness of the word ‘welcoming’ has the potential to induce transformation in clients to enable the capacity for a life worth living.

Limitations

As a qualitative study generalisability of research findings are not sought due to the experiential nature of qualitative research. The sample chosen was a predominantly white British residential home in the south west of England. However, this research does not reflect the diverse multi-cultural society that residential care homes may be made up of. Therefore, there is room for this research to look at a cross cultural expansion of the work. For example, how would research look in the Polish, Somali or afro Caribbean communities?

A further issue was that this sample was made up of working age adults, mostly an older population. This research may also have scope to be explored within a younger population which would also shed light on a set of different experiences within a different time point.

It should also be understood that IPA recognises a double hermeneutic with the researcher aiming to make sense of the participants making sense of their experiences of living in residential care. This analysis presents one of many possible constructs of the phenomenon under study which was influenced by the researcher's own subjectivity. Therefore, another researcher would have produced different themes dependant on their own set of experiences (Elliot et al., 1999).

If this research had fewer time limitations it would be have been advantageous to offer each participant an opportunity to review each transcript and review the quotes used in the write up of this work. This would have given the participants more power and control over the finished thesis. However, owing to time limitation of the professional doctorate and Covid restrictions it was not possible for the researcher to complete this in a timely manner. In Bacha et al.'s (2020) research, the participants interviewed were given an opportunity to review and report whether the findings were representative of their experiences. This would be a recommendation for future research in this area of client experience.

Conclusion

The findings in this study revealed four superordinate themes; Stories of change over time; an historical journey; Searching for care; The challenges of living in residential care and Learning to grow as a resident and in a residential care home . These themes developed from the interviews of the participants' who live in residential care. The focus of this paper has been on superordinate theme 'the challenges of living in residential care'.

Each participant experienced being part of the mental health system for many years and shared stories of significant change over time. The participants were able to reflect on power operating negatively in their lives inside and outside of residential care. There was a clear emphasis on a search for care from pre-existing emotional distress which had been exacerbated by living in a community in which they felt unsafe. Therefore, this research found residential care to be a safer space in the world with the potential to learn new skills to grow. This research documented how in the past residential care felt unsafe; this was articulated in the participants' interviews. More recently residential care has improved, participants suggest that having some care is better than no care.

This research explored the experiences of having complex mental health and the life experiences of the six participants to where they are today. Suggesting that there are a small minority of people in our world that may need residential care. However, not all people, for some, society can be cruel and presents challenges that are difficult to navigate and can exacerbate already pre-existing distress. This research suggests that the health care professionals that work in this area are aware of the power they possess and are able to reflect and be sensitive to the needs of the people in their care. This research argues that health care professionals foster relationships that are consistent, safe, trusting and protective in which they dismantle professional boundaries and establish more equitable relationships.

This research raised awareness of clients' experiences of being in residential care. Counselling psychologists are well placed to support people by understanding distress in a genuinely compassionate way. The research raises awareness of how vulnerable these participants feel when in the community and more recently how the participants' found residential care as a safer space in the world to begin to gain control, learn new skills and find acceptance. However, this was dependant on the practitioners who worked with them.

Secondary to this, the researcher found that by undertaking this important research impacted on her in the following ways. The study provided insight into the experiences of people that need residential care, and raised questions about accepted ways of responding to human distress. The analysis provided suggestions directly from the participants for the researcher and other health care professionals around fostering relationships that are consistent, trusting and protective in a residential care context. This included providing opportunities to question professional boundaries. The researcher had personal experience of residential care homes kitchens being locked, denying basic human rights such as independent access to food and drink. This research gains insight into how denying basic needs stands in the way of establishing equitable relationships. The researcher found the themes mirrored a similar journey to her own. This enhanced the determination to present a piece of work that can raise questions of all professionals who work in the field of complex mental health. Undertaking this research has given the researcher the confidence to question what is sometimes considered ‘the way we do it’ and question ‘why’? The study aims to raise awareness for all health care professionals including counselling psychologists around how to work with people that live in residential settings and consider interventions that support a person to live ‘their best life’.

> I had no life skills when I, I come to move over here and they helped me grow. Because make me feel I do my own washing, I,I can use the dryer, I go out and um just sensible rules there’s no hard rules, just sensible rules which we, which you have in life - Julie

References

Adshead, G., Burn, W., Byrne, L., Goslar, D., James, A., Khan, M., Lovett, K., Morris, D., Wallace, V. (2018). *Person-centred care: Implications for training in psychiatry*. England: The Royal College of Psychiatrists.

Allen, R. E. (2006). *The concise oxford dictionary of current English* (10th ed.). London: BCA.

American Psychiatric Association. (2000). *Diagnostic and statistical manual of mental disorders: DSM-IV-TR* (4th ed.). Washington, D.C: American Psychiatric Association.

American Psychiatric Association (2013). Diagnostic and statistical manual of mental disorders (5th ed.) Washington. D.C: American Psychiatric Association.

Anfossi, A. (2017). The current state of recovery colleges in the UK: final report. Nottingham: ImROC.

Anthony, W. A. (1993). Recovery from mental illness: The guiding vision of the mental health service system in the 1990s. *Psychosocial Rehabilitation Journal*, 16(4), 11-23.

Anthony, W. A. (2004). The principle of personhood: The field's transcendent principle. *Psychiatric Rehabilitation Journal, 27*(3), 205-205.

Bacha, K., Hanley, T., & Winter, L. A. (2019; 2020). 'Like a human being, I was an equal, I wasn't just a patient': Service users' perspectives on their experiences of relationships with staff in mental health services. *Psychology and Psychotherapy, 93*(2), 367-386.

Beresford, P. Perring, R. Nettle, Wallcraft, J. (2016). *From mental illness to a social model of madness and distress.* London: Shaping our lives.

Blackburn, P. J. (2012). Developing a psychological approach: The wellbeing service for homeless and vulnerably housed people in Bristol. *Housing, Care and Support, 15*(2), 66-70.

Boardman, J., Craig, T., Goddard, C., Henderson, C., McCarthy, J., McInerny, T., Whicher, E. (2010). *Social inclusion and recovery (SIR) strategy.* (). London: South London and Maudsley NHS Foundation Trust.

Brady, D., Clifton, A., Burr, V., and Curran, S. (2014). The infantilisation of older people: Is it a problem? *Mental Health Nursing (Online), 34*(5), 22.

Braun, V., and Clarke, V. (2013). *Successful qualitative research: A practical guide for beginners.* London : Sage.

British Psychological Society. (2019). The Delphi method. Retrieved from https://thepsychologist.bps.org.uk/volume-22/edition-7/delphi-method

Brocki, J. M., and Wearden, A. J. (2006). A critical evaluation of the use of interpretative phenomenological analysis (IPA) in health psychology. *Psychology and Health, 21*(1), 87-108.

Cabiati, E., and Raineri, M. L. (2016). Learning from service users' involvement: A research about changing stigmatizing attitudes in social work students. *Social Work Education, 35*(8), 982-996.

Chilvers, R., Macdonald, G. M., and Hayes, A. A. (2006). Supported housing for people with severe mental disorders. *The Cochrane Database of Systematic Reviews,* (4)

Clare, A. (1980). *PSYCHIATRY IN DISSENT*. New York: Routledge.

Clare, L., and Cox, S. (2003). Improving service approaches and outcomes for people with complex needs through consultation and involvement. *Disability and Society, 18*(7), 935-953.

Cockersell, P. (2016). PIEs five years on. *Mental Health and Social Inclusion, 20*(4), 221-230.

Conrad, P. (1987). The experience of illness: Recent and new directions. *Research in the Sociology of Health Care,* (6), 1-31.

Cooper, M. (2009). Welcoming the other: Actualising the humanistic ethic at the core of counselling psychology practice. *Counselling Psychology Review, 24*(3).

Cooper, M.,Dryden, W., Martin, K., Papayianni, F. (2016). Metatherapeutic communication and shared decision-making. In M. Cooper and W. Dryden (Eds), H*andbook of pluralistic counselling and psychotherapy* (pp. 42-54). London: Sage.

Copeland, M.E. (2002) *Wellness Recovery Action Plan*. USA: Peach Press

Cromby, J., Harper, D., Reavey, P. (2013). *Psychology, mental health and distress*. New York: Palgrave Macmillan.

Cutcliffe, J., and Happell, B. (2009). Psychiatry, mental health nurses, and invisible power: Exploring a perturbed relationship within contemporary mental health care. *International Journal of Mental Health Nursing, 18*(2), 116-125.

Cutts, L. A. (2013). Considering a social justice agenda for counselling psychology in the UK. *Counselling Psychology Review, 28*(2), 8-16

Davidson, L., Bellamy, C., Guy, K., Miller, R. (2012). Peer support among persons with severe mental illnesses: A review of evidence and experience. *World Psychiatry, 11*(2), 123-128.

Davies, K., & Gray, M. (2017). The place of service-user expertise in evidence-based practice. *Journal of Social Work : JSW, 17*(1), 3-20

Deering, K., Pawson, C., Summers, N., Williams, J. (2019). Patient perspectives of helpful risk management practices within mental health services. A mixed studies systematic review of primary research. *Journal of Psychiatric and Mental Health Nursing, 26*(5-6), 185-197.

De Silva. D. (2014). *Helping measure person-centred care: A review of evidence about commonly used approaches and tools used to help measure person-centred care*. England: Health Foundation.

Department of Health. (2011). *No health without mental health*. London: Department of Health.

Eldal, K., Natvik, E., Veseth, M., Davidson, L., Skjølberg, Å., Gytri, D., & Moltu, C. (2019). Being recognised as a whole person: A qualitative study of inpatient experience in mental health. *Issues in Mental Health Nursing, 40*(2), 88-96.

Fairfax, H. (2016). The role of counselling psychology in secondary adult mental health care. In Douglas, B. Woolfe, R. Strawbridge, Kasket, E. Galbraith, V. (Ed.) *The handbook of counselling psychology* (4th ed., pp. 511 - 529). London: SAGEFaulkner, A. (2017). Survivor research and mad studies: The role and value of experiential knowledge in mental health research. *Disability and Society, 32*(4), 500-520.

Field, B., I., and Reed, K. (2016). The rise and fall of the mental health recovery model. *The International Journal of Psychosocial Rehabilitation, 20*(2), 86-95.

Finfgeld, D. L. (2004). Empowerment of individuals with enduring mental health problems: Results from concept analyses and qualitative investigations. *Advances in Nursing Science, 27*(1), 44-52.

Foucault, M. (1989). *Madness and civilization: A history of insanity in the age of reason*: Routledge.

Gresham, M.,. (2015). The infantilisation of the elderly: A developing concept. *Nursing Forum, 2*, 195-210.

Hannigan, B., and Cutcliffe, J. (2002). Challenging contemporary mental health policy: Time to assuage the coercion? *Journal of Advanced Nursing, 37*(5), 477-484. doi:10.1046/j.1365-2648.2002.02109.x

Johnstone, L., and Boyle, M. (2018). The power threat meaning framework: An alternative nondiagnostic conceptual system. *Journal of Humanistic Psychology.*

Kahn, M., and NetLibrary, I. (1997). *Between therapist and client: The new relationship* (Rev. ed.). New York: W.H. Freeman and Co.

Kagan,C., Burton, M., Duckett, P., Lawthorn, R. and Siddiquee, A. (2011). *Critical community psychology*. West Sussex: BPS Blackwell.

Kernberg, O. F. (1967). Borderline personality organisation. *Journal of American Psychotherapy, 15*, 641-645.

Killaspy, H., & Priebe, S. (2020; 2021). Research into mental health supported accommodation - desperately needed but challenging to deliver. *British Journal of Psychiatry, 218*(4), 1-181.

Kitwood, T. (1990). The dialectics of dementia: With particular reference to Alzheimer’s disease. *Ageing and Society, 10*(2), 177-196.

Krotofil, J., McPherson, P., and Killaspy, H. (2018). Service user experiences of specialist mental health supported accommodation: A systematic review of qualitative studies and narrative synthesis. *Health and Social Care in the Community, 26*(6), 787-800.

Larkin, M., Watts, S., and Clifton, E. (2006). Giving voice and making sense in interpretative phenomenological analysis. *Qualitative Research in Psychology, 3*(2), 102-120.

Laugharne, R., and Priebe, S. (2006). Trust, choice and power in mental health: A literature review. *Social Psychiatry and Psychiatric Epidemiology, 41*(11), 843-852.

Law, H., and Morrison, A. P. (2014). Recovery in psychosis: A Delphi study with experts by experience. *Schizophrenia Bulletin, 40*(6), 1347-1355.

Leamy, M., Bird, V., Le Boutillier, C., Williams, J., and Slade, M. (2011). Conceptual framework for personal recovery in mental health: Systemic review and narrative synthesis. *The British Journal of Psychiatry,* (199), 445-452.

Levinas, E. (2006). *Humanism of the other*. Urbana, [Ill.]: University of Illinois Press.

Martindale, K., and Philips, R. (2010). Applying quality of life in mental health social work practise. *Social Work, 22*(1)

McAdams, D. P. (2015). *The art of science and personality development*. England: Guilford Press.

McPherson, P., Krotofil, J., Killaspy, H., Joanna Krotofil, (2018). What works? toward a new classification system for mental health supported accommodation services: The simple taxonomy for supported accommodation (STAX-SA). *International Journal of Environmental Research and Public Health, 15*(2)

Mead, S. and Filson, (2016) Becoming part of each other’s narratives. In Russo, J and Sweeney A Eds (Ed.), *Searching for a rose garden.* (2016). Ross-on-Wye: PCCS Books.

Mental Health Taskforce. (2016). *The five-year forward view for mental health*. England: Mental Health Taskforce to the NHS England.

NHS England. (2019). *The next steps on the NHS five- year forward view. A report from the independent mental health taskforce to the NHS in England*. London: NHS England.

NHS England. (2019). *The next steps on the NHS five- year forward view. A report from the independent mental health taskforce to the NHS in England*. London: NHS England.

NICE. (2009). *Borderline personality disorder: Recognition and management*. England: NICE.

NICE. (2011). *Service user experience in adult mental health: Improving the experience of care for people using adult NHS mental health services*. England: NICE.

NICE. (2012). *Antisocial personality disorder: Prevention and management*. England: NICE.

NICE. (2014). *Psychosis and schizophrenia in adults: Prevention and management*. England: NICE.

O'Hagan, M. (2016). International mental health leader with lived experience. Retrieved from http://www.maryohagan.com/about-mary.php

Open Dialogue. (2018). Developing open dialogue. Retrieved from http://developingopendialogue.com/

Parker, S., Hopkins, G., Siskind, D., Harris, M., McKeon, G., Dark, F., and Whiteford, H. (2019). A systematic review of service models and evidence relating to the clinically operated community-based residential mental health rehabilitation for adults with severe and persisting mental illness in Australia. *BMC Psychiatry, 19*(1), 55-55.

Perkins, R., and Slade, M. (2012). Recovery in England: Transforming statutory services? *International Review of Psychiatry, 24*(1), 29-39.

Piat, M., Seida, K., & Padgett, D. (2020). Choice and personal recovery for people with serious mental illness living in supported housing. *Journal of Mental Health (Abingdon, England), 29*(3), 306-313.

Pitt, L., Kilbride, M., Nothard, S., Welford, M., and Morrison, A. P. (2007). Researching recovery from psychosis: A user-led project. *Psychiatric Bulletin, 31*(2), 55-60.

Poloni, N, Zizolfi, D., Ielmini, M., Pagani, R., Caselli, I., Diurni, M., Callegari, C. (2018). A naturalistic study on the relationship among resilient factors, psychiatric symptoms, and psychosocial functioning in a sample of residential patients with psychosis. *Psychology Research and Behaviour Management, 11.*

Raanaas, R. K., Patil, G., and Alve, G. (2015). Patients' recovery experiences of indoor plants and views of nature in a rehabilitation centre. *Work (Reading, Mass.), 53*(1), 45-55.

Rapley, T. J. (2001). The art (fulness) of open-ended interviewing: Some considerations on analysing interviews. *Qualitative Research, 1*(3), 303-323.

Recovery in the Bin. (2017). *UBI: The good, the bad and the ugly*. Retrieved from https://recoveryinthebin.org/2017/09/04/ubi-the-good-the-bad-and-the-ugly/

Reid, K., Flowers, P., and Larkin, M. (2005). Exploring lived experience. *The Psychologist, 18*, 20-23.

Repper, J., and Perkins, R. (2003). *Social inclusion and recovery: A model for mental health practice*. Edinburgh: Baillière Tindall.

Roberts, G., and Wolfsen, P. (2004). The rediscovery of recovery: Open to all. *Advance in Psychiatric Treatment, 10*, 37-49.

Roberts, G., Good, J., Wooldridge, J., and Baker, E. (2011). Steps towards “putting recovery at the heart of all we do”: Workforce development and the contribution of “lived experience”. *Journal of Mental Health Training, Education and Practice, 6*(1), 17-28.

Roos, E., Bjerkeset, O., Svavarsdóttir, M. H., and Steinsbekk, A. (2017). Like a hotel, but boring: Users' experience with short-time community-based residential aftercare. *BMC Health Services Research, 17*(1), 832-10.

Royal College of Psychiatrists. (2019). *The health of the nation outcome scale (HoNOS).* Retrieved from https://www.rcpsych.ac.uk

Sapouna, L. (2012). Foucault, Michel. Madness and Civilization: A History of Insanity (2001). *Community Development Journal, 47*(4), 612-617.

Sartorius, N. (2007). Stigmatized illnesses and health care. *Croatian Medical Journal, 48*(3), 396-397.

Shah, P., and Mountain, D. (2007). The medical model is dead long live the medical model. *The British Journal of Psychiatry, 191*(5), 375-377.

Shepherd, G., Boardman, J., and Slade, M. (2008). *Making recovery a reality.* London, UK: Sainsbury Centre for Mental Health.

Sibbald, S. E. A. (2016). *The consensus statement for people with complex mental health difficulties who are diagnosed with a personality disorder: 'shining lights in dark corners of people's lives'.* Faculty of Psychosis and Complex Mental Health, Division of Clinical Psychology, British Psychological Society. London

Slade, M. Longdon., E. (2015). *The empirical evidence about mental health and recovery: How likely , how long, what helps?* Victoria: MI Fellowship.

Slade, M., Adams, N., and O'Hagan, M. (2012). Recovery: Past progress and future challenges. *International Review of Psychiatry, 24*(1), 1-4.

Smith, A., J., Flowers, P., and Larkin, M. (2009). *Interpretative phonological analysis*. London: Sage.

Smith, J.A. and Dunworth, F. (2003) *Qualitative Methodology*. In: Valsiner, J., Ed., *Handbook of Development Psychology*, London: Sage. , 603-621.

Smith, J., A. (2007). *Qualitative psychology: A practical guide to research methods*. London: Sage.

Smith, J. A., and Osborn, M. (2007). Pain as an assault on the self: An interpretative phenomenological analysis of the psychological impact of chronic benign low back pain. *Psychology and Health, 22*(5), 517-534.

The Kings Fund. (2018). *Case study 1: Deinstitutionalisation in UK mental health services*. Retrieved from https://www.kingsfund.org.uk/publications/making-change-possible/mental-health-services

Thornicroft, G. (2006). *Shunned: Discrimination against people with mental illness*. Oxford: Oxford University Press.

TurningPoint. (2014). *Factsheet 1- complex needs and dual diagnosis*. Retrieved from http://www.turning-point.co.uk/media/636823/appg_factsheet_1_-_june_2014.pdf

Valuing people now: A new three-year strategy for people with learning disabilities making it happen for everyone. (2014). Retrieved from https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/215891/dh_122387.pdf

Walton, K., and Walton, I. (2012). The need for all services to be psychologically informed. *Housing, Care and Support, 15*(2), 57-58.

Watson, J., Fossey, E., and Harvey, C. (2019). A home but how to connect with others? A qualitative meta-synthesis of experiences of people with mental illness living in supported housing. *Health and Social Care in the Community, 0*(0)

Willig, C. (2008). *Qualitative research in psychology* (2nd ed.). Berkshire: McGraw-Hill.

Wolfsen, P., Holloway, F., Killaspy, H. (2009). *Enabling recovery for people with complex mental health needs. A template for rehabilitation service.* England: The Royal College of Psychiatrists

Woolfe, R., Dryden, W., and Strawbridge, S. (2003). *Handbook of counselling psychology* (2nd ed.). London: Sage.