How does participation in clinical mental health services and community arts programmes for mental health influence the expression of Mental Illness Identity (MII) among individuals with chronic and serious mental health difficulties?

M. Dupin

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School of Health and Social Care

University of Essex

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Contents

Abstract

Background: Growing evidence points to the benefits of community-based participatory arts for mental health. Such non-clinical interventions differ from traditional interventions for mental illness, which are typically situated within clinical statutory services. Clinical intervention can emphasise a sense of 'patienthood' and *Mental Illness Identity (MII).* MII is said to be dynamic, and further understanding of the factors influencing it is warranted.

Aim: This study explored themes of MII and hopes for recovery in people with long-term mental illness, who have accessed both clinical services and a non-clinical arts programme for mental health.

Method: A four-week Photovoice methodology was used with nine participants recruited from a community mental health arts group. Three discussion groups and four follow-up semi-structured individual interviews were carried out. Data was analysed using reflexive thematic analysis.

Results: Four themes were identified: *Navigating identities: the struggle between mental illness and the whole self*; *Hierarchy, power and positioning*; *Performing the patient role;* and *Teetering between hope and hopelessness*. This study highlighted the dynamic nature of MII, which was mediated by interpersonal and environmental factors within each intervention setting.

Conclusion: The informal, non-hierarchical arts setting offered a safe, consistent space that contrasted with the outcomes-focused and time-limited nature of clinical care. This allowed participants to build trust and reconnect with an identity beyond mental illness. Although MII was less dominant in the art setting, it still persisted, indicating that negative self-belief is deeply held, and that identity reconstruction beyond mental illness is sensitive to changing interpersonal and environmental intervention factors. The findings have key implications for clinical practice, especially regarding power dynamics between clinician and client, shame in repeat help-seeking,

and understanding the whole person within brief interventions. Community art spaces for mental health offer a valuable space in which relational safety can grow, which is an important foundation for any future clinical intervention. Therefore, collaboration between creative and health sectors is recommended, such as referring clients to community groups and providing trauma-informed training for arts practitioners. Co-production with service users in developing and maintaining these spaces can promote empowerment through roles beyond ‘patienthood’ and promote sustainability of community arts spaces.

Chapter 1: Introduction

Chapter overview

This chapter begins with an outline of the prevalence of mental illness in the UK and the different theoretical constructions of mental illness. Implications for intervention and recovery are discussed, before further consideration is given to the impact of mental health stigma and internalisation of mental illness into identity. Then, the potential of creative arts interventions for mental illness and identity reconstruction are considered.

Mental illness prevalence in the UK

Mental ill-health is common in the United Kingdom (UK), with estimates that one in four people in England will experience a mental health problem, such as anxiety or depression, in a given year (Mind, 2024). More chronic and severe mental illness (SMI), such as bipolar disorder, schizophrenia and other psychotic disorders, personality disorders, major recurrent depression and long-standing anxiety, can cause significant distress and negative impact on daily life. In 2018, about half a million people in England were estimated to have SMI (Public Health England, 2018), though this only includes those in contact with services. SMI often involves recurring episodes which typically require repeated and ongoing support. However, services are facing significant challenges in meeting demand with over 2 million people on waiting lists for National Health Service (NHS) any type of mental health support in England (Mind, 2024).

Constructions of mental illness: a brief history

How mental illness is defined has important implications for how it is treated and responded to. Historically mental illness has been constructed as biological, pathological

disorder of difference, giving rise to classification systems in psychiatry such as the Diagnostic Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013) and International Classification of Diseases (ICD-11; World Health Organisation, 2022), which locate the problem within the individual. This approach is often referred to as the *medical model of mental illness*. Diagnosis marks the formal status as a psychiatric patient (Rose & Thornicroft, 2010), which can present both opportunities and challenges. On one side, diagnosis may present opportunities for treatment and a shared understanding of one's difficulties (Tekin, 2011). On the other side, negative social stereotypes and the medical model may limit hopes for recovery, and have a negative impact on one's self-concept, through the creation of a narrative that focuses on illness and overwhelms other aspects of personhood (Rose & Thornicroft, 2010; Tekin, 2011).

Critique of the medical model grew with the anti-psychiatry movement during the 1950s and 60s (Foucault, 1961; Laing, 1962; Goffman, 1961; Szasz, 1960). These authors argued that mental illness was better seen as "problems in living" (Szasz, 1960, p.113, 114), within a broader psychosocial lens. Foucault (1961) drew attention to the power that medical language and discourse hold over how we think about mental illness, and the application of *disciplinary power* under the medical gaze which operated in asylums.

In the decades that followed, the social model of disability emerged, claiming that people with impairments are excluded and disabled because of societal barriers, rather than because of the impairment itself (Hogan, 2019). This lens was initially applied to physical disability, and latterly also applied to mental illness, in the sense that mental distress is constructed as an understandable response to trauma, socioeconomic, and other pressures. This perspective suggests that social change (e.g. addressing structural inequalities) is required to improve mental health.

This research is set within a social constructionist, feminist lens which views mental health as more than just a physiological, individual problem, but rather one which is shaped by relational, societal and cultural norms, structures and inequalities, such as racism, sexism, ableism, classism, and so on. Patriarchal discourses exert their power in shaping views of mental health. Behaviours and actions which are seen outside of societal norms in a patriarchal system have been labelled as deviant and 'mad' (Scheff, 1999). For example, women are more likely to be pathologised as 'emotional' (Gupta, Madabushi & Gupta, 2023); and marginalised men, such as gay men, or men with mental health issues are more likely to be discriminated against by patriarchal society (Johnson & Parry, 2015), with men's suffering being silenced by ideals of emotional strength (Clark et al., 2020; Mokhwelepa & Sumbane, 2025).

Considerations of power, and how this operates within mental health intervention settings is important. Within medicalised settings, power differentials exist between medical professional and patient, for example, in how expertise is constructed, how services are accessed and how treatment is administered, such as compulsory admission and use of restraint (Beames & Onwumere, 2022). Within non-clinical settings, such as those described later on page 14, power differentials may be less unequal where interventions are peer-led and/or led by non-clinicians, which may support in reducing self-stigma (Sun et al., 2022) and foster a sense of belonging (Abou Seif et al., 2022). Further discussion about power and mental health is given in the Literature Review (p.51) and then a position statement on the use of psychiatric diagnoses and power is given in Chapter three (p.59).

Recovery approaches have been popularised in UK policy over the past 15 years, with a more explicit focus on person-centred care and recovery (Department of Health, 2009). The concept of mental health recovery is a complex and multi-faceted one. Views on what recovery

is and what it looks like will depend on the role an individual holds in relation to the mental illness. Those in carer or healthcare professional roles have been found to be more focused on clinical outcomes, such as symptom reduction and improved functioning as indicators of recovery. In contrast, those with mental health diagnoses, i.e. in the 'patient' role, spoke to the importance of finding meaning and transformation from their experience of mental illness (Jacob et al., 2017). To help with defining recovery and measuring outcomes for discharge from services, Leamy et al. (2011) developed the CHIME (Connectedness, Hope, Identity, Meaning and Empowerment) framework. It is widely endorsed and is still referred to in current research (e.g. Goodman-Casanova et al., 2024), though it has been criticised as over-optimistic and reductionist, overlooking socioeconomic disadvantage, social disparities, or trauma (Hine et al., 2023), and lacking cultural adaptation (van Weeghel et al, 2019).

Although a recovery approach may sound promising, caution is needed. Critics have pointed to the concept of 'recovery' as a rationale for reducing support and cutting services (Beresford et al., 2016; Taylor, 2014). There is an active anti-recovery movement (Recovery in the Bin, 2016), which views recovery as a weaponised term overly focused on outcomes, claiming that the concept of mental health recovery has been corrupted by neoliberalism and capitalism. They argue that recovery is not possible while social pressures and inequalities, which are risk factors for mental illness, remain unaddressed. This movement complements the rise of *Mad Studies*, which critiques the medical model and reclaims the stigmatised term *madness.*

Indeed, the 2009 policy directive, New Horizons, placed a strong focus on the financial burden of mental illness on healthcare services, the taxpayer and employers. Return to work or volunteering were positioned as markers of recovery, as was becoming an expert of one's own

needs. This could be interpreted as a shifting of responsibility to the individual, particularly if they do not 'recover', and once again, the problem is located within the individual at the expense of addressing social determinants of mental health, such as poverty and discrimination.

This study conceptualises recovery as living well with mental illness and finding meaning from the experience (Jacob et al., 2017), rather than focusing only on clinical measures of recovery such as symptom reduction (which may be a part of living well with a diagnosis).

Implications for treatment and recovery

Not all individuals facing mental distress will choose to seek help (Barnett et al., 2024; Bland et al., 1997; Erçel et al., 2025; Henderson et al., 2013), but for those who do, there are various care pathways they may encounter, depending on their condition and how this is conceptualised. Persistent and serious mental illness (SMI) are usually treated medically with drug treatment, alongside other offers, such as talking therapies.

Statutory services

Statutory health services in the UK operate within the medical model of mental illness. Government policy for England (Garrett, 2024) sets out that General Practitioners (GPs) and Primary Care services such as Talking Therapies are often a first point of contact. More complex or long-term needs are supported by Community Mental Health Teams (CMHTs) or specialist services like Early Intervention for Psychosis (EIP). Acute care is provided by crisis teams or hospital admission. Across these various service types, individuals may see a range of professionals, including psychologists, psychiatrists, nurses, occupational therapists, and social workers. Medication is a common intervention, which may be offered alongside talking therapy.

It is worth noting that not all service engagement is voluntary. For people who are in acute crisis and at risk of harm, compulsory treatment and/or detention under the Mental Health Act can occur (Mental Health Act, 1983; 2007).

Despite calls for more person-centred care, systematic review shows issues with communication, poor attitudes and mental health stigma persist in the relationships between professional and service users, limiting how empowering and responsive services are to individual needs (Newman et al., 2015).

Non-clinical, community-based interventions

As demand for traditional mental health services has risen (Gilburt & Mallorie, 2024; NHS England, 2024), there have been calls for alternative, holistic approaches to ease waiting lists and offer more personalised care (Melham, 2023). This approach can be seen as less focused on a medical view of mental illness, but one which also acknowledges social factors.

One such approach is social prescribing, whereby health professionals, usually within primary care settings, refer people to local community-based, non-clinical activities such as gardening, volunteering, befriending, arts activities, sports, cookery and healthy eating activities. These are usually delivered by non-statutory providers, such as charities. Social prescribing initiatives recognize that health and wellbeing are determined by social, environmental and economic factors, and therefore aims to provide an alternative model of care to the biomedical approaches that dominate the mental health literature (Royal College of Psychiatrists, 2021).

Social prescribing has gained in popularity and has seen an increase in investment across England following the launch of the NHS Five Year Forward View (2014), which acknowledged the importance of preventative approaches and the role of the voluntary sector in supporting such

aims. In 2019, the NHS long-term plan explicitly named social prescribing and incorporated it into aspirations for greater personalised care. Social prescribing offers a collaborative process between professional and service user, with choice and recognition of personal interests and assets to support engagement in community activities (Payne, Walton & Burton, 2020). For many, social prescribing activities offer a means to improved social connection, inclusion and community (Bhatti et al., 2021; Hassan et al., 2020; Kellezi et al., 2019; Todd et al., 2017; Wakefield et al., 2019; Woodall et al., 2018), mental wellbeing (Bickerdike et al., 2017; Chatterjee et al., 2018), physical activity and health (Elston et al., 2019; Moffatt et al., 2017; Redmond et al., 2019).

However, it has been criticised for shifting responsibility for health from the state to the individual while offering only an illusion of person-centred care (Gibson, Pollard & Moffatt, 2021; Poole & Huxley, 2024). It is also important to note that the evidence base for the effectiveness of social prescribing has been criticised for being of small scale and poor design quality, such as lacking control groups or use of standardised or validated measures (Bickerdike et al., 2017). Poole & Huxley (2024, p. 32) criticise the roll-out of these interventions as giving a "false impression of doing something about the social determinants of health". They argue that social prescribing alone is unlikely to produce lasting change in people who are most affected by poor mental and/or physical health. This is because those populations are also most likely to be negatively affected by deep-rooted, complex health and social inequalities (e.g. poverty), and short-term social prescribing programmes are inadequate to address these (Poole & Huxley, 2024).

Implications of SMI for the individual: stigma and devaluation

People with SMI are often exposed to stigmatizing attitudes. Stereotypes, such as dangerousness or incurability of mental illness, may add to a sense of homogenous "groupness" or othering by society (Corrigan, 2007). These negative public attitudes can become internalised as self-stigma over time (Corrigan, 1998; Vogel et al., 2013), leading individuals to accept and apply negative stereotypes to themselves (Catalano et al., 2021; Corrigan, Watson and Barr, 2006), This reflects Goffman's (1963) concept of *spoilt identities* among stigmatised groups and is linked to increased depressive symptoms (Marcussen, Gallagher & Ritter, 2019).

Associated feeling of devaluation and anticipated future discrimination undermines self-esteem and efficacy. In turn, this dissuades individuals from pursuing life goals or practices to achieve these, in what Corrigan, Larson & Rüsch (2009) called the 'Why Try' effect. This mental illness stigma can then hinder help-seeking, service engagement (Bathje & Pryor, 2011; Corrigan, 2004; Corrigan et al., 2009; 2014; Lannin et al, 2016) and treatment adherence (Carrara & Ventura, 2018). This has been noted particularly among ethnic minorities, men, young people, veterans and those working in health professions (Clement et al., 2015).

SMI diagnoses attract more negative public attitudes than depression (Angermeyer & Matschinger, 2003), and it is not uncommon for individuals to come to expect discrimination in future interactions (Rose et al., 2011). Emotionally Unstable Personality Disorder (EUPD) is one of the most stigmatised psychiatric labels, with negative impacts on self-concept, that is, how the individual perceives and thinks about themselves. This is thought to be mediated by negative attitudes from the public, relatives and healthcare professionals (Motala & Price, 2022). Frontline service staff have been found to regard this diagnostic group as 'challenging,

manipulative, time wasters, a drain on services and attention seekers' (Bradbury, 2022), which can play out as receiving unequal care and discriminatory practice.

Recent practice guidelines recommend alternatives to inpatient admissions for this group, as part of a so-called recovery-focused approaches which aim to support living well with mental illness. This may have, however, inadvertently worsened inpatient staff attitudes (Motala & Price, 2022). The implication of requiring more intensive services implies one has not taken adequate personal responsibility to 'recover'; the need for support then places strain on underfunded, overlooked and struggling "Cinderella" services (Taylor, 2014, p. 251). It has been suggested that it is these rejecting and shaming experiences, rather than the diagnosis per se, that impact self-concept (Motala & Price, 2022).

A systematic review of self-stigma in serious mental illness concluded that there are variations in self-stigma in different settings, with some studies reporting higher self-stigma in community outpatient settings than in inpatient services, with other studies reporting the opposite when admission is involuntary (Dubreucq, Plasse & Franck, 2021). The authors also reported that peer-support groups promote positive group identification and help reduce self-stigma through explicitly challenging negative views of mental illness. Peer support and service user collaboration in services can support a transformation of identity from someone who is dependent, to the self as an active contributor (Tang, Tse & Davidson, 2016). Further exploration of variations in mental illness identity and self-stigma in different intervention settings, particularly where there are differences in power dynamics, would be interesting.

Not all individuals with mental health difficulties will internalize negative stereotypes. Some will be empowered by their awareness of such prejudice (e.g. Corrigan et al., 1999) and take a 'righteous indignation' stance and feel more confident in the pursuit of their goals, while

others may be unmoved and ignore public prejudice altogether (Corrigan and Watson, 2002). The strategy of deflecting or distancing from one's own mental illness is associated with greater self-esteem and lower depression, as is participating in activism and education to challenge stigma (Marcussen, Gallagher & Ritter, 2021).

Research into internalised self-stigma has advocated for cognitive behavioural interventions at the individual and group level to reduce self-stigma (Carrara & Ventura, 2018; Corrigan, 1998; Vogel et al., 2013; Yanos, Roe & Lysaker, 2011) and promote empowerment (Corrigan, Larson & Rüsch, 2009) despite perceptions of public stigma. This approach, however, could be considered reductive and places yet another problem within the individual for not being 'resilient' enough to not bow to social stigma. National public anti-stigma campaigns (e.g. Time to Change) have gone some way to influencing public attitudes about mental health (Henderson, Evans-Lacko & Thornicroft, 2013), however research undertaken within a similar time period indicated a lack of change in levels of discrimination from health professionals (Corker et al., 2013).

Self-stigma and the Illness Identity Model

The Illness Identity Model (Yanos, Roe & Lysaker, 2010; Yanos et al., 2008; Yanos et al., 2020; Yanos et al., 2021) describes how individuals with chronic illnesses construct their identity. They suggest this is shaped by the way society views the illness (i.e. stigmatising attitudes) and how the individual copes with it (i.e. whether illness is accepted and stigma internalised). The model suggests that illness may become integrated into self-concept or rejected in an attempt to maintain 'normalcy'. While self-stigma can negatively affect identity,

positive social support can mean a more adaptive integration of illness into identity, with better coping and outcomes.

The Illness Identity Model, with its focus on internalised self-stigma, has connections to *Labelling Theory* and *Modified Labelling Theory* (MLT) (Link, 1987, 1989), which posit that self-concept is shaped by external perceptions. According to MLT, those with mental illness come to expect being devalued and rejected and therefore employ coping strategies such as secrecy and withdrawal to cope with this anticipated threat. Social support networks are impacted as a result of these strategies to deal with their stigmatized status. Oris et al. (2016; 2018) built on the Illness Identity model, but again the focus was on physical illness. The authors suggest that illness identity is dynamic and evolves over time, influenced by personal, social and environmental factors. They argue that illness identity interacts with other aspects of self, such as social and occupational identities. For those who can positively redefine illness identity, that is accepting the illness as just one part of identity (acceptance) and find meaning and purpose despite it (enrichment), are better able to manage the challenges it presents. Conversely, others may view the illness as unacceptable and neglect to treat it (rejection), whereas others may become dominated by illness, where illness is felt to consume identity (engulfment).

More recent research by Kent (2023) using the Illness Identity Questionnaire (IIQ, Oris et al., 2018) has added support for these states in relation to mental illness specifically, with rejection and engulfment predicting poorer functioning and clinical outcomes, and the enrichment state showing the opposite. He reported that the acceptance state was not necessarily related to clinical symptoms, but that it was related to more adaptive coping and lower self-stigma. Self-stigma was the strongest and most consistent predictor of mental illness identity (Kent, 2023).

Most literature on mental illness and identity has tended to focus on self-stigma, which has been shown to be positively associated with symptom severity and poorer outcomes (Dubreucq, Plasse & Franck, 2021; Kent, 2023; Livingstone and Boyd, 2010), lower self-efficacy and self-worth, and higher distress (Marcussen, Gary & Serpe, 2021). Yet other aspects of identity, such as a loss of self, 'derailment' in life and feeling unable to connect with one's former self (Kaite et al., 2015; Ratner et al., 2019; Wisdom et al., 2008) have also been identified as important narratives among people living with mental illness.

Eddington & Badillo-Winard (2024) critiqued the Yanos et al. model, arguing that, although internalised self-stigma is related to mental illness identity, this is insufficient to explain it fully. Carrying out a scoping review of relevant research, they identified that the term 'mental illness identity' (MII) is not used consistently across extant literature, nor is it consistently measured owing to heterogenous quantitative measures (Eddington & Badillo-Winard, 2024). Instead, much research spans disability identity, health-related identity as well as internalized self-stigma literature (Yanos et al., 2020; 2021; Marcussen et al., 2021), and connects to diverse theories, including labelling theory (Link et al., 1989), social identity theory (Tajfel & Turner, 1979) and symptom salience (Quinn et al., 2014). This diversity in views means that there has not been consensus over how to conceptualise and operationalize MII (Eddington & Badillo-Winard, 2024; Pelters, 2024). The authors propose three common categories across existing studies, which can be used to define Mental Illness Identity (MII). These are (1) the acceptance or rejection of a diagnostic label; (2) the salience of symptoms; and (3) the internalisation of stereotyped characteristics and/or symptoms. Positive MII is considered as acceptance and growth, whereas negative MII relates to engulfment and a loss of other aspects of identity, both of which can play out over time, in a non-linear fashion. Not only can MII change over time, but

it is said to be dynamic and dependent upon environmental and interpersonal contexts (Eddington & Badillo-Winard, 2024). This research has added to our conceptualisation of MII, but additional research is needed to explore the influence of intersecting factors, such as age, race, and gender on MII expression.

Eddington and Badillo-Winard's (2024) description of MII is, to my knowledge, the only paper which attempts to draw existing and broad concepts of mental illness identity together into a consistent definition beyond self-stigma. Although their work acknowledges the role of Social Identity Theory (Tajfel & Turner, 1979) on social categorization (us/them categorisations), intergroup discrimination and group membership on self-concept in previous studies of MII, this aspect seems to be missing in their final conceptualisation of MII. The authors explain that the studies included in their review mainly related to personal identity (symptoms and stigma) rather than social identity, and go on to say that other factors, such as race, culture, illness chronicity and severity, as well as other aspects like professional identity, may influence MII. Social aspects and group identification therefore need to also be taken into consideration in future research on the dynamic aspects of MII. Existing research has shown that, on the one hand, social identification as a depressed person magnified poorer wellbeing (Cruwys & Gunaseelan, 2016), yet identifying with others in ‘recovery’ predicts reduced distress and better psychological outcomes via collective empowerment (Cruwys et al., 2020).

The Social Identity Approach to Health, or the ‘social cure’ approach (Haslam et al., 2018; Jetten et al., 2009; 2017) is rooted in Social Identity Theory (Tajfel & Turner, 1979) and claims that social identities are formed through group interactions and memberships. Supportive group membership can positively impact mental health through a sense of belonging, purpose and support. Haslam et al. (2018) argue that experiencing a life change, such as being diagnosed

with a serious mental illness, can lead to the development of a new social identity, via what they termed the *social identity gain pathway*, where a sense of belonging, group norms and favourable group comparisons can be achieved. Alternatively, individuals can navigate a *social identity continuity pathway*, where group interaction can enable enactment of previously held social identities (such as familial roles, occupational roles) which protects against identity loss in the face of mental illness. This social cure framework has been applied to a variety of community groups for people with mental illness, including the arts (Peters et al., 2024; Williams et al., 2018; 2020).

Redefining one's sense of self is said to be a central task of the recovery process (Davidson et al., 2005). Increased identification with an 'ideal self' can increase hopefulness for recovery (Buckley-Walker, Crowe & Caputi, 2010). Conversely, where there is a sense a discrepancy with one's current and ideal self, this can impact negatively (Garcia-Mieres et al., 2019; Higgins, Klein & Strauman, 1985). Moving through illness-identity towards a new identity, or reclaiming previous sense of self, whereby MII is not all-encompassing is part of this process of redefinition. This does not mean that MII is gone; rather this concept refers to other parts of one's identity being expressed and embraced, with the hope that this contributes to a more balanced and fulfilling life.

Identity redefinition: moving away from dominant MII through creative interventions

Despite creativity and the arts being a fundamental part of human culture and society throughout history (Junge, 2015), it has only been incorporated into modern medicine in the West in recent decades (Malchiodi, 2011), and is now being utilised within community settings (such as via social prescribing pathways) as a non-medical approach to managing increasing

rates of mental health challenges in our society (Department of Health, 2007; Fancourt & Finn, 2019; Hacking et al., 2006; NHS England, 2019).

A growing evidence base suggests that creative expression for people experiencing mental illness, whether via formal art therapies or informal personal practice in the community, via visual arts, performing arts, creative writing, etc has potentially transformative power in terms of fostering positive identity change beyond mental illness (Peters et al., 2024; Sapouna & Pamer, 2014; Thompson, 2015), and challenging stigma (Aldam et al., 2017; Lamb, 2009; Twardzicki , 2008), as well as a range of other benefits.

Evidence from formal Creative Art Psychotherapies (CATs) led by qualified psychotherapists, such as visual arts, music, dance, poetry/bibliotherapy, have been shown to facilitate self- discovery and expression (van Lith, Schofield & Fenner, 2013; Van Lith, 2015), finding meaning in one's experience (Van Lith, 2014), and a new sense of self as an artist within a studio community (Thompson, 2015). Systematic reviews (Schouten et al., 2015; Uttley et al., 2015) point to improvement in mental health symptoms for individuals with non-psychotic diagnoses, however other reviews (Baker et al., 2018) found little effectiveness. Small numbers of studies and poor methodological quality limit interpretation of these findings. Further evaluation of art therapies is required, as the existing literature remains sparse and dominated by a few authors.

In contrast, the evidence for non-therapy community-based arts for mental illness (typically led by artists or peers) is growing rapidly. This may be driven by personal recovery-focused agendas and social prescribing pathways, as described previously. Research has been carried out with individuals from various backgrounds, including women from minoritised ethnic groups experiencing socioeconomic deprivation (e.g. Molewyk-Doornbos, 2022) and those in

isolated rural communities (e.g. Hui et al., 2019). Evidence points to benefits for mental wellbeing (Crone et al., 2018), including in people with severe mental illness (Saavedra et al., 2018b). Benefits have also been reported in social connection, belonging and solidarity (Bone, 2018; Crone et al., 2018; Dingle et al., 2013; Goodman-Cassanova et al., 2024; Hui et al., 2019; Molewyk-Doornbos et al., 2022; Saavedra et al., 2018a; Williams et al., 2020).

Participating in community-arts has also been found to support self-discovery, with an influence on spirituality, empowerment and self-validation (Lloyd, Wong and Petchkovsky, 2007) and can provide an opportunity for expressing experiences which are otherwise inaccessible and unspeakable (Hui et al., 2019; Sapouna and Pamer, 2014). Giving voice to one's inner world in this way can re-affirm identity and support a coherent self-narrative (Molewyk-Doornbos et al., 2022). Art in the community also allows individuals to develop new skills and sense of achievement, whether that is practical mastery of art materials (Van Lith, 2015), or the development of new coping skills such as mindfulness, emotion regulation, creative and flexible problem-solving and distraction (Bone, 2018; Molewyk-Doornbos et al., 2022).

There is evidence that community creative activities can be empowering; they can support the building of an artist identity, freeing them of an identity consumed by mental illness (e.g. Bone et al., 2018; Hui et al, 2019; Lawson et al., 2014; Ørjasæter et al, 2017; Sagan, 2015; Salomon-Gimmon et al., 2022; Sapouna & Palmer, 2014; Spandler et al., 2007; Stickley & Eades, 2013). The move towards an artist identity does not mean that the MII is gone. Rather, it offers a new and emerging aspect of identity, or the chance to reconnect with a part of self which was perhaps lost. New experiences as an artist allow for new and different doors to be opened and new opportunities are afforded which were not there when occupying a predominantly patient role in clinical services, which is more stigmatised (Gwinner, Knox & Brough, 2013).

Gwinner, Knox and Hacking (2009) suggest that undertaking art and exhibiting in the community allows individuals with mental illness to take up a more socially valued role, though they warn that this may be met with the label of 'outsider artist', with romanticised notions of the troubled artist which "fetishes the marginalisation of the artist's status" (Spence & Gwinner, 2014, p. 6).

A scoping review of the community-arts literature concluded that community-arts spaces offer a safe and non-judgemental environment which supports the rebuilding of a positive sense of identity (Goodman-Casanova et al., 2024). The authors argued that forming new relationships, self-expression, skills development and exhibiting art are some of the important mechanisms by which these spaces support mental health recovery and identity redefinition, which they mapped to the CHIME recovery framework (Leamy et al., 2011).

Despite evidence showing that identity is an important dimension in understanding recovery processes within SMI, it is often overlooked in evaluations of community interventions (Peters et al, 2024). In an effort to generate new theories to explain how community-arts enable identity redefinition in people with SMI, Peters et al. (2024) carried out a scoping review of the literature and concluded that a safe and empowering intervention environment was crucial to enabling three mechanisms, in what they termed the *Identity Change Recovery Process*. These mechanisms were identified as (1) feeling in control of SMI through finding new ways of coping, (2) finding acceptance through social connection, and (3) overcoming personal challenges. Drawing on theories of both personal identity in illness (Leamy et al, 2011; Higgins et al, 1985; Yanos, Roe & Lysaker, 2010) and social identity approaches to health (e.g. Haslam et al., 2018), they reported that community-arts participation leads to developing a more positive awareness of other parts of oneself. Non-judgemental interactions and shared experiences with others with

SMI enable positive self-comparisons, which allows for redefinition beyond mental illness. They highlight that a safe and empowering environment is essential if these benefits are to be achieved and that referral to community creative activities should be a key part of clinical care planning.

The evidence for community-arts for mental health appears overwhelmingly positive, but caution should be taken. There is a large degree of heterogeneity with regard to methodology and study quality. Most studies utilise small samples, and there is likely to be bias within these samples given that these are people who typically choose to continue attending arts groups. It may be the case that negative experiences of these interventions are not captured in the research because people who do not benefit from the space leave and do not take part in research. There is a need to understand the experiences of people who initially attend but choose not to return to these spaces. Also of concern is the lack of quantitative studies evaluating the effectiveness of community arts.

However, despite small samples in much of the extant literature, when drawn together, the evidence is encouraging. A large-scale review of more than 3,700 studies on the role of the creative arts on health and wellbeing by Fancourt and Finn (2019) identified a significant impact on illness prevention and treatment, and the promotion of health, across mental and physical health across the lifespan. The authors called for greater collaboration between culture, health and social sectors, inclusion of arts education within clinical training, and increased accessibility of the arts to service users from marginalised backgrounds. These findings have not gone unnoticed by UK policy makers tasked with addressing growing demands for mental health support. The All-Party Parliamentary Group (APPG) on Arts, Health and Wellbeing, in collaboration with the National Centre for Creative Health (NCCH), have produced a series of

policy recommendations in their Creative Health Review reports (2017; 2023), which champion creativity as an integral part of health and social care strategies.

The unique offering of community arts

Unlike formal Creative Art Psychotherapies (CATs), which are delivered in a therapeutic setting (such as the NHS, though provision is limited), community-based participatory arts programmes offer a non-clinical, more informal space in which to gain therapeutic benefits, without a focus on psychopathological interpretation of what is created (Saavedra et al, 2018b). Whereas art therapy within a clinical service may involve goal setting and treatment planning, participatory arts programmes focus on art making for the sake of art, which allows for freedom of expression and shared connection with a group beyond mental health (Sapouna & Palmer, 2014). These opportunities to feel connected with the community, learn new skills, gain new friendships can support increased self-worth and feelings of 'emancipation' from mental health service user labels (Secker et al, 2007).

Community arts are often delivered by artists and peers (e.g. Dingle et al, 2013; Lagacé et al., 2016; Lawson et al., 2014; Hui et al., 2019; Stickley, 2010;), though may also be delivered by nurses or occupational therapists if delivered with or by clinical services (e.g. Gunnarsson et al., 2010; Horhagen et al., 2014; Lloyd et al., 2007; Molewyk-Doornbos et al., 2022). The prominence of community arts for mental illness being delivered by non-clinical staff promotes a more egalitarian relationship between staff/facilitators and attendees. This contrasts with the rigidity of the biomedical model which still dominates mental health services (Sapouna & Pamer, 2014). Additionally, their accessibility in the community and in mainstream venues can facilitate feelings of belonging within the local community, without stigma often associated with

mental illness (Parr, 2006). Attending non-clinical mental health interventions, such as arts groups, may allow for mental illness identity to be expressed and negotiated differently. Therapy and recovery are not the primary tasks at an art group. By providing a safe, expressive space (Goodman-Casanova et al., 2024; Peters et al., 2024), community arts initiatives can help participants redefine their identities beyond their mental illness and challenge stigma, empowering them to embrace new roles and understand their experiences from a more holistic perspective.

Defining concepts for this study

Mental Illness Identity (MII) will be conceptualised as it is within current and emerging research on mental illness identity and the community-arts for mental health literature. Therefore, MII is “the extent to which a mental illness is integrated into a person’s self-concept", as defined by Eddington and Badillo-Winard, 2024 (pg.1). Self-concept refers to the way an individual perceives and thinks about themselves. Identity in this study will refer to *personal identities* (i.e. MII, personal traits such as gender, racial identity, neurodiversity) and *social identities* (after Haslam et al., 2018; Tajfel & Turner, 1979).

Whereas existing research refers to *Identity Change Recovery Process* (Peters et al., 2024), I will be referring to *dynamic MII expression.* This is to acknowledge that that MII is not replaced by a new identity, rather that other parts of self may emerge in different settings and with different people, and that this expression is not necessarily linear. This is also to acknowledge that the term *recovery* can be problematic.

Chapter summary

This chapter gave an overview of the conceptualisations of mental illness and associated implications for how it is treated, with reference to clinical and non-clinical interventions. Next, the existing literature on mental illness-related stigma, Illness Identity Models and the more recent move towards understanding the factors shaping mental illness identity were discussed. The evidence points to gaps in understanding dynamic factors, such as time, environment and interpersonal factors, which can shape this. This chapter also described the growing body of evidence for the value of community arts for mental health, including how the arts can support identity reconstruction beyond mental illness. Recent systematic reviews (Goodman-Cassanova et al., 2024; Peters et al., 2024) have spoken to the concept of identity within community arts interventions. Less is known in the extant literature about themes of identity in those accessing clinical mental health services. This gap will therefore be addressed within the next chapter, using a systematic literature review, as it will offer an interesting comparison of identity and self-concept in those accessing very different types of mental health support.

Chapter 2: Systematic Literature Review

Chapter overview

This chapter presents a meta-ethnography systematic literature review, which explores how mental illness identity is expressed within clinical mental health services in individuals with serious and long-term mental health conditions. Specific consideration is given to the experience of psychiatric diagnosis, interactions with healthcare professionals, and use of in-patient and/or community mental health services. Review findings, conclusions and limitations are then discussed. The chapter concludes with a rationale for the present study and the aims of this research.

Context for current systematic review

Given that mental illness identity (MII) is said to be dynamic depending upon environmental setting and interpersonal factors (Eddington & Badillo-Winard, 2024), and given that identity redefinition of oneself beyond mental illness has recently been reviewed within non-clinical, community mental-health art groups (Peters et al., 2024), it would be helpful to further explore the ways in which MII is expressed and negotiated within the clinical settings in which mental illness is typically managed.

Other reviews exploring sense of self within mental illness have been situated solely within an internalised self-stigma framework (Fernandez et al., 2023; Yanos et al., 2015) and have focused more on the influence of the diagnostic label, rather than explicitly exploring the way in which the intervention setting and interpersonal aspects within this may influence the ways in which MII manifests. Further exploration is therefore needed to understand how MII is

dynamically expressed in different settings and what potentially moderates this, beyond a purely self-stigma lens (Eddington & Badillo-Winard, 2024).

Literature review research question

This review seeks to understand how MII is expressed and enacted in people with mental health diagnoses, and how engagement with clinical services influences this.

This review defines MII as the extent to which mental illness is incorporated into self-concept (Eddington & Badillo-Winard, 2024), and is taken to include aspects of both *personal identity* (personal characteristics, e.g. race; self-worth and confidence; the labels one applies to self, including internalisation of stigmatised stereotypes; salience of symptoms in self-concept) and *social identity* (Haslam et al., 2018; Tajfel & Turner, 1979) (group memberships and social roles; gaining or maintaining these).

Clinical mental health services include acute in-patient, forensic units and supported residential care, and community-based services, such as Community Mental Health Team (CMHT), Early Intervention for Psychosis (EIP), Assertive Outreach Teams (AOT), Home Treatment Teams (HTT), or Primary Care Talking Therapies. Such services are staffed by multi-disciplinary health care teams, such as psychiatry, nursing, psychology, occupational therapy and social work.

This review considered not only the impact of diagnostic labels on MII, but also the influence of interactions with clinicians and the type of clinical service use (i.e. community mental health services or in-patient) on shaping MII. It was hoped that the review would provide insight into how clinical interventions can either reinforce or challenge existing notions of MII and how individuals navigate their identity in the context of mental illness and recovery

(i.e. whether the concept of identity reconstruction beyond mental illness is featured within these interactions).

The review focused on a UK context. Within the UK, the landmark policy document *National Service Framework for mental health* (Department of Health, 1999), marked a significant move away from the previous-dominant medical and pathological model of mental illness towards the recovery model of mental health. Whereas the medical model framed mental illness as pathological disorder, with responsibility on clinicians to manage symptoms and a long historical background of institutionalised care, the rise of the recovery model framed mental illness as something that can be lived with or redefined by the individual. This places emphasis on personalised care, social inclusion and recovery, with recognition of the psychosocial, cultural and political influences upon mental health (Department of Health, 2009). Given that positive identity-related change (e.g. renewed, positive view of self) has been identified as an important process within mental health recovery, this review on literature published from the year 2000 onwards, from which time these new recovery-focused policies were implemented into service delivery in the UK.

Method

Design

This literature review is set within an interpretivist epistemology, that is, the view that knowledge is constructed through subjective meanings, lived experiences and social contexts, rather than one universal and objective truth. Further discussion about the ontology and epistemology of this thesis is described in chapter three.

This interpretivist position lends itself to a method which considers meaning and therefore this literature review uses Noblit and Hare's (1988) seven-phase meta-ethnography. This is an iterative process for synthesising qualitative research. Syntheses of this nature have been described as "an interpretation of an interpretation of an interpretation" (Toye et al, 2014, p. 3) and create new meaning, rather than a mere description of data. To mitigate losing the context of findings, meta-ethnography pays close attention the context of the original studies when interpreting and synthesising concepts (Atkins et al, 2008).

Phase one: Getting started. Initial scoping was deliberately wide and explored identity-related themes in people with mental health problems. This brought up literature including milder symptoms of anxiety and depression, experiences of loneliness, as well as acute episodes of mental health problems, such as in students relating to educational pressures. It was decided to focus on serious and long-term mental health challenges, where it is more likely that mental illness becomes a more pervasive part of life. The literature review question was subsequently reframed as 'how is MII expressed and enacted in people with serious and enduring mental health diagnoses, and how is it influenced by engagement with clinical services?'

Phase two: Deciding what is relevant. An electronic search was carried out using EBSCOhost to search APA PsycArticles, APA PsycInfo, CINAHL Ultimate and MEDLINE Ultimate databases on 20 December 2024 using the following search terms:

1. mental health or "mental illness" or "mental disorder" or "psychiatric illness" or "mental health problem*" "serious mental illness" or "chronic mental illness" or "persistent mental illness" or "chronic depression" or schizophrenia or psychosis or "eating disorder" or "personality disorder" or bipolar or trauma or "post traumatic stress disorder" or PTSD

2. "mental health services" or "mental health care" or "psychiatric services" or "clinical intervention"
3. experience or perception or opinion or attitude
4. identity or "self-concept" or "self concept" or "self perception" or "self-perception" or “mental illness identity” or “illness identity”
5. #1 AND #2 AND #3 AND #4

A number of limiters were then applied to the search. The search was limited to peer reviewed literature and an age limiter of 18 years and above was included. Additionally, the search was limited to research located with the UK and Ireland, from 2000 – present day, in order to align the review with UK mental health policy.

In order to focus on the lived experience of individuals with SMI, the following were excluded: quantitative methodology; perspectives of staff, family or carers; mild/moderate anxiety, depression, loneliness; research focus was not primarily mental health (e.g. substance use, veterans, homelessness, domestic violence, gender identity). Additionally, to keep findings within a UK context, studies from outside the UK or Ireland were excluded. Systematic reviews and grey literature were also excluded. Retrieved records were screened by title and abstract. Where there was uncertainty whether inclusion and exclusion criteria were met, records were included for a full text review.

Table 1

Search Terms and Number of Papers Identified

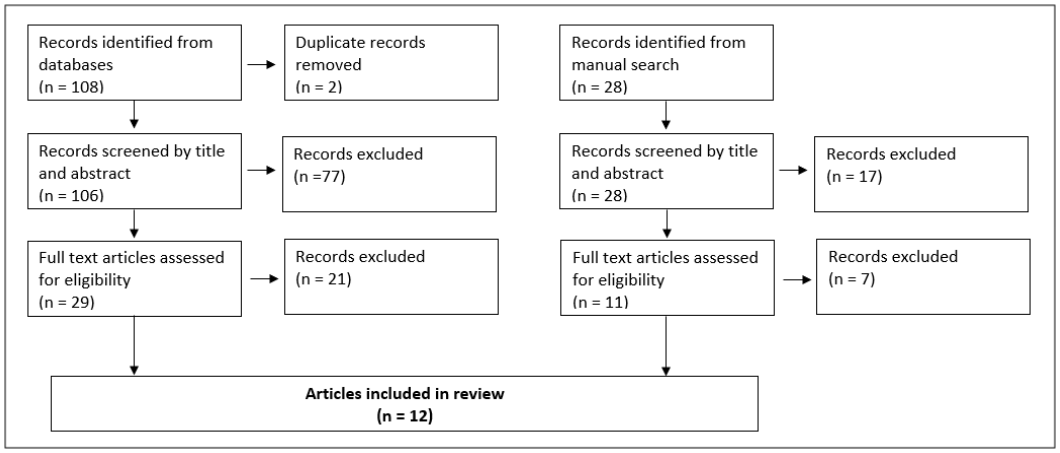
Search - MEDLINE Ultimate, APA PsycArticles, APA PsycInfo, CINAHL Ultimate (Search run on 20/12/24)	**Papers identified**
mental health or "mental illness" or "mental disorder" or "psychiatric illness" or "mental health problem*"	1,771,077
"mental health services" or "mental health care" or "psychiatric services"	389,789
experience or perception or opinion or attitude	5,120,862
identity or "self-concept" or "self concept" or "self perception" or "self-perception" or "mental illness identity" or "illness identity"	669,953
Search with AND 1 + 2 + 3 + 4	5,921
Peer reviewed limiter	5,165
Date limiter - 2009 onwards	3,680
Location limiter: UK and Ireland	297
Adult age limiter	108

It should be noted that papers explicitly exploring mental illness identity were hard to find, despite mental illness identity and self-concept being included in the review search terms. This is perhaps reflective of the fact that most literature to date refers to illness identity and is often applied to physical health, and the phrase *mental illness identity* has only been used more recently (e.g. Marcussen, Gallagher & Ritter, 2021; Marcussen, Gary & Serpe, 2021; Eddington & Badillo-Winard, 2024). Where papers did seek to explore mental illness identity, these were

quantitative in nature, or not with the target sample of a UK-based adult population. These papers therefore did not meet inclusion criteria for review. To overcome this challenge, it was decided to code any emerging identity concepts from the selected studies, using both inductive and deductive approaches, using theoretical concepts of MII, illness identity and self-stigma (after Eddington & Badillo-Winard, 2024; Yanos, Roe & Lysaker, 2010) and group membership and social identity (after Haslam et al, 2018; Tajfel & Turner, 1979) to infer the concept of mental illness identity. However, it is possible that the original authors' and participants' words have been misconstrued in my interpretations.

Phase three: Article selection and reading the studies. Twelve papers were included for review. Full details of the study characteristics of each of the selected papers, that is, study aims, setting, sample, method of data collection and analysis, is presented in Appendix B. Figure 1 illustrates the number of records retrieved and screened for final inclusion. These were each read several times, to evaluate quality and to draw out the main concepts from each.

Figure 1: PRISMA Flow diagram of screening and selection of studies



The final set of articles for review were quality-appraised using the Critical Appraisal Skills Programme (CASP) Checklist for Qualitative Research (CASP, 2018) to evaluate study

strengths and limitations (Appendix C). This appraisal was not used to exclude studies, but to guide the relative contribution of each to the synthesis (Atkins et al., 2008). Following Toye et al. (2014), a numerical score was assigned to each question to indicate whether it had been partially, fully or not met, giving a score out of a possible 20. Nine papers were deemed strongest methodologically (with a score of at least 16 out 20), so contributed most to the synthesis, as indicated in Appendix C.

Studies were read several times for familiarity. Common and recurring concepts, along with details of study characteristics were recorded. Specifically, notes were recorded of a) the authors' interpretations, theories and constructs of their data, which Schütz (1962) refers to as *second order interpretations*, and b) direct quotations from study participants, which Schütz (1962) refers to as *first order interpretations.* As discussed, concepts were identified both inductively from the data itself and deductively, informed by concepts of MII (Eddington & Badillo-Winard, 2024), dimensions of identity as within the CHIME framework (Leamy et al., 2011), illness identity (Yanos, Roe & Lysaker, 2010) and social identity (Haslam et al., 2018; Tajfel & Turner, 1979).

Phase four: Determining how the studies are related. In line with existing meta-ethnography research (Atkins et al., 2008; Barnard, Jones & Cruice, 2020; Britten et al., 2002), relationships between emerging concepts were identified to determine how the studies relate to one another. Concepts were mapped across all twelve papers. Common and recurring concepts were then grouped into categories.

Data from across the studies was organised to summarise relevant details of the study setting, sample and design, followed by examples of data from each study as it maps on to a particular concept. The table presented in Appendix D provides an example of one study, to

illustrate how data was extracted and recorded, as part of the task of determining how studies related to one another.

Phase five: Translating the studies into one another. As suggested by Britten et al. (2002), original authors' terminology was maintained to remain faithful to the original interpretations in each paper (second order interpretations). Direct quotations from study participants (first order interpretations) were not included as data for synthesis, but were recorded alongside the second order interpretations to help guide the synthesis while keeping connected with the original context for each study. Through iterative comparison, concepts were further organised into abstracted categories. Cross-comparison was carried out across all twelve studies to ensure that identified concepts did indeed represent the data in the selected articles. This is represented in a summary table in Appendix E.

Phase six: Synthesising the translations. An iterative process of noting emerging concepts and interpretations, and reviewing these against the other studies, and re-grouping concepts was carried out. From this, the commonalties across the studies' findings became more apparent. Concepts and interpretations across studies were found to demonstrate a reciprocal relationship. These concepts were then further synthesised into five encompassing categories, as illustrated in Table 2.

Table 2

Overview of Key Concepts and Broader Synthesized Categories

Key concepts from studies	Synthesised categories
Stigmatising experiences from others	Mental health stigma

Internalisation of stigmatising attitudes Togetherness in stigmatised identity	
Lost personal identities Lost social identities, roles and memberships	Lost identities
A dominating mental illness identity A need to be fixed	A journey into patienthood
Agency, choice and power Hierarchy – them and us Performing Resisting (power and narratives) Intersection of cultural and gender identity	Power, positioning and performing identities
Views on mental illness recovery Positively redefining self beyond mental illness	Towards recovery: regaining and reconstructing identity

Phase seven: Expressing the synthesis. The following results represents the final stage of Noblit and Hare's (1988) methodology: expressing the synthesis.

Results

Across studies, semi-structured interviews provided detail-rich data, despite generally small samples (seven of the twelve studies, where n≤12; range across studies n = 7 – 40 participants). The total number of participants across all studies was 201. Of these, 57% of the total sample were male. Nine of the studies reported on the ethnicity of their participants, (Chambers et al., 2014; Gault, 2009; Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002; Notley et al., 2012; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al., 2018; Watts & Priebe, 2002), though terminology differed across papers. Across those studies that did report on ethnicity, 69 participants were identified as having Black ethnicity (i.e. Black British, Black African, Black Caribbean); 62 participants as White ethnicity (i.e. White British, White Other, European); six reported as Indian or Asian and four as Mixed ethnicity.

Studies were situated within a range of clinical service contexts, including in-patient wards (including both detained and voluntary experiences of admission), community secondary mental health teams, as well as specialist services for psychosis. Participants were typically recruited through their key worker or care-coordinator, or through someone with whom they had a relationship with at their service.

Despite including a broad range of mental health conditions within the search terms, seven of the twelve studies exclusively sampled individuals with psychosis or schizophrenia diagnoses (Chase et al., 2010; Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al, 2018; Watts & Priebe, 2002). The remaining five studies sampled individuals with a range of diagnoses (e.g. OCD, bipolar, personality disorder, psychosis), or did not specify the diagnoses but referred to participants

being detained in hospital or under compulsory treatment in the community, from which it can be inferred that there is a serious mental health diagnosis for that sample.

Various methods of analysis were employed by researchers, including Thematic Analysis Interpretative Phenomenological Analysis (IPA), Grounded Theory, Relational Analysis and Positioning Analysis. IPA was the most commonly used method (Bacha, Hanley & Winter, 2020; Harris et al., 2012; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al., 2018). The following categories and concepts were devised from the meta-ethnography:

1. Exposure to and internalisation of stigma

Stigmatising experiences from others. Experience of stigma from others was common to most participants and featured across ten of the twelve studies. Participants described stigmatising comments or behaviours within the workplace (Lawrence et al., 2021) and within the local community (Lawrence et al., 2021; Meddings & Perkins, 2002; Tuffour, Simpson & Reynolds, 2019), with lasting impact in terms of social isolation (Wagstaff et al., 2018) and being gossiped about (Tuffour, Simpson & Reynolds, 2019). Feeling marginalised because of mental health stigma presented a barrier to help-seeking in several studies (Chase et al., 2010; Harris et al., 2012; Wagstaff et al., 2018). Stigma was also reported within mental health services themselves, where participants described being treated as 'not human', like a child, or as neurotic or even dangerous (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Davies & Allen, 2007; Gault, 2009) by health care professionals, both within and outside of mental health teams.

Internalisation of stigmatising attitudes. Stigmatising experiences within the community and in interactions in health care settings can become internalised, with participants across ten of the twelve studies using language referring to themselves in terms such as *labelled, passive*

objects, unworthy, difficult, weird, bad mother, mad, not normal (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Davies & Allen, 2007; Gault, 2009; Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002; Notley et al, 2012; Tuffour, Simpson & Reynolds, 2019; Watts & Priebe, 2002). Again, stigma and internalised shame became a barrier to seeking mental health support (Davies & Allen, 2007; Harris et al., 2012; Lawrence et al., 2021).

Togetherness in stigmatised identity. Some participants reported finding a sense of connection together through shared experience of difference and group membership as people with mental illness. This connectedness helps with reducing isolation, feeling understood (Chambers et al., 2014; Harris et al., 2012; Notley et al., 2012; Wagstaff et al., 2018), overcoming the shame of self-stigma (Harris et al.,2012) and this can be used to advocate for oneself and for others (Tuffour, Simpson & Reynolds, 2019).

2. **Lost identities**

Lost personal identities. Having mental illness was commonly described in terms of a loss of previously held parts of identity, including a loss of self-worth (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Meddings & Perkins, 2002), a loss of one's previous life course and aspirations (Chase et al., 2010), a loss of identity, credibility and autonomy (Gault, 2009; Lawrence et al., 2021; Wagstaff et al., 2018; Watts & Priebe, 2002). One study (Tuffour, Simpson & Reynolds, 2019) acknowledged the impact that medication can have on altering physical and cognitive parts of self-identity, such as weight and memory, with these changes representing another form of lost parts of self.

Lost social identities, roles and group memberships. Lost social identities, such as specific roles like employment or education, or in terms of social or familial circles were expressed as a part of mental illness (Chase et al., 2010; Gault, 2009; Wagstaff et al., 2018;

Watts & Priebe, 2002), however, these aspects did not feature as commonly as aspects of personal identity, above. The fear of losing possible future roles, such as motherhood, because of mental illness consuming life was also identified, specifically within the context of cultural norms (Tuffour, Simpson & Reynolds, 2019).

3. **A journey into patienthood**

A dominating mental illness identity. Most common across studies was participants referring to themselves as diagnosed mentally ill and/or as a patient, describing the overwhelming aspects of their symptoms, or feeling reduced to a collection of symptoms and behaviours (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Chase et al., 2010; Davies & Allen, 2007; Gault, 2009; Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002; Notley et al., 2012; Tuffour, Simpson & Reynolds, 2019; Watts & Priebe, 2002). Several studies described participants' resignation of accepting one's diagnostic fate (Chase et al., 2010; Harris et al., 2012; Watts & Priebe, 2002), where you may be unable to break free from cycles of service use (Lawrence et al., 2021). This aligns with the concept of engulfment, whereby illness dominates identity and the individual views themselves primarily as a patient (Oris et al., 2016).

A need to be fixed. For some, identity as a psychiatric patient meant that professional medical intervention is required and justified to stabilise illness symptoms and support moving forward (Bacha, Hanley & Winter, 2020; Gault, 2009; Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002; Tuffour, Simpson & Reynolds, 2019). Those who had experienced multiple hospital admissions were more likely to hold the view that their illness was too much for family to cope with, and so further medical input was seen as necessary (Notley et al., 2012). This intervention from services was sometimes resented but seen as a practical necessity,

particularly among older participants with a history of previously resisting engagement with services (Wagstaff et al., 2018).

4. **Power, positioning and performing identities**

Agency, choice and power. Power dynamics were reported on by eleven of the twelve studies. It was common for participants to describe feeling disempowered, passive and/or lacking choice or control over their treatment interventions (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Chase et al., 2010; Davies & Allen, 2007; Gault, 2009; Harris et al., 2012; Lawrence et al., 2021; Notley et al., 2012; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al., 2018; Watts & Priebe, 2002).

Studies which included participants with experience of detention in hospital or assertive outreach in particular made reference to coercive prison-like experiences (Chambers et al., 2014; Chase et al., 2010; Watts & Priebe, 2002). Experiences in an Early Intervention in Psychosis (EIP) or First Episode Psychosis (FEP) service were more mixed, with some participants describing a more equal dynamic with clinicians and a move from passive recipient of intervention to an active agent (Harris et al., 2012; Lawrence et al., 2021).

Hierarchy – them and us. Four studies made reference to an implicit hierarchy of people with mental illness in relation to others in society who are not mentally ill (Chase et al., 2010; Harris et al., 2012; Lawrence et al., 2021; Notley et al., 2012).

For other studies, the 'them and us' divide referred to an imbalance of power between clinician and patient, where clinicians were seen as 'expert' caregiver and participants as the 'mad' patients (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Wagstaff et al., 2018). Clinicians were positioned as a uniform, all-powerful paternalistic 'godlike' body, though this imbalance was lessened where therapeutic relationships were reportedly positive (Chase et al.,

2010). There was evidence of participant deference to the researcher in three of the studies (Davies & Allen, 2007; Lawrence et al., 2021; Notley et al., 2012), again indicating a positioning of 'them and us' by individuals with mental illness.

Some diagnoses, such as psychosis, were seen as more serious, more dangerous and more unacceptable than other diagnoses, such as depression. This suggested an implicit hierarchy of psychiatric diagnoses (Harris et al., 2012). Accessing specialist services (as opposed to mainstream mental health services) was seen as more shameful and further added to a 'them and us' mentality in participants accessing EIP services (Harris et al, 2012). Some studies revealed a strategy by some participants to distance themselves from other 'madder' and more severely unwell patients (Chase et al., 2010; Lawrence et al., 2021), perhaps as a means of retaining some sense of 'normality' in their own mental illness identity.

Performing. In response to power imbalances with healthcare professionals some studies revealed self-protective strategies by participants such as being passive, acquiescing and complying (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Lawrence et al., 2021; Wagstaff et al., 2018) in order to achieve better outcomes such as discharge (Gault, 2009; Tuffour, Simpson & Reynolds, 2019) or 'impression management' to preserve parenting roles (Davies & Allen, 2007).

Resisting. Conversely, in response to the dominance of the medical model of mental illness and of feeling disempowered by mental health services, some studies described resistance strategies employed by some participants to regain a sense of control and hold on to a pre-patient identity. This included choosing to disengage from services (Bacha, Hanley & Winter, 2020; Chase et al., 2010; Wagstaff et al., 2018; Watts & Priebe, 2002); rejecting the dominant medical model approach and instead normalising experiences within a psychosocial model to explain

their mental distress (Chambers et al., 2014; Harris et al., 2012; Lawrence et al., 2021); emphasising their strengths in roles such as motherhood (Davies & Allen, 2007); comply with taking medication in front of clinicians but deliberately not doing so in private (Gault, 2009; Tuffour, Simpson & Reynolds, 2019).

Intersection of cultural and gender identity. Half of reviewed studies acknowledged the intersecting influence of other aspects of identity, such as ethnicity and/or gender (Gault, 2009; Lawrence et al., 2021; Notley et al., 2012; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al., 2018; Watts & Priebe, 2002). Two papers specifically explored the experiences of Black service users and highlighted the importance of cultural beliefs in how mental illness is conceptualised (Tuffour, Simpson & Reynolds, 2019) and that individuals of African-Caribbean descent are more likely to be overmedicated than individuals from other ethnic backgrounds (Wagstaff et al., 2018).

The experience of Black men with mental illness pointed to a desire to appear strong and in control, in the context of historical disparity of power (Watts & Priebe, 2002). Participants in Gault's (2009) study described the implications for their treatment by clinicians owing to being Black and male, meaning that they are deemed as more dangerous and therefore receive more coercive interventions. Lawrence et al (2021) reported racial differences in narratives of mental illness, with Black British participants more likely to describe being lost within the system, feelings of self-stigma and engulfment by mental illness, and narrative of finding strength and meaning beyond the system. In contrast, they reported that White British participants were more likely to speak of the benefit of engaging with services, and to continue to hold past roles (e.g. employment) through illness and to hold 'self-protective' narratives of innate vulnerability

triggered by adversity to explain their mental distress. This alleviated feelings of shame, blame and self-stigma.

Davies and Allen (2007) sampled women only, to explore their experiences of mental health services through their identity as mothers, whereby it was common for the women to feel that their mental illness identity was incompatible with identity as a mother. This resulted in internalising a view of self as a bad mother or, conversely, being keen to demonstrate to clinicians their adequacy as a mother to avoid fearer repercussions of having the child removed. Similarly, Lawrence et al. (2021) identified that Black mothers in their sample placed greater emphasis on recovery and stability, to create distance from a mental illness identity, to emphasise their ability to care for their children.

5. **Towards recovery: regaining and reconstructing identity**

Views on mental illness recovery. Overall, the review revealed mixed views about recovery from mental illness. For some, there was a sense of negativity about recovery from mental illness, with some studies reporting participant views that mental illness was untreatable (Wagstaff et al., 2018). Medication was seen by some as ineffective and damaging to physical health, and hospital environments were viewed as not conducive to improving mental health (Bacha, Hanley & Winter, 2020). Participants held a negative view of their future after detention under the Mental Health Act, considering this tainting their future (Chambers et al., 2014), with fear that life will remain the same or get worse (Lawrence et al., 2021).

For others, contact with services (such as specialist services for psychosis) were viewed as necessary for moving forward (Harris et al., 2012). Some viewed in-patient wards as space to recover from an acute episode, from which future recovery can develop (Notley et al., 2012). Relationship with clinicians, specifically feeling understood and involved in decisions influenced

whether or not treatment was considered as helpful by participants for fostering hope for recovery (Bacha, Hanley & Winter, 2020; Harris et al., 2012).

Recovery was conceptualized in different ways. Some conceptualised recovery through a medical lens of symptom reduction and living well with ongoing illness (Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002; Notley et al., 2012; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al., 2018). Others viewed recovery through a social lens of the maintenance of or return to roles which are an essential part of self, such as parenthood, work, education, social activities (Chambers et al., 2014; Harris et al., 2012; Lawrence et al., 2021; Meddings & Perkins, 2002). A sense of getting to know oneself better as a result of experiencing mental illness and using this to give back to the community or connect with spirituality (Tuffour, Simpson & Reynolds, 2019) was also named.

Positively redefining self beyond mental illness. Some studies identified strategies by which participants either held on to other roles and aspects of their identity in the midst of experiencing mental illness, such as parenthood or employment (Davies & Allen, 2007; Lawrence et al., 2021), or aimed to reconnect with these parts of their identity once able to (Notley et al., 2012). Other studies indicated that people with mental illness consciously redefine their identity beyond mental illness identity, becoming an ‘ex-patient’ who can offer peer support to others (Harris et al., 2012; Tuffour, Simpson & Reynolds, 2019). Others reported taking spiritual meaning from their illness experience (Lawrence et al., 2021), developing a self-concept as someone who is stronger (Harris et al., 2012) and deliberately distancing oneself from aspects of mental illness to reinvent and overcome the associated stigma of this (Tuffour, Simpson & Reynolds, 2019).

“Line of argument” synthesis

According to Noblit and Hare (1988), meta-ethnography can lead to *reciprocal translation* (common themes and consistency across studies), *refutational synthesis* (offering an explanation for contradicting findings across studies) and/or a *line of argument synthesis* (a new overarching interpretation which goes beyond the individual studies). This can then be used to develop new questions for future research.

This synthesis revealed reciprocal findings that can then be drawn into a line of argument (Noblit & Hare, 1988). The review has shown that on experiencing mental illness symptoms and receiving a psychiatric diagnostic label, individuals can be exposed to stigmatising beliefs and behaviours from others, such as neighbours, employers etc. Beliefs about mental illness, including views that it is too much to cope with, or something to be feared, can be internalised as self-stigma. The experience of gaining a mental illness diagnosis is experienced as a journey, beginning with a sense of lost parts of self, whether this is felt to be lost group memberships and roles (e.g. standing in one’s community, job) or more personal parts of self, such as self-worth, or even cognitive aspects of self as a result of side effects of potent medication. This sense of loss and self-stigma can influence help-seeking, and if avoided, may well have the consequence of more coercive crisis intervention being required later on. In turn, this can further emphasise the loss of a life once known and a hoped-for future. This is met with a sense of resignation and passive receipt of care from ‘expert’ health care professionals, which can further diminish one’s sense of self-worth. In attempts to hold on to one’s selfhood, or to distance self from the stigma of mental illness, some people make attempts via implicit hierarchies, such as comparing themselves to other ‘madder patients’, or utilising strategies to resist authority figures in order to retain agency.

Mental illness identity has been shown to be dynamic. Important factors, such as stigma within wider society, power dynamics between clinician and service user and environmental conditions (such as ‘prison-like' wards) can shape how individuals view themselves. Interpersonal or environmental/intervention factors determine the extent to which individuals see themselves as passive and chronic patients engulfed by symptoms (i.e. passive recipient of care), or whether they can maintain agency and multi-faceted aspects of their identity, including self-worth and valued social roles (active collaborator), or whether they utilise other strategies to maintain a sense of agency (active resistor). Identity is not unidimensional, and the intersection of other parts of identity such as gender and ethnicity have important implications for how mental illness identity is understood and responded to.

Discussion

This meta-ethnography offers an additional contribution to the existing literature on mental illness identity (MII). Literature specifically on MII is relative sparse, as most existing research is located within wider concepts of illness identity and self-stigma (Oris et al., 2016; Yanos, Roe & Lysaker, 2010). Given previous calls for further research into the dynamic nature of MII (Eddington & Badillo-Winard, 2024), this review has explored the influence of clinical intervention and interaction with healthcare professionals on the expression of MII.

Findings from this review reinforce existing literature on the implications of mental health stigma on individual self-concept (e.g. Motala & Price, 2022; Rose & Thornicroft, 2010; Tekin, 2011). The illness identity literature describes how self-stigma can erode one’s sense of identity, self-esteem and hope for the future (Yanos, Roe & Lysaker, 2010) and similarly this review identified that the journey into mental health patienthood was experienced as a loss of

personal and social identities, and a lost hope for the future. This can, at least in part, be explained by the continued dominance of the medical model within clinical services (Sapouna & Pamer, 2014). Despite the reviewed studies being set within different intervention settings, both in-patient and community services, with multi-disciplinary non-medical staff (e.g. psychologists, social workers, occupational therapists), psychiatry, nursing and medication were commonly referred to across studies, suggesting ongoing dominance of the medical model.

This is despite UK policy over the past 25 years promoting a recovery model of mental illness, whereby more emphasis is placed on understanding the psychosocial aspects to mental health and moving away from a solely biomedical approach (Department for Health, 1999; 2009) and greater service user involvement in decisions about treatment (Department of Health and Social Care, 2018). Themes of a dominating mental illness identity and of lack of agency, choice and power were both present across eleven of the twelve reviewed studies, regardless of the type of clinical setting, including in the most recently published studies (Bacha, Hanley & Winter, 2020; Lawrence et al., 2021; Tuffour, Simpson & Reynolds, 2019). Issues of power may be heightened particularly for those who have been with services for a long time or multiple times. We can speculate that they may feel a sense of 'stuckness' or hopelessness, with a more engulfing illness identity.

Themes of recovery and 'positively redefining self beyond mental illness' were much less prominent across the review, although it should be noted that exploring these concepts were not core aims of the reviewed studies. Nevertheless, fewer than half the studies described participant experiences of a re-definition or expression of identity beyond MII. When this was mentioned, it was not clear if or how service use contributed to this, or whether this was something specific to the individual. Taken overall, these findings suggest that clinical mental health services are not

being experienced by service users as person-centred or recovery-oriented in the way that policy directives would hope for.

Implications

MII is said to be dynamic (Eddington & Badillo-Winard, 2024; Oris et al, 2016; 2018) and this meta-ethnography suggests that power, positioning and agency are mediating factors influencing how MII is expressed and enacted in clinical settings. This was further evidenced within the reviewed studies where there were several instances of participants showing deference not only to clinicians, but also to the researchers (Davies & Allen, 2007; Lawrence et al., 2021). This has implications for how research is carried out in order to minimise power imbalance between participant and researcher. The reviewed studies varied in their terminology, with some referring to *patients, clients or service users*. Again, the choice of language used by researchers and clinicians has implications for how mental illness is portrayed, and in turn how it is internalised into MII for those living with mental distress.

Within clinical practice, clinical psychologists aim to hold in mind power imbalances between themselves and the people they work with, with the hope of holding awareness of and minimising an 'expert' position which can jeopardise therapeutic relationships (Boyd, 1996). We use formulation and are informed by discourses on power and privilege (e.g. Johnstone & Boyle, 2018) as alternatives to diagnosis and problem-descriptions of people's challenges. However, the reality is that most clinical psychologists work within clinical, multi-disciplinary medicalised settings which sit with a wider system of a dominant biomedical culture. Clinical psychologists are well-placed to shape services and apply research findings towards innovating service delivery to consider adaptations or alternative approaches to supporting mental health

recovery, including supporting individuals with mental illness to maintain or reconstruct identity beyond MII in different intervention spaces. Non-clinical community interventions, such as arts groups, have been found to support this, where freedom of expression and shared connection promote a more egalitarian relationship between attendees, giving rise to hope for the future and challenging the stigma of mental illness (Goodman-Cassanova et al., 2024; Peters et al., 2024; Sapouna & Pamer, 2014). Joint working between arts, health and social care, delivering creative programmes away from clinical spaces and alongside people without mental health diagnoses can support inclusion and reduce public stigma (Saavedra et al, 2018b). This is considered to be a 'mutual recovery' approach (Crawford et al, 2015, cited in Saavedra et al, 2018b), which is not just about treating service users but building reciprocal relationships between service users, professionals and all community members who are involved in creative spaces.

Limitations

This review sought to explore experiences of MII expression and enactment across all types of serious mental health problems, however, despite broad search terms, almost two thirds of the reviewed studies focused on individuals with psychosis or schizophrenia. These are highly stigmatised conditions and so it is possible that the findings here may not extend well to the experiences of people with other forms of mental health diagnoses.

Generally, studies had small sample sizes of less than twenty participants, which may limit the generalisability of findings. However, the total number of participants across the review was fairly large (n = 201), with a quite well-balanced gender split (57% male, 43% female). Not all studies reported on participant ethnicity, but where this was reported, there was a similar

number of White British (n=62) and Black British (n = 69) participants. Other ethnicities were very underrepresented in the samples.

The decision was taken during article selection to exclude studies which primarily explored issues such as gender identity or ethnic identity, or where mental illness was not the main focus (e.g. experiences of veterans). This was to ensure a focus on mental illness as the primary concept; however, this decision may have meant that interesting findings on intersections of identity were not captured. The dearth of qualitative research on mental illness identity explicitly, particularly within the context of adult samples and the UK, is a limitation to this review. Concepts of mental illness identity were coded deductively from the selected papers, but it is acknowledged that these interpretations may differ from those of the original authors or participants in those studies. However, this lack of literature on participant views of mental illness identity further points to the need for the present study to add to the evidence on MII.

Future research

This systematic literature review has highlighted the influence of clinical intervention settings, both in terms of physical environment and the power dynamics within interactions with healthcare professionals, as important mediators to how MII is expressed and enacted.

This thesis will therefore further explore themes of dynamic mental illness identity and hopes for recovery in people with long-term mental illness, who have accessed both clinical services and non-clinical, participatory arts settings.

Research aims and questions

MII is said to be dynamic and further research is needed to understand the moderating influence of environmental and interpersonal factors, as people with mental illness move between different spaces. This research aims to explore how clinical services (which are often structured and focused on symptom management, diagnosis, and medical treatment) and community arts programs (which are more informal and typically emphasise creative expression and social inclusion) influence individuals' understanding and expression of their mental illness identity. Comparing participants' experiences of the two approaches will offer insight into the mediating influences of different interventions (clinical or non-clinical), environmental setting (NHS or art group) and interpersonal interactions/power dynamics (clinicians or peers/artists) on the expression of mental illness identity.

Specifically, this research asks: 'How does participation in clinical mental health services and community arts programmes for mental health influence the expression of Mental Illness Identity (MII) among individuals with chronic and serious mental health conditions?'

Secondary questions:

- What role does the setting play in reinforcing or challenging stigma associated with mental illness?
- What other aspects of identity are supported or subjugated in either setting?
- What role do social interactions and power dynamics in clinical services and community arts programs play in the development and expression of mental illness identity?

It is hoped that findings will add to our understanding of self-concept and illness identity in mental health, and how beliefs about oneself influence engagement and disengagement with different types of intervention. This has implications for how the arts and health sectors can learn from one another and collaborate to support mental health.

Chapter summary

This chapter presented the systematic review question on how mental illness identity is expressed within clinical services. The meta-ethnography method was described, and results presented, culminating in a synthesised line of argument pointing to the impact of mental health diagnoses and interactions with healthcare professionals upon self-concept, via the internalisation of stigma. Systematic review findings and their limitations were discussed, along with current gaps in the current research literature. This chapter concluded with the rationale and aims of the present study, which aim to address current research gaps.

Chapter 3: Methodology

Chapter overview

This chapter outlines the epistemological basis of this research, describes the research methodology and procedures followed during recruitment, data collection and data analysis. Explanation is given for the decision to use the Photovoice method, with an outline of the unique offerings of this approach. This chapter also discusses ethical considerations and plans to disseminate research findings.

Epistemological and ontological assumptions of this study

It is important for researchers to consider their ontological and epistemological stance, that is, beliefs about what knowledge is and how it can be acquired. These positions are important as they inform one's choice of methodology. Ontology refers to the nature of the world and what can be known about it. Ontological positions can be described as sitting on a continuum from realism - the stance that there is one true reality to be known – to relativism, that is, the position that there can be multiple, co-existing realities which are shaped by social experiences (Snape & Spencer, 2003; Braun & Clarke, 2013). Epistemology is concerned with what can be known how knowledge can be acquired. Epistemological stances range from positivism to interpretivism. A positivist stance seeks observable, objective measurement which is independent of researcher values. In contrast, an interpretivist stance holds that the researcher and social world influence one another. Objective, value-free research is not possible, but researchers can be transparent and reflective of their assumptions (Snape & Spencer, 2003).

Much of the existing body of literature on identity within mental health falls under the relativist position, that is, that social and individual experiences shape a person's reality.

Similarly, then, this research adopts a qualitative design which is grounded in a social constructionist, interpretive epistemological position and a relativist ontological stance, because the research questions are focused on understanding how participants have constructed their experience of identity and their mental health.

Position statement on the use of psychiatric diagnostic labels

Medical diagnoses, including psychiatric labels, are grounded in a scientific process of measuring and categorising observable symptoms and behaviours, which are underlined by a biological and psychological basis. This approach is usually associated with a positivist realist position, where objective symptoms can be measured using universal standardised tools, such as diagnostic criteria and checklists, e.g. Diagnostic and Statistical Manual of Mental Disorders (DSM) or International Classification of Diseases (ICD), typically by those who hold the professional positions and expertise to utilise these measures (McCann, 2016). Categorisation of symptoms therefore leads to specific evidence-based treatment offers, such as the National Institute of Health and Care Excellence (NICE) clinical guidelines.

In contrast, the social constructionist lens adopts a critical stance in regard to psychiatric diagnosis, which views the realist positivist perspective as reductive and overlooking subjective experience and social context (McCann, 2016; White, 2017). From the social constructionist stance, diagnoses are viewed as socially constructed categories that are informed by societal values and norms of what is considered ‘disordered’ or ‘normal’. The social constructionist lens moves focus away from individual deficit (McCann, 2016) and argues that societal norms and values are influenced by cultural and historical contexts (White, 2017), and that assigned labels have social and political consequences (Foucault, 1961; Goffman, 1961; Laing, 1962; Szasz,

1962). For example, until 1973, homosexuality was named as a 'sociopathic personality disturbance' or 'sexual deviation' in the Diagnostic and Statistical Manual of Mental Disorders (DSM-I and DSM-II, respectively; Drescher, 2015). This classification illustrates how cultural shifts in attitudes, shaped by the civil rights movement, change whether certain behaviours are pathologized or normalised, and by whom (McCann, 2016; White, 2017).

Diagnostic labels have been critiqued by the anti-psychiatry movement, which point out that diagnosis overlooks the social, economic and political contributions to poor mental health, creating marginalisation, oppression and power imbalance (e.g. Foucault, 1961; Goffman, 1961; Laing, 1962; Szasz, 1962). The British Psychological Society's Division of Clinical Psychology developed the Power Threat Meaning Framework (Johnstone & Boyle, 2018) as an alternative to more traditional approaches to psychiatric diagnosis. Though this framework has been critiqued as an oversimplification and neglecting biological factors, this approach is grounded in a narrative lens of sense making, moving away from 'What is wrong with you?' towards 'What happened to you?'

The current research takes a social constructionist approach to understanding mental illness and identity. As a clinician-researcher, I am informed by systemic and narrative therapy influences (e.g. White, 2001; White & Epston, 1990), which position mental distress as largely relational, and shaped by socio-political and cultural stories and influences, i.e. an *ecology of mind* (Bateson, 1972). For these reasons, it was decided to use the terms 'mental health difficulties' and 'mental health challenges' in the recruitment advert (Appendix F) and participant information sheet (Appendix G), rather than 'diagnosis'. The inclusion criteria invite those who identify as having long-term mental health difficulties, as well as those who have been given a psychiatric diagnosis, to take part. In this way, I aimed to not impose a psychiatric label

within my communication with participants. Inevitably though, through their contact with NHS mental health services, participants would have completed symptom checklists to meet threshold of need, and encountered diagnostic labels and terminology during their help-seeking journey. How this is internalised, constructed and expressed by participants (i.e. the meaning they make from this), is of interest in this study.

Justification for chosen methodology

A constructionist approach lends itself to a methodology based on meaning, narrative and storytelling. During the early stages of developing the research, it was intended to utilise mixed methods, with the inclusion of quantitative measures of self-concept, such as the Self-Concept and Identity Measure (SCIM, Kaufman, Cundiff & Crowell, 2019). However, on reflection, it was decided that asking participants to respond within a rigidly defined measure would go against the ethos of this research, that is, to allow for freedom of expression, individuality and personal constructions of identity and mental illness. Therefore, this research adopts a fully qualitative methodology.

Findings from the systematic literature review pointed to issues of stigmatisation and hierarchical power imbalance experienced by individuals with serious mental health difficulties. For this reason, consideration was given to using a research methodology that would be as empowering as possible. Consideration was also given regarding how to honour participants' creativity, given that they were regular attendees of a community arts programme. Two creative research methodologies were therefore explored: Photo Elicitation (Collier, 1957; Harper, 2002) and Photovoice (Wang & Burris, 1997).

Photo elicitation (PE) has its roots in anthropological methodology, first used by Collier (1957). It includes a visual image in the research interview, with proponents arguing that this evokes deeper and different types of exchange between researcher and interviewee than words alone (Collier, 1957; Harper, 2002). Selected images can extend along a continuum, from those which are images of generic objects, to images representing collective social/cultural pasts and artefacts, through to those which are directly connected to an individual's life (Harper, 2002). There is variation in whether PE uses photos produced by the researcher or the participant. Typically, PE refers to photographs taken and/or selected by the researcher, with terms such as *reflexive photography* or *autophotography* used to describe methodology where the participant takes the image, from which discussion is generated (Epstein et al., 2006; Glaw et al., 2017).

Photovoice (PV) is often used with marginalised populations whose voices have been silenced in political discourses (Sutton-Brown, 2014). Like reflexive photography, it is an ethnographic method, positioning participants as experts of their experience. It uses participant-generated photography to (1) record experiences and needs, (2) promote critical dialogue, and (3) share this knowledge with policymakers and/or the public to spark social change through sharing of the images with a participant-selected audience (Sutton-Brown, 2014). It is this last point which sets it apart from other photo-elicitation methods, such as reflexive photography or autophotography. PV has been successfully used in mental health research (Han & Oliffe, 2016; Rai, Gurang & Kohrt, 2023; Russinova, Mizock & Bloch, 2018; Tang, Tse & Davidson, 2016; Thompson et al., 2008; Werremeyer, Aalgaard-Kelly & Skoy, 2016) with different populations, including children and adolescents (Greco, Lambert & Park, 2016; Vélez-Grau, 2019;) and racialised groups (Keating, 2020), though the quality of existing PV studies varies (Stephens et

al., 2023). More recent studies have successfully adapted for online delivery (Tanhan et al., 2021).

The unique aspect of PV methodology which encourages participants to own and share their stories with their chosen audience was felt to be more empowering than a PE methodology. It was also more consistent with my own previous professional background in mental health activism and user involvement. Therefore, Photovoice PV was decided upon as a means to reducing power imbalance between participants and researcher. Given that this research samples people with experience of art-making, the PV method is intended to give voice and position participants as photographers and storytellers, in addition to someone with mental illness. This differs to the majority of mental health research, whereby participants are sampled solely for the experience of mental illness.

Arts-based research has been recognised for promoting a 'power with' rather than 'power over' stance, as it gives participants control about what, how and how much they bring and share about their experiences (Charura & Wicaksono, 2022). The use of a creative medium can support participants to share what they might otherwise struggle to share (Keating, 2020). This is particularly important in light of my systematic literature review findings of deference to researchers and clinicians by some participants, and in light of my dual role as both a researcher and trainee clinical psychologist.

Despite the intention for PV to provide a more equal power dynamic, it has been critiqued for taking a utopian stance, since in its' application to *marginalised groups*, the 'marginalised' label is ascribed to the group by the researcher, which in itself creates a power differential (Sutton-Brown, 2014).

Design

Setting

Participants were recruited via a community arts charity in a coastal town in South East England. In November 2024, while research was ongoing, the charity unexpectedly closed due to insufficient funding. It had offered 12-week art courses, 6-month access to an art studio and longer-term access to an art house collective for anyone over the age of 16 years in the county with mental health difficulties. The courses were led by artists and supported by volunteers, who previously went through the course. Participants were encouraged to exhibit and/or sell their work in local businesses and galleries. Participants could self-refer (and therefore may not have received a formal mental health diagnosis) or be referred by mental health services. While in operation, the charity lead was employed by the local NHS mental health Trust and had access to clinical care records and contact with care co-ordinators for any incidents of risk management. This was the only staff member and her role was in managing the site and charitable funding applications, rather than in delivering any of the art activities.

Procedure

Consulting the views of service users

It is acknowledged that ‘true’ PV methodology would have involved research participants in shaping all aspects of the research, including setting the research question. However, due to time restrictions and lack of funding to pay for User Involvement Group time, this was not possible. Informal discussion with the art charity staff and volunteers about timing and size of discussion groups while at initial site visits did inform thinking and planning of the subsequent research protocol.

Sample size

The aim was to recruit 12-15 participants. Twelve to twenty participants are suggested as a good sample size for a medium-sized thematic analysis project and is deemed as allowing adequate identification of patterns across the data (Braun & Clarke, 2013).

Inclusion and exclusion criteria

Participants were recruited in accordance with the inclusion and exclusion criteria outlined in Table 3. Initially, age criteria were limited to age 18 – 65 years, which aligns with the typical age range for most adult mental health secondary mental health services in the NHS (with anyone over age 65 years usually being seen by older adult mental health teams). The consideration behind this decision was to limit my focus on 'working age adults'. However, when recruitment commenced, there were several people who expressed an interest in participating but who explained they were older than age 65. It became apparent that this age restriction was limiting for recruitment. A revision to the inclusion criteria was therefore made and approved by the NHS Research Ethics Committee and University of Essex.

Table 3

Inclusion and Exclusion Criteria Used in Selecting Research Participants

Inclusion criteria	Exclusion criteria
Aged 18 and over	On the waiting list for support from the arts charity

Have experienced long-term or repeated mental health challenges (either received a diagnosis or identify as such)	Have never access NHS treatment for mental health
Currently attend activities with the arts charity	Unable to give informed consent
Have accessed or are currently accessing NHS mental health services	
Have access to a camera and/or mobile phone camera, and basic confidence in using it, or are willing to use a disposable camera	
Are able to read and understand English	
Do not have a dementia diagnosis, brain injury or any other condition which affects mental capacity	
Able to give informed consent	

Recruitment

Participants were recruited directly from the arts charity. Participants were recruited via various means: a) the researcher attended the service to inform attendees about the research and answer any questions in person on two occasions; b) recruitment flyers were displayed at the

service inviting participants to take part in the research; c) an electronic version of the recruitment flyer was emailed to charity members by the charity lead. Interested parties were contacted by telephone or email to provide them with the participant information sheet and consent form (Appendices G and H), and to ensure that they met the inclusion criteria before continuing. Once they had reviewed the information, they were contacted again to confirm their participation and to agree their attendance at a photography workshop. Informed consent procedures were completed in person at the photography workshop, where participants had another opportunity to ask any further questions.

To facilitate participation, a number of digital cameras were available to loan directly from the charity. Additionally, funds were secured via the University of Essex Facilitating Research Fund to cover the costs of disposable cameras and printing for anyone who did not have access to a digital camera or camera phone, or who did not feel confident in digital photography. These resources were not needed, and all participants utilised their own digital equipment.

Study sample

Eight women participated in the photovoice workshop task and the discussion groups. A ninth participant (Tracey - pseudonym) attended the photovoice workshop task and submitted images and captions but was not able to attend the discussion group. Four of the participants (Helen, Jenny, Kate, Nicky - pseudonyms) went on to take part in an individual interview, as illustrated in Table 4.

Table 4

Participation in Different Stages of Research

Participant (pseudonyms)	Photographs	Discussion group	Interview
Amanda	•	•	
Carolyn	•	•	
Helen	•	•	•
Jenny	•	•	•
Jessie	•	•	
Kate	•	•	•
Nicky	•	•	•
Poppy	•	•	
Tracey	•		
n	**9**	**8**	**4**

All nine participants were recruited from the arts charity. All participants were female. Eight of the women stated they were White British, and one was of White Other heritage. The other demographic information collected from participants is outlined in Table 5.

Table 5

Demographic Information about Participants

Demographic	N (%)
Age	

18 – 24 years	1 (11.1%)
25 – 34 years	1 (11.1%)
35 – 44 years	3 (33.3%)
45 – 54 years	1 (11.1%)
55 – 64 years	2 (22.2%)
65 years or over	1 (11.1%)
Marital status	
Married/civil partnership	1 (11.1%)
Cohabiting	1 (11.1%)
Divorced/separated	2 (22.2%)
Widowed	0
Never married	5 (55.5%)
Prefer not to say	0
Employment status	
Employed	3 (33.3%)
Unemployed	1 (11.1%)
Retired	1 (11.1%)
Prefer not to say	4 (44.4%)
Highest completed formal education	
GCSEs/GCEs/O-levels	1 (11.1%)
A-levels	0
Apprenticeship or Traineeship	0
Further education certificate or diploma	1 (11.1%)

University or higher degree	6 (66.6%)
Other	1 (11.1%)
Prefer not to say	0
Total participants	**9 (100%)**

Procedural steps and materials used

Phase one: Photovoice. The PV method does not have an exact or universal format to follow, and there is much variation in the procedures and analyses undertaken by researchers (Catalani & Minkler, 2009; Han & Oliffe, 2016; Seitz & Orsini, 2022). Findings from scoping reviews and methodological guides have informed the method utilised in this study (Han & Oliffe, 2016; Stephens et al., 2023; Sutton-Brown, 2014), and this method draws mostly from that developed by Wang and Burris (1997). The main steps identified in the literature include group training on photography, followed by a period of taking images (which may be done individually, or over a series of group workshops), followed by individual interviews and/or group discussion. The original protocol (Wang & Burris, 1997) calls for a final gathering where photographs are exhibited and participants share their experiences with their chosen audience. Each of the stages in this research is described below.

1.1 Workshop. Introducing participants to PV and providing training in photography are key to the PV method (Wang & Burris, 1997). This includes introducing practical aspects of the study, basic photography skills, as well as ethics of photography. Systematic review of the published PV literature shows that the training offered to participants varies, with some providing a series of weekly trainings, and others a one-off session (Han & Oliffe, 2016). Owing to budget and consideration to how much time to ask of participants for this study, it was decided

to offer a free one-off two-hour workshop at the arts charity site. Once they had given their consent to take part in the study, participants were introduced to PV and taught basic photography skills. This was facilitated with a local artist-photographer, who was selected by the charity staff through their network of artists. The workshop was funded by the University of Essex Facilitating Research Fund.

First, the workshop was introduced by the researcher, giving an overview of the PV approach and aims of the project. Copies of the Participant information sheet and Consent form were provided again for attendees to review and informed consent procedures were completed. Demographic questionnaires were also completed at this point (Appendix I) to record demographic information, the nature of their mental health difficulties, the length of time this had been occurring and the services they used (past and current) for their mental health.

Next, the photographer led the skills workshop, which introduced artistic principles and tips for photography, such as the use of light, composition etc. Emphasis was made throughout the workshop that the presented guidance was just a suggestion, and that there is no such thing as a wrong or a right image. There was a practical element to the workshop, where attendees put skills into practice, then had the opportunity to share as a group the images they had taken. The researcher participated in the skills workshop as an attendee, to support rapport-building with participants. At the end of the workshop, participants were then provided with the PV task by the researcher. This involved six prompt questions about how they view themselves, how they feel perceived by others, and their hopes for the future when attending clinical and arts interventions. Participants were invited to respond to through photographs and brief accompanying text over the subsequent four weeks. The task was described verbally by the researcher at the end of the

photographer workshop. Written instructions of the task prompts, including a reminder of timescales and guidance on ethical photography, were provided (Appendix K).

1.2 Discussion groups. The first step in Wang and Burris' (1997) participatory analysis is image selection, whereby participants choose the photographs for discussion, therefore giving them leadership in the direction of the discussion. Participants were invited to take as many images as they wanted to, but to then shortlist those that were most significant and most accurately reflected the experience they wished to share at the discussion group. Participants were asked to submit a maximum of two images in response to each prompt question. They had up to four weeks in which to complete the PV task and share their selected images with the researcher via email or secure cloud storage. Prior research (e.g. Jackson, Booth & Jackson, 2022) has suggested that this is a good period of time to keep participants engaged. It is possible that a longer period of time could lead to disengagement. Too long a period of time could also mean that participants take so many photographs that they then struggle to shortlist those that they wish to bring to the discussion group.

Each participant was then booked to join a small discussion group one month after starting the PV task. Three discussion groups took place at the art charity site. Before each discussion group, the photographs and captions which had been submitted were reviewed by the researcher, to check that they met the criteria for ethical photography. Photographs and captions were compiled into PowerPoint presentations, one for each discussion group, with a segment for each individual participant. At each discussion group, the presentation was projected onto a large screen so that all group members could see it, and this was used to elicit conversation related to the research question.

The next stage of Wang & Burris's 1997 protocol is *contextualising,* that is, participants discussing their chosen images and storytelling their subjective experience. Existing PV literature uses either individual interview (e.g. Erdner et al, 2009; Keating, 2020), focus groups (e.g. Russinova et al, 2018; Velez-Grau, 2019) or both (e.g. Cabassa, Nicasio & Whitley, 2013; Clements, 2012; Tang, Tse & Davidson, 2016; Werremeyer, Aalgaard-Kelly & Skoy, 2016) for this stage. Focus groups were initially decided upon for this research, as the group aspect felt more in-keeping with the ethos of PV as an empowering community approach to research. Participants expressed a preference for the term 'discussion group' instead of focus group, which is the term adopted throughout this study.

At the start of each discussion group, informed consent was again checked (verbally). Group rules were established, to agree that what was shared with within the group would not be shared elsewhere. Participants then decided who wished to present their images first. The length of the focus groups ranged from 120 minutes to 134 minutes, lasting 126 minutes on average, (plus breaks, with refreshments provided). During this time each participant had approximately 30 –40 minutes to discuss their images (depending on the number of participants in each group, and how many images they had submitted).

To prompt discussion and detail about the selected photos, the SHOWED acronym was used (Wang, 1999) to devise a topic guide (Appendix L). This is a series of prompt questions to guide participants to consider: What do we **See** here? What is **Happening**? How does this relate to (y)**Our** lives? **Why** are things this way? How could this image **Educate or empower** people? What can be **Done** about this? The photographs themselves were the main discussion prompts, and the SHOWED guide was mainly referred to only if participants needed more encouragement.

Photographs were presented on screen one by one via Microsoft PowerPoint and Whiteboard, using a digital projector.

Post-it notes were provided in discussion groups for participants to write anything that they wanted to share with the researcher, but not with the group. No participants used these.

The final stage in the participatory analysis, in which participants contribute to analysing data, is referred to as *codifying* (Wang & Burris, 1997). This involved each discussion group collectively categorising the presented images into overarching themes, which they felt represented the experiences presented by the group (e.g. Jackson, Booth & Jackson, 2022). Microsoft Whiteboard was used for this task, via a digital 'photo pile sort' (Cabassa, Nicasio & Whitley, 2013; Velez-Grau, 2019). Participants could include as many or as few photos into their categories as they deemed appropriate. The group then agreed upon key words or a title for each category. Witnessing of experience, such as via a photography exhibition, is an important part of action research such as Photovoice. It was therefore intended that these categories would be used by the charity when curating an exhibition of participant images, for those who had consented.

Phase two: Follow-up interviews. It was not possible to recruit the expected number of participants to discussion groups, therefore it was decided that additional data would be collected through follow-up individual interviews with group participants. This would also provide a valuable opportunity to gather richer and deeper information than what had been possible in a group setting. Furthermore, individual interview would be conducive to participants' sharing information which they perhaps did not feel comfortable sharing in a group.

An amendment was submitted to the NHS Research Ethics Committee and University of Essex, along with a new Participant information sheet and consent form, and topic guide. Once

approved, all existing participants who had opted in to follow-up contact on the original consent form, were contacted by email to invite them to participate in an individual interview.

The interview topic guide (Appendix L) consisted of bulleted questions covering areas that would ideally be discussed. There was not a specific order to these being asked and not all questions were covered in all interviews. Participants were encouraged to share their experiences quite freely, as long as it related to the research questions.

Three follow-up interviews were carried out online, and one person requested to be interviewed in person. This took place in a private space within a different art studio run by a separate organisation. Interviews lasted from 68 minutes to 109 minutes, lasting 82.5 minutes on average. Using feedback from participants at the discussion groups, fidget toys, pen and paper were provided during face-to-face interview to support doodling and distraction as a means of anxiety-management. A laptop and digital recorder were used to record discussion groups and interviews. Online interviews were recorded via Microsoft Teams and using the transcription function. Although not a central part of the research question, interviewees naturally shared their views on their experience in the Photovoice task and discussion groups.

Phase three: Participant-led exhibition. The empowering act of sharing the participant voice to a participant-selected audience to witness their testimony is one of the unique aspects of the PV methodology (Wang & Burris, 1997), and one of the reasons that this approach was decided upon. This ethos is congruent with person-centred care, which clinical psychology values. Although some PV literature does not describe completing this stage (e.g. Han & Oliffe, 2016; Velez-Grau, 2019), it is recommended as a strategy for sharing findings, influencing decision-makers and raising public awareness of identified issues (Han & Oliffe, 2016; Wang & Burris, 1997). Therapeutically, the concept of ‘outsider witnessing’ is also supported by narrative

therapy practice (White, 2000), as it is beneficial for sharing and strengthening 'preferred narratives.'

It was intended that the arts charity, with their experience of exhibiting, would support participants who wished to exhibit their research images to do so. In keeping with the ethos of 'power with' rather than 'power over' participants (Charura & Wicaksono, 2022), the intention was for ownership of this to belong to participants with the charity, and for the researcher to take a backseat, but to remain involved in supporting to identify a target audience and using connections within the local NHS Trust to facilitate invitations. Following the unexpected closure of the charity this was not possible. Most participants voiced no longer wanting to exhibit or considered this no longer possible, though one participant strongly voiced wanting to exhibit. It was therefore agreed to keep communication open about this after completion of the research, to consider ways to support or encourage the participant(s) to share their story with their chosen audience (e.g. directly with their mental health team, or through a blog piece facilitated by University of Essex or NHS Trust communications team).

Participants consented for their images to be included with research dissemination, as well as subsequent conferences or journal publications, as a means of honouring experience-sharing with a wider audience (Appendix N).

Participant reimbursement

It was not possible to offer reimbursement to each participant for their time; however, each participant was given the choice to opt-in to a prize draw to win one of three £20 Amazon gift vouchers. Participant names were entered into an excel spreadsheet and an online number generator was used to randomly select three rows in the spreadsheet of names to select winners.

Ethical considerations

Ethical approval

Ethical approval was granted by the National Health Service (NHS) Research Ethics Committee (REC) and the University of Essex ethics committee, as were subsequent amendments to ethical approval. A total of three amendments were made during the course of the research. Firstly, an amendment was made to change the inclusion criteria to include individuals over the age of 65 years. Secondly, an amendment was submitted to carry out follow-up individual interviews. Finally, a third amendment was filed to inform the committee of the closure of the charity. This involved altering the safeguarding protocol, as charity staff had been key to the initially-agreed protocol in the event of distress. Documents confirming ethical approval and amendments can be found in Appendix A.

Managing risk and the potential for distress

Discussing one's own mental health experiences, and hearing those of other participants within discussion groups, had the potential to cause emotional distress. All participants were provided with written information for local and national support services (Appendix J). During the first phase of the research, while the arts charity was in operation, risk could be managed via charity staff who, as NHS employees, had access to participant clinical notes, care coordinator, GP and other contact information. Following their closure, a new risk management protocol was developed and approved to ensure that participants were suitably supported and signposted to appropriate help in the event of distress.

The unexpected closure of the arts charity had the potential for increased distress, as the research questions asked participants to reflect on their experience a service that they had now

lost. During recruitment to follow-up interviews, several participants described a significant short-term worsening of their mental health following the closure of site. Additional discussion was had with supervisors, Head of Research and University ethics staff to consider whether it would therefore be ethical to continue with interviews. It was decided that the more ethical decision would be to proceed with the interviews and honour participants' motivation to continue with the research, rather than to paternalistically cancel the interviews, which could risk undermining their participation and creating another unexpected sense of loss.

Right to withdraw / informed consent

All participants were informed in writing via the Participant Information Sheet (Appendix G) and Consent form (Appendix H), and again verbally at the start of each research activity, that they had the right to withdraw from research at any point, without any negative consequence.

Personal safety / lone working

Most of the research did not involve lone working, with the exception of one face-to-face interview, which was not deemed to be high risk. An informal buddy system was used, by informing a personal contact of my arrival and location, and then confirming safe departure from the site.

Data protection / confidentiality

All data was saved securely on the University of Essex OneDrive system (Box), which is password protected and only accessible by the researcher. Hard copies of identifiable

information, such as completed demographic questionnaires and consent forms, were scanned in and stored electronically on OneDrive, and hard copies were destroyed. Participants shared their selected photographs via email. These were then transferred to OneDrive and emails were deleted. Any images which contained identifiable participant information (e.g. self-portrait) were redacted. All data collection recordings were destroyed once transcription was complete. Transcribed data was pseudonymised and stored securely on OneDrive. All data will be stored for a duration of time as stated by University of Essex protocol.

Ethical considerations for photography

The nature of the PV methodology requires consideration of additional ethical issues, such as copyright and the potential of distressing images (Creighton et al., 2018). Specific consideration was therefore given to ensuring responsible and ethical photography by participants, and use of these images in the research and future dissemination.

Participants were provided with written guidance to inform them of the types of images which could and could not be included in the research (Appendix K). These guidelines were also discussed verbally at the photography workshop, where participants had the opportunity to ask any clarifying questions. To avoid issues of seeking third party consent and to ensure safeguarding of others, participants were asked not to include photographs of third parties. Unidentifiable figures (e.g. in shadow or silhouette), or body parts (e.g. hands) were permitted. Participants were permitted to share self-portraits, though these were anonymised in any research outputs. For the purposes of safeguarding, participants were asked not to submit intimate or nude images. Photographs of children were not permitted. Identifiable locations, such as street names or NHS service names, were excluded, to protect participant anonymity. To protect against the

potential for distress, participants were advised that images depicting violence, self-harm or potentially distressing content would not be shared at the discussion group. Participants were asked to send the researcher their shortlisted images ahead of the focus group, which allowed the researcher to review them for any content which did not fit the agreed criteria.

Additionally, guidance was sought to ensure appropriate steps were taken to acknowledge ownership and image copyright by participants. Each participant has ownership of their images. They could take as many as they want for the 'assignment' and select up to 12 photos to contribute to their discussion group. Each participant owns the rights to those shortlisted images, but in sharing it during the discussion group and in the pile sort, they gave permission for those particular images to be used and shared as part of the research output. Participants were free to keep or destroy any other images they take in relation to the project and had no obligation to share any photos other than those submitted to the discussion group.

The researcher made clear in Participant information (Appendix G) that shortlisted photos would be disseminated as part of the research output (e.g. conference presentations), and that the researcher does not have control over how these images are then shared or accessed beyond that.

Analysis

The discussion groups and interview recordings were transcribed verbatim and pseudonymised before analysis. Locations or any other identifiable details were anonymised to protect confidentiality (see Appendix M for an excerpt of an interview transcript). The qualitative data analysis software NVivo (Version 14 Windows) was used to organise data and support the analysis process to develop a coding frame.

Selecting an analytical approach

There is no standardised analytical approach within PV (Han & Oliffe, 2016; Mooney & Bhui, 2023). That said, existing PV literature typically use inductive analytic approaches, including Thematic Analysis (Clements, 2012; Tang, Tse & Davidson, 2016; Velez-Grau, 2019; Werremeyer, Aalgaard-Kelly & Skoy, 2016) or reflexive thematic analysis (Pinfold et al., 2023), grounded theory (Cassaba, Nicasio & Whitley, 2013), Interpretive Phenomenological Analysis (IPA) (Keating, 2020; Tanhan et al., 2021), and hermeneutic analysis (Erdner et al, 2009; Greco, Lambert & Park, 2016). A scoping review of PV literature reported that many studies involved participants in the analysis stage (in keeping with Participatory Analysis ethos of PV), though most are still researcher-centric (Han & Oliffe, 2016; Mooney & Bhui, 2023). Few studies have included formal visual analysis of the photographs (Han & Oliffe, 2016). A number of analyses were considered for the current study. These are outlined in turn.

Narrative analysis. Narrative analysis (Frank, 1995) is a qualitative method which focuses on how people make sense of their experiences and identities through storytelling. This approach pays close attention to not only what is said, but how it is said, such as analysing tone of voice, body language and pauses in speech. Although this focus on stories could apply well to the current research on mental illness identity, it is usually used with individual interviews or autobiographical texts. Therefore, it was considered unhelpful for the current study, as this would not be a good fit for the data collected from group discussions, where there are multiple, and possibly conflicting, narratives. The focus on individual stories could have overshadowed the collective ethos of Photovoice. Additionally, researcher-led interpretation of data using identity typologies, such as Frank's (1995) narrative types (restitution, chaos and quest narratives) in relation to illness, could undermine participant voices.

Grounded theory. Grounded theory aims to generate new theory through inductively coded and categorised data (Glaser & Strauss, 1967; Charmaz, 2006). This approach uses theoretical sampling, where the researcher recruits, interviews and analyses the data one participant at a time, before recruiting additional participants whose characteristics would assist in answering the research question. This happens to the point of data saturation, where additional data would not further add to the emerging theory. This approach was not deemed suitable for the current study, with the collective focus of Photovoice. Additionally, true grounded theory is data-driven meaning that, ideally, researchers should not be informed by pre-existing literature prior to engaging in the research, which has been critiqued for not being feasible in practice (Braun & Clarke, 2013).

Iconographic (visual) analysis. This is an approach for analysing the content of photographs, such as composition, subject matter and symbolism (Rose, 2016). This has been used in some PV studies, which have incorporated analysis of (1) concrete depiction, (2) symbolic meaning on concrete content, and (3) abstract-level interpretation in the context of the wider literature (e.g. Mizock, Russinova & Shani, 2014; Russinova et al., 2018). However, analysis of an image is subjective, and there can be multiple meanings interpreted (Mooney & Bhui, 2023). This approach was felt to be reductionist and potentially undermining the participants' narrative, if the researcher is imposing their own, or theory-driven inductive interpretations on to the images. It was therefore decided to not to utilise this analysis and instead focus the written (captions) and verbal (group/interview) data generated by discussion of participant photographs.

Reflexive thematic analysis (TA). Reflexive thematic analysis is one version of thematic analysis (TA) within the TA family of methods (Braun & Clarke, 2019; Braun et al., 2023),

which identifies, analyses and reports on patterns, i.e. *themes*, within the data (Braun & Clarke, 2006). This identifying of patterns renders it suitable for both visual and narrative data (Mooney & Bhui, 2023). Reflexive TA offers an 'artfully interpretive' approach (Finlay, 2021, in Braun et al., 2022), going beyond description and summary, also giving consideration to how patterns may relate to wider social context, and the significance of these patterned meanings. The reflexive element requires the researcher to critically reflect on their positioning, values, assumptions and choices throughout the research process, acknowledging that this inevitably shapes not only the research design, but also the knowledge that is then created. Braun et al. (2023) emphasise that knowledge is indeed created by the researcher; it is not an objective truth passively waiting to be discovered.

The thematic approach is conducive to participant collaboration in the analysis, through identification of patterns in their interpretations and stories about their images, so that their photographs and narratives are never analysed separately from one another (Mooney & Bhui, 2023). The collective categorisation of themes by participants at the end of each discussion group (as detailed in *Codifying* section of this chapter) represents an opportunity for some initial, collective participant-led coding. This speaks to the participatory nature of PV research, sharing control with participants over how their experiences are interpreted.

Reflexive TA was considered most appropriate to the current study and was therefore implemented.

Six phases of reflexive thematic analysis

The analysis followed the six-phase method outline by Braun and Clark (2006; 2012; 2013; Braun et al., 2023). Each step is outlined below.

Phase 1: Familiarisation with the data. This involved listening to audio recordings and re-reading transcripts from discussion groups and interviews. As is advised by Braun and Clarke (2006), initial notes were made to record any aspects of the data which stood out, including any initial ideas or themes which related to the research question. Notes were also kept in the reflective journal to question any assumptions or beliefs which may shape what I was being most drawn to.

Phase 2: Generation of initial codes. Each transcript was systematically coded inductively through close reading of the data. As data collection took place over a protracted time period, coding began before the full dataset was collected. Code labels were created to describe the data, and these were refined and evolved as coding progressed, either breaking codes down into smaller codes, or combining similar codes. This involved going back and editing code labels or the boundaries of what was captured within a code, informed by new data. Some parts of the data were particularly rich and were assigned multiple codes. Participant photographs themselves were not coded by the researcher; only data from the discussion group/interview and any accompanying captions submitted by participants with their photographs were coded.

Phase 3: Generating themes. Next, similar codes were clustered to explore possible shared meanings as initial themes. These were reviewed with reference to the research question to ascertain whether a meaningful story and patterns were being generated. The existing codes were drawn out on separate colour-coded post-it notes and an initial thematic map was presented to supervisors, acting in the capacity of critical friends, to present the relationships between the themes. This was a useful exercise for identifying where themes were too ‘thin’ or conversely

too overlapping and needed refinement. Post-its were repositioned and re-grouped during the presentation and subsequent discussion, and a thematic map was recorded.

Phase 4: Reviewing themes. The thematic map was then reviewed again by the researcher, taking a step back to review whether themes adequately represented the coded data within them. Codes which had not been included within the initial themes were also reviewed, as was the dataset as a whole to ensure that the themes told a clear story of the data and allow for interpretation in relation to the research question. Themes were revised, expanded or collapsed as necessary to ensure they were each focused around a central organising idea.

Phase 5: Defining and naming themes. Themes were given names and a brief description. The coded data within each was then again reviewed to check that it was sufficiently represented and that the theme had not strayed too far from the coded data. Themes are multifaceted, unlike codes which are single-faceted, (Braun et al., 2023), so this stage provided an opportunity to check that richness and complexity was captured within the themes. Further refinement of themes was made where one theme contained too much and needed separating into more themes. Final theme definitions supported the decision about what order to present themes in, to most meaningfully tell the story of the data.

At this point, the group-categorised data (which participants compiled during discussion groups, see Appendix O) was revisited and compared with the researcher-generated themes. It was observed that there was a large degree of similarity in the categories devised by each group, and that these resonated with the researcher-generated themes.

Phase 6: Producing the report. Finally, the themes were written in the form of a coherent narrative representing the themes within the dataset. Exemplar data extracts (participant quotes and photographs which accompanied the related text) were selected to represent the core

concept of each theme. Care was taken to include exemplar data from all participants and for this to be as evenly spread as possible. Owing to the fact that some participants took part in both discussion groups and interviews, they are proportionally more represented in exemplar quotes.

Trustworthiness

Trustworthiness of qualitative research typically refers to credibility (that is, whether the findings represent plausible information and are a correct interpretation of the participants' data), transferability (that is, degree to which the findings can be transferred to other settings), dependability (i.e. the stability of findings over time), confirmability (i.e. the degree to which findings can be confirmed by other researchers) and reflexivity (that is, the process of critical self-reflection by the researcher) (Korstjens & Moser, 2017).

Credibility was supported through member check, by feeding back to participants the identified data themes and interpretations, along with their exemplar quotations and group-categories, to confirm the interpretation. Writing a rich and detailed results section was key to ensuring transferability of findings so that other researchers in other contexts can assess the generalisability of the results. Discussion of the coding process and initial codes and themes was discussed with supervisors, who acted as critical friends to the coding process (Mat Noor & Shafee, 2021). This supported dependability and confirmability via encouraging me to reflect on coding decisions and my own biases.

Reflexivity statement. In keeping with the reflexive thematic analysis protocol, a reflexive journal was kept throughout the research to allow regular reflection on my positioning, values and assumptions and how this relates to research decisions and how I constructed meaning from the data. My positioning as a clinician-researcher places me in a position of

authority and as an outsider to participants. As outlined in the Position Statement on the use of psychiatric diagnostic labels earlier in this chapter my assumptions from a social constructionist lens regarding mental illness are informed by my professional training. These factors influenced decisions regarding the research question and selected methodology. Simultaneously, I can also be positioned as an insider, as someone with lived experience of mental health challenges (albeit not as severe or as chronically as participants), and with experience of receiving clinical intervention, as well as personal use of the arts for supporting mental health. Inevitably, this positioning influenced my interest in this research question, and so it was important to be able to regularly reflect on my assumptions, particularly during analysis, to consider how my positioning and values shaped my interpretations. Further consideration to this is given in the discussion chapter.

Dissemination

Participants indicated whether or not they wished to receive a summary of research findings. Unique to the PV methodology is the option for participants to exhibit their photographs to an audience of their choosing. Initially, it was hoped that this would be organised with support from the arts charity, by staff and volunteers who have experience of exhibiting artworks in the local area. Subsequent to their unexpected closure, there are plans for the researcher to support participants who still wish to share their images and stories with their chosen audience, via an online platform, such as a blog with NHS Trust and the University of Essex communications teams.

At least one paper will be submitted for publication in an academic journal and proposals for presentation at relevant conference(s) will be made. The researcher has initiated contact with relevant forums, such as the London Arts in Health Forum for wider dissemination of findings.

Chapter conclusion

This chapter described the design and procedures used in this study, including challenges encountered and steps taken to overcome these. This section also described the methodological choices made and plans for future sharing of study findings.

Chapter 4: Results

Chapter overview

This chapter describes the demographic information of the individuals who took part in the study. It then offers in-depth exploration of four themes that were developed through the reflexive thematic analysis process. A selection of participant photographs and quotations are included to support the themes. Pseudonyms are used throughout.

Descriptive findings

Nine participants confirmed they had received one or more psychiatric diagnosis, though only eight specified what this was. The following diagnoses were named: anxiety disorders (87.5%), depression (87.5%), eating disorders (25%), emotionally unstable personality disorder (25%), bipolar (12.5%), obsessive-compulsive disorder (12.5%). Most of the women (87.5%) had been given at least two psychiatric diagnoses. Three women had been given three diagnoses, and one had received four diagnoses. Information about the mental health condition(s) and service use is reported in Table 6.

Table 6

Descriptive Information about Participants' Psychiatric Diagnoses and Service Use

Question	N (%)
Do you consider yourself to have a disability?	
Yes	7 (77.7%)
No	2 (22.2%)

Have you ever received a mental health diagnosis?	
Yes	9 (100%)
No	0
How long have you experienced mental health difficulties?	
Less than a year	0
1 – 3 years	0
3 –5 years	0
5 – 10 years	0
10 years of more	9 (100%)
How often do you attend the Arts Centre?	
Daily	
A few times a week	0
Weekly	3 (33.3%)
Fortnightly	4 (44.4%)
Monthly	1 (11.1%)
Occasionally	1 (11.1%)
	0
Total participants	**9 (100%)**

All participants were currently accessing multiple services and interventions for their mental health. All were attending the arts charity at the time of recruitment. Seven of the women

were taking medication (77.7%) and two women were under the care of the Community Mental Health Team (22.2%). One was accessing primary care Talking Therapies (11.1%) and another was on the waiting list for this (11.1%). One woman was also attending other local community activities for mental health.

All of the participants who answered questions about past mental health service use (n=8) had previously accessed medication and talking therapies (e.g. CBT, DBT, psychodynamic psychotherapy). All had accessed NHS therapies, but some had also accessed therapy privately or via charities. Half had previously been allocated a care coordinator within secondary care services. Two of the women (25%) had previously been admitted to a psychiatric ward.

Qualitative findings

Four themes with 12 sub-themes were generated in the data, as summarised in Table 7. The themes presented in this chapter are illustrated with a selection of participant photographs. Although not all images are included in this chapter, every image that was submitted offered meaningful information. To honour participants' visual testimony, a full catalogue of participant photographs is available in Appendix N.

Table 7

Summary of Themes and Sub-Themes Generated from the Data

Theme	Sub-themes
Navigating identities: the struggle between mental illness identity and the whole self	Dominated by mental illness: *"Is that my personality or is that my mental health condition?"*

	Beyond broken parts: community arts welcoming the whole person Community arts: a chance to connect with positive identities
Hierarchy, power and positioning	Experts and Equals Decision-making: who gets to choose? Societal stigma & Group membership through mutual otherness: *"I've found my flock. We're all a bit different, we're slightly separate from the world"*
Performing the patient role	Getting needs met Performing the tasks of therapy Be 'normal': masking and suppression Getting therapy right
Teetering between hope and hopelessness	Cycles of help-seeking: "*burnout from your burnout"* The hope of something different: a break from mental illness identity

Navigating identities: the struggle between mental illness identity and the whole self

This theme describes participants' experience of having chronic and recurring mental health struggles, which can often feel domineering, leading them to question whether illness is their overarching identity, or one part of it. Mental illness was described as something to battle

against, with support from various services, including healthcare professionals. Seeking this help can be both validating and shaming. Diagnosis can foster self-understanding and access to services, however, when clinical help is repeatedly sought, this can feel reducing and reinforce a dominating sense of self as broken and a problem to be fixed. In contrast, non-clinical spaces, such as dedicated community arts for mental health, give time and space to be seen as more than just mental illness, and be seen as a whole person. Mental illness is still there within one's sense of self-identity, but it exists as one part alongside other parts of identity. Such spaces allow for authentic self-expression, personal growth and (re)connection with other parts of one's identity.

Dominated by mental illness: "Is that my personality or is that my mental health condition?"

All participants had long histories (more than ten years) of experiencing mental health challenges and of using various types of mental health services, on multiple occasions. Many participants described the chronic nature of their mental health episodes, with the implication that life will always be this way. Most participants described their mental health in terms of being a "lifelong"' condition which requires "a long-term management strategy for your life" (Nicky). Mental illness was described by all participants as dominating the centre of one's life and self-concept, particularly when accessing traditional clinical interventions. As Amanda described, "when you have suffered with something for so many years...it becomes a part of you". Participants shared stories of the years lost to mental illness, including lost employment and "basically being a prisoner in my own home" (Amanda). They described a sense of resignation and acceptance that this is how it is, given the repeated challenges they had faced, and that one has to manage the best way possible:

> And you know, I'm OK with that, you know you can't fool yourself either, like you're going to have problems, you get it... You can't, you literally can't cure everyone's problems out there. But you can manage them. (Poppy)

The all-consuming sense of mental illness was well-illustrated by Jenny, who found herself questioning the extent to which her bipolar diagnosis is inherently who she is:

> Because I think I feel very much like, is that my personality or is that my mental health condition? How much of it is me and how much is it is ...I feel very much something like I don't really know who I am. It's like, is that me or is that who I am or is that because my brain chemistry makes me like that? And if I can take a tablet that changes my brain chemistry, then is that then my personality? I think having a mental health issue is caught up with your personality, isn't it? (Jenny)

Participants described feeling perceived by others (in society, in services) as less human because of their mental illness, though they did not describe themselves in this way. However, participants did appear to have negative self-concepts generally, in most areas of life. Participants consistently described that to have serious and long-term mental health challenges was to be different, "an oddball" (Nicky) and less than in some way. All participants frequently described themselves in enduring and hopeless negative terms, such as "broken" or "cracked" (Figure 2). These descriptions were reflected in both how participants feel perceived by others (in society, in services), and how they perceive themselves.

Feelings of difference and problems-focused thinking were common. More than half of participants described themselves as having always felt different to other people, primarily

because of neurodiversity, or because of not having typical gendered interests from a young age. In contrast, other participants described that mental illness had changed them and derailed life, and they wished to return to their pre-illness state, as indicated by Helen, who explained "If I could be a normal person again, then I would."

Figure 2

'Cracked' - photograph representing perceptions of living with mental illness

Note. © Jessie, 2024

Mental illness was described as affecting all parts of life, and this is felt like a battle to constantly be fought. Two participants shared their pride of being a survivor of such challenges:

> It is so difficult to be me. And all of us battle so hard. It's it's brutal, it's brutal, but here we are, you know. (Nicky)
>
> I'm still standing. (Amanda)

One strategy to fight the battle, for all participants, was to seek support from services. Participants constructed their experiences largely in medicalised terms, which informed where they sought help from.

> First and foremost, it should come doctors and you know psychiatrists and therapists because we're talking about an illness. And I think it shouldn't be...we shouldn't pretend that it doesn't need to be medicalized, because it does. (Jenny)

This medical lens and subsequent help-seeking was experienced as both validating and shaming. On the one hand, identifying with diagnostic labels was constructed by participants as necessary for accessing support, whether that was clinical services within the NHS (such as medication or therapy), accessing mental-health specific groups in the community (such as the mental health arts charity) or for having needs supported in the workplace. Yet mental health labels were also experienced as dehumanising:

> Socially. Or in the workplace or wherever you are. As soon as you've got a mental health problem, you're deemed less human. Well, that's how I feel anyway. There's that stigma. (Helen)

> As soon as it's mental health, you cease being a person, you immediately become a number, a statistic. It's not Oh, [name] suffers with, it's she has. (Jenny)

For some participants, diagnoses were a helpful way to make sense of their experiences, particularly in relation to neurodiversity diagnoses, such as Autistic Spectrum Disorder (ASD) or Attention Deficit Hyperactivity Disorder (ADHD). Having a diagnosis, or being on a waiting list for assessment, was described by Nicky as giving a "little flag" which is validating of one's

experiences and behaviours, and which also acts as a “door opener” for additional support, both now and in the future (e.g. employment support, social services). Other participants shared this view that diagnostic labels can support a greater self-understanding and a feeling of connection with others who have shared experience:

> Because it means I can learn about myself accurately...And also knowing that there are words to describe my experiences, that I'm not the only one, that's quite empowering for me, personally. (Kate)

On the other hand, others described a sense of shame, particularly in the context of having accessed mental health services over a long period of time, or on multiple occasions. This repeated cycle of help-seeking and service use was negatively constructed by participants as being a burden on services and society:

> Oh, I'm just the lowest of low and I'm dirt beneath people's feet. I'm useless. What am I to society? I'm not doing anything in society to help or whatever. (Amanda)

They described themselves as being a frustration to health care professionals. This perception of self was not usually derived from an experience of having this said to them, but a felt sense and internalised shame.

> To kind of be in a situation where you've had a lot of different therapies and they don't seem to be making much impact I feel like people do get frustrated within the services they work in. I don't think they necessarily say it. I mean, some of them do, to be fair. But I think it's a bit like, what do you want from us now? We've given you CBT, we've given

> you DBT, we've given you talking therapy, we've given you medication, we've given you a care coordinator. (Kate)

Consequently, several participants (Kate, Helen, Jessie) described being perceived by other people as someone who is wasting resources or taking resources from others who could make better use of it. This reinforced an enduring and dominating mental illness identity as someone who is broken and in need of repair (by others). As Kate described, there was a sense of being seen as dehumanised by clinicians, and as "a problem with a person attached." The act of repeatedly telling one's story, often to new clinicians with each episode of help-seeking, made participants feel exposed and focused on their perceived flaws, as Jessie described: "Split open. Every time, regurgitating the deepest, darkest depths. Open raw...for all to see...Not pretty."

Figure 3

Photo representing feeling "split open" when sharing mental health experiences in services

Note. © Jessie, 2024

These experiences of re-telling one's story and most vulnerable moments reinforced a medicalised and problem-saturated view of one's mental illness taking over their identity:

> It's like I'm a tough case and a challenge for you. But you go home at the end of the day, forget about your tough cases and have a cup of tea. I go home and I am the tough case and that sticks with you. (Kate)
>
> And so, you then have it stuck in your head somewhere that you're not normal, be normal. (Poppy)

Beyond broken parts: community arts welcoming the whole person

Many participants highlighted positive experiences of clinical care within the NHS and clearly valued the input of community psychiatric nurses (CPN), therapists, psychiatrists, and others. They also described challenges in using clinical care. For example, many participants viewed their mental illness through a lens of diagnosis and treatment and felt this was often a useful way to access support and understanding of themselves. However, this can also feel like being reduced to their diagnosis. There was a clearly expressed desire across discussion groups and interviews to be seen as a whole and unique person, beyond their diagnosis. Systemic issues, such as pressured and time-limited services, were named as possible reasons for feeling like many clinical encounters were of a 'tick-box' and functional nature.

These interactions were experienced by participants as focusing on problems to be solved, and failing to truly get to know the person in the room:

> I'm very interested in like Brutalist architecture...none of it tends to have any sort of decoration or individuality to it. It's got a purpose, and a purpose that does work and you need it there, and so there's a level of functionality, but that individuality is gone. Yeah,

like there's a purpose, give me medications, that sort of thing. There's a function to that and they do work and they do get to a level, but yeah, the individuality ain't there. (Poppy)

Figure 4

Photo representing impersonal, functional services

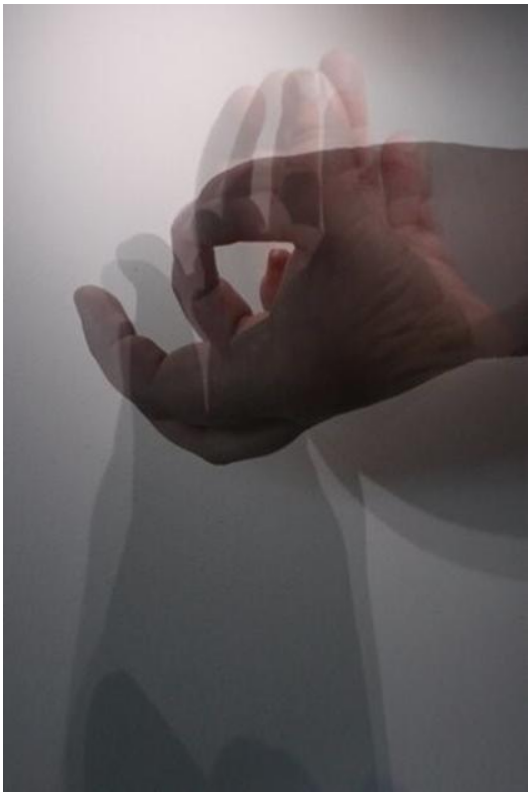
Note. © Poppy, 2024

Several participants described frustration at feeling like they are not seen or treated as a whole person within the NHS, where they have multiple needs. These included experiences of mental and physical health being treated separately, particularly with regards to gendered needs such as menopause support. Siloed services for assessment and support for neurodiversity were also named by three participants as a barrier to having their needs met within mental health services:

> ...it is very much that we go here for this thing, and here for this thing. And I'm like 'But what if my sensory needs are making my anxiety worse? Because the autism specialist wouldn't discuss anxiety and you wouldn't discuss sensory needs. So, it's like, do I have to be both in one room? How do I do that? Shall I like conference call you guys?! (Kate)

Figure 5

Image depicting stimming in participant with autism



Note. © Kate, 2024

This contrasted with experiences within community arts for mental health, where more time and flexibility allowed for participants to show parts of themselves on their own terms and in their own time. This included feeling more able meet neurodiverse sensory needs, such as stimming or wearing headphones without judgement, as well as being known for more than your

mental health, but being able to show more of your personal identity and interests and achievements (e.g. yoga, travel, art, TV and film):

> I feel more as if you know they are looking at you individually, who you are, rather than why you were referred here or whatever. (Poppy)

Figure 6

Image depicting a wish for services to take time to get to know the whole person, not just broken pieces

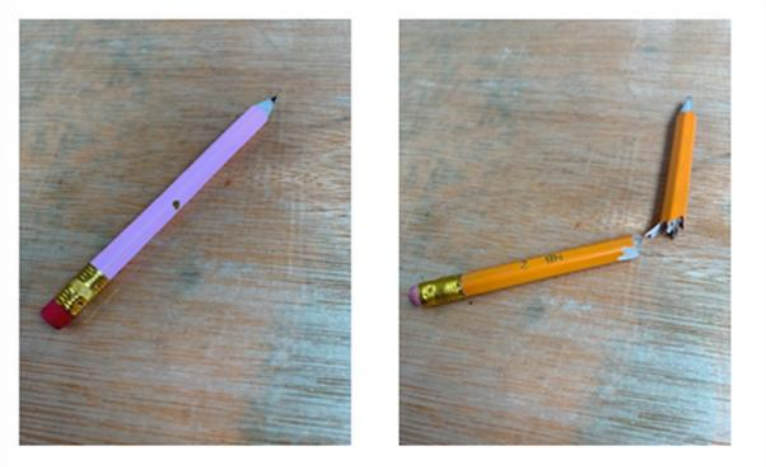
Note. © Poppy, 2024

All participants described feeling that they felt visible and accepted as a whole person to a greater extent within the community arts group than while entering clinical health settings and other settings in their daily life. For some participants, however, there was still an element of feeling a need to blend in or not feeling that they fitted in the group as much as others. Group dynamics and personality differences were named as possible reasons for this.

The informal and homely nature of the arts group also allowed for participants to take up new roles within the group. This included formal roles, such as being a volunteer at the centre, as well as informal roles such as being the one to remember everyone's individual choice of drink. Not only did this support attendees to feel valued and cared for, but it also offered a sense of being useful. As Helen described, "I feel complete, I've got a point, I've got a purpose." This offered a challenge to her internalised identity of being "utterly broken and pointless" in other settings, particularly when accessing NHS care (Figure 7).

Figure 7

The difference in self-concept in arts vs. NHS services



Note. © Helen, 2024

Despite feeling like more of a whole person within the arts group compared with clinical spaces, mental health identity was still salient here too. This seemed to connect with an internalised and self-stigmatising view of self as different and in need of a specific group for mental health, as explained by Jenny:

> You know that everybody else here has similar and very different experiences. We're all, it isn't, you know, it's the fact it's a mental... It's not just an art place. It is a mental health art place. (Jenny)

They constructed themselves as being unable to function or cope within a mainstream arts group. Reasons for this included having permission here to be one's true, authentic self with less judgement, as well as feeling safe in the knowledge that other people have shared experience and understanding of what it is to live with mental illness. The way in which participants positioned themselves was as an individual and collective othering, being outside of the mainstream:

> I can be weird, I can be quiet, I can be loud, I can be me. (Nicky)

> Well, when I come here, I feel more relaxed, that's for sure you know, because I think anybody that comes here is, like, the same, you know, like, know, I feel comfortable being myself, because there's lots of people here that like to be different, and are different. And that's why I feel comfortable. (Carolyn)

Community arts: a chance to connect with positive identities

In describing a desire to be seen as a whole person, who is not purely defined by mental illness, participants shared aspects of their other identities. For example, some participants spoke about their identity as a family member and friend. Just over half of participants chose to share examples of their achievements in education and the workplace, past and/or present. For some, these roles were ongoing, or new opportunities were emerging. For others, however, mental

illness was described as having taken this valued role away from them. Opportunities to develop new roles and identities, such as being a volunteer in the community and helping others, were highly valued and supported the development of a more positive self-concept:

> You just start to feel like maybe there was a little bit of you that is worth something. You start to feel like, maybe there's part of you that [...] has a right to exist. And isn't just a drain on resources and isn't just this weird freak. (Helen)

Most the participants (n=6) spoke of experiences of being nurtured in their creativity while attending the arts charity. Encouragement to try new things, to be creative and participate in exhibitions supported a feeling of personal transformation and improved self-confidence:

> But we're coping...and look at us being super, look at us being superstars at the same time like exhibiting, making stuff, being brave, sharing stuff. We're doing things more than we ever expected to do when we walked in the building. (Nicky)

Participants varied in their views of whether they considered themselves an artist. Those who had always been involved in creative activities, either from a young age or through participation in other groups or courses, found it easier to embrace a view of self as a creative person. However, most participants described some reluctance when they first joined the group, holding the belief that “I’m not an artist” (Helen). All participants spoke of their enjoyment of creating art and the benefits they feel it brings to their mental wellbeing, and all agreed that there was never any pressure to produce art of any particular type or standard. Participants appreciated the encouragement from the group facilitators/artists that ‘everyone’s an artist’, however despite

having exhibited with the group, three of the research participants explicitly named that they did not identify as artists.

> The only exhibition I've ever taken part in was the one in the hospital. And I still feel like I'm not. I'm not good enough, you know. I'm not that much of an artist. (Jenny)
>
> I'm not an artist. And I would be scared to go anywhere near a proper art group. (Helen)
>
> There's great artists out there. I'm a good trier. (Nicky)

This reflects some participants constructing themselves as other or less than others. Nonetheless, new skills, creative expression, friendships and achievements gained through participation at the arts charity were described by all participants, and this helped to build confidence. This was described as "magic" by Jessie (figure 8).

Figure 8

'Magic' - photograph representing the arts group

Note. © Jessie, 2024

The focus on what a person can do, as contrasted with problem-focused approaches within clinical settings, supported participants to learn new things about themselves and learn that they are “capable of what I did not believe was possible” (Jessie).

Hierarchy, power and positioning

This theme describes participant relationships and positioning with clinicians, who were often positioned as expert guides for managing mental illness. Other participants described a power imbalance and a desire for more collaborative and flexible care, particularly around discharge and (re)accessing services. In contrast, the nature of community arts groups facilitates a more equal positioning between members, owing to shared experience of mental illness. This fostered a sense of mutuality, equality, trust and belonging. The community arts space provided an opportunity for self-expression and connection, fostering a sense of "home" and safety that was often lacking in other parts of their lives. This was especially felt as a contrast to experiences of societal stigma, feeling marginalized or misunderstood by others due to their mental health challenges. This mutual otherness from the outside world was highly valued by all participants.

Experts and Equals

Participants positioned themselves as separate and different to clinicians and other professionals (e.g. Community Psychiatric Nurse (CPN), Psychiatrist, General Practitioner (GP), therapist). Doctors were positioned by several participants as being the expert, who should guide and advise on treatment plans, specifically medications. This point was made by Jenny, specifically in relation to the interactions of gender and mental health (hormones, menopause) not being understood. She expressed a need for “somebody who's an expert” to see the whole

picture. Without this guiding expertise, Jenny described a feeling of hopelessness that a solution would be found with regards to managing her symptoms of bipolar. This was echoed by other participants, who described that they look to healthcare professionals as experts to guide the way forward, which they themselves do not know how to manage:

> You know, and I think people kind of feel a bit lost. And then that's really damaging to my self-image, obviously, because if the people who are experts don't know what to do, how am I meant to carry on knowing what to do? (Kate)
>
> I'm not a psychiatrist, I don't know. (Nicky)
>
> ...you kind of need a CPN with you even when you're well, because then they're able to sort of pre-empt your deterioration or sort of deal with you (Nicky)

Two participants described feeling positioned by doctors, particularly by GPs, as being responsible for not feeling better or for making healthier lifestyle choices, such as doing regular exercise. This was constructed by participants as doctors not understanding the extent of their mental distress, with a sense of their struggles being minimised and trivialised. Others described ideal care being more collaborative in nature, with joint decision-making, but this was framed within a need for someone with more expertise to be guiding this. Again, this positions the person with mental illness as being led by, rather than a more egalitarian approach to care planning. Nicky also described that, in an ideal world, there would be a joining of clinical and creative staff, so that clinicians can offer a level of expertise and safety:

> I think it's having the professional staff there, as sort of guiding bodies of wisdom and safety nets for people attending the creativity, because there have been times when

> certainly I and others have turned up at [art space] when we're having a really bad day. (Nicky)

This can be interpreted as positioning people with mental illness as needing to be recipients of something more 'expert' and 'wise' from a clinician. While some wanted this expertise, other participants described that this power imbalance had led them to feel like they were being saved and had to be grateful. Linked to this idea of being grateful, some participants shared experiences of feeling unable to ask questions or challenge when they did not understand or feel comfortable with particular interventions.

When clinical care-seeking was repeated, as was the case with all participants, there was a theme of feeling like a burden, and a desire to instead be able to give something back. Some participants valued mutual peer support, which was possible within the community arts space, as illustrated in Figure 9.

Figure 9

Image depicting mutual support and shared experience

Note. © Jenny, 2024

In this context, giving and receiving support included offering a listening ear for mental health-related discussion, and also included more practical advice-giving around creative techniques and decisions, such as media choice:

> ...it's not just someone going 'I'm going to help you now, there you go' sort of thing, it's like there's people you can help. There's people that can help you. So, it feels more equal and less like you're taking from other people or resources. (Kate)

To be able to offer mutual support within the arts space was positively constructed as facilitating self-esteem:

> And it's nice when erm, I come here, people ask me for advice on something, like what do you think of this? What would you do next on this piece of work? It feels like I'm being trusted to enable them to carry on with what they're doing or a little bit of help in some way. So, yeah, I think that helps, when somebody's got low self-esteem, but somebody asks them for help, or what would you do. (Carolyn)

Underlying this wish to give back was a sense of being a drain on resources. To be able to give something back creates a more equal positioning which can counter the internalised messages of being a burden. To be able to give back via more active and mutual forms of support also allows space for recognition of one's strengths and skills, and not just one's problems and a passive recipient of care:

> ...this whole kind of us being able to give. I think I've got…yeah, just to be able to, almost like, not an exchange. I've got like a peer support qualification... (Jessie)

Several participants spoke of a so-called sixth sense from some staff, whether within the arts space or within the NHS, who are more understanding than others because of their own experiences with mental illness, even if this is not explicitly named or spoken about. This was constructed as facilitating trust, feeling understood, and being on a more equal footing:

> You can tell. You can tell the language the people use. You can't learn everything from just like having textbook. And you can tell if, you can tell in the approach and the language that's used, the questions that are posed to you, who has experience. (Poppy)
>
> Like a sixth sense. Someone's been through it, done it, got the t-shirt, gets it. (Nicky)
>
> ...because she's been there. She knows what you're probably thinking, what you're feeling ... I think because she recognises things from herself that she sees in others that it makes her so much better at being with people. (Amanda)

Decision-making: who gets to choose?

The obviously one-way interaction of receiving care from mental health services, and the power imbalance which emerges from this, was also mentioned in relation to being discharged from services. Most participants (n=7) reported feeling that they feel that care ends too soon and that the decision to end usually lies with the service, rather than when the service user is necessarily ready to end. This felt like a unilateral decision process, or one where service users have to go along with the decision, albeit this was understood by participants as being reflective of systemic limits and financial pressures, as Jenny explained, "...I'm starting to feel better but it finishes always before I'm ready and it's not my choice."

Many participants spoke about the time it takes to build trust and safety when working with a new healthcare professional, and spoke about the positive experiences where this rapport and "some incredible help" (Jessie) has supported positive gains for their mental health:

> ...so it should have been like six, eight sessions ... And I couldn't get out what I wanted to say. And it took me right until, and she extended my, she extended my session ... And it took me to like the 10th session, to actually get out what I wanted to, what I was trying to say. 10 weeks. I said it, I sort of blurted it out, and then it turned out that was my last session. (Jessie)

Although participants are aware of being able to re-access support in future, and have done, there is a feeling for many that the message is "we've done this work, so now you're, you're okay" (Jessie). However, for participants this feels premature, as Jessie expressed "Because there's many elements to what I struggle with. There's always something else."

This construction by participants that they need more support than is available from the NHS was mirrored by many participants. For example, Kate referenced her experience of being discharged, but this being at odds with her own understanding of her needs and situation, feeling that healthcare staff do not always appreciate the complexity of need:

> I find it so hard when I get told every time that I have a lot of insight and resilience...they can kind of use it as a way to reduce the caseload maybe or just reduce the appointment times or this or that. And very quick to see you as lower needs than you might actually be. (Kate)

Figure 10

Gate representing access to services

Note. © Carolyn, 2024

By comparison, within community arts, most participants spoke of a greater degree of choice and freedom in decision-making. This included choice such as when and what to attend, flexibility over volunteering opportunities, and adaptability to meet needs (e.g. to bring a support person along to first few sessions). This offered a sense of equality and shared decision-making, rather than having to fit into a system with rigid rules. Many participants appreciated that the informal structure of the arts charity allowed flexibility to fit the person and their needs, or at least attempt to. Importantly, all participants spoke of the open accessibility of the arts group, including no abrupt end point and the ease to return to the group even after a break:

> I always used to think that I was going be, 'cos I worked for a block, 12 weeks or something, the course, and I thought that was going to be it and I'll have to start again. But it wasn't. You're allowed to go on. It's been years. (Carolyn)

Accessing the group was described as simple, without complicated paperwork or long waiting lists. In fact, two participants named that they joined the group as an avenue of support while on long waiting lists for clinical intervention:

> It was so easy. It wasn't kind of like, well, you've got to fill in the referral, you know, we'll need to check if you're really, if your mental health problems are serious enough to be because we can only let certain people come. ... I think if there had been any barriers to it, like, 'oh, you've got to fill in a self-referral from or your doctor's got to refer you' or something like that, then I probably wouldn't have ended up there. (Jenny)

> ...the reason I chose to go for [arts space] in the first place was that I had to try something different and it was aside from waiting lists and all these things. (Kate)

The four participants who attended follow-up interviews shared their experience of the unexpected and sudden closure of the arts group, owing to the charity's financial issues. The closure was experienced as a loss for all interviewees; however, this was felt much more acutely by those for whom attending the group was a more regular part of their weekly routine, compared with those who attended less frequently, due to work or education commitments:

> Well, it's been heartbreaking for me. (Nicky)

> Felt like the floor had been ripped out from underneath me...just felt like I'd been kicked and punched in the stomach. And you couldn't breathe. It was just this loss. Yeah, it's real sense of loss.... It was a massive part of my life, a massive part of my week... I got very low. Very low I was feeling a bit lost. (Helen)

Several interviewees spoke about the financial crisis in health and social care, including experiencing similar losses of other community groups over the years. While some took a stance of resignation and acceptance, others described a desire to make an active attempt to save the space financially, while others described how a handful of members had found a new venue to run their own peer support art group, which they have ownership of:

> I think it is permanent. I just think that the money just isn't there. A real shame...I was sad, but I felt more sad for the people that worked there and the people that put all that effort in. (Jenny)

> What's been good is that the people who volunteered on like the [art space] as a charity have been able to kind of pick up one day a week running a drop-in group where you play and do similar things. It's not quite the same so they don't have the resources, physical art material resources. But that's been a bit of a kind of safety net because it's not completely gone. The people aren't completely gone things like that. (Kate)

Societal stigma and group membership through mutual otherness: "I've found my flock. We're all a bit different, we're slightly separate from the world."

Almost all (n=6) participants described experiences of negative stereotypes or active discrimination because of their mental health. This included instances of being disbelieved, or trivialised, as well as diagnostic overshadowing of physical health issues because of mental health diagnoses. These examples occurred across society, including in healthcare, the workplace or among family.

Several participants described being positioned negatively by other people in relation to education and work specifically. This included people expressing surprise at their educational attainment (e.g. university degrees) and wider societal discourses around work and benefits. As mentioned, most participants spoke about wanting to have a useful purpose and role in the community (e.g. volunteer, keep working, having a legacy), yet stigmatising attitudes emphasis illness and overlook skills, which can reinforce a pervasive mental illness identity in those with long-term or repeated struggles. This point is captured in the following interaction between Jenny and Kate, during a discussion group:

> [Jenny] Mmm. I do feel, especially working in my sector, working in education, that I'm almost like, like what I said, that I'm not supposed to be there really. [Pause] Working in any sector really. Are you well enough? I've heard people say to me 'Well, are you well enough to work?'
>
> [Kate] And then if you don't work, 'Why are you not working?' [Laughs]
>
> [Jenny] 'Why are you not working?' You know, it's like what? Who says? What sort of people are allowed to have a job? Those of us, those people that are not allowed to have a job? You know, what kind of work are we allowed to do? You know, am I allowed to go work in Sainsburys? Is that OK? But I'm not allowed to be in charge of your child's education.

It is unsurprising, perhaps, then that several participants across focus groups positioned themselves as being a drain on resources. Societal messages about stretched NHS services meant that this position was internalised into self-concept. While speaking about the shame of repeat help-seeking, words such as 'allocation', 'quota' and 'what you're allowed' were used in

discussion groups and again in interviews. Although aware that they could re-access services, the perception of having taken too much was apparent.

By comparison, participants did not describe themselves as being a burden while accessing the community art group, even when they had been attending regularly for years. In fact, this ongoing open access (until the charity folded) was the important factor in fostering community, which for some, may have been their only community. For some participants, the arts charity represented one of very few times in life where they had experienced belonging and that they "wasn't out of place" (Amanda). Consequently, the space and the people there were highly cherished, particularly when attending at regular times allowed for more opportunities to get to know others who also attended that time slot, allowing deep friendships to grow:

> I've made some good friends. Yeah, definitely people that I'd look at as my friends. (Carolyn)
>
> ... you found your tribe at last. (Nicky)
>
> I'm safe. And I'm loved...I know that through that door...there are people that care and that there are people that think, 'yeah I know, I feel you'. (Poppy)

Although participants had a range of various diagnoses and experiences, it was their shared experience of the often stigmatising and isolating lived experience of mental illness that led to bonding, as described by Nicky and illustrated in Figure 11:

> We may all have illnesses, they may all be different, but we're individual, so the individual stitches, but we're all together still and we all understand each other and we all empathise and we love each other. And all those stitches support each other. I thought that was great illustration of what we are and I feel safe. (Nicky)

Figure 11

Image depicting individuality within shared experience of mental illness

Note. © Nicky, 2024

Almost all participants in discussion groups and interviews described a feeling of belonging and being understood when attending community arts for mental health. Adjectives such as 'home' and 'family' were frequently used, across discussion groups and interviews, even for those who had returned to the group after a long period away. Each discussion group cited the staff's welcoming approach which was deemed as critical to them being able to attend. Several participants were keen to share staff's unofficial slogan: *Once a member, always a member.*

Although there was agreement across participants that the art group offered compassion and community, two participants explicitly described less of a sense of belonging or being their true self in this space. This was constructed as representative of how they feel like they do not fit

in most settings, however, there was still an appreciation for the opportunity for connection and community:

> I know that I'm not always my authentic self when I come anywhere...Sometimes I don't feel as seen...Mainly because. I find it very difficult to be my authentic self ‘cause I've masked my whole life. But also like I say, there is connection and a chance to be something a bit different to what you would be elsewhere. (Kate)
>
> I don't think I'm somebody that deals, that functions very well in any kind of group. (Jenny)

Feeling understood, for Poppy, was described as an implicit and unspoken experience, even though she had not divulged personal details of her life to other group members. She explained “I feel like I've said the least about myself in this environment, but I feel most understood.” This speaks to the meanings constructed by other participants that, by virtue of the group being specifically for people with mental health challenges, there is an unspoken shared experience from the outset. This facilitates a feeling of acceptance, non-judgement and compassion, even if the exact nature of one’s difficulties may not be known. This compassion perhaps allows for increased self-compassion, or the chance to challenge negative self-beliefs:

> And and then you suddenly start thinking, well, when you come to somewhere like here, and you don't see them as broken. You just see them as individual people. That are misunderstood. (Amanda)

Common to the experiences shared was an implicit separation of the group membership from others in society. Tracey, though she did not attend the focus group, submitted a number of

photographs and written testimony, which was also included in analysis. Figure 12 represents a feeling of group belonging, but with distancing of the group from others. This distance was described as providing safety, rather than marginalisation:

> I've found my flock. We're all a bit different, we're slightly separate from the world (represented by the water creating a barrier), but we're safe together. (Tracey)

Figure 12

Image representing a sense of belonging and safety with other arts charity members, away from others

Note. © Tracey, 2024

This idea of mutual otherness is reminiscent of what others said about not being able to or not wanting to attend "proper art groups" (Helen) or those which are not exclusively for mental health. This suggests that narratives of being different and defined by mental illness are dominant for participants.

Performing the patient role

This theme describes participants' experience of navigating mental health support, often feeling like they must take an active and assertive approach to getting their needs met. Routine tasks, such as completing outcome measures, were described as rigid and impersonal indicators, which could be misused to prematurely discharge service users from support which is highly valued. In contrast, the informal and open-ended nature of the community arts group meant that participants did not feel a pressure to discuss their struggles or show improvement on specific outcomes in a time-limited setting.

Getting needs met

Some participants spoke of the active approach they took in chasing up appointments and feeling that they sometimes have to be in "fighting mode" (Kate) to feel heard and supported (e.g. in scheduling psychiatry appointments).

Most participants discussed their frustrations with barriers to receiving support, such as long waiting-lists, eligibility criteria, and falling into crisis before being seen. Linked to this was a concern that routine outcome measures and 'tick-boxes' could be used as a means to not being offered mental health support. For example, Kate shared a concern that having a period of relatively improved mental health, or being deemed as having insight, could be used as reasons to be discharged from the service:

> No one wants to be going in like acting worse or better than they are but the pressure is there to be like 'Well, I need *this*, but you're not going to do it if I feel like <u>this</u>.' (Kate)

Support from all types of intervention was clearly valued and participants feared losing it. The open-ended nature of the arts group helped to remove some of this worry, but for some participants, becoming a volunteer at the centre offered a dual function. Not only did volunteering offer role and purpose, as mentioned previously, but it was also a useful strategy for removing the risk of losing access to a valued space and community:

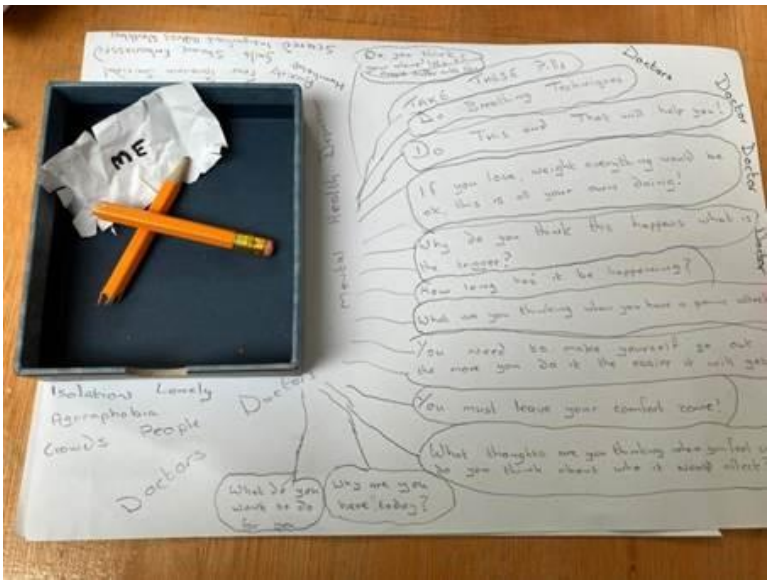
> Theoretically there was an end date to [art space] as well. But there never really was until [art space] ended itself. There was a 12-week course, but you knew that for the whole of that 12-week course that you then had the studio placements to go on to. So, then the placement was theoretically for six months. So, you knew that there was going to be finite time, but that just got extended and then I started being a volunteer. (Helen)

Performing the tasks of therapy

There are unspoken rules within clinical services, such as what is spoken about, when and by whom. Participants described feeling that there are right things or wrong things to talk about in services, such as in therapy. In clinical services, you are there to address mental health problems, and naturally, this then becomes the focus of discussion (i.e. you must talk about difficult things in order to process them; you must answer questions from clinicians; you must try new techniques and practice the homework exercises).

Figure 13

Image depicting conversations in clinical settings, which feel bombarding, and the impact on self-concept



Note. © Amanda, 2024

This can feel overwhelming and impersonal, as depicted in Figure 13 and as described by Amanda: "...is bombarding them, with stuff like do groups, take this...I think a lot of times, textbooks, you gotta do this, and that. It doesn't work with people." Most participants named that this reinforces a problem-saturated view of themselves.

Additionally, within clinical services, there was a felt pressure to reveal deeply vulnerable information to someone you do not really know, in a very short amount of time. As described previously, this vulnerability is one-way between patient and so-called expert:

> I don't think there's enough time given as well in most services for people to actually feel comfortable. Like six weeks of CBT, you know, or one session every four months for a with the psychiatrist or something, you don't know that person...and then it's suddenly like tell us your life story. (Kate)

In contrast, attending the arts charity did not make such demands on attendees. Participants unanimously agreed that attending for the focus on art, rather than on mental health, alleviated the pressure to talk about certain things or behave in particular ways. Several participants spoke of the value they placed on having the option to talk (about their mental health, or about anything), or the option to not speak at all. The focus is on the art, not problems:

> I'm not baring my soul, I'm not erm constantly talking about what's wrong with me, because that's something else ... If you want to talk about your problems, then of course you can. But it's not. You're not expected to. There's no expectation. (Jessie)

> I don't have to talk about my personal life, I don't have to talk about my background, I don't have to talk about that. I can just talk about art and I can talk about art for ages, you know. I can talk about other people's art. I don't feel any sort of anxiety then. (Poppy)

More than half of participants named that having a practical task to work on and focus attention on (i.e. creating something of your choosing) became a tool for socialising and conversing, when to do so in other situations would feel too uncomfortable:

> I'm very distrustful of people, but I still like to be around them in some capacity. So, I've found this is sort of the only environment where I feel safe and comfortable to be around people. And it definitely is having the purpose, doing something, so it takes it away from talking all the time. (Poppy)

Two interviewees, Kate and Nicky, spoke of the difference between attending informal arts groups for mental health, compared to formal therapy groups. They described that therapy

groups felt more school-like, in the sense of having a more didactic, structured nature, with less opportunity to get to know one another. Seating arrangements and materials such as handouts and whiteboards were felt as emphasising this. Nicky described feeling that she should sit properly and formally, unlike at the arts group, where she felt the freedom to move around and go into the garden if overwhelmed:

> It's interjected with a bit of mental health, but also you might be talking about EastEnders....what you're doing in [art space], you're chatting about your things, whereas DBT is an instruction… (Nicky)

Kate described the uncomfortable experience of sharing in a therapy group as feeling like being in the "spotlight". Helen observed that, similarly not wanting to be in the spotlight, the act of making art in a group becomes a tool to be with others, without feeling looked at:

> It allows me to be in a group which, I'm still not overly comfortable with…But when you're doing it [art] and everybody else is focused on their own task, you don't feel like you're being looked at. (Helen)

Be 'normal': masking and suppression

Participants with and without diagnosed neurodiversity frequently described their tendency to mask in most settings in everyday life. It felt more acceptable to "let the mask slip off" (Nicky) within the safety of the art group, though there was still some hesitation and shame of doing so here too. Examples of masking, illustrated by Figure 14, included pushing themselves through uncomfortable situations, feeling they had to explain themselves and their

needs to others, or suppressing needs altogether, such as avoiding stimming in appointments because of concern that this would be medicalised.

Others described an ongoing sense of policing themselves to present their "acceptable version" (Jenny). This implies a self-belief that to do the things they need to in order to feel comfortable means they are somehow unacceptable. Others described masking and putting on a brave face as a means to protect loved ones from the realities of their distress:

> ...the outer shell of me being okay, happy and smiley and bubbly ... and underneath I was just, well, awful ... I didn't know it was okay to show your, the other side...always stiff upper lip... (Jessie)
>
> Is this okay? Is this socially acceptable? To sit in a group and not be, and not be part of that group?... It is ok, but still... feel I shouldn't ... because I'm putting my needs ahead of everybody else's. (Jenny)

Figure 14

Anonymised image depicting masking

Note. © Nicky, 2024

Social norms and expectations, as well as fear of judgement of not being perceived as a so-called normal person, were some of the reasons for this masking, even within the arts charity. Seven of the eight focus group shared experiences of judgement, stigma and negative stereotypes about their mental health, including from family members and colleagues. Masking was constructed by one participant as inauthentic, particularly when forcing oneself to neglect special interests and talk about more mainstream or pop culture topics. In contrast, Carolyn described embracing her difference from an early age to challenge the judgement she had received at school.

> But I also don't want to come across weird or too much... (Kate)
>
> I've had to package and hide and push down so much to try and appear like a normal human being. (Nicky)

Self – monitoring also included checking in with self about mood, "like constantly therapizing yourself" (Jenny) to pre-empt and manage mental health symptoms and fluctuations. This indicates the salience of mental health within daily life and its prominence within identity, as well as the medicalised solutions for managing these fluctuations:

> Oh, am I going down? Am I going up? Do you need to take more of this tablet? (Jenny)

Getting therapy right

Most participants spoke about how they value support from the NHS, with examples of positive experiences, as well as instances of negative interactions. All participants had accessed NHS mental health services on multiple occasions. In the context of stretched services and long

waiting-lists, mental health services were described as a treasured commodity which you take hold of when offered:

> I mean, I was sort of out there on my own. Treading water. And hoping that I would get something that would make a difference. So, when you're offered something, you grasp it with both hands. (Helen)

For some, this meant accepting any support that is offered, even if that felt or the aims of the intervention were not fully understood. For example, Helen described her experience of being referred to psychotherapy and feeling that if she was not seen as making progress within the allocated sessions, that this could result in future support being withheld. Within this was the self-belief that not progressing was indicative of her inherent 'brokenness', which serves to reinforce a negative self-view and dominant mental illness identity:

> [Helen]: I put myself under pressure, because I feel like this support is so rare.
> And it's so hard to get hold of that you feel like you put yourself under pressure to get something from it.
> [Researcher]: If you're, if you don't get that hoped-for fix within the number of sessions, what does that tell you about yourself?
> [Helen]: Just reinforces how broken you are. Just reinforces how use useless you are. I think the fact that you only get six weeks of therapy or whatever, that it feels like, I see it as somebody that's going in with a problem they can sort out in six weeks. And then everything will be fine. So, if you're not fine after that, then you're obviously defective.

Several participants spoke about outcome measures which services use to evaluate progress. While most agreed that outcome measures can feel arbitrary or tick-boxing, there were mixed views on what it means to achieve outcomes, or not. For example, for some participants, such as Helen, there was a perceived pressure to "force some sort of breakthrough" because to not do so would be to "let the clinician down and, yeah, maybe they won't give me any more help." This was constructed as being her fault, because if mental health does not improve, it means that she has not followed expert advice well enough. Improved mental health was constructed as being fixed by 'correctly' working towards recovery. This is indicative of recovery being thought of as a return to pre-illness state:

> I've not performed. Yeah, I feel like it's my fault that I haven't been fixed, rather than, OK, maybe that therapy wasn't for me or I wasn't in the right place to do it.... I've obviously done that wrong. (Helen)

The idea of meeting the therapist's needs was shared by Kate. While for Helen this meant not letting the therapist down, for Kate, this was experienced as a protectiveness for the therapist and/or a lack of trust that they could meet her needs. Specifically, this related to her self-concept of being too much for the therapist to handle:

> And then you can always see this therapist kind of panicking, like, well, how am I going to help if she's done all this? (Kate)
>
> I don't want my therapist to feel bad for me or be impacted by what I've just said in some way. And then I'm thinking that rather than thinking about what's going to help me... (Kate)

Unlike talking therapy, she described that expressing emotion through art and other creative practice (e.g. poetry) felt like a "safety net" (Kate), for self and for therapist, or other audience, because the art creates some emotional distance, and the therapist can choose what they look at and interpret from it.

Extensive therapy over the years was internalised by some as being too slow to improve. Again, this implies an inherent wrongness in how the service user does therapy. Embedded within this was shame, because services are stretched, so to need more help felt like a failure or drain on resources. Jessie described how she feels the NHS must perceive her, and others in her situation:

> How can we have people needing our services for this long? Where is this person heading? Why do they keep on coming back? (Jessie)

Figure 15

'Slow'. Depiction of using services for many years, and still feeling there is much to unpick

Note. © Jessie, 2024

Others spoke of concerns that to have improved outcome measures, or to be viewed as resilient, in services would mean discharge before they are ready. This left many fearful of relapse and of having to once again enter of cycle of more help-seeking. Several participants described a wish for long-term engagement and contact with services, such as a "constant CPN all the way through" (Nicky), instead of what felt like a stop-start approach to seeking, and waiting for, help each time. This reinforces an engulfing mental illness identity:

> ...whatever mental health condition you have, there's many times that you're going to come back into that circle. And there are times when you don't need any support, which is fine. But there are times when you are in crisis and you need support and you need it quickly. And we can't wait. 'Cause you're going back at the beginning. yeah. And it's like, I don't, I'm not at the beginning. I don't need to go through all of that again. I need to go back to where I was. (Jenny)

Figure 16

Image depicting underfunding in the NHS and a wish for a complete circle of care

Note. © Jenny, 2024

In contrast to clinical mental health services, attendance at community arts was, at the time of the discussion groups, open-ended and flexible. This countered the sense of having an allocated quota of support that could run out. Prior to the unexpected closure, the apparently indefinite access "took that expectation away to have gained something in a short amount of time." (Kate), unlike the outcomes-driven approach of clinical support.

All participants spoke about feeling free to be more of their authentic self within community arts, which contrasted with feeling like there were certain ways to present and tasks to be performed within clinical services. All participants consistently spoke about the benefits to their mental health which were gained through attending the community arts group, even if they did not speak about their mental health there:

> ...you're not doing all like the, as in going to therapy and talking about things and doing your homework and, you know, whatever. It's not that, and yet it helps with like, like, it helps in incredible amounts. Like, noticeable differences. (Jessie)
>
> In a weird way, we are a sort of holistic, unorthodox, therapy for each other, but we're doing it without each other realizing it. (Nicky)

These benefits to mental health were experienced by all, and the long-term attendance of members and their passion for speaking about the group in this research was testament to the value they saw in it.

Teetering between hope and hopelessness

This theme outlines participants' cyclical patterns of clinical help-seeking, which contributed to feelings of hopelessness and burnout. This hopelessness was exacerbated by societal stigma, systemic issues (such as long waiting lists) and a sense of being undeserving of care. While participants named positive experiences with clinicians, these were often seen as exceptions, leading to a sense of inequality and reinforcing the power imbalance between clinicians and service users. In contrast, attending a community arts group for mental health fostered a sense of belonging, self-expression, the development of new skills and achievements. These experiences enhance self-concept and identity beyond mental illness, and alleviated the pressure of feeling a need to be 'fixed'.

Cycles of help-seeking: "burnout from your burnout"

Discussion of their cyclical experiences of help-seeking and discharge from services revealed the exhaustion felt of being in need once again. Nicky described the efforts of getting help as causing "burnout from your burnout". Having to seek out help from the beginning again, or actively chasing up psychiatry review appointments, contributed to an overwhelming hopelessness. Negative self-concept and mental health stigma, partnered with societal discourses of a struggling NHS, amplified the hopelessness, as well as feelings of being underserving of the help that does not come soon enough:

> I don't feel I deserve the help that I've had to fight for. And that isn't enough. It's too little, too late. You still feel like you don't deserve it. (Helen)

Despite the challenges of accessing help, seven participants explicitly named positive experiences within NHS services. This included positive rapport with clinicians and/or improved mental health and daily functioning (e.g. getting out of the house; improved self-concept). While this did give participants a sense of hope, several named the precarious feeling that these gains will be lost, either if the support ends before they feel ready, or if life events trigger a return to poorer mental health:

> …been very grateful to have some really incredible therapy in the NHS, really incredible therapy. And they did begin to shift the way I thought about myself. But then I have other things in my life come in and kind of reaffirm to me what I've always thought about myself. So, sort of, you know, I feel like, Oh, I've got somewhere. And then sort of something else has come in and kind of like, almost like, just bowled me over and kind of set me right back, oh, well that, you know, that opinion of yourself is correct… (Jessie)

Three participants constructed these positive experiences as being the exception to the norm, or lucky in some way:

> I had at least 10 [sessions], and she kept on saying, I'm really not supposed to be doing this. (Jessie)

> I think sometimes there are some heroes out there who do care more than that. I've I have seen that where they go… beyond the calls of duty. (Nicky)

> … I am actually really lucky to have a really good GP who I can go to and who does listen … but that's very unusual. (Jenny)

Participants found it hard to hold on to hope for future clinical support because they saw good experiences with professionals as the exception to the norm. This apparently unequal and luck-of-the-draw construction of how services are received amplifies power differentials between clinicians and service users. This, with perceptions of feeling judged by staff, can reinforce self-concept as a drain on resource, particularly if feeling that there are other services users who are more deserving of help. This can then bring participants back to a place of hopelessness. Kate described the guilt of feeling like she is taking resource away from others. Having used services for many years, she has a hopelessness that she cannot be helped, or feels that this is what staff must be thinking:

> I've been in situations like I've been in mental health hospitals before, and I've literally been in absolute critical crisis. And I've been begging the staff to let me go home because someone will need the bed more than me. And it's like that's a symptom of, like, how much, at least for me, I feel treated like I'm just another person that's wasting resource...I've been in the system for years, why bother? Give it to somebody who you help. (Kate)

The hope of something different: a break from mental illness identity

The decision to attend a community art group offered a new and different approach to managing mental health for most participants. Some had attended other types of art activities previously (either specifically for mental health, or mainstream community art classes), or had previously enjoyed creativity at home. For most participants, though, either stumbling across the group or being recommended it by someone else who had previously benefitted, opened up a

chance to take things into their own hands, do something different to the other mental health interventions they had tried, and see what would come of it:

> I think it was because it was something I hadn't really tried. I'd been in services for quite a long time with my mental health and to hear there was, you know, something specific for mental health that wasn't a long wait ... It seemed quite a unique option, I suppose as well because it wasn't really therapy-based or some talking group or something, it seemed like it was just like-minded kind of people in similar situations but doing something different. (Kate)
>
> I thought ... I can't do art. But I thought, ok, look, I've tried just about everything else. Let's give this a go. And then from the second I walked into ... Just felt like you're all in it together. (Helen)

Feeling welcome and sharing in the experience of mental illness provided optimism, in addition to the sense of belonging. Additionally, the act of creating, whether via the instructor-led courses or the open studio, provided hope through a number of mechanisms.

Firstly, the act of making art offers cognitive benefits. Artmaking encourages mindfulness and distraction from intrusive negative thoughts. Trying new things just for the pleasure of it, without a focus on a particular outcome, encourages play and escape into "a never-ending universe" (Nicky) of imagination. This can challenge the otherwise engulfing mental illness identity, because artmaking provides "...opportunities to be someone other than the person that's mentally ill all the time." (Kate). Crucially, within an informal mental health intervention, participants were reminded that there is more to them than their mental health. This contrasts with formal mental health interventions.

Secondly, creativity provided an alternative, and emotionally safer, means to communicating one's inner world. For those who felt less able to express their experiences and emotions verbally, as is usually required in clinical settings, artmaking helped to create a tangible representation. This could be used as a conduit for talking about mental health. Overall, participants agreed that artmaking and photography provided a means to be known – whether that was showing a part of one's personality and humour, as well as emotional difficulties:

> I'm very self-expressive in my art. So sometimes that's the only way I can say what I want to say, but be what I want to be and express, you know, how I feel. (Kate)
>
> If I took some photos of my artwork, I think you would definitely get me then. (Carolyn)

Thirdly, attending the art group nurtured the development of new skills and achievements, which many participants had not imagined possible. This included both creative and social achievements. For example, most participants shared that they had learnt new art techniques, which they had mastered, and gone on to be part of exhibitions. This felt validating and rewarding. Socially, many participants explained that making art facilitated socialising, as it removes the pressure of eye contact and provides obvious topics for conversation which do not have to be focused on personal life. Three participants spoke of their personal achievement in joining day trips to art galleries and an art residential, which they would not have been able to achieve without the support and structure of the group making them feel safe to do so. Focusing on what you can do, rather than concentrating on one's difficulties, was liberating and offered hope of life beyond mental illness:

> ...there's more focus on the positive. Like what you can do. Like, look at what you create and what you're doing. Look what you're capable of. (Jessie)

The positive, strengths-based focus of the arts charity laid the foundation for discovering new parts to one's identity, or reconnection with previously valued parts. Participants named being nurtured as an artist, even if they did not all see themselves as such. Group membership allowed participants to shape their role within the group (e.g. "I've become Mother Hen" - Amanda). That is not to say that mental illness identity is removed altogether. Connecting with others with mental illness, and therefore self-concept as someone with mental illness, was a crucial aspect in building relational safety within the group. This safety made it possible for other parts of self to be shared:

> When you come to [art centre] your problems don't go away, but it's more like a hat that you put on. Yeah, like, I'm happy to put that hat on. Yeah, I like that hat a lot. (Poppy)

Figure 17

Image of different hats, representing different parts of self which can be prioritised in community arts

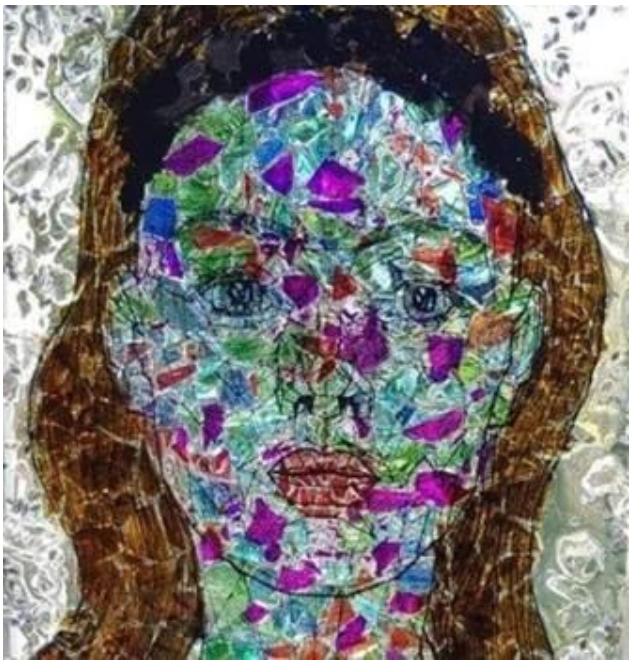
Note. © Poppy, 2024

Several participants commented that arts are not a substitute for clinical care for managing mental illness, though it provides a valuable holistic approach that can counter all-consuming illness and problem-saturated narratives. Hope then builds through the development of a more positive view of self, where strengths are acknowledged and can flourish while coexisting alongside mental illness:

> Like it's broken glass and don't quite fit and stuff. But … [art charity] has allowed me to be beautiful. And shine out 'cos when I have that up against my window, all the colours shine out. And I feel like a beautiful kaleidoscope, like a sort of beautiful [inaudible] and beautiful, accepted person. (Nicky)

Figure 18

Photo of glass mosaic, representing a 'beautiful accepted person' made from broken glass



Note. © Nicky, 2024

The arts charity was described as acknowledging and permitting bad days to happen. Unlike in other settings where participants felt they had to either put on a brave face (e.g. at work, with family), or achieve improved mental health outcomes within a limited timeframe (e.g. therapy), the open-ended and consistent nature of the arts charity gave participants permission to show their authentic emotions, good or bad. This in itself supported hopefulness and reduced the pressure participants placed on themselves, because it felt reassuring to not be aiming for a specific end-point on a linear trajectory:

> But I feel like, somewhere like [art space], you feel like it's ok to just be who you are on that day. Whereas I suppose in clinical settings, you're still feeling like you're on this straight line between being broken and being fixed. And it's very linear. Whereas [art space] is more open, it's more fluid. It's more, ups and down and roundabouts and swings and that's OK. It's about the journey. I think, I think that's probably what it is. It's about the journey, because in clinical settings, it's very linear and it's very black and white. And you're either fixed or you're not. With [art space], it was 'Hey, you're ok. Just be yourself'. (Helen)

Collectively agreed themes by participants at the discussion groups

Unique to the PV participatory analysis methodology, each discussion group collectively agreed upon the themes which they felt represented their shared experience within their group. They grouped photographs on screen and then named each category. There was great similarity in the categories created across all three discussion groups. These can be found in Appendix O.

The group categories were referred back to after an initial round of coding data, as a form of member check. These categories were not used at the start of coding, in order to allow

for both inductive and then deductive codes and themes to be generated, rather than purely deductive on the basis of the literature review and discussion group categories. There was a large degree of similarity between the themes devised by participants, and the initial themes being generated during the thematic analysis.

Participant experiences of the Photovoice task

Two of the interviewees described some reservation about choosing and presenting their images. Both described feeling that there was a right and a wrong answer of what I would be looking for and the types of image/content they should share. One described concern that getting it wrong would then ruin my research but felt motivated to take part in order to give something back and be useful, naming their gratitude to people who had participated in a family member's research. A third interviewee also described some initial worry that she would not be able to complete the task. However, participating was then felt as an achievement.

All four interviewees described gaining something positive from participation. This included: enjoying the process, learning about other people's experiences and reflecting on the similarities to their own, and learning a new skill when participating in the photographer-led practical workshop. Hearing other people's stories within the discussion group was described as being validating and helped participants to feel closer to other group members.

Within one of the discussion groups, Carolyn likened the experience to a therapist inviting her to bring in her artwork to support her talking about her traumatic experience. She valued this approach, both clinically and as a research method. She explained that the use of the photographs in the research "leads you into that way of talking about yourself in ways that I didn't even think I would".

In addition to hearing each other's stories, the collective categorising activity was valued, although useful learning is that more time should be allocated to this task. The choice of a creative methodology was also valued, because it felt personalised to the group's interests and also because it opened up a different way of reflecting on their mental health experiences:

> And also the fact that we had at the beginning you know the photographer come along meant that we learned something ... new and different that we wouldn't have had the opportunity to learn otherwise. So it kind of puts a different perspective on things. It isn't just about 'Are we going to sit here and talk about our mental health', which we've done hundreds of times before ... And just being different to start with and also giving you a focus in a different way, a visual way... (Jenny)

Several participants named that having small discussion groups afforded each person the chance to be heard individually was important, and this facilitated a feeling of safety in the room.

Chapter conclusion

This chapter described demographic data about mental health diagnoses of participants, along with detailed description of the themes which emerged from the data. The chapter concluded with a summary of the feedback from participants on their experience of the Photovoice methodology.

Chapter 5: Discussion

Chapter summary

This chapter gives an overview of the main themes identified from the findings in relation to the research question. Connections to existing literature and theory are made. The strengths and limitations of the current research are discussed, and consideration is given to the clinical, research and wider implications of the findings.

Discussion of findings

The findings from this study added valuable knowledge to our understanding of the dynamic nature of Mental Illness Identity (MII). MII is a relatively new term in the research literature, emerging from existing research on the Illness Identity Model (Oris et al., 2016; Yanos, Roe & Lysaker, 2010). Recent research has highlighted a need for greater understanding into the dynamic nature of MII over time, place and interpersonal contexts, beyond simply using a self-stigma lens (Eddington & Badillo-Winard, 2024). The findings from this study highlight the importance of intervention and environmental factors, as well as relational factors in influencing how MII is expressed. The findings also point to the prevailing nature of internalised self-stigma (e.g. negative self-view) across these settings.

Prevailing negative self-concept as a result of mental illness identity: the role of self-stigma

Mental illness was a dominant part of participants' identity and diagnostic labels were generally acknowledged as useful and/or validating. Mental illness took up a lot of participants' time, whether that was through managing symptoms, 'fighting' for help, or attending various mental health interventions. Participants spoke of personal and social identities (e.g. careers,

relationships) which had been lost to mental illness. This mirrors findings in the systematic literature review (Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Chase et al., 2010; Meddings & Perkins, 2002; Gault, 2009; Lawrence, et al., 2021; Wagstaff et al., 2018; Watts & Priebe, 2002). Consequently, participants in this study held prevailing negative self-beliefs because of their mental illness. These beliefs followed them in most parts of their lives, including in both types of treatment setting, in a way that meant that mental illness felt like "part of you".

The finding that most participants constructed their mental health through a medical lens was interesting and may explain their trust in different types of interventions to help them to cope. This research takes a social constructionist lens and therefore considers how participant demographics, that is, an all-female, all-White, westernised, educated group, with average age range of 35-44 years, might shape their constructions of MII, shame and help-seeking. Women have been found to be more likely to seek professional help (Liddon, Kingerlee & Barry, 2018; Oliver et al., 2005), and women are more likely to be branded by society as 'emotional' during ordinary interactions (Frasca, Leskinen, & Warner, 2022), which may reinforce negative self-perceptions as being 'too much' and a 'burden', as was frequently expressed in this sample. Social and political discourses on recovery are often framed within goals of work and productivity (e.g. Department of Health, 2009), which is likely to have shaped thinking in this sample, as indicated by their themes of feeling like a burden and wanting to contribute. Taking a feminist psychology approach, we can also consider societal discourses around women's roles as caregivers and how this might have further shaped this sample's sense of purpose coming from undertaking helping roles, such as volunteers at the art group, peer supporters, and in their professional roles as teachers, tutors and in service user involvement. These other roles and identities focussed on helping others and also related back to mental illness in some way, which

again emphasises the dominance of mental illness within identity, as well as the possible tendency to prioritise others over oneself. This may be indicative of deeply held self-stigma and low self-worth in this sample.

Overall, participants described feelings of resignation as they accepted their illness and internalised stigmatising descriptors and stereotypes, such as being broken or a burden to others. This finding supports extant literature on applying societal stigma inwards (Catalano et al., 2021; Corrigan, Watson and Barr, 2006). Existing literature is mixed with regard to the impact of mental health stigma and subsequent MII on help-seeking. Some researchers suggest that self-stigma leads to a withdrawal away from help (Bathje & Pryor, 2011; Corrigan, 2004; Corrigan et al., 2009; 2014; Lannin et al, 2016) and others suggesting that identification with illness identity and an acceptance of diagnostic labelling leads to actively seeking help (Klik, Williams & Reynolds, 2019).

This study found that participants largely accepted and identified with the diagnostic labels they have been given. These labels were described as validating and supported them knowing where to seek out help from multiple forms of mental health support on repeated occasions throughout their lives. However, this repeated cycle of help-seeking was met with strong feelings of shame, and perpetuating self-stigmatising language, such as being a burden, useless or broken. The shame of utilising the NHS repeatedly, and perhaps the hopelessness of needing support multiple times, encouraged participants to try something different (i.e. arts) as a means to managing.

The deeply-held beliefs of being different were accompanied by strategies such as masking and policing oneself to be perceived as more ‘acceptable’. This too can be thought about as a form of self-stigma, as described by extant research (Oris et al., 2016; Yanos, Roe &

Lysaker, 2010; Yanos et al., 2020; 2021). Participants described feeling safer among others with shared experience of mental illness and associated stigma. Their description of needing a specialist mental health art group can be understood as further internalised stigma, viewing themselves as too different and broken to access another type of group setting.

Although this dominant MII and accompanying self-stigma was present in most areas of life, there were some differences in how this was expressed and negotiated depending on environmental, intervention and relational factors. This is described in further detail in the sections that follow.

Dynamic factors influencing the expression of MII

Intervention type and its environmental context. The intervention type (i.e. traditional clinical services, in the NHS/private therapy/ GP vs. non-clinical, community arts group) and its environmental setting (i.e. sitting still in an appointment vs. permission to move around the arts space) either emphasised or minimised a sense of 'patienthood'. Specifically, attending clinical interventions emphasised a felt need in participants to perform a patient role. For example, clinical-related tasks to be completed by patients, such as attending appointments, sitting in brightly lit, uncomfortable waiting rooms, filling in outcome measures and talking about problems and risk, created a felt pressure to be 'fixed' and get better, or otherwise participants felt as if they had failed at therapy and wasted resources. This reinforced MII, where repeated telling of one's story to new clinicians with each new referral, strengthened the self-view of brokenness, with shame and fear of needing to start help-seeking again. This problem-focus means that clinicians do not get to know the person as a whole, again, reinforcing a narrow identity dominated by mental illness.

Conversely, the environment of the community arts group permitted participants to connect with other parts of themselves beyond mental illness. For example, participants described improved self-concept when they became art volunteers, peer supporters and members of a close-knit group. This finding supports existing literature which points to the important role of positive redefinition of identity beyond mental illness as part of mental health recovery (Peters et al., 2024), along with having purposeful activity and role (Goodman-Cassanova et al., 2024; Leamy et al., 2011).

It is noteworthy that MII was still present in the arts setting too. Participants felt that they relied on a mental-health specific art intervention, because this felt more accepting and safer than a non-mental health group, which they othered themselves from. However, MII was expressed to a lesser extent in the arts setting. Here, mental health was just one part of identity and was less dominating than in clinical interventions. There are several reasons why this may be. Firstly, the physical environment of the arts group and the ease of accessing the group meant that there was more freedom and choice about when to attend, what to say and do while there, to sit silently with headphones on and the option to move freely about the space as needed. Unlike clinical interventions, in the arts group there was no requirement to speak about mental illness, and instead attention is focused on creative practice and informal chat. This contributed to environmental safety. Safety within intervention contexts has been identified as an important factor influencing mental health recovery outcomes (Goodman-Cassanova et al., 2024).

Secondly, the act of artmaking provided multiple benefits for participants. Some of these benefits were explicitly related to creativity itself. Artmaking provided mindful distraction from the worries of mental illness, which reflects findings by other researchers (e.g. Bone, 2018; Molewyk-Doornbos et al., 2022). Results in this study also showed that artmaking offers a break

from MII by supporting new ways of coping, which aligns with findings by Peters et al. (2024). Participants described how creativity offered exploration and connection with one's inner world. Some researchers have suggested that this could be utilised to tangibly express emotion (van Lith, Schofield & Fenner, 2013; Van Lith, 2015). This concrete expression felt safer and more psychologically containing than verbal expression. Participants felt that this safety was important both for themselves (i.e. control what they share, and see it contained visually) and also for the audience of their art, because individuals felt that their verbal expression of their distress could be too overwhelming for the recipient. This sense of their emotional needs being too much for others again speaks to negative and dominating MII, but artmaking at least offered a new means of expressing this.

Third, the arts intervention nurtured participants' creativity so that they learned new skills and techniques. Over time, participants exhibited their artwork, which fostered a sense of achievement that they previously had not thought possible. This was described by participants as increasing confidence and providing validation of one's value as a person beyond mental illness. However, in contrast to other art group research (Bone et al., 2018; Hui et al, 2019; Lawson et al., 2014; Ørjasæter et al, 2017; Sagan, 2015; Salomon-Gimmon et al., 2022; Sapouna & Palmer, 2014; Spandler et al., 2007; Stickley & Eades, 2013), participants in this study did not internalise an identity as an artist as a result of their art-making and exhibiting. This is perhaps reflective of the deeply entrenched nature of their negative self-concept and MII, meaning that other potential identities (such as artist) are dismissed.

Although MII was somewhat diluted in the non-clinical arts intervention, compared with clinical settings, it is important to note that it was still present within the art group too. For example, participants spoke in ways which indicated that they see themselves as distant from

mainstream community services (i.e. non-mental health art groups or classes). Instead, they spoke of needing a mental health-specific group. This indicates a deeply entrenched MII and this may explain why they were more easily able to adopt mental health-related roles and identities, such as peer supporter and mental health group volunteer within the art group, rather than more mainstream and/or socially desirable identities, such as artist (Gwinner, Knox and Hacking, 2009).

Although participants broadly did not identify as artists, they did speak of increased confidence and self-worth, and seeing themselves as more than a person with mental illness. This corresponds with existing research (e.g. Lawson et al., 2014). As such, we can understand that group artmaking helps to dilute (not remove) an otherwise all-consuming MII. This aligns with Oris et al.'s (2016; 2018) concept of *acceptance* of illness, rather than being totally *engulfed* by it.

Finally, artmaking offered practical benefits to participants. The act of making (rather than creativity per se) supported participants to be in the company of others without the need for much eye contact. Looking down while artmaking not only facilitated conversation without the need for eye contact, but also the art and materials provided topics of conversation other than about oneself, thereby allowing the participant and their mental health to be out of the spotlight. Being under the spotlight was commonly felt within clinical intervention settings, which highlighted in participants that they must talk about certain things, within a limited amount of time in order to make the most of the support. In contrast, the arts setting allowed for open-ended access over many years. This removed a sense of pressure to achieve something positive within a certain amount of time. Consequently, participants felt more at ease to reveal other parts of themselves, such as their interests, aspects of their personality, etc, over time, as they grew

relational trust and safety, where they could develop new relationships and valued roles. The open-ended nature of the community art group also provided consistency and stability, which, for some, may have been their only experience of reliable structure in their life, and this contrasts with the time-limited and often high staff turnover in clinical services.

Interpersonal and relational factors. The arts space was constructed by participants as offering a greater sense of mutual experience with less hierarchy than clinical interventions. The experience of working with 'experts' to improve mental health is highly valued, yet this also emphasises symptoms and outcomes which can reinforce MII. This finding corresponds with other research on experiences of being a mental health service user (e.g. Bacha, Hanley & Winter, 2020; Chambers et al., 2014; Chase et al., 2010; Davies & Allen, 2007; Gault, 2009; Harris et al., 2012; Lawrence et al., 2021; Notley et al., 2012; Tuffour, Simpson & Reynolds, 2019; Wagstaff et al., 2018; Watts & Priebe, 2002), where professionals can be experienced as more powerful, especially within the dominant medical model of healthcare (Sapouna & Pamer, 2014). The more mutual arts group gave a sense of permission to have a bad day and less focus on outcomes. Conversely, in clinical spaces, the patient role must be performed, and one's difficulties need to be emphasised, because professionals hold the power to discharge if they see signs of resilience or recovery. Equally, participants feared being discharged from clinical services if they were not seen to be 'getting therapy right'. This resulted in participants feeling they must navigate a complicated task of showing clinicians that they are making steps towards recovery, but not so much so that they will have care removed before they feel ready.

In the non-clinical art space, shared lived experience meant that participants could be experts in this space. Here, they could share peer support and advice (on mental health and on art), in a way that did not feel possible with healthcare professionals to the same extent. Taking

up this more ‘mutual expert’ position supported a more positive self-image, albeit one that is still highly connected to mental illness. In this non-clinical setting, masking of neurodiversity needs was still present, but felt less shameful because of an unspoken shared experience and understanding from peers. In this setting, participants reported having permission to have a bad day, without this being pathologised or overshadowing other parts of their identity. This is because in the arts setting, other parts of identity were seen and nurtured. Here, participants could grow their peer supporter, volunteer, friendship parts of identity. This helps dilute MII and facilitates feelings of hopefulness.

As mentioned above, the time-limited or open-ended nature of an intervention is important. Time interacts with interpersonal factors, in the sense that interpersonal trust and safety take time to build. This study has highlighted the potential to feel misunderstood and minimised to symptoms if there is not enough time to feel safe enough to show one’s authentic whole self. The art-space offered long-term, consistent engagement, with many participants attending over years. This supported time to show an authentic self and grow connection with others. Connection and belonging were named as the most beneficial aspects of the arts group intervention. This finding corresponds with existing research onto the social benefits of community activities for mental health (Bone, 2018; Crone et al., 2018; Dingle et al., 2013; Goodman-Cassanova et al., 2024; Haslam et al., 2018; Hui et al., 2019; Molewyk-Doornbos et al., 2022; Saavedra et al., 2018a; Williams et al., 2020). It seems then that artmaking serves as a vehicle for forming new connections and friendships, akin to the *social cure,* where they gain new or maintain previously held social connections (Haslam et al., 2018; Jetten et al., 2009; 2017). The fact that participants had been attending the art group over many years, during which these trusting relationships could grow, made the unexpected closure of the group all the more

devastating for members. This sudden and unplanned ending served as a significant loss, which was re-traumatising for some participants (as verbally described to me). This has implications for services in terms of how endings of any kind are planned and managed, in ways which are as trauma-informed as possible.

In terms of MII, this study has shown that individuals with serious mental illness benefitted from connecting with other people with shared lived experience of mental illness, where they shared an identity as people othered and marginalised by society, and therefore felt understood. This mirrored findings from the systematic literature review (Chambers et al., 2014; Harris et al., 2012; Notley et al., 2012; Wagstaff et al., 2018). Although some researchers suggest that positive peer group identification can reduce self-stigma by challenging negative stereotypes (Dubreucq, Plasse & Franck, 2021), and identification with a stigmatised group can lead to 'righteous anger' about the stigma experienced (Corrigan & Watson, 2002), others have pointed out that social identification with the mental illness can worsen outcomes (Cruwys et al., 2016). It was beyond the scope of this study to explore whether this group identification improved or worsened mental health outcomes, however, it seemed that there was more of a sense of joint resignation and acceptance of stigma, rather than 'righteous anger' to try to challenge this. In contrast to the findings in the systematic review, participants in this study did not indicate any form of 'mental illness hierarchy' depending on the type of diagnosis within the art group. Instead, a strong sense of connection, safety and belonging, against the rest of the world, was expressed.

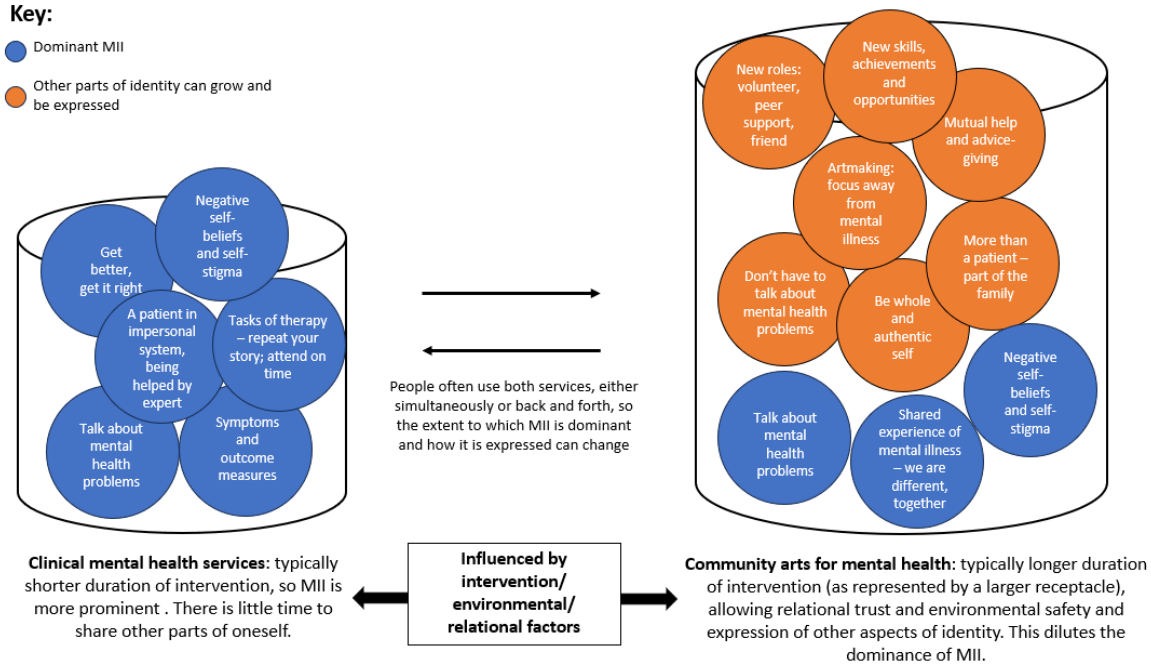
Understanding the dynamic nature of MII

Some researchers have suggested that identity-related changes are part of a mental health recovery process (e.g. Leamy et al., 2011; Peters et al., 2024). This suggests a unidirectional, linear pathway from illness towards wellness. The findings from this study point to a more dynamic nature to identity in mental illness, where the MII can be more or less prominent depending upon contextual factors (e.g. environment and intervention type; relational factors). It is suggested that, when accessing several types of intervention, the dominance of MII can vary back and forth. That is to say that the gains made in an arts setting do not necessary extend when returning to a clinical setting. Despite attending the community arts group for many years, simultaneously alongside various clinical interventions, MII and negative self-belief were still present in all participants. The intervention factors, power dynamics within the clinical setting, and continued societal stigma can contribute to a more dominant MII again in clinical settings. Further research into this is necessary to confirm this suggestion.

Figure 19 represents the interacting, dynamic factors which can influence how dominant MII is expressed in an individual, depending on the type of intervention they access and the relational and environmental factors which surround this.

Figure 19

Representation of the varying dominance of Mental Illness Identity (MII) in different intervention settings, which is influenced by dynamic factors such as: intervention type and duration, intervention environment, relational and interpersonal factors.



The findings in this study align with internationally recognised trauma-informed practice principles, of safety, peer support, trust, collaboration and mutuality, empowerment and choice (Substance Abuse and Mental Health Services Administration, SAMHSA, 2014). These were all occurring within the community art group quite naturally. Longer-term participation in a consistent space allowed for relational safety to form, which in turn generates the trust that participants needed to be able to open up and show their 'whole self', including the parts where they were having a bad day.

Implications of the study

Clinical implications

One of the most important implications from this research is that the negative connotations and stigma of having chronic mental illness are deeply felt and internalised, and that this perception can be exacerbated or reduced depending on the interpersonal and environmental factors that are experienced in clinical vs. non-clinical settings. It is important for healthcare professionals to be aware of the interpersonal dynamics that can play out within intervention settings between themselves and service users. The expert position which professionals occupy can magnify MII, resulting in feelings of shame (especially in repeat help-seeking), and some service users acquiescing with decisions out of fear of letting their clinician down, or fear of being turned away from future help. The impact of such power dynamics should be included in staff training, including the compounding effect of intersectionality. Professionals should be supported to reflect on this within supervision and team consultation spaces.

This study has highlighted the pressures often felt within stretched clinical services to offer time-limited interventions in order to meet high demand. Healthcare services and individual clinicians were highly valued and spoken about positively, but it was the systemic and structural limitations of the healthcare system which reinforced negative MII and power imbalances. For example, time-limited interventions often mean brief assessments that are predominantly focused on problems, without much time on strengths or other aspects about the individual. Participants also described feeling the need to make progress within a short time-limited number of sessions. They described having to share vulnerable experiences with professionals with very little time to build therapeutic safety first, which reinforced shame, especially if they were had to repeat their experiences to a new person when re-entering services again. Therefore, it is important for

services to build in enough time within their interventions for adequate assessment which includes time for building trust, and time to get to know the service user beyond their mental health struggles. Building trust, safety and collaboration, along with empowerment, choice and cultural sensitivity, are core values in trauma-informed practice. Trauma-informed care is increasingly spoken about within services as a framework for good practice (e.g. SAMSHA, 2014; Office for Health Improvement and Disparities, 2022), and the findings in this study highlight the importance of such an approach.

Increasingly, shame is being recognised as key to trauma-informed care (e.g. Dolezal & Gibson, 2022) and the findings for this study certainly highlighted high levels of shame in this population. Therefore, staff training and service delivery should be centred around shame-informed practice. Although therapists will typically consider an individual's prior service use and their relationship to help (Reder & Fredman, 1996), more time should be made to discuss with individuals how they feel about returning to services if they are repeat service users, particularly in relation to how this impacts their sense of self-image, self-worth and hope for the future.

Healthcare professionals should consider additional, creative ways to get to know their service users beyond the use of clinical interview and routine outcome measures. This study has shown that a lot can be learned about an individual and their life via a few photo-prompt questions and subsequent (and relatively brief) dedicated conversation about these. For example, one of the participants in this study shared a lot about her personal network, her hobbies, and some family stories with ease during one of the discussion groups from just a few photographs. All of these additional parts of her life would be helpful for any clinician to be aware of, and can help with tasks such as formulation, resourcing and goal-setting. Therefore, using photography,

or asking clients to bring in images or objects which represent them and important aspects of their lives, could be a helpful way to build a fuller picture of the person and their context, past and present, and also their hoped-for self. This is a simple, quick and accessible way to explore hidden stories, strengths and resources which might not otherwise be brought into the therapy room. Indeed, systematic review points to the benefits of integrating the arts into mental health settings (either community arts groups, or clinician-led activities), particularly for self-expression and self-discovery (van Lith, Schofield & Fenner, 2012). Camic (2007; 2008) has promoted the use of creative approaches within clinical and health psychology and suggested it is incorporated into professional training. He argues that the use of creative approaches in the therapy room can support assessment and treatment, in both individual and group sessions, as well as more general health promotion approaches. This is not to say that health or clinical psychologists would be offering what art psychotherapists offer, but a recognition of how creative thinking and creative materials can enhance our practice and offer more choice to service users in how to communicate with us. Many psychologists already use simple creative approaches, such as the Tree of Life (Darewych & Riedel-Bowers, 2017; Ncube, 2006), particularly when working with children and young people (e.g. Treisman, 2017). The idea that artmaking offers mindful distraction and a "break" from MII can be more consistently applied in clinical settings to help clients connect with other aspects of self-concept and counterbalance the overwhelming presence of mental illness identity.

This study has also highlighted the importance of services preparing service users for endings, whether that is the ending of a specific therapeutic ending, or the closure of community services. It is important for healthcare staff at all levels and disciplines to be trained in the impact of endings and preparing for discharge in a collaborative manner.

Prior research has suggested that self-stigma in mental illness can be targeted through specific cognitive-behaviour therapy (CBT) interventions (e.g. Carrara & Ventura, 2018; Corrigan, 1998; Dubreucq, Plasse & Franck, 2021; Vogel et al., 2013; Yanos, Roe & Lysaker, 2011). CBT interventions address *negative automatic thoughts* and negative *core beliefs* about self, others and the world. This can be argued to locate the problem of 'faulty thinking' in the individual, rather than acknowledging wider societal experiences and discourses (such as societal stigma) which affect mental health. The findings from the current study illustrate that the shame-loading in individuals with chronic mental illness is already dominating, and so to offer additional interventions at the level of 'faulty thinking' could be interpreted as not being resilient enough to resist the pressures of societal stigma. This would likely only serve to increase that shame. The results in this study would not indicate the benefit of such an intervention in those experiencing negative self-concept in relation to their mental health and service use. Much of the shame expressed in this sample related to feeling responsibility for using up stretched resources, and this shame can be understood as a symptom of an underfunded and under resourced healthcare system.

Wider implications

This study supports the use of community-based arts programmes for mental health and highlights their potential for offering empowerment and relational safety, which are such important factors in recovery and are therapeutic in their own right, even if not within a clinical therapy setting. Participants described the ease of access (e.g. self-referral, referral by healthcare professional) to this particular group. It is important for multi-disciplinary staff in health and social care services to be aware of the potential benefit of such interventions, and for referral

pathways to be simple and accessible. Conversation about local community groups should be a part of care planning conversations within health and social care, with recognition of their potential for offering a safe and psychologically containing space to complement any clinical support, whether that is while on a waiting list for clinical intervention, or alongside intervention.

As shown in this study, community arts groups can be effective at containing and supporting individuals with complex and long-term mental health difficulties. It is important for staff and volunteers in such programmes to be offered support such as reflective practice and supervision from clinical services, to support staff wellbeing, mitigate the risk for vicarious trauma and to support risk management and information-sharing. The stability and consistency of long-term access offers more than a 'nice to have' activity; they lay the foundation for deeper therapeutic work (e.g. building a support network, reclaiming life beyond mental health problems, relational safety, cognitive flexibility in seeing self as more than illness). Commissioners should therefore consider the value of such spaces and how they can work effectively alongside clinical mental health services.

It is important for the long-term sustainability of community arts groups to be considered. Service-user involvement within such services not only supports individual skill-building and empowerment, but also builds staffing capacity and offers the insight of lived experience to shape service delivery through co-production. For co-production and service user involvement to be fair and meaningful it should afford reciprocal and collaborative decision-making and ownership of decisions, rather than just consultation (Conquer et al., 2021).

This study has added support to existing Photovoice literature on the potential utility for this approach in sharing the service user voice, for example with service managers and commissioners, as a novel and creative way to service user involvement and empowerment. It is

worth holding in mind, however, whether some individuals would need extra support in any public sharing of images, in case such disclosures could inadvertently lead to re-traumatisation for some people, particularly where there is a history of stigma.

Critique of methodology/strengths and limitations

This research has added to a growing literature base on the dynamics of MII. The use of the Photovoice methodology, with its visual component, group discussion and follow-up interview, offered a rich and in-depth approach to understanding the lived experiences of people with serious and chronic mental health problems, in a way which may not have been achieved through traditional interviews alone. Additionally, the use of the group categorisation task acted as an initial form of thematic analysis by participants themselves, which supplemented additional member checking. Taken together, these steps give credibility to the presented findings.

Participants gained skills via a photographer-led workshop, as part of their participation. This workshop, along with several visits to the research site during the planning stages of this research, helped to build trust and rapport with participants. Offering a creative method to data collection was named by participants as a considerate approach given their involvement in the arts. It can be argued that this fostered a more empowering sense of creative identity beyond a mental illness identity, compared with more traditional research methods which may emphasise MII and a problems-focussed narrative and which may highlight power inequalities between researcher and participant. This is particularly important given my role as a clinician-researcher, in light of literature review findings of power differentials between professionals and service users.

Participants fed back that the act of taking photographs to reflect on prompts in advance of the discussion group gave them a chance to reflect on their experiences in a way that they had not previously, which they found beneficial personally, and this also helped them feel prepared ahead of the group discussion.

This study also had some limitations. It was intended to recruit 12-15 individuals however this was not possible. The intended sample size has been suggested to be a good number for a medium-size thematic analysis (Braun & Clarke, 2013), but this study recruited 9 individuals in total, and not all of these participated in each phase of the study.

It is acknowledged that the use of Photovoice may not have appealed to everyone, particularly the group component of this study, if they felt unable to take part within a group setting. Additionally, this method may have excluded anyone who was unable or unwilling to operate a camera, and these aspects may have impacted recruitment. This small sample size may limit the transferability of the findings. That said, existing Photovoice methodology varies in terms of sample size, with some studies recruiting as few as four (Velez-Grau, 2019) or five participants (Tang, Tse & Davidson, 2016). A systematic review of Photovoice research shows samples varied from five to as many as 42 participants (Han & Oliffe, 2016).

Also limiting transferability of findings was that the final sample were all female. During initial recruitment visits to the site, several male attendees expressed an interest in participating but were unfortunately older than the original inclusion criteria (as were several female group members). The delay in seeking an ethical amendment to recruit individuals above age 65 likely disrupted engagement with these individuals. Although women made up more of the art group membership, it would have been helpful to also recruit some male participants to this study. The recruitment materials specifically mentioned having experience of clinical services as well as the

arts group. Given that statistics show that men are generally less likely to seek support for their mental health (Oliver et al., 2005), it is possible that male group members may not have met this inclusion criteria and therefore did not come forward. Transferability of the findings is also limited by the sample all being of White ethnicity. Although the sample was representative of the local ethnicity demographics in the region where the research was conducted (Office for National Statistics, 2023), this limits transferability of findings to other ethnic groups more generally. Future research could explore the experiences of people from various ethnic backgrounds, paying closer attention to issues of intersections between race, mental illness and relational power/hierarchy in clinical and non-clinical (arts) intervention settings.

This study only recruited from one art group, and so findings may not be representative of other community arts groups. This study and the transferability of its findings could have been strengthened by including multiple art groups for mental health, and/or art groups which are not explicitly for mental health. Additionally, there was variation in the clinical services participants were currently, or had previously, accessed. Some had been admitted to in-patient care, while others had only experienced community services. The study could have been strengthened by directly comparing service users' experiences of the same services. The study could have also been strengthened by limiting participation to those currently using clinical services. The inclusion criteria here allowed for past or present clinical service use in order to maximise recruitment, however, it is acknowledged that to ask participants about past experiences of a service relies of them recalling their experiences, which may be open to bias and changing perceptions over time.

It is acknowledged also that participants had a broad range of mental health diagnostic labels. Some diagnoses, such as schizophrenia and personality disorder, typically carry more

stigma than others (Choe, Baldwin & Song, 2020; Hazell et al., 2022) and therefore perceptions of self and MII may differ between participants with different diagnostic experiences in this study.

Finally, it should be noted that all the participants were broadly familiar with one another prior to the study, some more so than others. This may have had a positive impact on the study, helping rapport and a sense of ease during the group tasks, but may also have had a restricting impact if some individuals did not feel able to disagree with other participants. Several participants were volunteers at the centre, and it is possible that their experiences may have been positively biased about the art intervention. In the context of the group discussions, this may have silenced different or more negative experiences being shared by others. The inclusion of individual interviews mitigated against this, as did the provision of pen and paper (post-it notes) for group participants to add additional comments confidentially. It was observed that three of the four participants who came forward for individual interviews all came from Discussion Group 2, though it is unclear why this is.

Practical limitations and lessons learned

There were a number of practical challenges and lessons learned about the Photovoice method. Running the discussion groups felt slightly rushed, particularly at the end during the group categorisation task. On reflection, it would have perhaps worked better to have a slightly longer session with additional breaks. The small group sizes (n= 2 to n=4) worked well overall, with positive feedback from participants that this felt a comfortable number. From a facilitation perspective, a maximum of three participants per group would have felt more manageable within the time constraints. On reflection, there were too many prompt questions (n=6) given to

participants at the start of the study. Fewer, more generalised prompts (e.g. n= 3) may be more effective and allow more time to discuss the photos produced in response to each prompt.

Seeking an additional ethical amendment after the discussion groups to then go ahead with individual interviews took a long time. Consequently, there was a long gap (approximately four months) between the two phases of the research. This meant that any member checking relied largely on retrospective memory. It may also explain why fewer participants did not engage with the follow-up interviews. On reflection, it would have been better to have planned for both groups and individual interviews from the outset of the study.

Directions for future research

Given this study's finding that participants felt they needed to attend a mental health-specific art group, it would be interesting to explore experiences of MII in individuals with long-term and complex mental health challenges who attend art groups which are not specifically for mental health. To gain a deeper understanding of relational factors, specifically the power dynamics between clinicians and service users on the expression of MII, it would be interesting to compare MII expression in those who attend specific art groups, compared with those who take part in art activities which are led by clinical services (such as in-patient settings).

Future studies using quantitative or mixed methods designs would be helpful to further our understanding of MII expression within both clinical and community arts settings, for example using the Illness Identity Questionnaire (IIQ; Oris et al., 2018). Longitudinal designs could add to our understanding of MII expression over time.

Considering that MII was still present in the non-clinical setting to a large degree, albeit less than within clinical spaces, it is unclear whether the gains in identity redefinition beyond

mental illness made in one setting (i.e. the arts group) can hold and extend outside that space. Further research is needed to better understand the expression of MII over time and place.

This study found that interpersonal benefits such as sense of connection and belonging were spoken about more by participants than artmaking itself. A growing artist identity did not emerge in the data, and so it would be interesting to compare whether other non-clinical interventions, such as walking or community groups, also allow individuals to connect with other parts of their identity. Beyond intervention factors, it would also be interesting to explore the other aspects of participant lives, such as their workplace and personal relationships, to understand how these factors also shape their view of themselves in relation to mental illness. Lastly, further exploration into the intersections of identity, such as gender, neurodiversity, race, etc, is warranted, particularly in relation to interpersonal power dynamics. Similarly, it would be helpful to compare MII in those with different types of psychiatric diagnosis which attract more or less stigma, since this was not possible in this small sample.

Self-reflexive statement

As described in the methods chapter, a reflexive journal was kept throughout this research in order to support regular reflection on my own positioning and assumptions in relation to research decisions and data interpretation. This is a core factor in reflexive thematic analysis (Braun et al., 2023).

My professional positioning as a clinician-researcher who uses art for wellbeing, and as someone with a previous career in the voluntary sector and in mental health service user involvement, influenced my choice of research question and methodology. This will have shaped how I responded to and interpreted the data. For instance, I was aware during some points of data

collection and transcribing where I leaned into my clinical position more, at times feeling a sense of defensiveness on behalf of stretched clinical services and clinicians. At other times, I noticed other parts of my positioning being activated by what I heard, where I noticed alignment with and shared frustration with participants about their experiences, because my data here echoed that which I'd gathered ten years previously in my previous career, with seemingly little positive change for service users.

My position as a trainee Clinical Psychologist who identifies with social constructionist and systemic ways of working influences my view of mental illness, i.e. less through a medical lens and taking up more of a biopsychosocial approach. I was aware of feeling surprised by the heavily medicalised language used by some participants and used my reflective journal to consider what I was attending to most, and what I may have been overlooking in my interpretations.

Checking my interpretations of the data with participants via member check, and also working with my supervisors as critical friends during my coding process, were helpful to ensure that I was capturing different perspectives that were truly reflected in the data and not getting caught up in my own assumptions or focusing too much of the louder voices in the data. In particular, I reflected in my journal and in supervision of my own relationship to artmaking and my incorporation of creativity in my some of my clinical practice. My positive beliefs about creativity and its applications for mental wellbeing, and my lived experience in artmaking, means that I could have fallen into focusing on aspects of the data which support my perspectives. I became aware during coding that I identified with participants' comments of the art group feeling very welcoming and home-like; this mirrored my experience of being made to feel very welcome and included during each of my site visits.

My disclosure to participants during recruitment visits that I have experience of using creativity for my own mental wellbeing may have facilitated rapport. I also share the same gender identity as the participants, and these factors together may have helped to make it feel safe enough for participants to be open and generous with both their time (over many months), and with what they shared with me.

My dual role as a clinician and researcher was challenged when the arts centre suddenly closed. Several participants disclosed worsening mental health following the closure, which heightened my sense of responsibility for them.

Conclusion

This study has contributed to a growing body of evidence on Mental Illness Identity (MII) and its dynamic expression in individuals with serious and long-term mental health difficulties, when accessing different types of support intervention. Intervention-specific factors, such as duration of intervention, the physical environment in which it is set, and the tasks to be completed within the setting, as well as interpersonal and relational factors, such as expertise and mutuality, sense of belonging and taking up different interpersonal roles, were found to influence the dominance of MII in clinical and non-clinical (arts) services for mental health.

Although MII was less dominant in the non-clinical art setting, it still persisted. Therefore, it seems that identity reconstruction beyond mental illness can ebb and flow and is sensitive to these dynamic factors.

The study has identified a number of implications for clinical practice, and for wider work between health, social care and the voluntary sector in terms of supporting people with complex and long-term mental health difficulties. This thesis also identified areas for future

research, to further explore the different dynamic factors and how these interact with intersections of identity, such as gender, race and neurodiversity.

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Appendices

Appendix A: Ethical approval

NHS
Health Research Authority

East Midlands - Leicester South Research Ethics Committee
Health Research Authority
2 Redman Place | Stratford | London
E20 1JQ

Telephone: 0207 104 8143

Please note: This is the favourable opinion of the REC only and does not allow you to start your study at NHS sites in England until you receive HRA Approval

04 April 2024

Ms Melanie Dupin
Trainee Clinical Psychologist
University of Essex / Essex Partnership University Trust
School of Health and Social Care
University of Essex
CO4 3SQ

Dear Ms Dupin

Study title:	**Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings.**
REC reference:	**24/EM/0043**
Protocol number:	**N/A**
IRAS project ID:	**335901**

Thank you for your letter of 26 March 2024, responding to the Research Ethics Committee's (REC) request for further information on the above research and submitting revised documentation.

The further information has been considered on behalf of the Committee by the Chair.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above

research on the basis described in the application form, protocol and supporting documentation as revised, subject to the conditions specified below.

Good practice principles and responsibilities

The UK Policy Framework for Health and Social Care Research sets out principles of good practice in the management and conduct of health and social care research. It also outlines the responsibilities of individuals and organisations, including those related to the four elements of research transparency:

1. registering research studies
2. reporting results
3. informing participants
4. sharing study data and tissue

Conditions of the favourable opinion

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

Confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or NHS management permission (in Scotland) should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA and HCRW Approval (England and Wales)/ NHS permission for research is available in the Integrated Research Application System.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations

Registration of Clinical Trials

All research should be registered in a publicly accessible database and we expect all researchers, research sponsors and others to meet this fundamental best practice standard.

It is a condition of the REC favourable opinion that **all clinical trials are registered** on a public registry before the first participant is recruited and no later than six weeks after. For this purpose, 'clinical trials' are defined as:

- clinical trial of an investigational medicinal product
- clinical investigation or other study of a medical device
- combined trial of an investigational medicinal product and an investigational medical device

Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: Quality assurance - Health Research Authority (hra.nhs.uk)

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at: Learning - Health Research Authority (hra.nhs.uk)

IRAS project ID: 335901 Please quote this number on all correspondence

With the Committee's best wishes for the success of this project.

Yours sincerely

pp.

Dr Nana Theodorou
Chair

Email: leicestersouth.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers"

Copy to: Dr Mantalena Sotiriadou

Lead Nation England: approvals@hra.nhs.uk

- Final report
- Reporting results

The latest guidance on these topics can be found at Managing your approval - Health Research Authority (hra.nhs.uk)

Ethical review of research sites

NHS/HSC sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to confirmation of Capacity and Capability (in England, Northern Ireland and Wales) or management permission (in Scotland) being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

Non-NHS/HSC sites

I am pleased to confirm that the favourable opinion applies to any non-NHS/HSC sites listed in the application, subject to site management permission being obtained prior to the start of the study at the site.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document	*Version*	*Date*
Copies of materials calling attention of potential participants to the research [Flyer]	v2	19 March 2024
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Insurance indemnity evidence]	V1	01 August 2023
Interview schedules or topic guides for participants [Photovoice task guide for participants]	v2	19 March 2024
IRAS Application Form [IRAS_Form_31012024]		31 January 2024
Letter from sponsor [Letter from sponsor]	V1	19 January 2024
Letters of invitation to participant [Template email invitation]	V1	26 March 2024
Other [Demographic questionnaire]	V1	29 November 2023
Other [Focus group topic guide for researcher]	v2	26 March 2024
Other [Information and response to REC panel]	V1	26 March 2024
Participant consent form [Consent form]	V1	16 November 2023
Participant consent form [Consent form]	v2	19 March 2024
Participant information sheet (PIS) [Participant Information]	v2	19 March 2024
Research protocol or project proposal [Research protocol]	v2	19 March 2024
Schedule of Events or SoECAT [Schedule of events]	v2	27 March 2024
Summary CV for Chief Investigator (CI) [CV Melanie Dupin]		
Summary CV for supervisor (student research) [Dr Lowry CV]		

- other clinical trial to study a novel intervention or randomised clinical trial to compare interventions in clinical practice.

A 'public registry' means any registry on the WHO list of primary registries or the ICMJE list of registries provided the registry facilitates public access to information about the UK trial.

Failure to register a clinical trial is a breach of these approval conditions, unless a deferral has been agreed by the HRA (for more information on registration and requesting a deferral see: Research registration and research project identifiers).

Where a deferral is agreed we expect the sponsor to publish a minimal record on a publicly accessible registry. When the deferral period ends, the sponsor should publish the full record on the same registry, to fulfil the condition of the REC favourable opinion.

If you have not already included registration details in your IRAS application form you should notify the REC of the registration details as soon as possible.

Where the study is registered on ClinicalTrials.gov, please inform deferrals@hra.nhs.uk and the Research Ethics Committee (REC) which issued the final ethical opinion so that our records can be updated.

Publication of Your Research Summary

We will publish your research summary for the above study on the research summaries section of our website, together with your contact details, no earlier than three months from the date of this favourable opinion letter. Where a deferral is agreed, a minimum research summary will still be published in the research summaries database. At the end of the deferral period, we will publish the full research summary.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit: Research summaries - Health Research Authority (hra.nhs.uk)

It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).

After ethical review: Reporting requirements

The attached document "After ethical review – guidance for researchers" gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study, including early termination of the study

IRAS Project ID 335901. HRA and HCRW Approval for the Amendment

leicestersouth.rec@hra.nhs.uk<noreply@harp.org.uk>
To: Dupin, Melanie G S; Sotiriadou, Mantalena
Cc: Dupin, Melanie G S

Reply | Reply all | Forward
Tue 07/01/2025 09:36

You replied on Tue 07/01/2025 19:04

CAUTION: This email originated from outside our organisation. Do not click links or open attachments unless you recognise the sender and know the content is safe. If you are not sure it is safe, please contact the IT Helpdesk.

Dear Ms Dupin,

IRAS Project ID:	335901
Short Study Title:	Identity and self-concept in mental health recovery Version 1
Amendment No./Sponsor Ref:	ETH2324-1159
Amendment Date:	20 December 2024
Amendment Type:	Non Substantial Non-CTIMP

I am pleased to confirm **HRA and HCRW Approval** for the above referenced amendment.

You should implement this amendment at NHS organisations in England and Wales, in line with the guidance in the amendment tool.

User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/

Please contact [amendments@hra.nhs.uk]amendments@hra.nhs.uk for any queries relating to the assessment of this amendment.

Kind regards

Kevin Ahmed
Health Research Authority
2nd Floor | 2 Redman Place | Stratford | London | E20 1JQ
E.amendments@hra.nhs.uk
W. www.hra.nhs.uk

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Ethics applications: Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings.

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Application	Date submitted	Date of outcome	Status
ETH2425-0641*	10 Jan 2025	10 Jan 2025	Approved
ETH2425-0421*	21 Nov 2024	22 Nov 2024	Approved
ETH2324-1159	09 Apr 2024	10 Apr 2024	Approved

Final ethics approval from University of Essex, including amendments

---

University of Essex

10/01/2025

Miss Melanie Dupin

Health and Social Care

University of Essex

Dear Melanie,

Ethics Committee Decision Application: ETH2425-0641

We are writing to advise you that your application to amend a registered external ethical approval of your research project entitled "Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings." has been reviewed by the REO Research Governance Team. We are pleased to inform you that the University of Essex will accept the ethical approval granted by HRA NHS REC for the project named above and you will not be required to make a full application for ethical approval through the University's ethics review process.

Please do not hesitate to contact the REO Research Governance Team (reo-governance@essex.ac.uk) if you require any further information or have any queries.

Yours sincerely,

REO Research Governance Team

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom

T 01206 873333

www.essex.ac.uk
@Uni_of_Essex /uniofessex /uniofessex

Appendix B: Literature review - study characteristics

Characteristics of the studies selected for review

Method and concept	**Bacha, Hanley & Winter (2020)**	**Chambers et al. (2014)**	**Chase et al. (2010)**	**Davies &Allen (2007)**	**Gault (2009)**	**Harris et al. (2012)**
Purpose	To explore service user perspectives of the emotional impact of therapeutic relationships with staff in psychiatric services	To explore service user experiences of detained mental health care	To expand understanding of the psychosocial factors that facilitate or inhibit engagement with mental health services	To explore the interactional frames in the relationship between healthcare professionals and mothers with mental illness	To understand service user and carer perspectives on compliance and compulsory treatment in community mental health settings	To explore experiences of being in contact with Early Intervention in Psychosis services
Setting	England (Nort h) Secondary mental health services (psychiatry, nursing, occupational therapy, psychology, support workers, CBT therapy, social work)	England (South East) Three mental health hospitals where participants were detained (acute admission ward, psychiatric intensive care unit, forensic inpatient ward)	England (London) Assertive Outreach Services	Wales (South East); Community Mental Health Team (CMHT)	England, Under Supervised Community Treatment (SCT) orders	UK (unspecified) Multi-disciplinary EIP services (psychology, psychiatry, community psychiatric nursing)

Sample	N = 8 (4 male, 4 female) adults aged from 20s – 60s Range of mental health conditions (e.g. PTSD, schizophrenia, eating disorder, personality disorder, depression, bipolar)	N = 19 (12 male, 7 female) adults aged 19-53 years (mean age 35), 7 were Black British, 10 White British, 2 other ethnic origin Currently detained under MHA Section 3 and who had experienced coercive intervention (control/restraint/rapid tranquilisation/seclusion).	N = 40 (29 male, 11 female), mean age 40 years. Psychosis	N = 11 (female) Ages not reported Various mental health diagnoses (OCD, bipolar, depression, psychosis, postnatal depression)	N = 19 (11 service users, 8 carers) – only service user views included in review (10 male, 9 female), aged 20 – 89 (mode = 20-29 yrs) 7 European, 11 Afro-Caribbean, 1 Asian Diagnoses not reported	N = 8 (5 male, 3 female), aged 21-37 (mean age 25 years); 5 White British, 2 White and Asian, 1 White and Black Caribbean Psychosis
Data collection and analysis	Interview; Interpretive Phenomenological Analysis (IPA)	Semi-structured interview; inductive Thematic Relational Analysis	Unstructured interview; Positioning Analysis (variant of Discourse Analysis)	Semi-structured interview;	Semi-structured Interviews; Grounded Theory	Interviews; IPA

Table 2 continued…

Method and concept	Lawrence et al. (2021)	Meddings & Perkins (2002)	Notley et al. (2012)	Tuffour et al. (2019)	Wagstaff et al. (2018)	Watts & Priebe (2002)
Purpose	To explore social and cultural processes which shape different responses to mental illness and interactions with services	To explore the meaning attached to 'getting better' by staff and services users	To explore experiences of an in-patient mental health rehabilitation unit, to inform service development	To explore Black African service users' experiences and conceptualisations of recovery from mental illness	To explore the experiences of mental health services for men with a diagnosis of schizophrenia, who describe their ethnic identity as 'black' and have a history of disengagement from mental health services.	To understand clients' perspectives of assertive community treatment
Setting	UK (unspecified) First-episode psychosis services	England (London) Multi-disciplinary rehabilitation service for serious and ongoing mental illness (residential hostel and outreach team)	England (London) Multi-disciplinary in-patient rehabilitation unit	England (experience of any mental health service)	England (West Midlands) 8 Assertive Outreach Teams	England (London) Assertive Community Treatment services (ACT)
Sample	N = 35 (17 male, 18 female), aged	N = 20 service users (14 male, 6 female), mean	N = 10 (6 male, 4 female), aged	N = 12 (3 male, 9 female), aged 19 – 57 (mean	N = 7 (male), aged 31 – 64	N = 12 (8 male, 4 female),

	21 – 50 years. 17 Black Caribbean, 15 White British, 3 White Other First-episode Psychosis	age 40.1 years. 6 African Caribbean/African, 14 White British Schizophrenia *Also 10 staff (only service user responses included in review)*	28-47 years (mean 36.7 years). 5 White British, 3 Indian, 1 Asian, 1 Mixed ethnicity Schizophrenia and bipolar. Not detained in the unit.	age 33.25 years). First or second generation Black African Schizophrenia	years (mean age 49 years) Black British Schizophrenia	average age 38 years. 9 British African-Caribbean, 1 British Asian, 2 White British Schizophrenia (all with past hospital admissions)
Data collection and analysis	Interview; Thematic narrative analysis	Semi-structured interview; Content Analysis	Semi-structured interview, with photo elicitation	Semi-structured interview; Interpretative Phenomenological Analysis (IPA)	Two interviews; Interpretative Phenomenological Analysis (IPA)	Interviews; Grounded Theory

Appendix C: Literature review - CASP quality checklist

CASP quality appraisal

Papers scoring 16 or above (i.e. 80% or higher quality score) will be used most to inform the synthesis (Atkins et al., 2008; Toye et al, 2014)

	Yes = 2, Can't tell = 1, No = 0	Bacha et al. (2020)	Chambers et al. (2014)	Chase et al. (2010)	Davies & Allen (2007)	Gault (2009)	Harris et al. (2012)	Lawrence et al. (2021)	Meddings & Perkins (2002)	Notley et al. (2012)	Tuffour et al. (2019)	Wagstaff et al (2018)	Watts & Priebe (2002)
Section A: - are the results valid?	**Was there a clear statement of the aims of the research?** •what was the goal of the research? •why was it thought important? •its relevance	2	2	2	1	1	2	2	2	2	2	2	1
	Is a qualitative method appropriate? Consider: •If the research seeks to interpret or illuminate the actions and/or subjective experiences of research participants •Is qualitative research the right methodology for addressing the research goal?	2	2	2	2	2	2	2	2	2	2	2	2
	Was the research design appropriate to address the aims? Consider if the researcher has justified the research design (e.g., have they discussed how they decided which method to use)	2	2	2	1	2	2	2	1	2	1	1	0
	Was the recruitment strategy appropriate to the aims? Consider •If the researcher has explained how the participants were selected •If they explained why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study •If there are any discussions around recruitment (e.g. why some people chose not to take part)	2	2	2	1	2	2	1	1	2	2	2	1
	Was the data collected in a way that addressed the research issue? Consider •If the setting for the data collection was justified •If it is clear how data were collected (e.g. focus group, semi-structured interview etc.) •If the researcher has justified the methods chosen •If the researcher has made the methods explicit (e.g. for interview method, is there an indication of how interviews are conducted, or did they use a topic guide) •If methods were modified during the study. If so, has the researcher explained how and why •If the form of data is clear (e.g. tape recordings, video material, notes etc.) •If the researcher has discussed saturation of data	2	2	2	1	1	2	2	1	2	2	2	2

(continued)

	Yes = 2, Can't tell = 1, No = 0	Bacha et al. (2020)	Chambers et al. (2014)	Chase et al. (2010)	Davies & Allen (2007)	Gault (2009)	Harris et al. (2012)	Lawrence et al. (2021)	Meddings & Perkins (2002)	Notley et al. (2012)	Tuffour et al. (2019)	Wagstaff et al (2018)	Watts & Priebe (2002)
	Has the relationship between researcher and Ps been adequately considered? Consider •If the researcher critically examined their own role, potential bias and influence during (a) formulation of the research questions (b) data collection, including sample recruitment and choice of location •How the researcher responded to events during the study and whether they considered the implications of any changes in the research design	1	1	0	1	0	1	2	0	2	2	1	1
Section B: What are the results?	**Have ethical issues been considered?** Consider: •If there are sufficient details of how the research was explained to participants for the reader to assess whether ethical standards were maintained •If the researcher has discussed issues raised by the study (e.g. issues around informed consent or confidentiality or how they have handled the effects of the study on the participants during and after the study) •If approval has been sought from the ethics committee	2	2	2	1	2	2	2	0	2	2	2	1
	Was the data analysis rigorous? Consider •If there is an in-depth description of the analysis process •If thematic analysis is used. If so, is it clear how the categories/themes were derived from the data •Whether the researcher explains how the data presented were selected from the original sample to demonstrate the analysis process •If sufficient data are presented to support the findings •To what extent contradictory data are taken into account •Whether the researcher critically examined their own role, potential bias and influence during analysis and selection of data for presentation	2	1	2	1	2	1	2	1	2	1	2	1
	Is there a clear statement of findings? Consider •If the findings are explicit •If there is adequate discussion of the evidence both for and against the researcher's arguments •If the researcher has discussed the credibility of their findings (e.g. triangulation, respondent validation, more than one analyst) •If the findings are discussed in relation to the original research question	2	1	2	1	2	2	2	2	1	2	2	1
Section C: Will results help locally?	**How valuable is the research?** Consider •If the researcher discusses the contribution the study makes to existing knowledge or understanding (e.g., do they consider the findings in relation to current practice or policy, or relevant research-based literature •If they identify new areas where research is necessary •If the researchers have discussed whether or how the findings can be transferred to other populations or considered other ways the research may be used	2	2	1	1	2	2	2	2	1	1	1	1
	Total out of 20	**19**	**17**	**17**	**11**	**16**	**18**	**19**	**12**	**18**	**17**	**17**	**11**

Appendix D: Literature review - sample of key concepts determined during the meta-ethnography

This table provides an extract of one study's key identified concepts, which formed a part of the wider phase of 'determining how studies are related'. Entries in quotation marks are authors original wording. *Entries in italics and quotation marks are original participant quotes.*

Key concepts	**Bacha, Hanley & Winter (2020)**
Stigmatising experiences from others	Mental health system as dehumanising and disempowering; treated like a guinea pig or a child
Internalisation of stigmatising attitudes	'Am I a person or just an object in the system?'
Togetherness in stigmatised identity	n/a
Lost personal identities	Diminished self-worth stemming from traumatic experiences with staff; lost sense of self

	‘Being treated as a human being helped to improve their own sense of self-worth’
Lost social identities, roles and memberships	n/a
A dominating mental illness identity	‘her mental torment felt like a runaway train’ Being treated as a patient, rather than a unique individual and human being
A need to be fixed	Mental illness as a ‘battle’ that needs help from professionals An illness to be fixed by staff; symptoms need to be stabilised and cured
Agency, choice and power	Disempowered, ignored and disrespected with no control. Some positive experiences with consistent and attuned practitioners who treat them like an individual.
Hierarchy – them and us	Unequal power dynamics between staff and patient in in-patient care. ‘Help-seeker and caregiver dynamic’

Performing	'in response to feeling threatened, disempowered…in mental health services, the participants lied, became passive or disengaged…to regain a sense of control'
Resisting (power and narratives)	n/a
Intersection of cultural and gender identity	n/a
Views on mental illness recovery	Treatments viewed as ineffective and damaged mental and physical health; 'a sense of futility' 'Others came to the conclusion that the hospital environment was not an effective environment to help them overcome their mental health problems' 'When practitioners understood and put the participants' needs at the centre of decisions about their care, participants said the treatments provided were more effective'

Positively redefining self beyond mental illness	n/a
Explanation/theory (second order interpretation)	'By entering a psychiatric system dominated by the biomedical 'disease' model, service users can instantaneously experience being dehumanized.' A need to humanize psychiatric services which provide more care and less control, focusing on relational components of power, safety and identity.

Appendix E: Literature review - cross-comparison of concepts across studies

Cross-comparison of studies by concept - (studies marked with * contributed most to the synthesis)

Key concepts	Bacha, Hanley & Winter (2020)*	Chambers et al. (2014)*	Chase et al. (2010)*	Davies &Allen (2007)	Gault (2009)*	Harris et al. (2012)*	Lawrence et al. (2021)*	Meddings & Perkins (2002)	Notley et al. (2012) *	Tuffour, Simpson & Reynolds (2019)*	Wagstaff et al. (2018)*	Watts & Priebe (2002)
Stigmatising experiences from	X	X	X	X	X	X	X	X	-	X	X	-

others												
Internalisation of stigmatising attitudes	X	X	-	X	X	X	X	X	X	X	-	X
Togetherness in stigmatised identity	-	X	-	-	-	X	-	-	X	X	X	-

Lost personal identities	X	X	X	-	X	-	X	X	-	X	X	X
Lost social identities, roles and memberships	-	-	X	-	X	X	-	-	-	X	X	X
A domina	X	X	X	X	X	X	X	X	X	X	-	X

ting												
mental												
illness												
identit												
y												
A need	X	-	-	-	X	X	X	X	X	X	X	-
to be												
fixed												
Agency	X	X	X	X	X	X	X	-	X	X	X	X
, choice												
and												
power												
Hierar	X	X	X	X	-	X	X	-	X	-	X	-
chy –												
them												

and us												
Performing	X	X	-	X	X	-	X	-	-	X	X	-
Resisting (power and narratives)	X	X	X	X	X	X	X	-	-	X	X	X
Intersection of cultural and gender	-	-	-	X	X	-	X	-	X	X	X	X

identity												
Views on mental illness recovery	X	X	-	-	-	X	X	X	X	X	X	-
Positively redefining self beyond mental illness	-	-	-	X	-	X	X	-	X	X	-	-

Appendix F: Recruitment advert

Participants needed for creative research project!

I'm a trainee clinical psychologist at the University of Essex studying self-identity in adults who have experienced mental health difficulties, and who have used mental health services and taken part in creative arts at [redacted]

I want to understand how different types of mental health support influence people's perception of themselves and their thoughts about recovery.

What's involved?

This is a creative study using photography to capture your experiences and perspectives in response to some prompt questions over a period of up to four weeks.

Participants will then be asked to take part in a group discussion with 4 participants and the researcher (up to 2 hrs, plus a break) where we will discuss your photographs, experiences and opinions.

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If interested or to find out more please contact Melanie Dupin on md22822@essex.ac.uk or speak to [redacted]

IRAS number 335901. V2. 19.03.24

What are the benefits of taking part?

- A free photography workshop prior to taking part (at [redacted]
- The chance for your views to inform healthcare staff about what you'd like from services
- The option to exhibit your photos with [redacted]

Who do we need?

- Adults aged 18-64 years
- Currently attending activities at [redacted]
- Have received a mental health diagnosis (or identify as such) which is long-term (i.e. occurring for a year or more, or repeated episodes);
- Have accessed or are currently accessing NHS mental health services;
- Have access to or are willing to use your own digital camera or phone camera (or a disposable camera can be provided);
- Are able to read and understand English;
- Are able to give informed consent.

Participants will have the chance to win one of three £20 Amazon vouchers in a prize draw

Appendix G: Participant Information Sheet

Stage one (Photovoice and group discussion)

University of Essex

School of Health and Social Care
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598
www.essex.ac.uk

PARTICIPANT INVITATION AND INFORMATION SHEET

Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings.

Who am I?

I am a trainee clinical psychologist in the School of Health and Social Care at the University of Essex. As part of my training, I am conducting a study to understand themes of self-identity within adults who experience long-term mental health challenges. I am particularly interested in how people with long-term mental health challenges experience their identity and think about recovery when they are in different mental health support settings, such as within National Health Service (NHS) mental health services or in community activity settings. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Aims

To investigate how different support services for mental health influence how clients view their own identity and their thoughts about recovery.

Why?

Research suggests that people facing mental health challenges can experience stigma, including self-stigma, which may reduce help-seeking. Receiving a mental health diagnosis and accessing mental health services may impact how people perceive themselves. Research also tells us that arts-based activities may have a positive impact on identity. We hope this study will increase knowledge about this area to promote recovery outcomes in different settings.

What will the research involve?

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This research will be using a method called Photovoice. This involves participants taking photographs in response to a number of prompts, over a period of up to four weeks. This will be followed by a group discussion lasting approximately two hours (plus a 30-minute break halfway) with up to four people plus the researcher (Melanie Dupin). In this discussion, we will talk about your selected photographs and their personal significance.

My research has been approved by the School of Health and Social Care Research Ethics Committee at the University of Essex and by the Health Research Authority Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my research as you attend creative activities a[redacted] and have confirmed that you also use/have used NHS mental health services.

You are free to decide whether or not to participate and should not feel coerced.

To be eligible for this study you must:

- Be aged 18-64 years
- Currently attend activities at[redacted]
- Have received a mental health diagnosis (or identify as such) which is long-term (i.e. occurring for a year or more, or repeated episodes);
- Have accessed or are currently accessing NHS mental health services;
- Have access to or are willing to use a digital camera, your phone camera or disposable camera;
- Are able to read and understand English;
- Are able to give informed consent.

Choosing to take part in this research project will not impact on your participation in any courses or activities provided by[redacted]

What will your participation involve?

You will be asked to sign a consent form to confirm your wish to take part in the study before you undertake any of the activities related to this project. Next, you will be asked to fill in a short demographic information form (e.g. age, gender, history of illness), which should take no longer than 10 minutes.

Once you have given your consent to participate, you will be asked to attend a preliminary 90-minute group workshop on 9th July 2024 in the afternoon at [redacted]ill be run by me

University of Essex

(researcher, Melanie Dupin) and Tessa Hallmann (photographer with [redacted] which will provide:

- Basic photography skills and top tips
- Considerations for ethical photography
- More information about the task and an opportunity to ask questions

You will then be given the Photovoice task, including a written description of the task and prompts. You will have up to four weeks to complete the Photovoice task in any way that you choose. You may use your own camera equipment (e.g. digital camera, camera phone). If you do not have access to a digital camera, a disposable camera will be provided and the costs of processing the film will be covered by the research funds.

You may take as many photos as you wish but then will be asked to select up to twelve photographs (two for each prompt) and to write or record a short description of what they represent. You may not need as long as four weeks and are welcome to submit your photographs sooner if you wish. Digital photographs can be submitted to me via email to md22822@essex.ac.uk. Alternatively, if you are using a disposable camera, you will need to hand this in to Jo Keay at [redacted] The film will be processed and you will then have an opportunity to review your photographs and select the ones you wish to share with this project.

You will then be invited to attend a group discussion (4 participants and the researcher), where we will discuss your images and your written description of each image, what they mean to you and how they relate to your experiences. We will have a wider discussion about themes of identity and recovery within different support settings. Together we will then categorise everyone's photographs into common themes and try to agree to rank these categories in order of importance to the whole group. The group discussion is expected to last two hours (plus a break) and will take place at [redacted] in mid-August (exact date will be shared with participants on sign-up).

I will audio record our discussion during the group discussion. I will then transcribe (type up) the recording. Only my supervisor, Dr Ruth Lowry, and I will have access to the recordings and the transcription. Any identifiable information (e.g. your name, town name) will be replaced with a pseudonym (a false name) to protect your confidentiality.

The ownership of photographs and images created by yourself and submitted to the project remains with you. You are asked to grant to the Researcher, Melanie Dupin, and to the University of Essex, a free, perpetual, non-exclusive licence for research and academic purposes, including (but not limited to) research outputs such as reproduction in a thesis, conference presentations, summary reports and any academic publications. Your name would

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not be included in order to protect your confidentiality; instead, a pseudonym will be used in all research outputs, crediting your work as a research volunteer. Photographs which identify you will not be used in any research outputs. You are entitled to exhibit any of your photographs as you wish, in agreement with [redacted] (separately to research outputs).

Benefits of participating and payment

- You will receive a free workshop covering basic photography skills at the start of this project.
- [redacted]ay exhibit photographs from this research project, along with other artworks which may stem from this project. If you wish for your photographs to be exhibited, you will need to give written consent for your personal data (your name, contact details and photographs) to be shared by me (researcher) with [redacted] You will retain full ownership and copyright of any exhibited works.

What are the disadvantages of taking part?

The use of cameras to photograph your experiences and issues of concern may have potential risks, such as emotional distress. Reflecting on your experiences in response to the task prompts may bring up uncomfortable feelings.

In addition, you may feel some discomfort or embarrassment from participating in the group discussion because the stories behind your photographs may be very personal. However, you do not have to share or discuss anything you do not wish to discuss and you are free to stop the dialogue at any time. At the group discussion, there will be the chance for you to write down any comments or additional information that you do not wish to say in front of the other participants.

If you experience any stress or discomfort during your participation in this study, you will be provided with information about specific agencies that offer emotional support. In the event of distress, crisis or risk to yourself or others, the researcher will have a duty to breach confidentiality and follow local procedures for information-sharing and risk-management (in line with policies from Essex Partnership University NHS Trust). In such instances, the researcher would share information with [redacted]taff, who will follow your agreed care plan that they hold on file, which may mean contacting your GP, care co-ordinator or other named support.

It is important that others' privacy and rights are respected and do not share with others what is spoken about in the group discussion. For the purpose of this study, we ask that you do not include any identifiable people or places in your photographs. We also ask that you do not include photographs of children, or images depicting sexual content and nudity, violence

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(including self- harm) and/or criminality. All images will be checked before the group discussion. Any photographs which do not meet these guidelines will be removed and will not be used for the remaining research activities. Any physical copies of these photographs will be returned to you at this point.

Will I be reimbursed for taking part?

I will not be able to pay you for participating in my research however, if you wish, you may be entered into a prize draw to win one of three £20 Amazon vouchers. To be entered into the prize draw, please mark the relevant box on the consent form. Winners will be announced a week after the final group discussion has taken place.

Issues of confidentiality and safety

During the research task:
This research involves several group activities (i.e. the preliminary group workshop and group discussion). This means that it will not be possible to guarantee your anonymity in participation. Due to the fact that other participants will be taking part in the group discussions, it is not possible to guarantee that what you say will not be shared outside of the group. However, steps will be taken to minimise this, for example through group agreement at the start of the discussion to respect other participants' wishes to not share information with other people.

I will maintain your confidentiality during write-up and in sharing the research findings:

- Participants will not be identified in any written material resulting from the data collected, or in any write-up of the research.
- Participant identity will be protected using a pseudonym (a false name) on all information you give me.
- Photographs which identify you or other participants will not be included in any of the research outputs (e.g. write up, conference presentations, exhibition).

Your safety will be respected at all times:

- **Participants do not have to answer all questions asked of them and can stop their participation at any time.**
- Opportunities to seek support after the study will be detailed in writing following the group discussion.

What will happen to the information that you provide?

The material that you provide (including your personal data, photographs, recordings and transcriptions) will be stored securely on the University of Essex cloud-based storage system.

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All participant identifiable information will be held in a separate password protected file only shared by Melanie Dupin (researcher) and Ruth Lowry (supervisor).

Data will be stored in accordance with the University of Essex policy on research data storage, up to a period of five years, after which it will be destroyed.

How will I use information about you?
I will need to use information from you for this research project.

This information will include your name, contact details and demographic information (e.g. age, gender, history of illness). People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead.

Only my supervisor and I will have access to your personal data. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. If you wish to withdraw from the study, please notify the Researcher, Melanie Dupin, via email (md22822@essex.ac.uk) or in-person if she is on-site at the time. Alternatively, you may speak w[redacted]an then liaise with Melanie about your wish to stop participating.
We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team on the contact details below
- or, by sending an email to the University of Essex Information Assurance Manager at dataprotectionofficer@essex.ac.uk.

Who is the Data Controller?

The University of Essex is the Data Controller, and the Information Assurance Manager may be contacted by email at dataprotectionofficer@essex.ac.uk or by phone on 01206 872285. Further information is available at https://www.essex.ac.uk/staff/working-with-information-and-data/data-protection-introduction

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What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. However, if you withdraw, I would reserve the right to use material that you provide until that point in my analysis of the data.

Debrief

Should you feel in any way upset after the interviews, or have any questions please contact the researcher of her supervisor using the contact details below.

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal investigator of the project, Melanie Dupin, using the contact details below.

If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact the departmental Director of Research in the department responsible for this project, [name and e-mail address]. If you are still not satisfied, please contact the University of Essex Research Integrity Manager, Mantalena Sotiriadou (email: ms21994@essex.ac.uk).

Contact details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

Melanie Dupin md22822@essex.ac.uk – researcher

If you have any questions about how the research has been conducted please contact the research supervisor, Dr Ruth Lowry, School of Sport, Rehabilitation and Exercise Sciences, University of Essex.

Dr Ruth Lowry r.lowry@essex.ac.uk – supervisor

Thank you for reading this information sheet.

Stage two (individual interview)

University of Essex

School of Health and Social Care
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598
www.essex.ac.uk

PARTICIPANT INVITATION AND INFORMATION SHEET

Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings - *follow-up individual interview*

Who am I?

I am a trainee clinical psychologist in the School of Health and Social Care at the University of Essex. As part of my training, I am conducting a study to understand themes of self-identity within adults who experience long-term mental health challenges. I am particularly interested in how people with long-term mental health challenges experience their identity and think about recovery when they are in different mental health support settings, such as within National Health Service (NHS) mental health services or in community activity settings. Before you agree it is important that you understand what your participation would involve. Please take time to read the following information carefully.

Aims

To investigate how different support services for mental health influence how clients view their own identity and their thoughts about recovery.

Why?

Research suggests that people facing mental health challenges can experience stigma, including self-stigma, which may reduce help-seeking. Receiving a mental health diagnosis and accessing mental health services may impact how people perceive themselves. Research also tells us that arts-based activities may have a positive impact on identity. We hope this study will increase knowledge about this area to promote recovery outcomes in different settings.

What will the research involve?

You kindly participated in the first part of my research, which involved you taking and sharing photographs in response to some research prompts. We then discussed these in small groups.

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This next part of my research is to gain a deeper understanding of your individual experiences and perspectives by carrying out an individual interview lasting between 45 to 90 minutes. The interview can be carried out either online, via MS Teams or Zoom, or in-person within a safe and confidential location of your choosing. If our interview is held online, you may choose whether to have your camera switched on or off.

My research has been approved by the School of Health and Social Care Research Ethics Committee at the University of Essex and by the Health Research Authority Research Ethics Committee. This means that my research follows the standard of research ethics set by the British Psychological Society.

Why have you been asked to participate?

You have been invited to participate in my follow-up research as you previously participated in the Photovoice task and small group discussion.

You are free to decide whether or not to participate and should not feel coerced.

To be eligible for this study you must:

- Be aged 18-85 years
- Currently attend activities a[redacted]
- Have received a mental health diagnosis (or identify as such) which is long-term (i.e. occurring for a year or more, or repeated episodes);
- Have accessed or are currently accessing NHS mental health services;
- Have access to or are willing to use a digital camera, your phone camera or disposable camera;
- Are able to read and understand English;
- Do not have a dementia diagnosis, brain injury or any other condition which affects mental capacity;
- Are able to give informed consent.

Choosing to take part in this research project will not impact on your participation in any courses or activities provided b[redacted]k.

What will your participation involve?

You will be asked to sign a consent form to confirm your wish to take part in the study before you undertake any of the activities related to this project.

Once you have given your consent to participate in the interview, we will arrange a mutually convenient time and location (either online or face-to-face in a safe and confidential location of your choosing). The interview will last between 45 to 90 minutes and we can take breaks as needed.

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In order to make the interview feel as safe and comfortable as possible, I will:

- I will provide a topic guide ahead of the interview to give you an indication of the things we will discuss;
- Discuss with you how you can let me know if you are feeling distressed, do not wish to answer a question, or if you wish to withdraw your participation;
- Discuss with you who you can contact in the event of needing additional support.

You are welcome to use fidget toys, art materials or anything else during the interview which may make you feel more comfortable.

I will audio record our discussion during the interview. I will then transcribe (type up) the recording. Only my supervisor, Dr Sagaradevi Barratt, and I will have access to the recordings and the transcription. Any identifiable information (e.g. your name, town name) will be replaced with a pseudonym (a false name) to protect your confidentiality.

Benefits of participating and payment

Your participation will help to inform emerging research on the role of community arts for adults with long-term mental health challenges, and will increase our understanding of the impact of different intervention settings on individuals who attend them. It is hoped that this will inform clinical and community practice.

What are the disadvantages of taking part?

Taking part in the interview may have potential risks, such as emotional distress. Reflecting on your experiences in response to the questions may bring up uncomfortable feelings.

Issues of confidentiality and safety

If you experience any stress or discomfort during your participation in this study, you will be provided with information about specific agencies that offer emotional support.

Participants will be provided with signposting information for support services to contact, in the event of distress. In the event of immediate risk to yourself or to others during participation, the researcher (Melanie Dupin) will have a duty of care break confidentiality and to contact emergency services, if you are unable or unwilling to do so. This would only be done after talking with you and if there were no other support options available.

I will maintain your confidentiality during write-up and in sharing the research findings:

- Participants will not be identified in any written material resulting from the data collected, or in any write-up of the research.
- Participant identity will be protected using a pseudonym (a false name) on all information you give me.

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- Previously submitted photographs which identify you or other participants will not be included in any of the research outputs (e.g. write up, conference presentations, exhibition).

Your safety will be respected at all times:

- **Participants do not have to answer all questions asked of them and can stop their participation at any time.**
- Opportunities to seek support after the study will be detailed in writing following the group discussion.

Will I be reimbursed for taking part?

Unfortunately, I will not be able to pay you for participating in my research.

What will happen to the information that you provide?

The material that you provide (including your personal data, previously provided photographs, recordings and transcriptions) will be stored securely on the University of Essex cloud-based storage system.

All participant identifiable information will be held in a separate password protected file only shared by Melanie Dupin (researcher) and Dr Sagaradevi Barratt (supervisor).

Data will be stored in accordance with the University of Essex policy on research data storage, up to a period of five years, after which it will be destroyed.

How will I use information about you?

I will need to use information from you for this research project.

This information will include your name, contact details and demographic information (e.g. age, gender, history of illness). People who do not need to know who you are will not be able to see your name or contact details. Your data will have a pseudonym instead.

Only my supervisor and I will have access to your personal data. We will keep all information about you safe and secure. Once we have finished the study, we will keep some of the data so we can check the results. We will write our reports in a way that no-one can work out that you took part in the study.

What are your choices about how your information is used?

You can stop being part of the study at any time, without giving a reason, but we will keep information about you that we already have. If you wish to withdraw from the study, please notify the Researcher, Melanie Dupin, via email (md22822@essex.ac.uk) or in-person if during the interview.

University of Essex

We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Where can you find out more about how your information is used?

You can find out more about how we use your information

- at www.hra.nhs.uk/information-about-patients/
- our leaflet available from www.hra.nhs.uk/patientdataandresearch
- by asking one of the research team on the contact details below
- or, by sending an email to the University of Essex Information Assurance Manager at dataprotectionofficer@essex.ac.uk.

Who is the Data Controller?

The University of Essex is the Data Controller, and the Information Assurance Manager may be contacted by email at dataprotectionofficer@essex.ac.uk or by phone on 01206 872285. Further information is available at https://www.essex.ac.uk/staff/working-with-information-and-data/data-protection-introduction

What if you want to withdraw?

You are free to withdraw from the research study at any time without explanation, disadvantage or consequence. However, if you withdraw, I would reserve the right to use material that you provide until that point in my analysis of the data.

Debrief

Should you feel in any way upset after the interviews, or have any questions please contact the researcher of her supervisor using the contact details below.

Concerns and Complaints

If you have any concerns about any aspect of the study or you have a complaint, in the first instance please contact the principal investigator of the project, Melanie Dupin, using the contact details below.

If are still concerned, you think your complaint has not been addressed to your satisfaction or you feel that you cannot approach the principal investigator, please contact the departmental Director of Research in the department responsible for this project, Dr Kostis Roussos (email: k.roussos@essex.ac.uk). If you are still not satisfied, please contact the University of Essex Research Integrity Manager, Mantalena Sotiriadou (email: ms21994@essex.ac.uk).

Contact details

If you would like further information about my research or have any questions or concerns, please do not hesitate to contact me.

University of Essex

Melanie Dupin md22822@essex.ac.uk – researcher

If you have any questions about how the research has been conducted please contact the research supervisor, Dr Sagaradevi Barratt, School of Health and Social Care, University of Essex.

Dr Sagaradevi Barratt barrattc@essex.ac.uk – supervisor

Thank you for reading this information sheet.

Appendix H: Consent form

Stage one (Photovoice and group discussion)

Consent Form

Title of the Project: **Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings.**

Research Team: Melanie Dupin, Dr Ruth Lowry

Please initial box

1. I confirm that I have read and understand the Pariticipant Information Sheet provided at the beginning of my involvement in the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily. ☐
2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any data collected up to the point of my withdrawal will be destroyed unless it has already been anonymised and the anonymised data used in analysis. ☐
3. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained. ☐
4. I understand that my fully anonymised data will be used for the purposes of this research project only. ☐
5. I understand that the focus group discussion will be audio recorded and give permission for this. The recordings will be transcribed and any identifiable content will be anonymised. ☐
6. I give permission for the de-identified audio recordings and anonymised transcripts will be deposited in a research data repository. ☐

7. I agree that my anonymised information can be quoted in research outputs. ☐

8. I agree to joint copyright of the photographic data to Melanie Dupin [researcher] for the purposes of sharing the findings of this research (e.g. inclusion of a copy of the photographs in a summary report or conference presentation). ☐

9. I understand that [redacted] would like to exhibit my photographs as part of wider publicity once this research project has finished, but that I may opt-out of this if I do not want to exhibit my photographs. ☐

10. I give permission for the researcher (Melanie Dupin) to share my personal data (name, contact details and photographs) with [redacted] if I wish to take part in the exhibition. ☐

11. I understand that I retain copyright of photographs which may be used by [redacted] in any future exhibition or publicity, and that I may withdraw my photographs from such purposes by contacting [redacted] directly. ☐

12. I agree to take part in the above study. ☐

Participant Name	Date	Participant Signature
_____	_____	_____

Researcher Name	Date	Researcher Signature
_____	_____	_____

☐ Copy for participant

☐ Copy for researcher records

Stage two (Individual interview)

Consent Form

Title of the Project: **Self-identity in mental health recovery: using Photovoice to explore changing identities of people with long-term mental health challenges within NHS treatment settings and community participatory-arts settings - *follow-up individual interview***

Research Team: Melanie Dupin, Dr Sagaradevi Barratt

	Please initial box
1. I confirm that I have read and understand the Participant Information Sheet (version 1 of 20/12/24) provided at the beginning of my involvement in the above study. I have had an opportunity to consider the information, ask questions and have had these questions answered satisfactorily.	
2. I understand that my participation is voluntary and that I am free to withdraw from the project at any time without giving any reason and without penalty. I understand that any data collected up to the point of my withdrawal will be pseudonymised and retained for data analysis.	
3. I understand that I will be signposted to relevant support services that I can contact in the event of distress.	
4. I understand that in the event of immediate risk to myself or to someone else, that the researcher (Melanie Dupin) will have a duty of care to contact emergency services, if I am unable or unwilling to contact support services myself.	
5. I understand that the identifiable data provided will be securely stored and accessible only to the members of the research team directly involved in the project, and that confidentiality will be maintained.	
6. I understand that my fully pseudonymised data will be used for the purposes of this research project only.	
7. I understand that the interview will be audio recorded and give permission for this. The recordings will be transcribed and any identifiable content will be pseudonymised.	

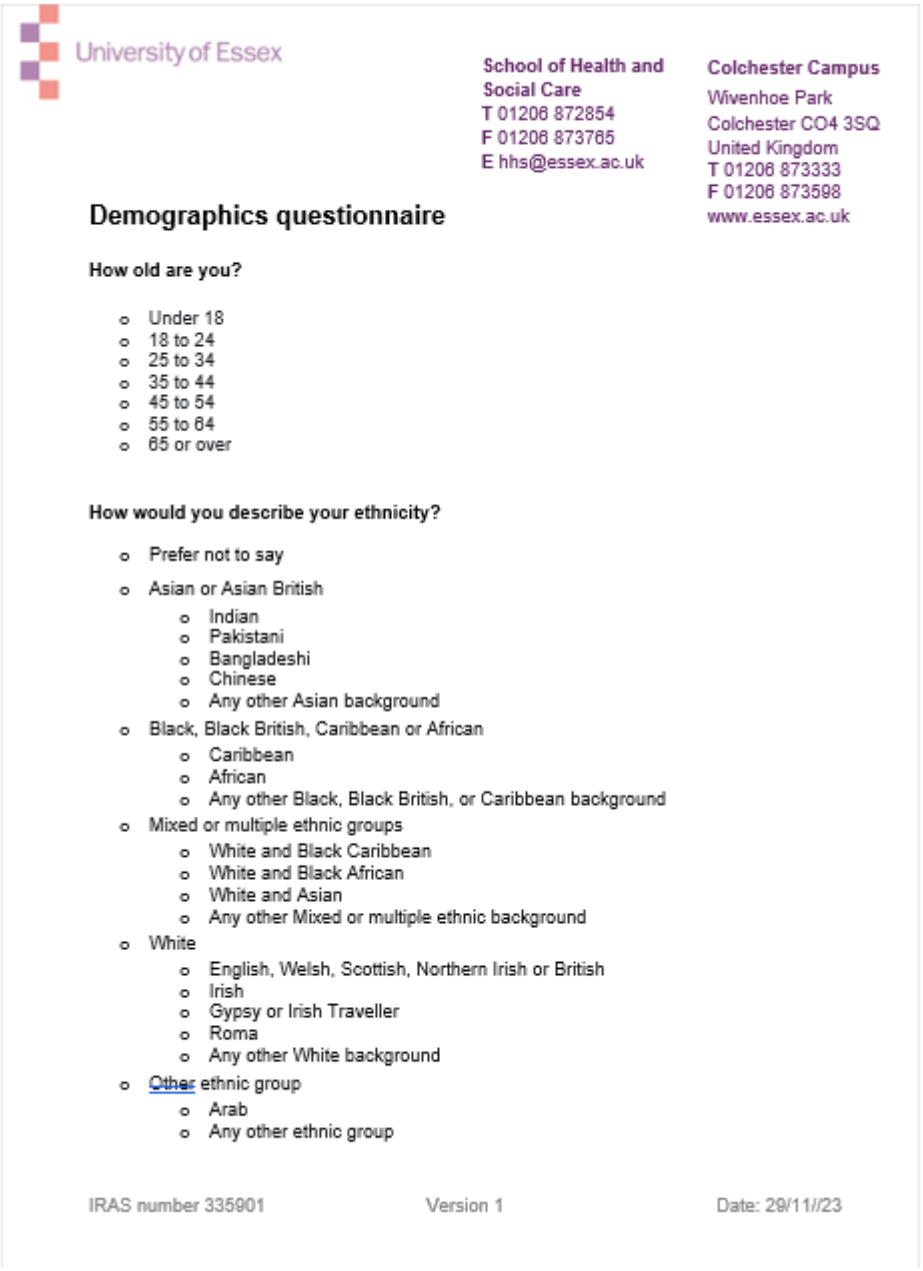
8. I give permission for the de-identified audio recordings and pseudonymised transcripts will be deposited in a research data repository. SS	
9. I agree that my pseudonymised information can be quoted in research outputs.	
10. I agree to take part in the above study.	

Participant Name _____ Date _____ Participant Signature _____

Researcher Name _____ Date _____ Researcher Signature _____

	Copy for participant
	Copy for researcher records

Appendix I: Demographics questionnaire



University of Essex

School of Health and Social Care
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598
www.essex.ac.uk

Demographics questionnaire

How old are you?

- Under 18
- 18 to 24
- 25 to 34
- 35 to 44
- 45 to 54
- 55 to 64
- 65 or over

How would you describe your ethnicity?

- Prefer not to say
- Asian or Asian British
  - Indian
  - Pakistani
  - Bangladeshi
  - Chinese
  - Any other Asian background
- Black, Black British, Caribbean or African
  - Caribbean
  - African
  - Any other Black, Black British, or Caribbean background
- Mixed or multiple ethnic groups
  - White and Black Caribbean
  - White and Black African
  - White and Asian
  - Any other Mixed or multiple ethnic background
- White
  - English, Welsh, Scottish, Northern Irish or British
  - Irish
  - Gypsy or Irish Traveller
  - Roma
  - Any other White background
- Other ethnic group
  - Arab
  - Any other ethnic group

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How would you describe your gender identity?

- Male
- Female
- Trans-male
- Trans-female
- Non-binary
- Other
- Prefer not to say

How would you describe your marital status?

- Married/civil partnership
- Cohabiting
- Divorced/separated
- Widowed
- Never married
- Prefer not to say

What is your employment status?

- Employed
- Unemployed (seeking work)
- Retired
- Prefer not to say

What was your most recent job title?

_____

- Prefer not to say

What is your highest completed formal education? / What age did you leave school?

- GCSES/GCES/O-levels
- Apprenticeship or Traineeship
- Further Education Certificate or Diploma
- University or higher degree
- Other
- Prefer not to say

Do you consider yourself to have a disability?

If yes, please specify: _____

Do you consider yourself to have mental health difficulties?

- Yes
- No

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Have you received a mental health diagnosis?

- Yes
- No

If yes, please specify: _____

How long have you experienced mental health difficulties?

- Less than a year
- 1-3 years
- 3-5 years
- 5-10 years
- 10 years or more

What mental health support/treatment have you accessed in THE PAST? (tick all that are relevant)

- Medication
- Talking therapies
- Care coordinator
- Hospital admission
- Community-based activities (please state what) _____
- None
- Other _____

What mental health support/treatment are you accessing CURRENTLY? (tick all that are relevant)

- Medication
- Talking therapies
- Care coordinator
- Hospital admission
- [redacted]
- Other community-based activities (please state what) _____
- None
- Other _____

How often, on average, do you take part i[redacted] activities?

- Daily
- A few times a week
- Weekly
- Fortnightly
- Monthly
- Occasionally

Appendix J: Support information for participants

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If anything that we have discussed in this interview has caused you to feel distressed and you need urgent support, please contact any of the following services:

- NHS 111 (option 2)
- Samaritans, 24 hours a day, on 116 123
- Your GP
- Your care co-ordinator (if you have one) or the duty worker at your local mental health team

If you do not feel able to keep yourself safe, or if you are at immediate risk from anyone else, please call 999 or attend your nearest emergency department.

Appendix K: Photovoice task prompts sheet

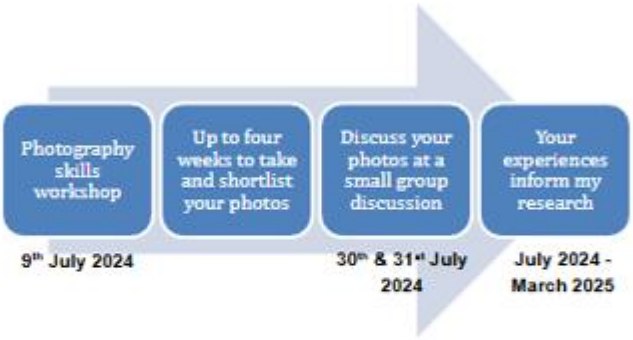
School of Health and Social Care
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598
www.essex.ac.uk

[redacted]

Photovoice information and instructions

What to expect



Preliminary photography workshop

Once you have signed a consent form to confirm that you would like to take part in this study, you will be invited to join a one-off introductory photography workshop with [redacted] at [redacted]x on 9th July 2024.

This workshop will provide more information about the study as well as teaching skills in photography, such as: composition, light, reality and symbols to tell stories through images.

Photovoice task prompts

Over the next four weeks, please take as many photographs as you wish that represent the following points.

You will then need to **pick two for each category** to share with me. We will then discuss these together with other people participating in this research at our group discussion on either 30th or 31st July 2024 [redacted]

1. Photographs that represent how **you feel about yourself** in **NHS settings**	2. Photographs that represent how you feel **other people perceive you** in **NHS settings**
3. Photographs that represent how **you feel about yourself** at [redacted]	4. Photographs that represent how you feel **other people perceive you** when you attend [redacted]
5. Photographs that represent **hope and recovery** (in each setting, i.e. NHS [redacted] Arts)	6. Photographs that represent what you would like **mental health professionals to know** about ideal care

Ethical photography

You may include:

- Images of yourself (i.e. self-portrait)
- Inanimate objects
- Nature and pets
- Unidentifiable people or parts of people (e.g. someone in blur or in silhouette, a close up of hands, not showing their face)
- Unidentifiable locations (e.g. a close up or part of a building or street scene)

Please do not include:

- Any photographs of children
- Identifiable images of people (i.e. where they are recognisable)
- Identifiable buildings, addresses or locations (e.g. a picture of your GP surgery building, a street name sign or shop signage that would allow people to know where it is)
- Images depicting sexual content and nudity, violence (including self- harm) and/or criminality

Please only use your own images, do not use an image taken by someone else. Please follow local rules and requests (e.g. if a shop or place or worship requests no photography).

Have fun and be as creative as you like! You can include photos that are spontaneously captured moments, or images that are posed and set up as a still life. You may use filters or digitally edit your images (e.g. using photoshop or camera filters) if this is something you know how to do and can access.

A few examples:

✓	✗
 *Self-portrait by Ilse Bing*	 *From photovoice.org*
 *From Rutgers*	 *From photovoice.org*
 *From The Nature Conservancy*	 *From R.L. McBee at mdpi.org*
 *From photovoice.org*	
 *From photovoice.org*	

Shortlisting your images

You are free to take as many photos as you wish during this process, but remember that you will need to select just **two for each category on page 1** (i.e. a **total of 12 photographs**). Please share your chosen images with me, either via email (md22822@essex.ac.uk) or [redacted] images will be checked for identifiable details (people, places) and against the other criteria listed on page 3. Any photographs which do not meet these criteria will be removed and will not be used for the remaining research activities. Any physical copies of these photographs will be returned to you at this point.

Some useful questions to ask yourself when selecting your chosen images are:

- What do I see in this picture?
- What does it represent to me?
- How does this answer the prompt questions in the box on page 1?

Remember, the most important part of this photovoice research is the story that belongs to your photos!

It's not about choosing the most beautiful photos, but the ones which have the most meaning to you in response to the prompt questions.

Writing your captions

Please write a short description of no more than 4 sentences (about 50 words) for each of your shortlisted photographs.

Some useful questions to ask yourself when writing your captions are:

- Why did I take this photo?
- What does it represent to me?
- Why is this important to me?
- What would I like people to know about this?

Here are some examples from the photovoice.org Care Leavers in Focus project (2020):

"Love can come from many places, its not only through families. Care leavers should be supported to find love and their identity in things that make them feel good – hobbies, nature, friendships. Through these things, we can learn to love ourselves. In this way, love really has no boundaries."

"The colours of the leaf stand out like I do. This is how it feels when you have care experience. CAMHS is positive but we need more mental health support."

Group discussion

The group discussion will take place at [redacted] on either 30th or 31st July 2024 and will include up to 4 research participants and the researcher. Our discussion will be audio (voice) recorded, as this will help me to then analyse the main themes for my research write up. The group discussion will be quite long, lasting 2 hours, plus a chance for breaks.

Each person will get up to 15 minutes to share their shortlisted photographs and speak about their personal meaning. I will ask some informal questions to guide our discussions and each person will also have the opportunity to write down any comments that they don't want to share in front if the group.

We will then take everyone's photos and categorise them according to common themes that emerge from everyone's individual stories and experiences. We will then make a decision together about which you feel are the most, to least, important themes for the group overall.

Exhibition

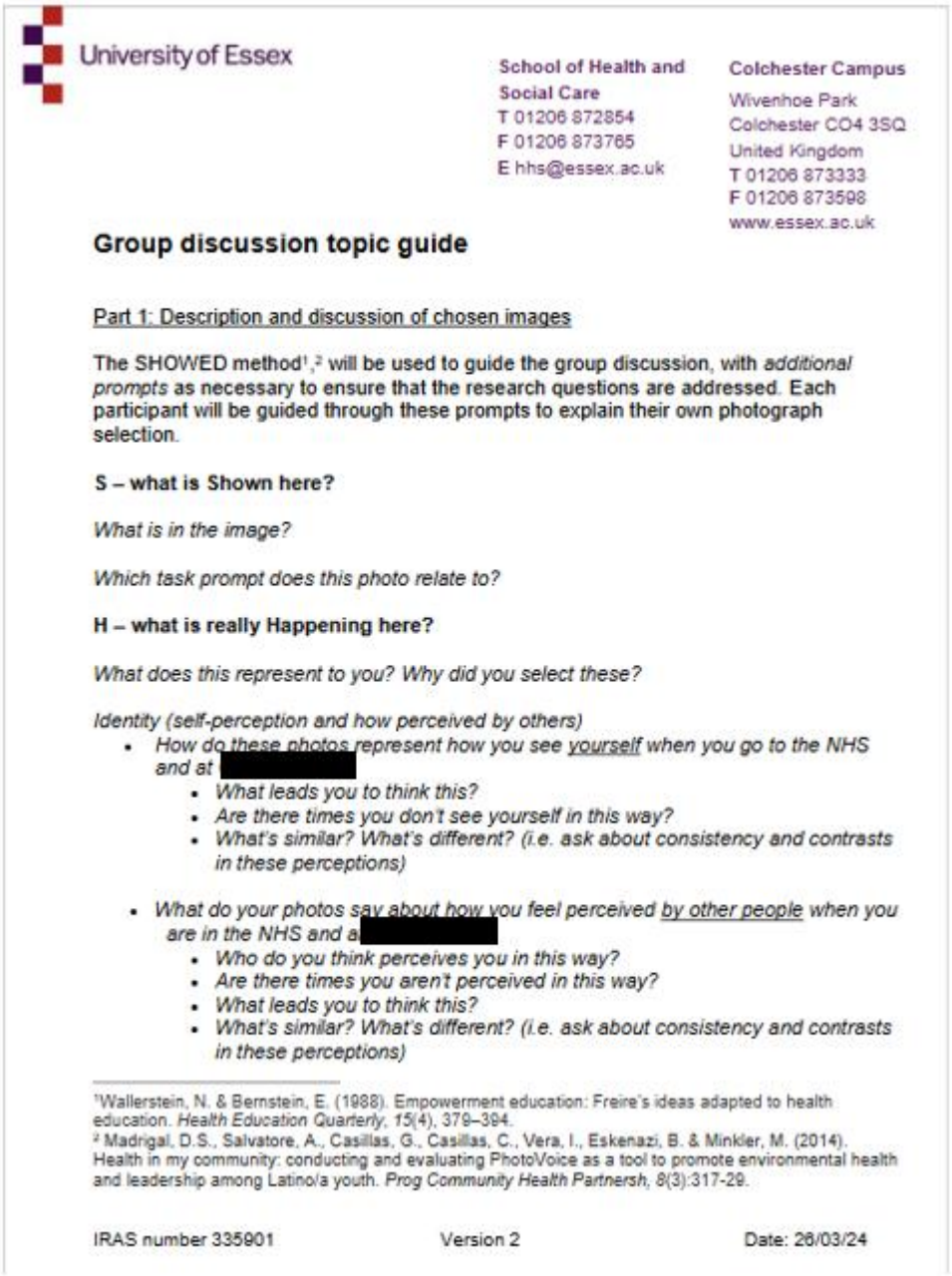
[redacted] hope to exhibit photographs from this research, possibly along with other photographs from any future projects which may stem from this project.

This means I will share your name with [redacted] so that they know that you participated in this research project. This will allow them to invite you to exhibit your photographs with them, if you want to. You may opt-out of exhibiting your images if you prefer, or you can choose to exhibit your image and ask [redacted] to keep your identity anonymous. You will retain ownership of your images.

The details of what you tell me and the group discussion will remain confidential and will only be used for the purposes of the research, as described in the Participant Information Sheet and Consent Form. Questions about this can be directed to me, Melanie Dupin, University of Essex, on md22822@essex.ac.uk

Questions on how and where photographs will be exhibited, and how to opt-in or out of this, can be directed to [redacted]

Appendix L: SHOWED guide and interview topic guide



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School of Health and Social Care
T 01206 872854
F 01206 873765
E hhs@essex.ac.uk

Colchester Campus
Wivenhoe Park
Colchester CO4 3SQ
United Kingdom
T 01206 873333
F 01206 873598
www.essex.ac.uk

Group discussion topic guide

Part 1: Description and discussion of chosen images

The SHOWED method[1],[2] will be used to guide the group discussion, with *additional prompts* as necessary to ensure that the research questions are addressed. Each participant will be guided through these prompts to explain their own photograph selection.

S – what is Shown here?

What is in the image?

Which task prompt does this photo relate to?

H – what is really Happening here?

What does this represent to you? Why did you select these?

Identity (self-perception and how perceived by others)

- *How do these photos represent how you see yourself when you go to the NHS and at* [redacted]
  - *What leads you to think this?*
  - *Are there times you don't see yourself in this way?*
  - *What's similar? What's different? (i.e. ask about consistency and contrasts in these perceptions)*

- *What do your photos say about how you feel perceived by other people when you are in the NHS and a* [redacted]
  - *Who do you think perceives you in this way?*
  - *Are there times you aren't perceived in this way?*
  - *What leads you to think this?*
  - *What's similar? What's different? (i.e. ask about consistency and contrasts in these perceptions)*

[1]Wallerstein, N. & Bernstein, E. (1988). Empowerment education: Freire's ideas adapted to health education. *Health Education Quarterly, 15*(4), 379–394.
[2] Madrigal, D.S., Salvatore, A., Casillas, G., Casillas, C., Vera, I., Eskenazi, B. & Minkler, M. (2014). Health in my community: conducting and evaluating PhotoVoice as a tool to promote environmental health and leadership among Latino/a youth. *Prog Community Health Partnersh, 8*(3):317-29.

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- *Hope and recovery*
  - *What does this tell us about illness, about hope, about recovery?*

O – how does this relate to Our (your) lives and experiences?

How long how you thought of yourself in that way?

What does that mean to you? What is it like to think of yourself in that way?

What is it like to feel that others think of you in that way?

In what ways does this impact your life?

Do you see this changing?

W – Why are things this way?

What contributes to you thinking about yourself in that way when you in the NHS or at [redacted]

What contributes to people's perceptions of you when you in the NHS or at [redacted]

Are there particular expectations, stories or stereotypes about mental health and recovery?

Are there particular expectations, stories or stereotypes about arts and creativity?

Are these things we want to promote or change?

Perceived aids and barriers to recovery

- *What, if anything, helps with your recovery, in the NHS?*
- *What, if anything, helps with your recovery, at* [redacted]
- *What barriers are there to hope and recovery in the NHS?*
- *What barriers are there to hope and recovery at* [redacted]

E – how could this image Educate people? / how can we become more Empowered by understanding this issue?

How would you like to be seen?

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Hopes for optimal services and support - thinking about what we've discussed so far, in terms of what works and doesn't work for you in different settings, what would you like mental health staff to know or do differently?

D – what should be Done about this?

How could that happen?

What are the barriers?

What resources and strengths are there? Where? Who?

Part 2: Photo categorisation task prompts

Following individual discussion of their photograph choices, the group will thematically group their collective images, in accordance with the codifying stage of the photovoice methodology by Wang and Burris (1997)[3].

The group will collectively group the photographs into categorical piles.

- What are the common themes that have come from your photographs?
- How can we group the photos?
- What shall we call the categories?
- Would you like to add a short caption/description of each category?
- Who would you like to see these?
- How shall we rank these categories, from most important to least important?

In accordance with methodology from Jackson et al (2022)[4], each photo can only be assigned to one pile; not all photos can be assigned to the same pile; photos cannot form their own individual pile/category.

[3] Wang, C. C. & Burris, M. (1997). Photovoice: Concept, methodology, and use for participatory needs assessment. *Health Education & Behavior, 24*(3), 369–387.
[4] Jackson, B., Booth, R. & Jackson, K.T. (2022). The Good, the Bad, and the Vision: Exploring the Mental Health Care Experiences of Transitional-Aged Youth Using the Photovoice Method. *Qualitative Health Research*, 32(12), 1915-1931.

Follow-up interview: summary and topic guide for participants

Thank you for agreeing to take part in the recent photovoice task and subsequent discussion group, which was the first part of my research project.

During that group task, we explored:

- how you feel about yourself within different mental health intervention settings, specifically, traditional clinical NHS services and at [redacted]
- how you feel other people perceive you in these spaces;
- I also asked you about what, if anything, in either space offers you hope;
- And lastly, you had the chance to share your views on what you would like clinicians to know.

During the photovoice task and our group discussion, you chose to share these images [have visible on screen] and you spoke about [name their individual key themes]. Did I understand that right?

I'd now like to ask you some questions on an individual basis to get a deeper understanding of your personal experiences (including anything which you could not/did not share in the group, or perhaps differing views to what other participants said).

Specifically, I'd like to ask you about:

- Your experiences of seeking support for mental illness;
- How you feel about yourself in different mental health intervention settings;
- Your views on how making art, attending groups or being in particular environments matters for mental health;
- The things that you think are most important for contributing to keep well and managing your mental health.

Semi-structured interview prompts for researcher

Help-seeking journey

Can you tell me about your experiences of getting support for your mental health?

- Which services have you used before? *[Prompt: refer back to their demographic questionnaire]*
- Which do you use now?
- Do you have experience of going back to services on more than one occasion?
  - If so, what impact did that have on you?
  - How has that influenced how you see yourself?

(If not captured in the above):

How did you come to be a [redacted]? *[Prompts: Can you tell me how that happened? / What made you decide to try a community arts group?]*

- What experience did you have of making art at that point?
- Whose idea was it? What did you think about that idea? *[Prompt: what degree of choice was there?]*
- What is different here to the other services you have accessed?

Identity and self-concept

In the previous photovoice task and group discussion, you explained that in the NHS you feel [xxx] an[redacted] feel [xxx] about yourself.

- Can you give me an example of a time you felt that?
- Are there times when that is different?

Does the way you feel about yourself change if/when you move between both types of intervention settings or in other places? If so, if what ways? *[i.e. if gaining a positive sense of self with[redacted]is that maintained in other settings?]*

In the group discussion, it seemed that many people felt they were not treated as a whole person by the NHS

- Which parts of yourself are most valued or emphasized in the NHS? By whom?
  - How do you know you are valued in that way?
  - Can you remember a particular time when you felt that?
- Which parts of yourself are most valued or emphasized at [redacted]? By whom?
  - How do you know you are valued in that way?

- Can you remember a particular time when you felt that?

- Which parts of yourself are least valued or emphasized in the NHS? By whom?
  - What leads you to think that?
  - Can you remember a particular time when you felt that?
- Which parts of yourself are least valued or emphasized [redacted] By whom?
  - What leads you to think that?
  - Can you remember a particular time when you felt that?
- What parts of yourself do you choose to show or not show in each setting? *[Prompts about group discussion on masking]*
  - What makes that happen?
- What impact does this have on you, if different parts of yourself are valued or emphasised in different places?

What matters: intervention type, place or people?

What does [NHS mental health services] [redacted] offer you, which the other cannot? *Vice versa*

Do you make art anywhere else?

- Where?
- With whom?
- How does making art support your mental health?
- How do you think and feel about yourself when you make art?
- What does making art mean to you?

How does [redacted] compare with other art groups, which are not specifically aimed at supporting mental health?

How do other mental health groups (e.g. peer support groups; group therapy) compare with [redacted]?

What are the most important things in your life that contribute to your mental health? *This may include services and groups but it may also include friendships, family, hobbies etc.*

- How do these impact your sense of self?

Is there anything else you would like to tell me that I have not asked about?

Thank you for taking the time to participate in my research.

Appendix M: Transcript excerpt, Discussion group 2 (31 July 2024)

30:06:40 [Researcher] Which brings us to the next part actually, which is about how you feel at [art centre].

[Image and quote projected on screen]

I'm no longer 'High and Dry'. The support from [redacted] allows me to float. The tide will go out again, but I know exactly when it is due back in.

30:12:31 [Jenny] So I'm just, was down at the sea front and I saw boat that was high and dry and I looked around and there were a lot of other boats as well. And then as I walked back I saw that the tide was in. It's kind of like, so yeah, obviously this tide goes in and out all the time, but I think with here, there is a definite there's a schedule that's kind of like you know where it is and you know when you're meant to come. You know what's expected of you. They know if and I don't have to be my acceptable self, so I still do

police myself, I have to say. There are many times when I think ooh, don't know. I mean, there was, last week I was sitting in the studio on Tuesday afternoon and I did find it quite hard, quite noisy, so I thought, but I don't want to leave. So, I put my headphones in, listened to some music for a little while, and then I felt OK, but I felt, but I did feel very much like, oh am I being really rude by doing this or but it's coming like this is a place where you can do those things, yeah.

31:26:16 [Helen] It's acceptable.

31:28:61 [Researcher] Yeah. So, so here you've got more freedom to do what you need to do and so your needs…

31:34:27 [Jenny] Yeah to say I need a bit of quiet at the moment, I just need to step outside, or you know, without everyone going 'ooooooh'.

31:40:04 [Researcher] Whereas elsewhere in policing yourself, it's that kind of questioning? 'Am I being rude? How will other people feel about this?'

31:47:95 [Jenny] Yeah, elsewhere I wouldn't have done that. I would have said no Jenny, you have to deal with whatever's going on.

31:53:36 [Kate] Push yourself to the edge, don't you?

31:56:73 [Jenny] Yeah. And then and then it'd be like [breathes in and pulls stressed facial expression].

32:00:78 [Researcher] Yeah, so here you can be yourself. And what… what contributes to that, do you think what allows that to be?

32:07:31 [Jenny] Think it's, you know, like we'll you know that everybody else here has similar very different experiences. We're all, it isn't, you know, it's the fact it's a mental. It's not just an art place. It is a mental health art place. But it is…

32:26:98 [Helen] The emphasis is the art.

32:30:83 [Jenny] Is the art, yeah. But it's a safe place. I think if it was just art, it would be, it would be different. I have been to many art classes and joined many art things. And again I've kind of policed myself.

32:49:66 [Researcher] Yeah. So, there's something unique in this setting?

32:52:41 [Jenny] Yeah and I've been away from it for a long time and I've just come back since it's reopened here and it's like it's just like coming back. You know, you don't feel like oh it's all changed, you know the same people are here, you get, you feel like you could. You're always part of it doesn't matter how long you've been away, you just come back and it's like, oh, you know

33:15:94 [Helen] It’s like coming home.

33:16:09 [Jenny] It is. That is how it feels. And nobody says ‘where have you been, we haven’t seen you for years’. It’s just like oh hello, come in, you know.

33:28:51 [Researcher] Yeah. That sounds very different to what we were talking about earlier where there’s just kind of categories and expectations.

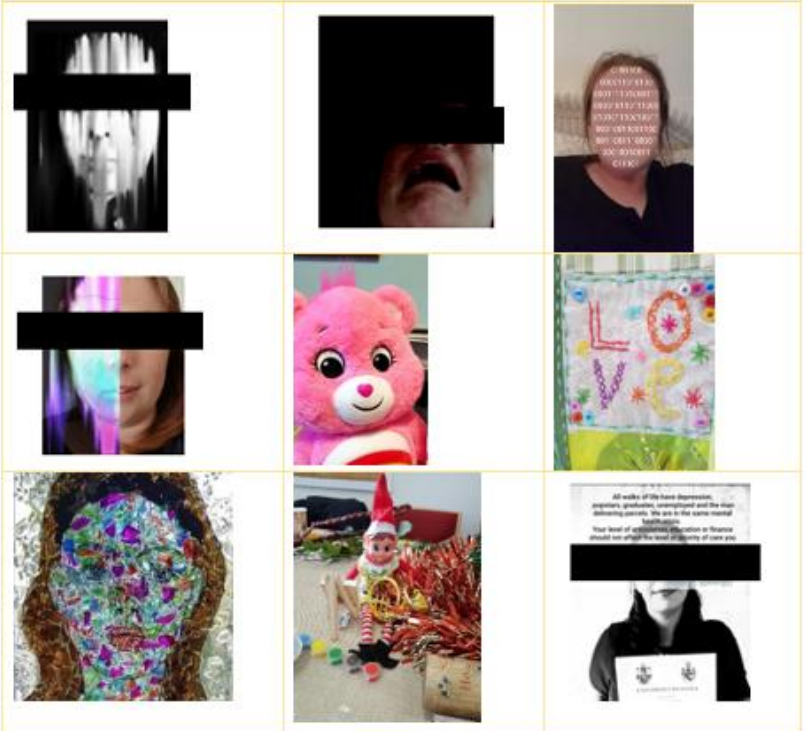
33:36:19 [Jenny] Exactly. Sort of ‘Oh well, you haven't been here for a long time, so you'll have to go on a waiting list and we’ll see if we can fit you in’. You know, it's never like that. If you speak to [staff name], it's like, yeah, fine, it's never problem. It's like always, or if they can’t do it, they’ll find something else that you can do.

33:51:36 [Helen] That you can do.

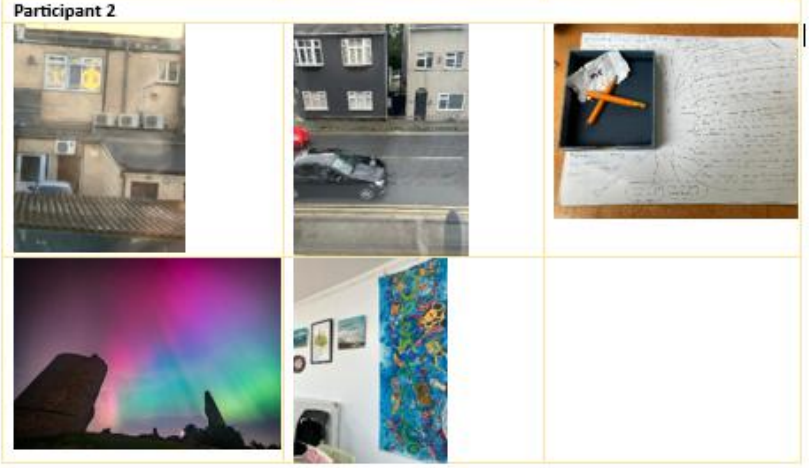
33:54:48 [Jenny] Never been told ‘No, sorry go away’

Appendix N: Participant photographs

Participant 1



Participant 2



Participant 3



Participant 4











Participant 5







Participant 6





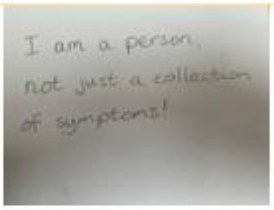






Participant 7





Participant 8




Participant 9







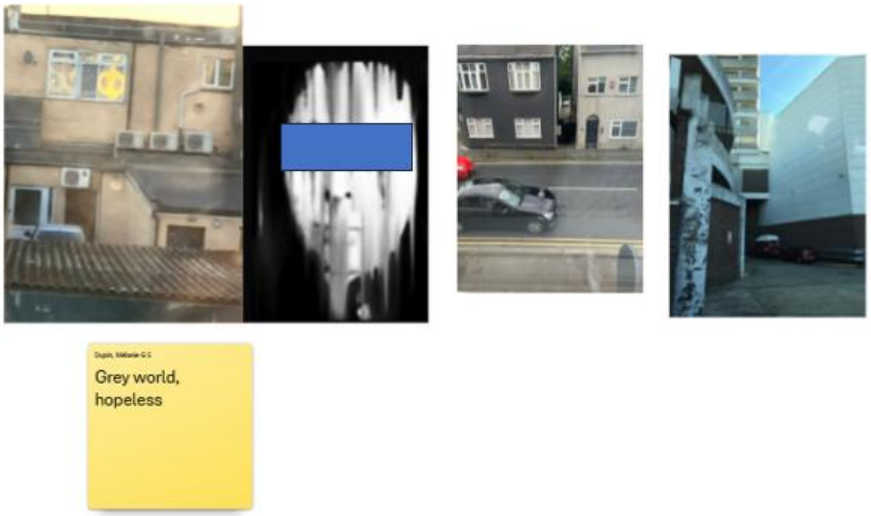




Appendix O: Participant-led group categories of photographs during the codifying stage

Participant photo pile task, carried out on Microsoft Whiteboard, via projector, during discussion groups, where participants grouped images which represented similar messages

Group 1:



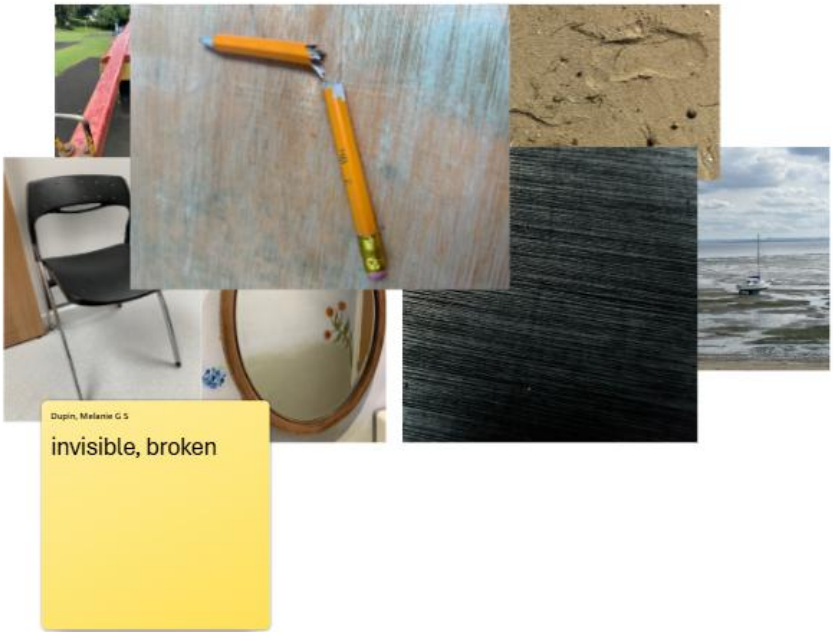
Dupin, Melanie G S

acceptance, merging, masking

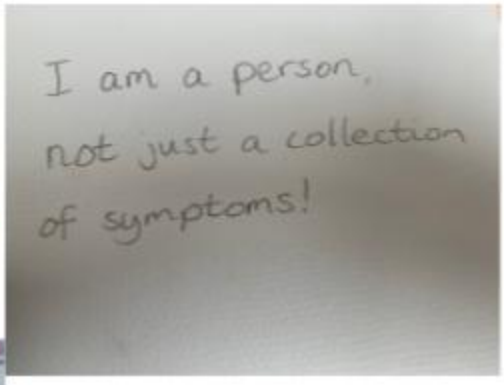
Dupin, Melanie G S

awareness

Group 2:


Dupin, Melanie G S
invisible, broken


Dupin, Melanie G S
intersectional -
parts of self treatted
together
treated as a whole
holistic (hope for
services)



Dupin, Melanie G S

current - not a whole person approach

Dupin, Melanie G S

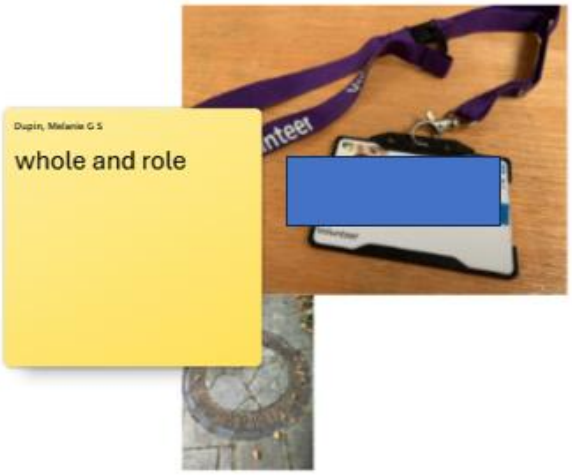
hopeful pathway, open, structure

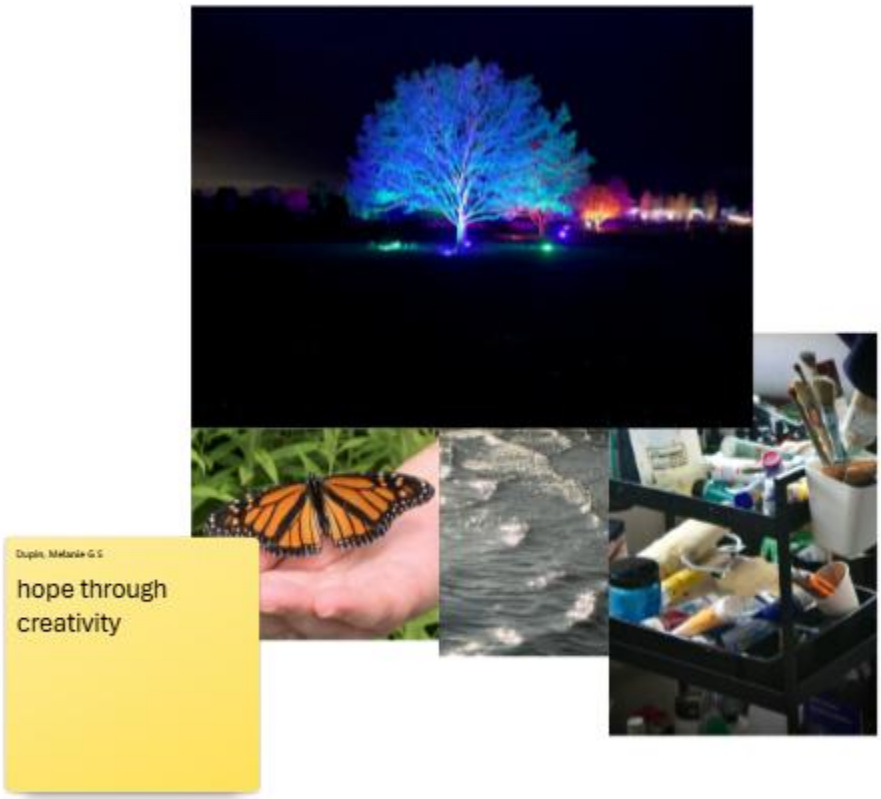
Dupin, Melanie G S

community

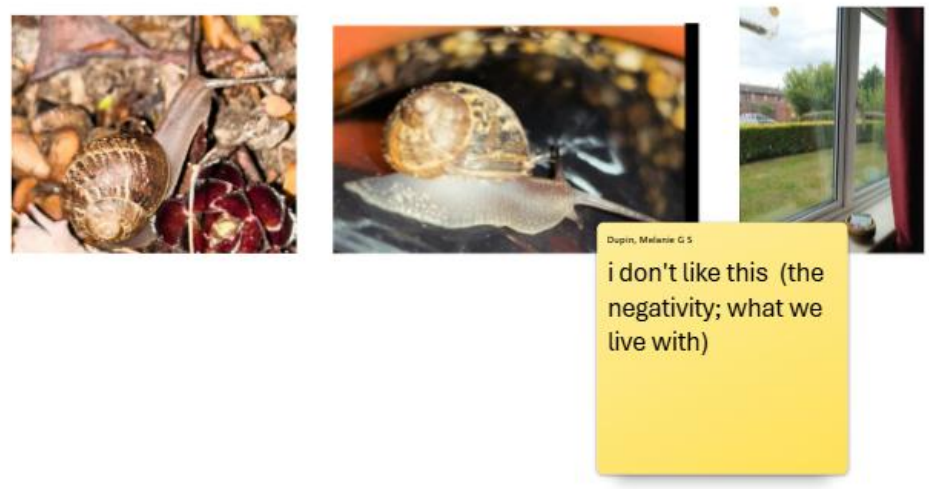
Dupin, Melanie G S

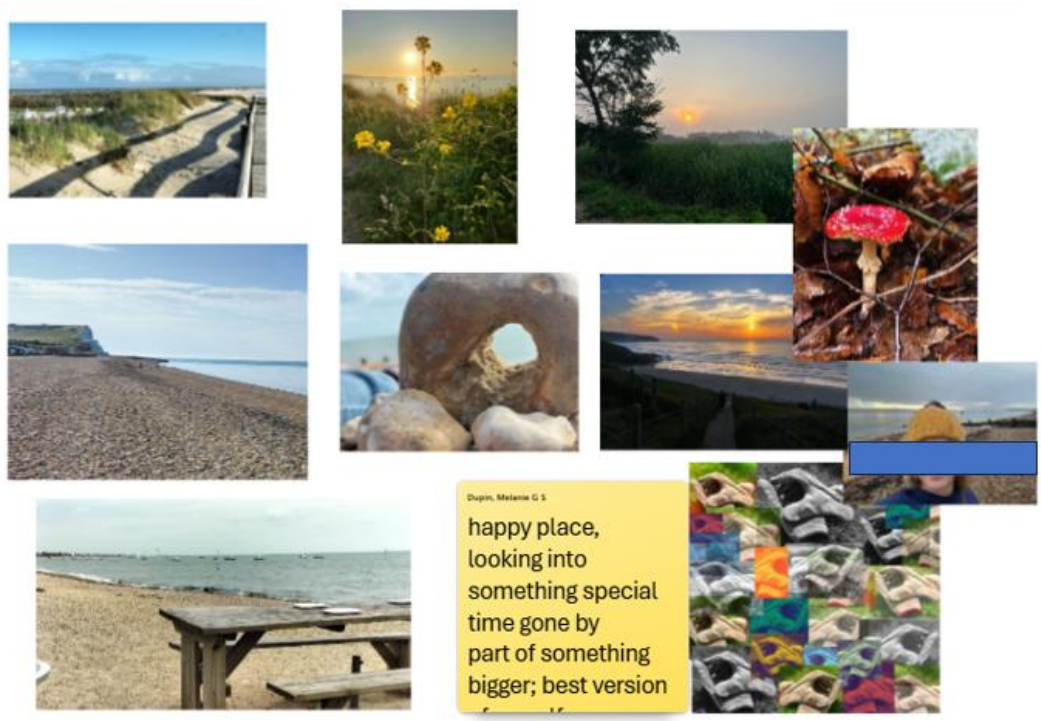
hope, fulfilment, individuality


Dupin, Melanie G S
whole and role


Dupin, Melanie G S
hope through creativity

Group 3:


Dupin, Melanie G S
i don't like this (the negativity; what we live with)


Dupin, Melanie G S
happy place, looking into something special time gone by part of something bigger; best version

Dupin, Melanie G S

this is me

Dupin, Melanie G S

the whole person - more than just my struggles