

Portfolio Volume 1: Major Research Project

Falling Through the Cracks:
A Constructivist Grounded Theory of How Service
Provision Impacts the Experiences of Those with Co-
Occurring Mental Health Difficulties and Problems with
Substance Use

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Glossary of Terms

Clinical Commissioning Group (CCG): The majority of NHS England's budget is allocated to CCGs; they have responsibility for commissioning (assessing healthcare needs of the area, planning service format, procuring services and then monitoring their quality and performance). In 2021/2022 CCGs are being incorporated into integrated care systems (ICS), following new plans from NHS England.

Commissioning Support Units (CSUs): Following a number of merges, there are now five CSUs in England and they are governed by NHS England. They provide services for a range of organisations that include local authorities and hospitals as well as CCGs and NHS England, and they are increasing their support to whole systems rather than just individual organisations.

Community Mental Health Team (CMHT): Usually a team of many different professionals who provide assessment, diagnosis, treatment and follow up for people with 'severe and complex' mental health difficulties, in a community setting.

Department of Health and Social Care (DoH): UK Government department responsible for government policy on health and adult social care matters in England. NHS England is one of the arms of the department, setting the framework for commissioning of healthcare services.

Drug and Alcohol Service: There are many different types of drug and alcohol services, some provided by the NHS, others by third sector organisations or charities. Usually, these will provide information and advice about substance use, as well as recovery planning through offering pharmacological, psychosocial and structured treatment programmes.

'Expert by Experience' (EbE): The notion that people can become experts on an issue through their own personal experience rather than through professional development learning, research, or by working closely with people who are personally affected by that issue.

Fellowship Meetings: e.g., Alcoholics Anonymous (AA), Narcotics Anonymous (NA), Cocaine Anonymous (CA). These groups tend to have a Christian underpinning and offer peer support through a 12-step programme framework. Anyone who expresses a desire and determination to stop using substances can attend meetings of any fellowship.

Harm Reduction: Describes a range of approaches, measures and supports that aim to reduce the risk and harm associated with substance use, as opposed to punitive action. Peer education and peer support have been and are crucial to the development of harm reduction practices.

Health and Wellbeing Boards: Formal committees of the local authority, tasked with promoting greater integration and partnership between the NHS, public health and local government. They have a statutory duty, with CCGs, to produce a

joint strategic needs assessment and a joint health and wellbeing strategy for their local population.

Integrated Care System (ICS): Evolved from STPs and take the lead in planning and commissioning care for their populations and providing system leadership. They bring together NHS providers and commissioners and local authorities to work in partnership in improving health and care in their area.

Local Authority: An organisation that is officially responsible for all the public services and facilities in a particular area. There are 152 local authorities across England, who are responsible for commissioning publicly funded social care services. Since 2013, local authorities have also been responsible for commissioning many public health services, including drug and alcohol services.

National Health Service England (NHS England): Is made up of seven regional teams which have strategic oversight across NHS services in England, as well as responsibility for some direct commissioning of specialist services and primary care. NHS England is responsible for monitoring and assuring the quality of CCG commissioning through a yearly assessment process.

National Institute for Health and Care Excellence (NICE): An executive non-departmental public body of the Department of Health and Social Care in England that published guidelines relating to the use of health technologies,

clinical practice, guidance for public sector workers on health promotion and ill-health avoidance, as well as guidance for social care services and users.

Primary care: Services that a person usually first sees when they have a health problem. For many people with mental health difficulties or problems with substance use, this is often a General Practitioner (GP) or an Improving Access to Psychological Therapies (IAPT) service. Primary care is based on caring for the person holistically, rather than standalone difficulties. Primary care refer on to more specialist services if needed.

Primary Care Networks (PCNs): Forming the building blocks of the NHS long-term plan (NHS, 2019). They consist of a number of general practices, with the purposes of integrating with the wider health and care system.

Public Health England (PHE): An executive agency of the Department of Health and Social Care which fulfils the Secretary of State for Health and Social Care's statutory duty to protect health and address inequalities, and to promote the health and wellbeing of the population.

Recovery: A journey for people away from the harm and the problems which they experience, towards a healthier and more fulfilling life (Scottish Government, 2018).

Relapse: Substance use after a period of more controlled use or abstinence.

Secondary Care: Services provided by healthcare professionals who generally do not have the first contact with a service-user. Secondary care services are usually based in a hospital or clinic, though some services may be community based. They include mental health services, such as CMHTs.

SMART Recovery: Similar to fellowship meetings, but promote a 'secular' 12-step programme to aid recovery from substance use.

Sustainability and Transformation Plans (STPs): NHS organisations and local authorities in different parts of England came together to develop 'place-based plans' for the future of health and care services in their area. However, most STPs have now evolved into Integrated Care Systems (ICS).

Third Sector Organisations: An umbrella term for organisations that are neither public nor private sector. This includes, voluntary organisations, community organisations, registered charities, co-operatives and social enterprises.

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Abstract

Existing literature focusing on co-occurring mental health difficulties and problems with substance use predominantly focuses on prevalence and associated risk factors. This research aimed to explore how service provision impacts the experiences of people with both mental health difficulties and problems with substance use, living in Luton. Semi-structured interviews were carried out with 10 adults, with current or historic experiences of co-occurring mental health difficulties and problems with substance use. Data was analysed using a Constructivist Grounded Theory (GT) methodology. A theoretical model was co-constructed, showing process-oriented understanding of participant experiences. These experiences were categorised as social processes between participants and structural issues; 'Navigating Services Working in Silos', service level issues; 'Swallowing the Jagged Pill' and interpersonal interactions; 'Doubting Adequacy of Support'. Through collaborating, understanding and trusting, other processes were facilitated, such as, 'Becoming One of the Lucky Ones', underpinned by 'Benefitting from Relationships'. The research goes beyond existing literature, focusing on the direct impact of wider structures, discourses and political agendas affecting service provision. The GT model presented presents dynamic interactions of social processes and mechanisms that help to explain how and why individuals might remain 'stuck' within service provision, and why some can benefit and, consequently, move forward with recovery. The importance of positive relational interactions has been highlighted as key to support being beneficial to those accessing services. The findings have led to recommendations for anyone working with this group, as well as policymakers and commissioners.

Keywords: Substance (mis)use, dual-diagnosis, service provision, mental health difficulties, mental health services

1. Introduction and Systematic Literature Review

1.1 Overview

The main aim of the introductory chapter is to give the reader contextual information surrounding experiences of service provision for people with mental health difficulties and problems with substance use, leading to a rationale for the research. Relevant terminology and concepts relating to co-occurring mental health difficulties and substance use will be introduced, as well as explaining the personal interest of the researcher in the field and their epistemological stance. The researcher will summarise published literature in the field and issues relating to service provision in the United Kingdom (UK) and more specifically, Luton (Bedfordshire). A systematic review of the literature will provide evidence relating to first-hand experiences of accessing services for people with both mental health difficulties and problems with substance use. The chapter will end by clearly stating the rationale and aims for the research project.

1.2 Personal Interest of the Researcher

Societal narratives and attitudes towards substance use have been a longstanding interest of the researcher. Their undergraduate dissertation focused on healthcare professionals' attitudes towards patients admitted to general hospitals with 'substance dependency'. The researcher has experience of working in a number of mental health services, and observed, from a professional perspective, how the use of drugs and/or alcohol can become a barrier to accessing mental health support. In terms of personal familiarities, the researcher has acted as an advocate for a close family member and an ex-partner, who have struggled to access mental healthcare services due to having problems with substance use. These experiences will have

undoubtedly shaped conscious and unconscious biases that may impact the research. However, the chosen inductive methodology has allowed the researcher to stay very close to the data and this is expected to minimise the impact of personal experiences on the findings. A reflective diary has been maintained throughout the project and supervision from the research team has been utilised to consider biases and potential blind spots.

1.3 Epistemological Position of the Researcher

A statement outlining the epistemological stance of the researcher is integral to the transparency of the research. The works of Thomas Kuhn, Lev Vygotsky, Kenneth Gergen, Gregory Bateson and George Herbert Mead, amongst others have provided a foundation from which the researcher has been able to form their own tangible theory of knowledge. It is understood that interactions with others impact our way of being and in turn, sense of self is developed through relationships. Language is integral to the relational nature of human sense-making and the creation of knowledge. An important foundation of this research is the idea that knowledges are constructed *between* the researcher and the interviewee and shaped by the lived experience of both parties, from which it is not possible to separate. The research will endeavour to embrace multiple layers of knowledge co-constructed through the interview process.

The researcher's epistemological position aligns most with Critical Realism. This postmodern approach corresponds with the researcher's understanding of how subjectivity and interpretation are fundamental and irremovable when understandings of reality are constructed between two people (Charmaz, 2014). In other words, the researcher would not consider that one can be impartial through

any data collection process and the data collected cannot be a representation of any one 'truth' in line with a measurable external reality. The researcher is not seeking for, nor believes in, the possibility of finding a 'truth' or objective reality. It is understood that reality exists separately from human understanding, and the way that is interpreted and described is moulded by individual experiences. For example, the inequalities described by participants in the study are existing actualities, but they are distinct from their own subjective experience. In order for the participants and researcher to make sense of these experiences, they will construct an understanding of the phenomena together through discourse. In other words, knowledge is created between the researcher and interviewee, based on subjective, individual lived experience (Henwood & Pidgeon, 2003).

As has already been acknowledged, the researcher understands the importance of considering their own biases from the preliminary planning stages of the project, throughout data collection, analysis and beyond. They have made conscious efforts to grapple with their own epistemological position and lenses in approaching the project, holding certain power and status within the interviewer/interviewee interaction and co-creation of knowledge. The findings of the research, therefore, will undeniably be influenced by the individual contexts of researcher and participants (Madill, Jordan & Shirley, 2000; Clarke, 2019).

1.4 Terminology and Key Concepts

Nearly two-thirds of people starting treatment with drug and alcohol services, in England, between 2020-2021 said they had a mental health difficulty, 25% of which were not receiving any mental health support (Office for Health Improvement and Disparities, 2021). Of the people who indicated that they were receiving mental

health treatment, 55% of people said this was through a primary care setting, such as a General Practitioner (GP) surgery. At the present time, drug and alcohol services commissioned by Clinical Commissioning Groups (CCGs) in the UK, are not responsible for mental health assessment and treatment (Heath, 2014). There is evidence to suggest that mental health difficulties are experienced by the majority of people who have problems with drug (~70%) and alcohol (~86%) use (Weaver et al., 2003; Delgadillo et al, 2012). In the UK, individuals are frequently excluded from mental health services until they resolve their drug or alcohol problem and excluded from drug and alcohol services until their mental health problems have been addressed (Black, 2021). Adequate support for individuals with coexisting mental health and substance use problems has been a longstanding issue in the UK and debate rages on as to how services should be provisioned (Neale, Sheard & Thompkins, 2007; Lawrence-Jones, 2010; Alsuhaibani et al., 2021).

The term 'dual-diagnosis', has been commonly used to allude to individuals experiencing concurrent mental health and substance use problems, since the early 1980s (Caton, 1981; Pepper, Kirshner & Ryglewicz, 1981). 'Dual-diagnosis' is a recognition of a wide spectrum of co-existing difficulties, which can vary from an individual experiencing low mood following the use of 'recreational' stimulants to 'severe and enduring' mental health difficulties and chronic use of 'hard drugs' such as heroin (Department of Health and Social Care [DoH], 2002; Bryant-Jefferies, 2006). Despite the ambiguous nature of the term, it remains synonymous with people not 'engaging' with services, having 'complex needs' and displaying behaviour deemed to be 'challenging' (Pawsey, Logan & Castle, 2011). The prevalence of co-occurring substance use and mental health difficulties is unclear, due to differences in how 'dual-diagnosis' is defined (Lowe & Abou-Saleh, 2004;

National Institute for Health and Care Excellence [NICE], 2016). The process of 'diagnostic overshadowing' is also thought to add to the poor understanding of prevalence; healthcare professionals should reflect on their own biases and the role they could play in 'diagnostic overshadowing' (Nash, 2013; Stoklosa, MacGibbon & Stoklosa, 2017). For example, a clinician may assume that 'psychotic symptoms' are a direct result of longstanding drug use, when perhaps the voice hearing started prior to drug use, and using drugs has been a way to help the person cope.

Despite the many inconsistencies within the literature (Drake et al., 2001; Roberts & Corcoran, 2005), individuals labelled with 'dual-diagnosis' have been found to be more likely to experience inadequate service provision, including, inconsistent clinical interventions and being regularly signposted to alternative providers (Velleman & Baker, 2008). The majority of research looking at prevalence of 'dual-diagnosis' are with forensic populations, i.e., people detained in prisons or in the criminal justice system. 'Dual-diagnosis' has long been identified as disproportionately higher in prisoners, compared to the general population. A study conducted in UK prisons, found 80% of prisoners across 131 prisons in England and Wales had co-occurring mental health difficulties and historic or current problems with substance use (Office for National Statistics [ONS], 1998). The term 'dual-diagnosis' has only been used by the researcher when searching existing literature in the field. It has not been used when advertising the research to potential participants or during data collection. That being said, it has not been overlooked that the term 'dual-diagnosis' has played a part in highlighting the need to support co-existing difficulties and is a step toward promoting collaboration between mental health and substance use services (Guest & Holland, 2011).

It is important to recognise how substance use is defined, quantified, experienced and perceived in research and healthcare services. Common terminology includes; 'addiction', 'dependency', 'abuse', 'misuse' and 'substance use disorder'. For the purposes of this research, a 'problem with substance use' will be identified by the participant themselves, i.e., the use of drugs and/or alcohol is having or has had a negative impact on their life. The word 'misuse' infers a judgement with regards to whether use of a substance is helpful or detrimental to an individual. 'Problems with substance use' has been identified as preferable terminology, moving away from language that can perpetuate stigma (Scottish Drugs Forum [SDF], 2020). The vast majority of the population use drugs and alcohol in some capacity, so the chosen terminology hopes to distinguish self-identified 'problematic' use of substances. In addition, 'substances' will be all encompassing and refer to pharmaceutical drugs (e.g., opioids, benzodiazepines), illicit drugs (e.g., heroin, cocaine), 'legal' highs (e.g., solvents, mephedrone) and alcohol. Problems with nicotine or caffeine use have not been captured in the research.

Literature in the field of mental health is vast; frequently used terminology for mental health difficulties include: 'mental illness', 'mental disorder' and 'mental ill health'. Specific diagnostic terms are also used, such as, 'psychosis', 'depression', 'anxiety', 'personality disorder' and variations of which, are defined as diagnoses in diagnostic manuals such as, *The Diagnostic and Statistical Manual of Mental Disorders* (5th ed.; DSM-5; American Psychiatric Association [APA], 2013) and *The International Classification of Diseases* (11th ed.; ICD-11; World Health Organisation [WHO], 2019). Such terminology is commonly used by healthcare professionals, researchers and people with lived experience of distress. However, the postmodernist perspective of the researcher would endeavour to move away from a

seeming requisite for healthcare services to categorise individual experiences of psychological distress (Crossley, 2005). This is in no way to deny lived experience, but an attempt to remove the invitation to reduce a person's experiences to a single word or phrase, where there tends to be an assumption of shared understanding. That being said, the phrase 'mental health difficulties' will be used throughout, when a participant has self-identified experiencing psychological distress.

1.5 Socio-Political Context of Drug Use

It is important to consider how cultural, political and social contexts have shaped societal narratives around drug and alcohol use and how this in turn, shapes our attitudes and behaviours, which naturally filters through to healthcare service provisions. The 'war on drugs' began in the United States (US) with Henry Anslinger who commanded the Treasury Department's Federal Bureau of Narcotics. Anslinger's regime (1930-1962) was undeniably fuelled by racism, targeting Chinese and Black communities, demonising drug use through the media, as well as mass detention and murder (McWilliams, 1991). The 'war on drugs' was rather a war on people who use drugs, a mechanism to criminalise and marginalise. The Nixon (1969-1974) and Reagan (1981-1989) administrations spread the war on drugs from the US, across the world to South America, South-East Asia and the Middle East. Communities in these areas have experienced widespread violence and poverty at the hands of the 'war on drugs', without any notable reduction to drug production, trafficking or harms caused by drug use. The 'war on drugs' continues to be a powerful political tool used to control vast populations (McWilliams, 1991).

The United Kingdom (UK) is no exception, the 'war on drugs' tends to be spoken about in the context of debate around de-criminalising drug possession or

legalising and regulating certain drug use. In response to an independent report conducted by Dame Carol Black, a 10-year drugs plan was set out by the UK Government in 2021. As a foreword to this 'plan for real change', the Prime Minister, Boris Johnson, highlights 'drug misuse' as costing the UK £20 billion a year. He references 'innocent families whose home are broken into by addicts seeking to feed their habits' and that '300,000 heroin and crack addicts in England who...are responsible for nearly half of all burglaries [and] robberies...these serial offenders should be properly punished for the crimes they commit' (DoH, 2021, pg. 3-4). Drug users continue to be branded as criminals, inherently selfish and able to control their use. This is evidence that to this day 'addicts' are publicly shamed and positioned on the lowest social strata.

1.6 Substance Use and Mental Health Difficulties: A 'Complex' Co-Morbidity

There are a number of theories relating to the supposed phenomena of 'dual-diagnosis'. It challenges a number of medical explanatory models, including aetiological understandings of substance use on the occurrence of mental health difficulties, as well as conflicting ideas about the underlying environmental, genetic and biological factors that may contribute. Despite this, there is a consensus in the literature that 'dual-diagnosis' does not represent two distinct difficulties, existing in parallel, but rather substance use and mental health difficulties becoming interlinked and making the overall outcomes worse (Carrà et al., 2015). It is well known that alcohol or illicit drugs are frequently used to cope with or mask a range of psychological and physical experiences. The 'self-medication' hypothesis (Khantzian, 1997; Robinson et al., 2011) would suggest that people with mental health difficulties use substances in order to cope. For example, if an individual

suffers with low mood, they might find themselves using an over-the-counter opioid to elevate their mood.

However, from a phenomenological perspective, it has been suggested that substance use can be seen as an attempt to survive stress or other consequences of mental health difficulties, such as social exclusion and marginalisation (Drake & Wallach, 2000). However, if substance use was effective in relieving or managing mental health difficulties, then there would be no evidence to suggest substance use can, in fact, exacerbate difficulties and worsen outcomes for an individual. There is a catalogue of evidence to suggest substance use can make pre-existing mental health difficulties worse, for example, specific strains of cannabis being linked to long-term psychotic symptoms (Moore et al., 2007). 'For many people with mental health problems it offers a way out of suffering. I actually felt much better about myself and life with the use of drugs. It gave me some control over my psychosis and lifted my mood...[However], the psychosis was considered to be caused by the drug use and nothing could be done until the drug use had stopped.' (Boait, 2021).

Co-occurring substance use and mental health difficulties can manifest in the context of, or lead to, a number of social issues such as; becoming involved with the criminal justice system, compulsory detention, unemployment, homelessness, physical health problems, disability and family breakdowns (Livingston, 2020; Black, 2021). However, it is still not clear whether these findings are causes or consequences of problems with substance use. Experiences of significant childhood adversity (Messina et al., 2007; Levenson & Grady, 2016), long-term stress (Brady & Sinha, 2005) and certain personality traits (Kotov et al., 2010), have been identified as factors that can increase the likelihood of an individual suffering with both mental health difficulties and problems with substance use. Healthcare professionals and

researchers continue to debate the contentious issue of whether substance use is an objective cause of mental health difficulties or vice versa (Tripp et al., 2015; Wahlstrom et al., 2015). A systematic review of the literature looking at how to understand how people with mental health difficulties experience substance use, found that substance use can provide individuals with perceived gains, such as mediating mental health stigma, regaining control to foster a preferred identity, as well as increasing opportunities for being part of a social group (Chorlton, & Smith, 2016).

1.7 Service Provision, Policy and Guidelines

Service provision for people who have severe mental health difficulties and use substances remains inconsistent across the UK, with the frequent retendering of services resulting in changeable treatment pathways and poor continuity of care (Royal College of Psychiatrists [RCP], 2019). Individuals labelled with 'dual-diagnosis' regularly fall between mental health and drug and alcohol services, neither service wishing to offer support and treatment until the 'other problem' has been addressed (Pawsey, Logan & Castle, 2011). This is well illustrated by a quote from a service-user published in a recent independent report into drug treatment provision; 'We can't treat your mental health until we've treated your substance use, we can't treat your substance use until we've treated your mental health...It's one thing!' (Black, 2021). A systematic review conducted by Priester et al., 2016 found that only 7.4% of individuals with 'co-occurring mental health and substance use disorders' were receiving support with both disorders and 55% of people were receiving no support at all.

In contrast to the everchanging landscape of service provision, the published policy and guidelines underpinning healthcare provision for people with co-occurring mental health difficulties and problems with substance use, have remained mostly unchanged, since the turn of the millennium (Hammond, 2006). In 2002, the Department of Health and Social Care (DoH) published the 'Dual-Diagnosis Good Practice Guide' (DoH, 2002), which stipulated that mental health services were responsible for providing integrated care for individuals presenting with co-occurring difficulties (Guest & Holland, 2011). In 2011, NICE published guidelines stating that treatment for both mental health and substance use difficulties should be provided by secondary mental health services (e.g., Community Mental Health Teams [CMHTs]) and specialist advice could be sought from drug and alcohol services, if required. The most recent NICE clinical guidelines (NICE, 2016; 2019) relating to working with people with co-occurring mental health difficulties and problems with substance use, explicitly state;

- *Commissioners* should commission services for mental health difficulties and for substance use and ensure that they have joint strategic working protocols so that people are not excluded from either service because of their coexisting condition.
- *Service providers* are responsible for having policies and training in place to ensure that staff do not exclude people from the service because of mental health difficulties or any problems with substance use.
- *Service providers* should support and train staff to work with people with problems with substance use and mental health difficulties

- *Healthcare practitioners* should not exclude people from a service because of mental health difficulties or substance use.
- People with mental health difficulties and problems with substance use should not be refused care and support from a drug and alcohol or mental health service because of their mental health difficulties or their drug or alcohol use.

Despite clear guidelines calling for integrated support to be provided, unfortunately, the reality for people accessing services seems to be quite different. Subsequent service structures and commissioning appear to have mitigated against integrated provision. Mental health and substance use services are divided, with drug and alcohol services often provided by third sector organisations and funded by Public Health England (PHE), commissioned through local authorities. In 2001, the National Treatment Agency for Substance Misuse (NTA) was established as a special health authority within the NHS. This authority worked in partnership with local commissioners and treatment providers to improve the quality of services. However, in 2012 this agency was disbanded and the budget for drug and alcohol treatment in England was transferred to local authorities, using the public health grant. Local authorities are now tasked with assessing local needs for treatment and commissioning services to meet those needs, to promote population health and address health inequalities (DrugScope, 2013; Heath, 2014).

At the present time, separation of mental health and substance use service agendas have made effective joint working almost impossible (British Psychological Society [BPS], 2012). There are ongoing concerns that since drug and alcohol services have been funded by PHE there is more of a focus on prevention and health at a population level, in comparison to NHS services, which are more likely to focus on treatment at an individual level (Newton et al., 2017). In addition, unlike the

NHS, local authority spending on drug and alcohol services is not stipulated; councils have been forced to cut services due to reduced central government funding (Drummond, 2017). In addition to the barriers which prevent effective joint working, funding to drug and alcohol services has continued to decrease since 2014 (cuts between 30-50%), resulting in widening health inequalities and substantial unmet needs within communities (Black, 2021). Cuts to drug and alcohol services in the context of the COVID-19 pandemic, have resulted in additional pressures on mental health services, emergency departments and GPs, who may not have the necessary knowledge or skills to provide appropriate support (Marmot et al., 2020; Office for Health Improvement and Disparities, 2021).

1.8 Service Provision in Luton

Service provision for people with mental health difficulties and problems with substance use is variable across the UK. For the purposes of this research, service provision in the town of Luton in Bedfordshire will be the focus. As of 1st April 2022, three CCGs (Bedfordshire CCG, Luton CCG and Milton Keynes CCG) have become a single organisation. This CCG is aligned to the BLMK (Bedfordshire, Luton and Milton Keynes) Integrated Care System (ICS), consistent with NHS England's long-term plan (NHS, 2019) and the ICS five-year plan (BLMK CCG, 2021). Integrating health and social care has been on the agenda for more than 30 years but only recently started to gain momentum with the introduction of the Health and Care Bill, (currently in the final stages of Bill passage) which proposes a reform of the delivery and organisation of health services in England. Once passed, the Bill will champion joined-up services and a reduction in the variation in care provision across the country (House of Commons, 2022).

Luton is a relatively small urban area, but one of the most densely populated towns in the UK, home to 213,500 people and ranks 70th most deprived out of 317 local authorities in England (Ministry of Housing, Communities & Local Government, 2019). Luton's highest deprivation ranking (25th) is in the category of 'Barriers to Housing and Services'. Child poverty has increased in the most deprived areas of Luton, with 37% of children living in poverty in comparison to 33% in 2015 (Luton Borough Council [LBC], 2018). The town is culturally diverse, with approximately 55% of the population being from ethnically minoritised groups, with significant Pakistani, Bangladeshi, Indian, East European and African Caribbean communities. Table 1. shows Luton population data by ethnicity, collected in 2019 (LBC, 2022). Luton's population age is younger than average, with a higher proportion of younger people compared to the UK population and a lower proportion of older people. (ONS, 2020).

Table 1.

Table Showing Luton Population Data by Ethnicity

Ethnicity %	2019
White	48.2%
Dual-heritage	5.2%
Asian	34.7%
Black	10.3%
Other	1.7%

Funding for drug and alcohol services in Luton, in line with the national trend, has been reduced yet again this year, totalling a £1 million decrease over the past five years (LBC, 2021). The main drug and alcohol service provider, commissioned

by LBC is funded by a charity which is the largest provider of drug and alcohol services nationally, with 150 services across the UK. The drug and alcohol service are not commissioned to provide support specific to mental health difficulties. There are a considerable number of different mental health service provisions in Luton, including, NHS primary care services, such as GP contact, Improving Access to Psychological Therapies (IAPT) services (provided by a third sector organisation), NHS secondary care services, such as CMHTs and Crisis Teams and NHS inpatient facilities. There have been efforts to implement a 'dual-diagnosis' care pathway to improve joint working across services, but there is still a way to go for this protocol to become realised.

1.9 Re-Imagining Luton

'Re-imagining Luton' is a project currently taking shape across Luton, aiming to look at how mental health services are accessed, with the view to create better links between services. The project is working to develop a new 'front door' or single point of access for mental health support. Organisations involved include the local NHS Trusts, LBC, the CCG, drug and alcohol services, charities, third sector organisations, as well as service-users and carers. This initiative is being funded by a National Lottery grant and the plan for Luton will be based on the Lambeth Living Well approach (Living Well UK, 2019). The Living Well approach has co-production and collaboration at its heart, to utilise the whole system when commissioning services. Luton is still in the early stages of the 'Re-imagining Luton' project, after delays as a result of the pandemic.

1.10 Service-user Experience

There is a lack of empirical evidence based on first-hand experiences of service provision for people with mental health difficulties and problems with substance use. However, the research that is available is consistent in reporting that services are difficult to navigate, and service structures do not match the intertwined nature of 'dual-diagnosis' (Lawrence-Jones, 2010; Searby, Maude & McGrath, 2016). Qualitative research has identified barriers to treatment being related to individuals trying to access services having little knowledge about what is available to them, long waiting times between referral and first appointment and inflexibility of service criteria (Staiger et al., 2011). There has been a call from service-users for a more holistic and individualised treatment approach, for healthcare professionals to see the person 'behind the symptoms' and to include peer support as an integral aspect of treatment (Lawrence-Jones, 2010; Pawsey, Logan & Castle, 2011; De Ruyscher et al., 2017).

Issues that people with mental health difficulties and co-occurring problems with substance use can face have been highlighted in this section. The systematic literature review of empirical evidence will look to identify a gap and scope for a novel research project.

1.11 Systematic Literature Review

1.11.1 Overview.

Literature in the field of co-occurring mental health difficulties and problems with substance use appears to revolve mostly around risk factors and prevalence. There appears to be little exploring how services are provisioned for this group and the resulting impact. That being said, two published systematic reviews have been identified (Ness, Borg & Davidson, 2014; De Ruyscher et al., 2017), which explore

factors that contribute to recovery for people with co-occurring difficulties, some of which directly relate to healthcare services. Both reviews synthesise findings from international research published between 2000-2015. Ness, Borg & Davidson's (2014) review focuses on how individuals with co-occurring mental health and substance use problems describe factors which facilitate and disrupt their recovery journey. The clinical recommendations relate to the importance of individualised, person-centred care when working with this client group. Similarly, De Ruyscher et al's (2017) systematic review explores first-person perspectives of recovery in relation to 'dual-diagnosis'. Four themes are described; the importance of family and peer support, the need for holistic treatment and therapeutic relationship; the importance of personal beliefs and spiritual values; and the value of meaningful activities.

Both reviews provide coherent insights into factors that can facilitate recovery, however, neither of the existing systematic reviews focus specifically on the impact of service provision. In addition, the studies included in each review are from a number of different countries, so the findings cannot be related to specific structural contexts or healthcare systems, underpinned by policy, commissioning and care pathways. In order to understand how healthcare service provision impacts the experiences of people with both mental health difficulties and problems with substance use, a systematic review of peer-reviewed empirical literature was conducted to find existing knowledge to answer the following question;

What are the experiences of people with both mental health difficulties and problems with substance use when accessing healthcare services in the United Kingdom?

1.11.2. Search strategy.

Three bibliographic databases were sought to perform the searches: SCOPUS, CINAHL+ and PsycArticles. The final search strategy was informed by pilot searches in order to capture common terminology and relevant articles. Initial exploration of existing literature informed the decision to narrow inclusion criteria to the UK with only studies published since 2012. Given the socio-political context and huge variation in healthcare provision across the world, it would be a challenge to compare research across countries, informing the decision to focus on research with a sample from the UK. This is also familiar to the researcher, who lives and works in the UK. Two of the studies included had samples made up in part from UK participants, these were included as it was possible to distinguish the data collected from UK participants. The rationale behind the publication date limit was to capture research conducted after the change in funding arrangements and consequent service provision for drug and alcohol services, which became the responsibility of Public Health England in 2012 (DrugScope, 2013). The review focused on first-person experiences of service users, therefore, research exploring the experiences of carers, family members or healthcare professionals was excluded. This is partly due to an overrepresentation of healthcare professional and family members' experiences being portrayed in the evidence base (e.g., Ness et al., 2016; Hughes et al., 2018; Merrick et al., 2022) and first-person service user experiences not being adequately captured in the field. In addition, quantitative studies that did not address lived experience or first-person accounts were excluded from the searches. Due to the limited resources and timescale of the study, only articles written in English were included. A number of search strategies took place before the search terms were

refined (see Appendix A for key search terms used in initial searches). Table 2.

Indicates the final search terms used for this review.

Table 2.

Table Showing Final Search Terms Used in The Systematic Review

Concept	Search Terms
1. Service-user experiences	(experienc* OR narrativ* OR qualitative OR "grounded theory" OR IPA OR "Interpretative phenomenological analysis" OR phenomenology OR "thematic analysis" OR "first hand" OR "first-hand" OR "first person" OR "first-person" OR "service-user*" OR "service-user*")
	AND
2a. Mental health difficulties	("mental health" OR "mental illness" OR "mental disorder" OR schiz* OR psycho* OR depress* OR anxi*)
	AND
2b. Substance use	("drug addict*" OR "substance* addict*" OR "alcohol addict*" OR "substance* *use" OR "drug *use" OR "alcohol *use" OR dependenc* OR alcohol* OR "dual-diagnosis" OR "dual diagnosis")
	AND
3. Service provision	("integrated service*" OR rehab* OR "mental health team*" OR "mental health service*" OR "drug and alcohol service*" OR "substance *use service*" OR "addict* service*" OR "harm reduction")
	AND NOT
	(child* OR adolesc* OR staff OR "healthcare professional*" OR professional* OR nurse* OR doctor* OR carer* OR "family member*" OR relative* OR "sexual health")

1.11.3 Systematic review method.

A review protocol for the systematic literature review has been registered with PROSPERO (ID: CRD42022299986).

Relevant articles were exported from the bibliographic databases into Mendeley reference manager software and screened through a staged process of reviewing titles and abstracts in line with the inclusion and exclusion criteria (see Table 3.). After duplicate articles were removed, a total of 984 articles were screened

using the inclusion and exclusion criteria, after reading the titles and abstracts, 824 articles were excluded. Following this, 36 full text articles were then assessed against the inclusion and exclusion criteria. Of these, six articles met criteria for inclusion in the review. Subsequent reviews of key papers' reference lists and key journals led to two additional articles being included. Therefore, eight articles were included in the current systematic literature review (see PRISMA flowchart, Figure 1). Table 4. summarises key information from each included study.

Table 3.

Table Showing Inclusion and Exclusion Criteria for Systematic Review

Inclusion criteria	Exclusion Criteria
Adult sample (18+)	Sample of children and/or adolescents
Focus on first-hand, individual experiences of healthcare services from the perspective of a service-user	Research exclusively looking at the experiences of carers or healthcare professionals (including friends, family members, befrienders, volunteers)
Sample of participants with identified mental health difficulties AND problems with substance use (drugs and/or alcohol)	Articles focusing on mental health or substance use difficulties/services separately.
Focus on individual experiences of healthcare services when struggling with mental health difficulties and problems with substance use	Articles that described specific interventions or prevalence related to co-occurring difficulties.
Sample or part of participant sample from the UK	International sample, i.e., participant sample from any country other than the UK
Qualitative methodology or mixed-methods design	Quantitative methodology or review, not addressing first-person experiences
Articles published in peer-reviewed journals	Grey literature, systematic literature reviews, narrative review
Article available in English	Articles written in a language other than English

Figure 1.

Figure Showing PRISMA Flowchart of Systematic Literature Search Process

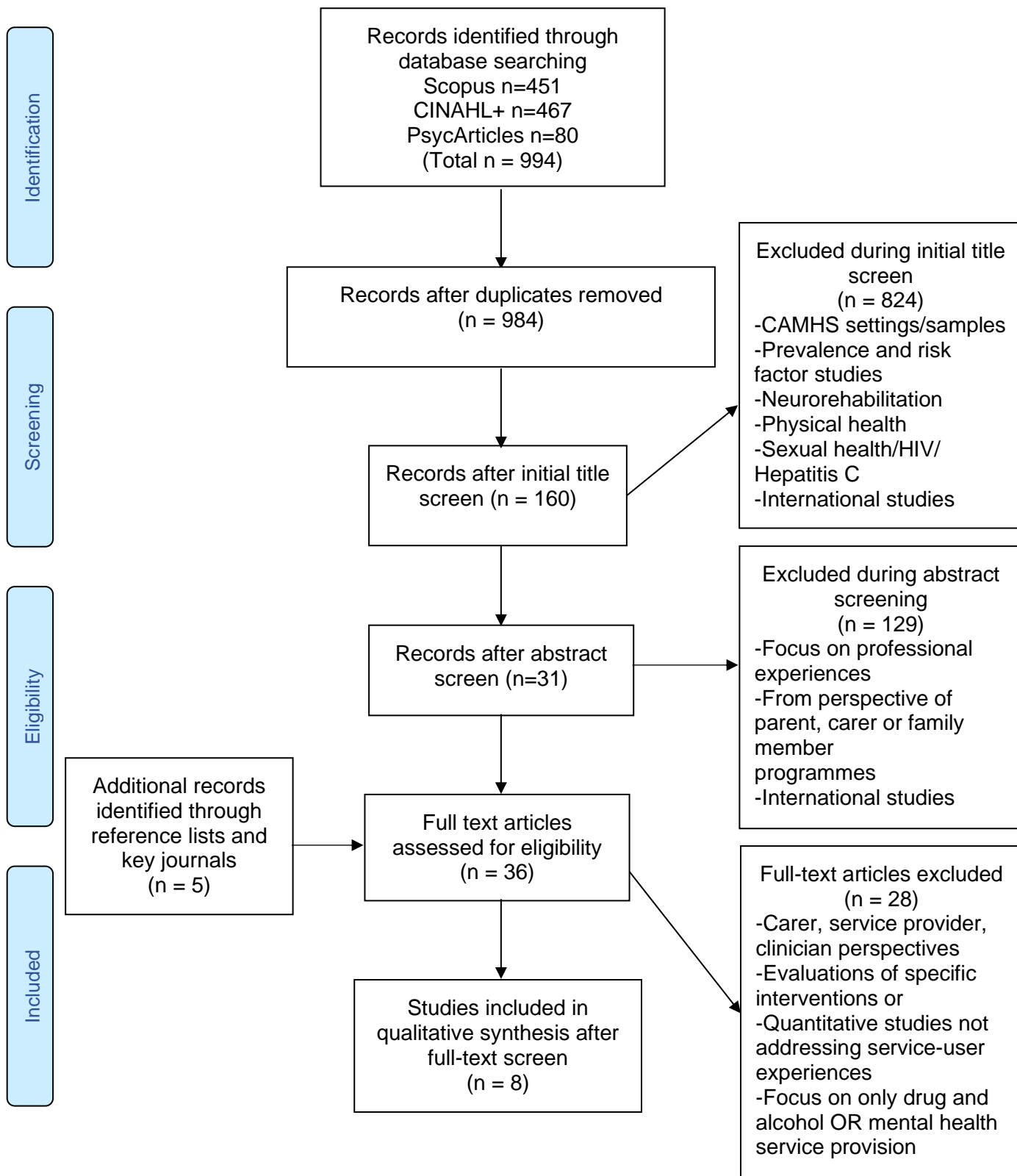


Table 4.*Table Showing Summary of Studies included in Systematic Literature Review*

Authors (Year)	Title	Aims	Methodology	Participants	Key Findings	Strengths	Limitations
Edward, K. & Robins, A. (2012)	Dual Diagnosis, As Described by Those Who Experience The Disorder: Using the Internet As a Source Of Data	To explore personal experiences of people with 'dual-diagnosis' through online forums with the hope to inform treatment options. To inform future research related to quality of life, resilience and coping for this client group	Design: Inductive, explorative, qualitative design Data collection: narrative data collected from online peer support groups for 'dual-diagnosis' Data analysis: Content Analysis used to identify similarities and differences across the data	Authors of the narratives posted in online forums and peer support group websites based in the United States, Australia, UK, Ireland and Thailand 108 statements across the online forums were identified by the research team that related to experiences of 'dual-diagnosis'	The importance of honesty with one's self and others were highlighted as a key theme It was found that people with 'dual-diagnosis' are often expected to independently navigate two differing systems (mental health services and drug and alcohol services) and frequently receive conflicting advice regarding interventions	Personal narratives published online were arguably more detailed and less influenced than they may have been if the data was collected via an interview (sense of freedom, anonymity and security). Arguably making the internet a rich data source Implemented Scott's (1990) quality criteria for assessing and identifying data sources	Only freely accessible, open online forums were used as a source of research The countries hosting the websites have very different healthcare systems which may limit cross-cultural applicability related to the relatively small sample of data

			Direct quotes were taken from the narrative data to support themes		The importance of peer support in recovery was an additional finding	Produced valuable insights related to perceived barriers and enablers to accessing healthcare services	
Elison, S., Weston, S., Dugdale, S., Ward, J., & Davies, G. (2016)	A Qualitative Exploration of U.K. Prisoners' Experience s of Substance Misuse and Mental Health Difficulties, and the Breaking Free Health and Justice Interventions	To explore prisoners' lived experience s of substance use and mental health difficulties, in order to examine how they might be associated with recovery during engagement with services	Data collection: in-depth, semi-structured interviews Data analysis: Qualitative, Thematic Analysis	32 (29 male, 3 female) adult prisoners in the North West of England. Age range 23-56 years old, average age 35.5 years. All White British. Historical substance use of participants included; heroin, crack cocaine, cannabis. Mental health difficulties of participants included; low mood, anxiety,	The findings revealed that prisoners' substance use was framed within difficult and traumatic childhood events. Mental health difficulties were conceptualised as reactions to adverse life events. The majority of participants reported significant difficulties when trying to access support for their	The study provided valuable insights into the difficulties that substance using prisoners have faced in terms of accessing services Inherent subjectivity of the qualitative approach is a strength	UK self-selecting sample of participants, it cannot be assumed that the experiences and opinions are generalisable to the general prisoner population, in the UK or globally Arguably, the recollection of autobiographical experiences can be deemed to be unreliable

				psychotic symptoms	substance use and mental health difficulties. Many stated that prison has given them an opportunity to access support and begin their journey to recovery. Need for more collaborative, inter-agency working		and/or overly subjective
Klingemann, J., Welbel, M., Moskalewicz, J., Nicaise, P., Priebe, S., Matanov, A. & Bird, V. (2019)	Assessment and Treatment of Patients with Comorbidity of Mental Health Problems and Alcohol Use Disorders: Experience	To explore personal experiences of co-occurring mental health difficulties and alcohol use, from the perspective of clinicians	Data collection: in-depth, semi-structured interviews Data analysis: Qualitative, Thematic Analysis	UK patient participants (n=41), Polish patient participants (n=40). Primary diagnosis of a psychotic disorder, affective disorders or anxiety disorders with concurrent	Service-user participants with 'Alcohol Use Disorder' reported receiving minimal support for alcohol use during inpatient hospital admission. Clinical implications: need for	High level of homogeneity of the data collected across the UK and Poland, and between clinicians and service-users, in line with the methodology and suggesting increased validity of the findings	Service-user participants were diagnosed with psychotic disorder, affective disorders or anxiety disorders, people with other co-occurring mental health difficulties and

	s of Clinicians and Patients in the UK and Poland	and patients regarding efficacy of assessment, treatment and organisation of care		problems with alcohol use. Mean age 48 years, 45% female sample, Participants were on a mental health inpatient ward or under the care of a community mental health team	screening instruments in the process of assessment of 'Alcohol Use Disorder', training mental health professionals in how to support motivation and adherence to treatment. More collaboration between mental health and drug and alcohol services needed		'Alcohol Use Disorder' were excluded from the study, which limits transferability.
Matheson , C., Hamilton, E., Wallace, J. & Liddell, D. (2019)	Exploring the Health and Social Care Needs of Older People with a Drug Problem	To identify the healthcare and social support needs of older people with a drug problem in a cross-sectional sample	Data collection: Mixed methods design, using a questionnaire (quantitative) with 28 questions and interviews (qualitative)	Participants (n=123) were between 35-57 years old, injecting heroin, living in Scotland. 76% were male, 91% of the sample reported suffering with depression, 89% with	Of 123 participants, 78.9% lived alone and 91.1% had been homeless at some time. The majority had been in treatment several times with mixed experiences including feeling	The study deliberately used non-NHS facilities as the sampling frame to ensure those not currently using treatment services were included in the sample. The questionnaire	The questionnaire used was not a validated measure, which could be seen as a limitation. The study was focusing on 'older people' but the minimum

		across Scotland.	Data analysis: Quantitative, simple descriptive statistics, chi-square test to compare proportions of subgroups. Qualitative, thematic analysis	anxiety and 53% with chronic pain. Only n=30 participants took part in the interview, in addition to the questionnaire	'forgotten about'. 75.1% had overdosed during their lives. Mental health problems were rated as important by 92% of participants., Isolation and loneliness emerged as a key theme as did stigma, especially when seeking treatment for comorbidities	was tested by the research team and developed in collaboration with an expert working group	participant age was 35 years, which arguably does not constitute an older person population.
Notley, C., Maskrey, V. & Holland, R. (2012)	The Needs Of Problematic Drug Misusers Not in Structured Treatment – A Qualitative Study of	To explore barriers to treatment and reasons for not seeking treatment for people with problematic drug use	Data collection: in-depth, semi-structured interviews (5) and focus groups (6) contained between two and nine mixed age	Participants (n=43, 31 men, 12 women) were not in structured treatment for problematic drug use. Age range 18-45 years. All using class A drugs,	Key reported barriers are related to organisational systems, as well as social and interpersonal factors. Barriers included perception of a long waiting time, stigma and	The researchers undertook a full systematic literature review in order to identify a gap in the literature, clear aims based on the results. Diverse sample of participants,	Sample cannot be considered representative nor generalisable. Relatively small sample, selection bias is inherent

<p>Perceived Treatment Barriers And Recommendations for Services</p>		<p>and sex participants. Data analysis: Qualitative, Thematic Analysis</p>	<p>predominantly intravenous heroin use, but also crack cocaine and amphetamines</p> <p>Focus group participants; homeless group, Portuguese groups x2, needle exchange group, sex worker group, snowballed group</p> <p>Individual interview participant; one person from a traveller community, one homeless person and sex workers (x3)</p>	<p>perceived lack of understanding.</p> <p>Implications for practice: improve advertising parameters of services, including estimated waiting times and information about what to expect. Participants suggested drop-in clinics, appointment reminders, improvements to primary care service provision and a need for outreach work in the community</p>	<p>achieved through purposive sampling, to give breadth of experiences.</p> <p>Findings support previous research looking at barriers to treatment</p> <p>Views expressed may be transferrable to other out of treatment drug using populations</p>	<p>'Over-sampling' of Portuguese population living in Norfolk – specialist translation services available to the research team</p> <p>Focus groups may have limited individual discourse and disclosure</p> <p>Perceptions of barriers may be in relation to historical service use, and may not be relevant to the current service structures following changes</p>
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				Limited demographic information presented in the paper			
O'Sullivan, M., Boulter, S. & Black, G. (2013)	Lived Experiences of Recalled Mentally Disordered Offenders with Dual Diagnosis: A Qualitative Phenomenological Study	To explore the experiences of individuals in medium secure units with dual diagnosis who have been recalled, in order to inform treatment for this population.	Data collection: semi-structured interviews, open-ended questions and non-directive with minimal probes Data analysis: Interpretative Phenomenological Analysis (IPA)	All participants were detained in a London medium-secure unit in the UK (NHS). All participants were adult males, that had been detained under the mental health act after committing an offence, discharged after treatment then subsequently recalled. Self-identified ethnicities; Afro-Caribbean (3), British Caucasian (1)	Five themes were identified relating to identity, control, autonomy and recovery. Clinical implications include increasing service-users' awareness of available post-diagnosis identities, which meet the needs of individuals' lived contexts and promotion of recovery-oriented care in forensic settings.	Interview setting allowed for participants to reflect on their own experiences without fear of judgement or reprisal. Implications: Need for person-centred planning and recovery-oriented care when treating this population. Importance of readiness to change.	Generalisability of this research is limited to the group studied. However, the sample was quite representative of dual diagnosis populations, considering the over-representation of Afro-Caribbean ethnicity and history of polysubstance use This study only examined the experience of male offenders. The

				<p>mixed heritage - Trinidadian, Grenadian and White British (1), age range 26–42 years, primary diagnosis; Paranoid Schizophrenia (3), Schizoaffective Disorder (2) and history of substance use</p>	<p>Results support the integration of service-user values in decision making and giving tools so that they are able to make informed decisions, to bring more autonomy into forensic settings.</p>		<p>experience of females, particularly in relation to substance use, may be quite different.</p> <p>Recruitment bias: clinical team acted as gatekeepers; particular participants representing a certain viewpoint may have been put forward ahead of others</p>
<p>Parkman, T., Neale, J., Day, E. & Drummond, C. (2017)</p>	<p>How Do People Who Frequently Attend Emergency Departments for Alcohol-Related Reasons</p>	<p>To fill a gap in current knowledge by providing insights into how people who frequently attend</p>	<p>Data collection: in-depth, semi-structured interviews</p> <p>Data analysis: A coding frame was developed based on</p>	<p>Participants were recruited from six emergency departments in hospitals across South and West London. The 30 participants included n=18 men and n=12</p>	<p>Emergency department usage over the last 12 months was high, use of specialist addiction services was low. Little evidence of structural barriers</p>	<p>The paper states that the researchers did not seek to convey empirical generalisability beyond the sample, however themes and patterns have the potential to be</p>	<p>Data was derived from a small qualitative study conducted in just one city. As such, their findings cannot be generalised to other locations,</p>

<p>Use, View, and Experience Specialist Addiction Services?</p>	<p>emergency departments use, view, and experience specialist alcohol services.</p>	<p>deductive codes, derived from the topic guide, and inductive codes that emerged from the transcribed interview data. Data indexed to these codes were systematically analysed using Iterative Categorization (Neale, 2016) according to the principles of the Framework (Ritchie & Spencer, 1994)</p>	<p>women, with a mean age of 47.9 years (range 20–68 years). Nineteen participants described themselves as White British; four as Asian British; three as Mixed Race British; three as German; and one as Somali Participants had attended emergency departments between 10-84 times over the past 12 months</p>	<p>preventing participants from attending specialist services, participants seemed not to require help with their alcohol use. When asked what support they desired for their drinking, only 11/30 participants identified alcohol-specific treatment. More commonly, they wanted help relating to psychosocial support and mental health problems</p>	<p>transferrable to other settings. Diverse sample, varying ethnicities, genders and ages</p>	<p>either within the United Kingdom or beyond. All of the participants were recruited via hospitals with specialist alcohol teams. Findings are therefore not generalisable to hospitals without this provision. Rural areas in the UK are likely to have different experiences in comparison to London</p>
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<p>Stott, A. & Priest, H. (2018)</p>	<p>Narratives of Recovery in People with Coexisting Mental Health and Alcohol Misuse Difficulties</p>	<p>To use a narrative approach to explore the process of recovery as an individual journey in a social context, exploring how services may help or hinder recovery.</p>	<p>Data collection: Unstructured interviews Data analysis, qualitative, narrative analysis.</p>	<p>Ten people took part in the study; mental health diagnoses and current substance use was established through self-report. Male (60%), female (40%), diagnoses included depression, borderline personality disorder, post-traumatic stress disorder, anxiety. Alcohol was the primary substance use difficulty. Participants were required to have been under the care of a specialist</p>	<p>Most participants' narratives shared a three-part structure, from a traumatic past, through an episode of change, to an ongoing recovery phase. Change and recovery were attributed to several factors including flexible and practical support from services, therapeutic relationships with key professionals, and peer support. Some participants redefined themselves and their alcohol use in relation to</p>	<p>Originality in exploring recovery narratives of a population which has been overlooked by previous research. The narrative methodology enables the study to draw links between personal stories of recovery and wider social influences, allowing comment on the implications for services.</p>	<p>The research excluded people who recover outside of services, replicating a shortcoming of much research in this area. By only analysing transcripts of recorded interviews, the study neglected possible benefits of using wider narrative material such as diaries, photographs or films. Participant verification of narratives were not used, limiting the extent to which the study can</p>
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				<p>mental health service and drug and alcohol service over the past two years</p>	<p>ideas of what it is to be 'normal'.</p>		<p>claim to be empowering of its participants.</p> <p>The study is the product of its particular context, generalisability of findings is limited.</p>
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1.11.4 Critical evaluation of study quality.

The qualitative studies and mixed-method study were evaluated using the 'Big-Tent' Criteria for Excellent Qualitative Research (Tracy, 2010) quality appraisal tool. This was selected as most appropriate for appraising the quality of qualitative studies with varying methodologies, including; IPA, Content Analysis, Thematic Analysis and Narrative Analysis (Tracy & Hinrichs, 2017) and offered a detailed and in-depth analysis of the quality of body of literature, as opposed to a more standardised but less detailed tool, such as the Critical Appraisal Skills Programme (CASP; 2018). Consideration was given to the value of using an additional quality appraisal tool for the study using a mixed-methods design, such as the Mixed-Methods Appraisal Tool (MMAT; Hong et al, 2018). However, a decision was made to consistently evaluate all studies with the 'Big-Tent' criteria (Tracy, 2010), as the qualitative data was the focus of the review. The quality appraisal framework of the 'Big-Tent' criteria (Tracy, 2010) with detailed evaluative notes is included in Appendix B. A general overview of the quality of studies included in the review can be found in Table 5.

All eight studies included in the review have contributed meaningful knowledge to the evidence base, and the papers were comprehensively presented, with a clear thread throughout. There were no studies excluded from the review due to poor quality. The majority of studies provided clear research aims, with all situating the research in the context of existing literature and identifying a gap that the research would be seeking to fill. The only exception was the paper by Elison et al., (2019), which did not clearly identify originality of the study, or a gap in the evidence base that the research would aid. They did however, comment on the relevance of the research and highlighted the application of the findings to prisons

and healthcare services. Similarly, Matheson et al. (2019) did not state a rationale for implementing a mixed-methods design, and it was not clear how much the quantitative data added to the overall findings of the research. In contrast, Notley, Maskrey and Holland (2012) took a systematic approach to identify a gap in the literature, outlining a comprehensive systematic literature review, undertaken by the authors at the beginning of the paper.

Every study was considered to be rigorous in terms of participant samples, data collection and analysis process used. For example, Edward and Robins' (2012) study used Scott's (1990) quality criteria for assessing data sources. It was also highlighted how multiple members of the research team reviewed the data analysis at different stages; data saturation is defined and acknowledged. Similarly, Klingemann et al. (2019) made reference to the consistency of coding across data sets by utilising the process of memoing, as well as themes being discussed and agreed between the two research teams. Unfortunately, this was not true for all studies; the data analysis was conducted independently by the researcher in two studies (Parkman et al., 2017 and Notley, Maskrey & Holland, 2012), resulting in emerging themes and coding not undergoing checking processes, such as with participants or colleagues. Every study included direct quotes taken from the qualitative data to support themes; this enhanced credibility of the studies. All of the studies gave clear definitions of the terminology use and the concepts that were referenced. However, in one study (Klingemann et al., 2019) some of the language used could be considered pathologising; for example, the use of 'Alcohol Use Disorder' and using an identified diagnosis of a participant to reference their quotes in the results section, e.g., 'PL:F36/psychotic disorder'.

Three studies made significant efforts to obtain a diverse sample of participants, which was in line with the methodologies employed. For example, Notley, Maskrey and Holland (2012) had a diverse sample of participants, which they achieved through purposive sampling; however, the sample was arguably over-representative of the Portuguese population living in Norfolk. Parkman et al. (2017) recruited from emergency departments in South and West London, allowing for a diverse sample of participants with varying ethnicities, genders and ages. In line with the qualitative methodologies of the studies, all were reluctant to convey empirical generalisability beyond the sample, but made the case that themes and patterns have the potential to be transferrable to other settings. All of the studies listed clinical implications and recommendations based on the findings. O'Sullivan, Boulter and Black (2013) were the only paper to reference a specific theoretical structure or model (Social Identity Theory; Tajfel & Turner, 1986). Looking across all the studies White, male voices are more present in the research and people of other ethnicities and women are relatively absent. However, three of the studies do not provide adequate demographic data to confirm this appraisal. A spectrum of ages between 18-65 years are represented across the studies.

The majority of data collected was obtained via semi-structured and unstructured interviews. Notley, Maskrey and Holland (2012) also used focus groups to collect data, although this may have limited individual discourse and disclosure. O'Sullivan, Boulter and Black (2013) were the only paper to comment on the development of their interview schedule, using existing literature in the field and peer researchers to inform the topics/questions. Stott and Priest (2017) were the only paper to comment on interviews being restrictive when collecting data, stating that the study neglected possible benefits of using wider narrative material such as

diaries, photographs or films. Edward and Robins (2012) used the internet as their data source, consent was assumed as the data was publicly available and the researchers' made assumptions with regards to the accuracy and motivation of the written accounts. Matheson et al. (2019) were the only study to implement a mixed-methods design, administering a questionnaire with quantitative elements, as well as semi-structured interviews, this allowed for the largest sample out of all the studies included. However, the questionnaire was not a validated measure, despite comments that it had been widely tested.

Not all papers explicitly commented on the values, lenses or biases of the researcher(s) and transparency relating to chosen methodologies and challenges was rare. The exceptions were Elison et al. (2016), who clearly stated the researchers' intention relating to their epistemological position and not seeking an objective truth, but rather a desire to capture participants' own understandings of their experience. Similarly, Stott and Priest (2017) make reference to their epistemological position, as well as evidencing reflexivity of the researcher by situating the aims of the study and reflecting on researcher biases. Another notable display of sincerity was Notley, Maskrey and Holland (2012) acknowledging the importance for the interviews and focus groups to take place in neutral, non-stigmatising locations. In addition, O'Sullivan, Boulter and Black (2013) were transparent in stating their aims and approach to examine personal lived experience of participants and how they would make sense of those, without pre-identified ideas being imposed on the data. They also gave consideration to the over-representation of black men in forensic services, and reflected on this being apparent in the participant sample. The researcher was also tentative about their role and implicit power dynamic, maintaining sensitivity to the context of data collection.

The majority of studies obtained ethical approval from either a research ethics committee (REC) or a university ethics board. Edward and Robins (2012) stated that they consulted with a University Human Research Ethics committee but were exempt from a formal ethical review due to the research proposing to collect non-identifiable data, with 'negligible risk'. The researchers also suggested that consent was 'implied' due to public availability. However, after considering anonymity, pseudonyms were used, despite the online, non-consensual collection of data. All other studies were clear in stating how they went through ethical approval processes, as well as data protection, to maintain confidentiality and anonymity. A number of studies (Matheson et al, 2019; Notley, Maskrey, & Holland, 2012; Parkman et al., 2017;) compensated participants for their time and involvement, ranging from a £10-£15 gift voucher. Four studies provided transparent information relating to grants and funding for the research (Klingemann et al., 2019; Matheson et al, 2019; Notley, Maskrey, & Holland, 2012; Parkman et al., 2017).

Overall, the studies included should be considered robust and largely of good quality. Therefore, weight can be given to the findings, giving a degree of insight into answering the question; *What are the experiences of people with both mental health difficulties and problems with substance use when accessing healthcare services in the United Kingdom?* However, due to the limited participant samples, the meta-synthesis of findings should be considered as speaking to the particular experiences of participant groups highlighted; the majority of whom were in the criminal justice system, White, male participants. Consequently, the findings speak to a rather more limited overview of experiences of those with both mental health difficulties and problems with substance use in the UK, rather than one which is comprehensive and all-encompassing.

Table 5.

Table Showing Evaluation of the Quality of the Studies According to the 'Big-Tent'

Criteria for Excellent Qualitative Research (Tracy, 2010)

Criteria	Totally Met	Partially Met	Not Met
Worthy topic	7 studies: <ul style="list-style-type: none"> • Edward & Robins (2012) • Klingemann et al. (2019) • Notley, Maskrey, & Holland (2012) • O'Sullivan, Boulter & Black (2013) • Parkman et al. (2017) • Stott & Priest (2018) • Matheson et al. (2019) 	1 study: <ul style="list-style-type: none"> • Elison et al. (2016) 	
Rich rigor	6 studies: <ul style="list-style-type: none"> • Edward & Robins (2012) • Elison et al. (2016) • Klingemann et al. (2019) • O'Sullivan, Boulter & Black (2013) • Parkman et al. (2017) • Stott & Priest (2018) 	2 studies: <ul style="list-style-type: none"> • Notley, Maskrey, & Holland (2012) • Matheson et al. (2019) 	
Sincerity	4 studies: <ul style="list-style-type: none"> • Elison et al. (2016) • Notley, Maskrey, & Holland (2012) • O'Sullivan, Boulter & Black (2013) • Stott & Priest (2018) 		4 studies: <ul style="list-style-type: none"> • Edward & Robins (2012) • Klingemann et al. (2019) • Parkman et al. (2017) • Matheson et al. (2019)
Credibility	7 studies: <ul style="list-style-type: none"> • Elison et al. (2016) • Klingemann et al. (2019) • Notley, Maskrey, & Holland (2012) • O'Sullivan, Boulter & Black (2013) • Parkman et al. (2017) 	1 study: <ul style="list-style-type: none"> • Edward & Robins (2012) 	

	<ul style="list-style-type: none"> • Stott & Priest (2018) • Matheson et al. (2019) 		
Resonance	<p>7 studies:</p> <ul style="list-style-type: none"> • Elison et al. (2016) • Klingemann et al. (2019) • Notley, Maskrey, & Holland (2012) • O'Sullivan, Boulter & Black (2013) • Parkman et al. (2017) • Stott & Priest (2018) • Matheson et al. (2019) 		<p>1 study:</p> <ul style="list-style-type: none"> • Edward & Robins (2012)
Significant contribution	<p>All 8 studies:</p> <ul style="list-style-type: none"> • Edward & Robins (2012) • Elison et al. (2016) • Klingemann et al. (2019) • Notley, Maskrey, & Holland (2012) • O'Sullivan, Boulter & Black (2013) • Parkman et al. (2017) • Stott & Priest (2018) • Matheson et al. (2019) 		
Ethics	<p>6 studies:</p> <ul style="list-style-type: none"> • Elison et al. (2016) • Klingemann et al. (2019) • Notley, Maskrey, & Holland (2012) • O'Sullivan, Boulter & Black (2013) • Stott & Priest (2018) • Matheson et al. (2019) 	<p>2 studies:</p> <ul style="list-style-type: none"> • Edward & Robins (2012) • Parkman et al. (2017) 	
Meaningful coherence	<p>All 8 studies:</p> <ul style="list-style-type: none"> • Edward & Robins (2012) • Elison et al. (2016) • Klingemann et al. (2019) • Notley, Maskrey, & Holland (2012) 		

	<ul style="list-style-type: none"> • O'Sullivan, Boulter & Black (2013) • Parkman et al. (2017) • Stott & Priest (2018) • Matheson et al. (2019) 		
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1.11.5 Meta-synthesis of findings

The review synthesised the eight identified articles' findings by following the best practice guidelines set out by Siddaway, Wood and Hedges' (2019). Following review and familiarisation, central and recurring concepts were identified in order to group these into relevant categories, using a thematic synthesis to integrate the qualitative aspects of the research. This included line by line coding, in order to locate key themes, concepts and theories, relating to the experiences of people with mental health difficulties and problems with substance use when accessing healthcare services in the UK. Descriptive themes were drawn, which led to the generation of analytical themes across the eight papers (Thorne, Kirkham & O'Flynn-Magee, 2004). Table 6. Illustrates the thematic analysis undertaken and representation of each theme across the papers. The five emerging themes are described in detail below.

1.11.5.1 Readiness for change

The first theme encompasses the feeling or state of readiness that an individual needs to reach in order to be ready for change, whether this relates to seeking professional help, making a decision to abstain from substance use, feeling worthy of receiving help or allowing others to help them. This theme speaks to Motivational Interviewing (Miller & Rollnick, 2013), commonly used in drug and alcohol services to ascertain one's readiness for change. Across the studies,

participants spoke of experiencing internal battles on the road to seeking help and being ready to change. There were feelings of ambivalence, fear and unwillingness towards getting help to stop using substances, when this was used as a means of escapism and coping (Elison, et al., 2016; Parkman et al., 2017; Stott & Priest, 2018). In addition, a feeling of powerlessness (O' Sullivan, Boulter & Black, 2013; Stott & Priest, 2018), despair or a lack of motivation were also common (O' Sullivan, Boulter & Black, 2013; Notley, Maskrey & Holland, 2012). Some participants reported not wanting to change or wanting change but not feeling ready to engage with treatment and services after previous negative experiences (Klingemann et al., 2019; Parkman et al., 2017). The theme is illustrated by the following participant quotation;

I just wasn't ready. You can't be forced into doing something. That's why it has taken me so long to do it. If they say 'no drugs' and force you to do it, it doesn't work. (O' Sullivan, Boulter & Black, 2013, pg.411).

Similarly, the importance of autonomy in making the decision to change was also present across a number of papers. This was positioned as an individual needing to reach out or seek help in the first instance, rather than services or professionals coming to them (Edward & Robins, 2012; Elison et al., 2016; Matheson et al., 2019; Stott & Priest, 2018). This is illustrated by the following participant quote;

Just be honest and open with them, go to them and let them help you.
(Edward & Robins, 2012, pg.554)

1.11.5.2 *Many hurdles to cross*

The second theme embodies factors relating to accessibility of services and the many barriers identified across the studies. In every study there were varying examples of barriers; this was perhaps related to the specific sample of participants and where they were recruited from e.g., detained in prison or a medium secure setting. Despite the variation in samples, there was unanimous finding of participants having experiences of services being inaccessible and perceiving there to be a number of barriers before being able to receive assessment and interventions. It was expressed that to gain access to treatment, whether mental health support or interventions to help with substance use, there was a sense of having to 'jump through hoops' (Notley, Maskrey & Holland, 2012; Matheson et al., 2019; Parkman et al., 2017). In a number of the studies, in addition to support being difficult to access, there were reports of care being restricted or taken away when it was needed most (Elison, et al., 2019; Klingemann et al., 2019; Notley, Maskrey & Holland, 2012).

A few studies suggested that alternative services had been signposted to participants, resulting in a 'dead-end' with no support. This meant that participants had to be re-referred to the original service, again extending the wait for support (Klingemann et al., 2019; Notley, Maskrey & Holland, 2012). Interestingly, a small number of participant samples reported deliberately committing crimes or using substances in order to be admitted to specialist facilities or detained in order to access mental health support and/or substance use interventions (Elison, et al., 2016; Klingemann et al., 2019). Perhaps these behaviours were an attempt to bypass the hurdles and barriers, which participants had faced in the past. Lacking options and having negative experiences of treatment were identified across many of

the papers as barriers to accessing services (O' Sullivan, Boulter & Black, 2013; Notley, Maskrey & Holland, 2012; Stott & Priest, 2018). A perceived lack of options and desperation to avoid hurdles and access care and support is conveyed by the following quote:

If you are not gonna help me get off it, I'm just gonna come back to probation – keep breaching until you send me to prison so I can detox there.(Elison, et al., 2016, pg.10).

1.11.5.3 Judgement of moral failings

The theme of 'judgement of moral failings' relates to participants perceiving judgement from both professionals and wider society for using substances. Across the studies participants described judging themselves or feeling judged by others for their substance use. A number of studies referenced the impact of societal perceptions of 'addiction' on how an individual's substance use is understood as a 'moral failing'; that they are weak and make bad decisions. None of the studies made connections between societal understandings of substance use and how services are commissioned, however, there was sense that treatment could be given or taken away by services as a punitive action. This could be understood as services acting in a way to punish someone for their 'moral failing'. In one paper, this judgement resulted in participants receiving substandard care leading to feelings of mistrust (Edward & Robins, 2012). There were findings across a few of the studies indicating that services were inflexible and overly punitive in discharging from services or withholding treatment (Notley, Maskrey & Holland, 2012; Stott & Priest, 2018; Matheson et al., 2019). This is expressed in the quote below;

If you do not do exactly what they want...they use it like some kind of punishment...I didn't turn up at the appointment...they simply stopped my treatment and I had to wait two and a half months without treatment.(Notley, Maskrey & Holland, 2012, pg.46)

Across the studies, there was a repeated appeal from participants for healthcare professionals to have a better understanding of the complex intertwine of drug use and mental health difficulties. Many participants described the underlying reasons for using drugs was to cope with mental health difficulties, but felt this was rarely understood by services or healthcare professionals (Klingemann et al., 2019; Notley, Maskrey & Holland, 2012). This was in reference to mental health impacting on treatment compliance (Matheson et al., 2019), mental health difficulties as a result of drug use (Elison et al., 2016), drug use as a result of mental health difficulties (Matheson et al., 2019) and the experience of withdrawal being minimised (Notley, Maskrey & Holland, 2012). This theme is illustrated by the quotes below;

No one asked me why I drank.(Stott & Priest, 2018, pg.21)

It's difficult to say...the cause and effect with regards to alcohol, my psychiatrist's way of looking at it was just to abstain from alcohol, and all my problems will be resolved.(Klingemann et al., 2019, pg.282)

Unfortunately, experiences of discrimination were apparent across many of the papers. This resulted in being embarrassed to ask for help (Elison et al., 2016; Matheson et al., 2019), a fear of not being listened to or respected or shamed for

'self-medicating' (Notley, Maskrey & Holland, 2012). This further impacted on how honest service-users felt they could be with healthcare professionals and how willing they were to foster therapeutic relationships (Edward & Robins, 2012). The impact of social stigma can be seen in the following quote;

You know if someone sees you coming here 'why is he going there he has a drug problem'.(Notley, Maskrey & Holland, 2012, pg.44)

1.11.5.4 Importance of connection

The next theme; 'Importance of connection', describes the findings across all the papers, which signal the importance of therapeutic relationships with peers and healthcare professionals. Participants in all of the studies highlighted the importance of healthcare professionals prioritising fostering trusting, reliable relationships and how vital human connection is on the pathway to recovery. A robust therapeutic relationship with healthcare professionals was identified as a key factor in moving to recovery, across all the papers (Edward and Robins, 2012; Klingemann et al., 2019; Matheson et al., 2019; Notley, Maskrey & Holland, 2012; O' Sullivan, Boulter & Black, 2013; Parkman et al., 2017; Stott & Priest, 2018). This is illustrated by the following quote;

He was a super person, yeh he actually spoke to you on a level... some of them are very clinical but [name] used to sit and talk to you like a person.(Matheson et al., 2019, pg.497)

In addition, the importance of connection with peers was also highlighted in the majority of papers. Peer support was frequently identified as being integral in adding meaning, purpose and value to one's life (Edward & Robins, 2012; Matheson et al., 2019; Parkman et al., 2017; Stott & Priest, 2018). Supporting the importance of connection, loneliness was identified as a perpetuating factor of substance use across a number of the studies (Edward & Robins, 2012; Matheson et al., 2019; Stott & Priest, 2018). Edward and Robins (2012) commented that hearing stories from people who have experienced similar difficulties, brings a sense of connectedness to others and the world. This is illustrated by the quote below;

It's sitting there with somebody else who's been in the same situation... You tell them your stories and then they'll tell you... And the events might have been one chalk, one cheese. But the feelings in the middle are all the same. (Stott & Priest, 2018, pg.23)

1.11.5.5 Necessity of reliable support

The final theme; 'Necessity of Reliable Support', illustrates the vital importance for services to be reliable and consistent in the support that is offered and delivered. A number of participants in the studies described an unstable and sometimes 'chaotic' life experiences; services that are consistent, predictable and reliable in times of need are particularly important for people who have mental health difficulties and problems with substance use. However, reliable support was conceptualised as being correlated with flexibility of services. Across the studies there were a variety of findings giving insight into how reliable support can be maintained; collaboration (Edward & Robins, 2012; Klingemann et al., 2019),

continuity of care (Notley, Maskrey & Holland, 2012), regular appointments (Edward & Robins, 2012), clear expectations (Notley, Maskrey & Holland, 2012; Parkman et al., 2017) and out of hours support (Notley, Maskrey & Holland). There appears to be a number of variable ideas and a lack of consensus, perhaps due to the varying contexts of each empirical study. The importance of reliable support is expressed by the following quote:

I was being seen by a service (out of county) and then when I changed to (local service) it took a long time to get an appointment...The prescription should go with you. It was a few weeks buying [heroin] because I was not on the script [methadone].(Notley, Maskrey & Holland, 2012, pg.44)

The importance of individualised care is conceptualised in a number of the studies, including services supporting service-users with psychosocial issues, physical health, housing and employment (Edward & Robins, 2012; O' Sullivan, Boulter & Black, 2013; Parkman et al., 2017; Matheson et al., 2019). The findings across all studies spoke to individualised interventions being key; tailoring to the needs of an individual, rather than remaining rigid or restricted to specific care pathways. Under the umbrella of individualised care, the need for more information, choice and collaboration around interventions was apparent across a number of the papers. It is clear throughout the studies, that from a service-user perspective, a need for more collaboration and joined-up working between drug and alcohol services and mental health services will be vital in being able to offer comprehensive, reliable care to meet the needs of individuals with co-occurring difficulties (Edward & Robins, 2012; Klingemann et al., 2019; Notley, Maskrey &

Holland, 2012; Matheson et al., 2019; Stott & Priest, 2018). This sentiment is exemplified by the following quote;

I felt like I'd been moved from pillar to post within the system. Trying to get hold of some recovery, but I found that everything was being pulled from underneath me.(Elison, et al., 2016, pg.10).

In summary, the meta-synthesis of findings gives a valuable insight into how people with mental health difficulties and problems with substance use experience healthcare services in the UK. A need for choice around treatment and care in order to support service-user autonomy in their recovery journey is a consistent finding across the studies included in the review. This was very much linked with perceived judgement by society and healthcare professionals, and fears of not being listened to or respected in healthcare settings. Another consistent finding was that co-occurring mental health difficulties and problems with substance use are not clearly understood by professionals, leading to mistrust and negative experiences, resulting in a reluctance to seek help. A need for individualised, flexible yet consistent service provision has been identified as key in order for services to engage this client group.

Table 6.

Table Showing Representation of Each Theme Across the Papers Included in the Systematic Literature Review

	Themes				
Journal Article	<i>Readiness for Change</i>	<i>Many Hurdles to Cross</i>	<i>Judgement of Moral Failings</i>	<i>Importance of Connection</i>	<i>Necessity of Reliable Support</i>
Edward & Robins (2012)	-Feeling out of control, on a downward spiral -Self-medicating to cope -Asking for help -Being honest with self and others		-Professionals not understanding drug use	-Feeling alone -Being honest with staff -Being helped by people with similar experiences	-Mixed messages from clinicians -Regular appointments -Being held accountable by services
Elison et al. (2016)	-Criminal justice system involvement as a catalyst for positive change	-Using substances to cope -Services not easy to access -Support taken away when it was most needed		-Support from family and friends	-Moved from pillar to post -Unable to access support when needed -Previous negative experiences of being abandoned by services
Klingemann, et al. (2019)	-Reluctance to address alcohol use -Rejecting clinician advice vs. starting treatment	- Need for joint working - Simplistic view from services -Barriers related to self-referral -Treatment perceived as inadequate	-Reluctant to talk about alcohol use -Embarrassed to ask for help	-Good relationship with specific clinician	-Inadequate treatment, not individualised -Knowing where to go and ask for help -Need for collaboration of services

Matheson et al. (2019)	-Mental health impacting on compliance	-Jump through hoops to get treatment -Negative perception of services based on previous experiences	-Punitive use of treatment -Perceived judgement of clinicians, stigmatised -Shamed	-Good relationship with staff -Talk to you like a person -Peer support	-Physical health complexities overlooked -Never offered mental health support
Notley, Maskrey & Holland (2012)	-Want for change -Fleeting motivation	-Back to square one -Previous treatment as a barrier -Having to start all over again -Perception of long waiting lists -Lack of knowledge	-Withdrawal not understood by professional -Overly punitive, inflexible	-Quality of therapeutic alliance -Need to feel listened to and respected	-Moving in and out of treatment -Confusing treatment pathways -Lack of continuity -Individualised care
O'Sullivan, Boulter & Black (2013)	-Feeling determined -Overcome obstacles independently -Being ready to change	-Lack of choice -Feeling disempowered -Unable to do anything sober, unable to doing anything whilst using	-Feeling dehumanised -Social exclusion -Being labelled	-Weak therapeutic alliance -Damaged relationship	-Moving in and out of services (revolving door)
Parkman et al. (2017)	-Not ready for treatment -Denying problem with alcohol use	-Anxious to attend services -No knowledge of what services offer -Previous support was unhelpful -Physical health problems		-Peer support (supporting each other) -Relationships with clinicians -Reduced loneliness, improved wellbeing	-Needing help with health and social issues
Stott & Priest (2018)	-Confusion about difficulties, not seeking help	-Using alcohol to cope -Services being overstretched	-Being misunderstood and rejected	-Alcohol use to identify with a social group	-Services not meeting expectations

	<ul style="list-style-type: none"> -Personal responsibility 		<ul style="list-style-type: none"> -Clinicians being punitive -Stereotyped 	<ul style="list-style-type: none"> -Pushed by sponsor -Relying on others -Importance of therapeutic relationship -Peer support 	
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1.5.9 Conclusions and Implications

The aim of this systematic literature was to gain better knowledge and understanding about the experiences of people with both mental health difficulties and problems with substance use when accessing healthcare services in the UK. Eight empirical studies were identified in providing first-hand experiences to this effect. A number of findings from this review, align with the aforementioned published systematic reviews (Ness, Borg & Davidson, 2014; De Ruyscher et al., 2017). Both highlighted the need for integration of services to provide more joined-up working, with a need for more inclusivity and awareness from services when working with this client group. In addition, learning from 'experts by experience' was coined as essential; 'social justice is only possible when the expertise of those who are theorised about begin to have their own voices heard, in all their complexity and contradictoriness' (De Ruyscher et al., 2017). There was also an acknowledgement of structural inequalities needing to be addressed in the first instance (Ness, Borg & Davidson, 2014). Despite both these reviews calling for change, it appears that services continue to remain stagnant. More research is needed to better understand the obstacles that are limiting change. The current review could also be further enhanced by including articles that focus on family member, carer, and healthcare professional perspectives. This would perhaps provide a more comprehensive overview to inform service development and direct future research. It would be enlightening for future systematic reviews to explore services' readiness to change (as opposed to service-users' readiness to change) at a structural, service level.

This review is explicit in focusing on the experiences of people in the UK, post 2012, when commissioning of drug and alcohol services was transferred from the NHS to Public Health England. The systematic reviews (Ness, Borg & Davidson,

2014; De Ruyscher et al., 2017) mentioned above, do not focus on the direct impact of healthcare service provision on the experiences of people with both mental health difficulties and problems with substance use. By only including studies in this review that relate individual experiences to service provision the meta-synthesis of findings gives a sense of what overall experiences are for this group, when accessing healthcare services, and implications for how to improve services. The literature included in the review was found using three databases, it should be noted that further research and grey literature may also be relevant and available. The limited number of studies included in the review can challenge both the internal and external validity of this review. In addition, using secondary data is arguably limiting, as there may have been themes that were considered as irrelevant or unimportant by the original researchers, but once collated in this review they may have shed additional light.

The meta-synthesis of findings give an overall impression of how things are for this group across the UK, the studies included used samples from the North-West of England, Norfolk, South-West of England, London and Scotland. Despite this there is still little known about the direct impact of service provision, as service provision is so variable in different areas of the UK. It will be important to gain a thorough understanding of specific commissioning and set-up of services, in order to understand how different provisions, impact individual experiences. This will clearly demonstrate specific recommendations based on the unique provision of healthcare services for people with both mental health difficulties and problems with substance use in a specific locality. Therefore, research focusing on a specific area of service provision will be necessary in understanding the direct implications on individual

experience and perhaps gain better knowledge of how structural inequalities are being perpetuated through local healthcare systems.

1.12 Rationale and Aims

1.6.1 Rationale.

As the systematic literature review indicates, no research has been identified that explores how specific service provision in the UK directly impacts individual experiences of people with co-occurring mental health difficulties and problems with substance use. Despite changes in policy and new guidelines, studies continue to suggest that people with co-occurring difficulties frequently express mixed or poor experiences of services and/or have had difficulties accessing them (Lawrence-Jones, 2010; Hipolito, Carpenter-Song & Whitley, 2011; Ness, Borg & Davidson, 2014; Brekke et al., 2016; De Ruyscher et al., 2017; Searby, Maude & McGrath; 2016). The systematic literature review clearly highlights a mismatch in how policy is encouraging joint work between services, to support this specific group of service-users, yet people continue to 'fall through the cracks' and are receiving substandard care. Individual studies included in the systematic review suggested a number of recommendations to improve service provision, but there was no consensus. Therefore, it will be necessary to focus on a specific area in the UK, for recommendations to be made that are relevant to how services are set-up in the local area.

'Re-imagining Luton' is a mental health transformation project that is hoping to address accessibility of services in Luton, Bedfordshire. The project is founded on hopes to improve joined-up working between healthcare services in the local area, including NHS mental health services, primary care, charity and third sector

organisations. This project alludes to a readiness to change from a service level and a valuable opportunity to conduct a piece of research to empirically understand the experiences of an often-overlooked service-user group. As this project is addressing some of the concerns highlighted in the systematic literature review, it will be an important locality to focus on. Therefore, individual experiences of service provision in Luton, Bedfordshire is the area of focus in this research study. Understanding how service provision in Luton impacts first-hand experiences of people seeking support for their mental health, alongside problems with substance use will provide a meaningful, novel contribution to the evidence base.

1.6.2 Research question.

'How does service provision in Luton impact the experiences of people with both mental health difficulties and problems with substance use?'

1.6.3 Aims.

Due to the majority of research in the field being unrelated to specific healthcare service provision, the overarching aim of this research is to use a GT methodology to explain the direct impact of service provision in Luton on the experiences of people with both mental health difficulties and problems with substance use. It is hoped that the GT model will offer a more theorised and process-oriented understanding of the general themes presented in the systematic literature review, thereby identifying and addressing specific obstacles, in order to bring about change.

2. Methodology

2.1 Overview

This chapter will explain the rationale for undertaking qualitative research, specifically, the chosen method of constructivist Grounded Theory (GT), in line with the epistemological position of the researcher. Ethical considerations and methods of consultation are described, before detailing the study design, recruitment, participant criteria, data collection and analysis. The researcher's theoretical assumptions and personal reflections are noted throughout.

2.2 Methodology

2.2.1 Qualitative research.

Qualitative methodologies allow for an inductive approach, gaining insights from the data, without the constraints of applying an existing framework or theory (Prus, 1987; Corbin, Strauss, & Strauss, 2014). If little is known about a phenomena or social process, an inductive or abductive approach (Peirce, 1878; 1958) can make new connections between data and add to what is already known (Coffey & Atkinson, 1996; Van Maanen, Sørensen & Mitchell, 2007). Consequently, a qualitative methodology has been chosen with the view to explore social processes relating to experiences of people with both mental health difficulties and problems with substance use in the context of service provision.

2.2.2 Constructivist grounded theory.

Constructivist GT fits with the researcher's critical realist epistemological stance. This postmodernist approach allows for 'layers of reality', subjectivity and

interpretation from both the researcher and participants through the process of data collection and analysis (Charmaz, 2014). GT was first outlined by Glaser and Strauss (1965), as a novel methodology with capabilities to generate original theory by implementing systematic data collection in order to produce a multidimensional conceptual theory (Glaser & Strauss, 1965; Strauss, 1987; Glaser, 1998). Since this time there have been developments leading to variations of the original GT blueprint (Urquhart & Fernández, 2013). Arguably, both Straussian and Glaserian GT approaches are profoundly positivist in nature and aim to 'shoehorn' data into existing analytic frames (Charmaz, 2014). That being said, GT methodologies have the same key underpinnings of constant comparison between codes, categories and the original data, holding theoretical sensitivity (i.e., the researcher's ability to examine their assumptions, knowledge and experience and how these impact data analysis) and developing meaning by linking abstract concepts to inform understanding (Urquhart & Fernández, 2013). Differences between GT methodologies tend to be around epistemology and the specific process of coding data (Hutchinson, Johnston, & Breckon, 2012). Therefore, it is particularly important for researchers to explicitly state their epistemological position and chosen 'flavour' of GT methodology, evaluating the application throughout the research.

The aim of using a qualitative approach in this research was to allow for resonant, subjective human experiences to be captured. A constructivist GT methodology has been the most appropriate to research the social phenomena of how service provision impacts the experiences of people with both problems with substance use and mental health difficulties, which is not yet well understood. The research had hoped that the chosen methodology would be used to systematically construct theory using an inductive approach (Charmaz, 2014). Ordinarily, the

constructed theory of social processes should be identifiable and familiar to participants taking part in the research, as well as others who have experience of them (Hutchinson, Johnston, & Breckon, 2012). However, due to the impact of the COVID-19 pandemic on the recruitment pathways and resulting participant numbers, a new theory of well-developed theoretical rendering of the phenomena as a whole has not been possible to present at this time. The researcher does not claim to have been able to move beyond description to a high level of abstraction or claim transferability of the model presented. That being said, 'data sufficiency' (Dey, 1999) and 'conceptual depth' (Nelson, 2017) have been achieved based on the depth of understanding in relation to the theoretical categories presented. These concepts are more in line with the researcher's critical realist epistemological position. Data saturation would suggest a certain 'completeness' or that there is a fixed point to reach, which would fit more with a realist epistemological position.

The crossover of a critical realist epistemology underpinning constructivist GT has been particularly important in this research where the model is presented around issues of equality and social justice, alongside more concrete recommendations for practice (Oliver, 2011). In addition, using 'intercoder' checking and being clear about the substantive nature of the model aligns with the critical realist position (Urquhart & Fernández, 2013; Yin, 2009). If the epistemology of the researcher had been social constructionism, the pragmatic nature of the research would be illogical. Constructivist GT fits with a critical realist epistemology due to the shared understanding regarding the links between empirical knowledge, theory and application, which can be accepted without the necessity of being 'proved', in a positivist sense of the word (Oliver, 2012).

2.3 Design

An exploratory, qualitative methodology was deemed more appropriate to elicit a greater depth of understanding of participants' experiences of services, particularly as this is a relatively unexplored field (Barker, Pistrang & Elliott, 2002). This was achieved by conducting semi-structured interviews with people who have lived experience of mental health difficulties and problems with substance use. Constructivist GT analysis was used to begin to develop a theory from the data (Charmaz, 2014).

2.3.1 Consultation.

In the preliminary stages of the development of the research study, a number of professionals were consulted to allow the researcher to understand how services are currently provisioned. The researcher was able to meet and consult with a Clinical Psychologist working at the primary research site, a local drug and alcohol service, throughout the research project. In addition, the researcher was able to meet with all three sub-teams operating within the local drug and alcohol service; a team working with opiate use, non-opiate and alcohol, a team working specifically with service-users between 18-25 years and a team working with people involved in the criminal justice system. A meeting was also facilitated with two commissioners from the local Clinical Commissioning Group (CCG), which improved the understanding of the researcher around how services are commissioned in Luton and to hear a commissioning perspective on mental health transformation projects happening locally. These meetings allowed the researcher to gain a better understanding about how services are provisioned, service structures and treatment

options provided, as well as being to raise awareness about the research and receive feedback.

It was essential to consult with someone with their own lived experience of mental health difficulties and problems with substance use for the project, in order to challenge professional lenses and gather multiple perspectives. The researcher has attended a number of 'Luton Collaborative' meetings and 'Luton Live Well' open access group meetings over the past 18 months. Both forums are made up of professionals from the local NHS Trusts, Commissioners, drug and alcohol services, the police, local charities and third sector organisations based in Luton, as well as service-users and carers. The researcher was able to present the proposed research at a Collaborative meeting in June 2021, feedback was received relating to advice about the recruitment strategy and potential challenges were highlighted with regards to recruiting people with lived experience of drug and alcohol problems.

The primary consultant for the research was contacted by the researcher via social media, after seeing their campaign 'See the Bigger Picture', calling for the UK government to improve how people with both mental health and substance use issues are assessed for treatment. The primary consultant co-constructed the interview topic guide with the researcher, as well as improving language used on the participant information sheet and consent form. They have been an invaluable asset to the project and their lived experience has shed light on important topics and questions to be included in the interview topic guide, which arguably makes the research more relevant and impactful (Wykes & Trivedi, 2002; Wilson, Fothergill, & Rees, 2010). A pilot interview was conducted with the primary consultant once the interview topic schedule had been finalised. Feedback from this led to further improvements to the interview topic schedule, in terms of the order of topics and

introducing a thorough explanation of the interview schedule and questions from the offset. They have been compensated for their time and involvement with the research project.

2.4 Ethical Considerations

2.4.1 Ethical approval.

The research was conducted in line with the British Psychological Society (BPS) Code of Human Research Ethics (BPS, 2021). The research was required to be reviewed by an NHS Research Ethics Committee (REC). Despite not being an NHS service, the local drug and alcohol service is commissioned by Luton CCG, and as the main research site, required REC approval. See Appendix C for confirmation of favourable opinion from the REC. In addition, ethical approval was also granted through the Change Grow Live (CGL) Research Oversight Group prior to beginning participant recruitment, email correspondence can be found in Appendix D.

The research was also granted ethical approval and received sponsorship in full from the University of Hertfordshire (see Appendix E.), as well as being covered through the University's Professional Indemnity and Employer/Public Liability insurance. Throughout the processes of being granted ethical approval for this research study, informed consent, confidentiality and participant wellbeing were considered in great detail.

2.4.2 Informed consent.

Potential participants who contacted the researcher and expressed interest in the study were sent a copy of the participant information sheet (see Appendix F.). They were encouraged to contact the researcher if they had any questions or

queries. Once an expression of interest was made, the participant was sent a copy of the consent form (see Appendix G.) and demographics questionnaire (see Appendix H.). Participants were asked to return a signed consent form and demographics questionnaire back to the researcher, prior to the interview.

Each item of the consent form was again discussed with the participant before beginning the interview. This included stating that consent for the study includes an agreement for the conversation to be audio-recorded, an agreement that anonymised extracts from the transcribed interview may be published in the final write-up and papers for publication. Participants were informed that they have the right to withdraw up to 14 days after the interview, without having to give reason. The GT methodology meant it would not be possible for data to be withdrawn after 14 days had passed since the interview, due to themes and codes being used to inform lines of inquiry in subsequent interview questions and topics.

2.4.3 Confidentiality.

Before each interview took place, confidentiality was discussed in detail with each participant. The remits of confidentiality were also clearly outlined in the participant information sheet (see Appendix F.). All data collected throughout the research project has been anonymised and kept confidential in compliance with the Data Protection Act (1998) and General Data Protection Regulation (GDPR) legislation. Person identifiable information about participants and third parties were removed from the interview transcript. A pseudonym was selected by each participant and used to refer to them throughout the report. Participants were assured that any information relating to current or historic drug use would be kept confidential and not reported to any authority. No concerns were identified or acted

upon throughout the duration of the study. Confidentiality of participants and third parties has been maintained throughout the study.

2.4.4 Participant wellbeing.

It was not anticipated that the interviews would cause significant distress, however, participants were reminded to only share what they would feel able and willing to talk about and were under no obligation to answer all of the questions. Participants were made aware that they did not have to provide detail about any distressing experiences but could refer to them in a way that felt manageable, for example, talking more generally and abstractly. The researcher was mindful when asking clarifying questions to do so in a way that made it possible to follow the account, without asking for the specifics of an event. There were no participants who reported or appeared distressed throughout data collection. No participants have withdrawn from the study. All participants were provided with a debrief information sheet (see Appendix J.) detailing a list of local services should they wish to access additional support following the interview.

There were no direct benefits identified for participants, however, it was acknowledged that participants could experience some indirect benefits of participating in the research. Each interview session endeavoured to provide a safe space where participants could freely share their individual experiences of mental health difficulties and concurrent problems with substance use. The semi-structured nature of the interview gave an element of freedom and autonomy around how participants shared their stories, which may have been helpful in making sense of their experience.

2.4.5. Ethical concerns.

Each participant received a gift voucher of their choice equivalent to £20, to compensate them for their time and taking part. After a slow start with recruitment there was an unusual flurry of interest from potential participants, around three months after recruitment had started. These potential participants reported seeing the study advertised on social media platforms. After the sudden interest from a number of people, interviews were arranged with ten additional participants. Unfortunately, after two of these interviews had been facilitated, it became apparent that the information provided seemed disingenuous. At this point the researcher contacted the research team to raise their concerns about the two participants having little, or no knowledge about the services they claimed to have accessed, as well as their accounts being inconsistent and unbelievable. The researcher received support from the wider research team at the University and was advised to suspend recruitment. Advice was also sought from the Health Research Authority (HRA). As there was no concrete proof of the participants being insincere, they were still compensated for their time with a £20 gift voucher. The audio recordings of the interviews were destroyed and the data collected from the two participants described has not been included in any aspect of the research. Reflections on this experience can be found in Appendix O.

All prospective participants booked in for interviews were contacted, thanked for their interest but informed that, unfortunately, recruitment had to be suspended for the time being. It was hypothesised that the advert for the study had been shared in an online forum and the people who were in contact were incentivised by the £20 gift voucher. It was helpful for the researcher to utilise supervision and support from the wider research team around this time, to contextualise the experience and

sustain motivation to carry on with recruitment. From this point, the local drug and alcohol service were the sole point of contact for recruitment, which enabled the credibility of participants to be assured. This experience allowed the researcher to reflect on the ethical implications of compensating participants for their time and contribution to research and making sure to avoid coercion through payment, especially in 'hard to recruit' fields of research. However, the researcher maintains that the amount of the £20 gift voucher was given great consideration, and equivalent to what a service-user would be given for taking part in service development projects of other 'expert by experience' responsibilities in an NHS Trust. Going forward, the researcher would explicitly state the type of gift voucher, given to compensate participants for their time and involvement, rather than a gift voucher of their choice.

2.4.6 Data Storage.

The University of Hertfordshire OneDrive has been used to securely store data, managed via a remote login. Consent forms and demographic questionnaires with identifying information (names, age bracket, gender and ethnicity) have been password protected and stored in separate file locations from interview data (both recordings and transcriptions). Audio recordings of the interviews were immediately uploaded to the OneDrive and permanently deleted from the encrypted Dictaphone device. Audio files were shared securely with the transcription service through file sharing capabilities of OneDrive. Consent forms, demographic data and audio recordings will be deleted on completion of the study. Transcripts will be kept for 5 years following completion of the study, before being securely destroyed.

2.5 Data Collection

2.5.1 Inclusion and Exclusion Criteria.

Participants were required to meet the criteria shown in Table 7.

Table 7.

Table Showing Inclusion and Exclusion Criteria for Participants

<i>Inclusion Criteria</i>	<i>Exclusion Criteria</i>
Aged 18 years or above	Under the age of 18 years
Lived experience of 'problematic' substance use (self-identified)	No personal experience of 'problematic' substance use
Lived experience of a mental health difficulty	No personal experience of a mental health difficulty
Lived experience of seeking mental health support in Luton and/or Bedfordshire	No personal experience of seeking mental health support in Luton and/or Bedfordshire
Willing to take part in an individual interview	No experience living in Luton or wider Bedfordshire
Happy to use an interpreter during the interview if English is not easily understood or spoken	
Access to either a computer with internet access or a mobile phone/landline.	

2.5.2 Recruitment Strategy.

Recruitment in the area of co-occurring mental health and substance use difficulties is known to be challenging (Subbaraman & Kerr, 2015). The sampling approach did not aim to gain a 'representative' sample of people in Luton with mental health difficulties and co-occurring problems with substance use, rather to find participants with a range of differing experiences and contexts (Barbour, 2013). The main recruitment site for the research has been a local drug and alcohol service. The primary contact was able to distribute the participant recruitment poster (see Appendix K.) and recruitment video (see Appendix L.) to members of staff, in order

for them to cascade to users of the service and other members of staff, where appropriate. A member of the Communications team, responsible for the social media presence of the service, shared the poster and video on their social media platforms (Instagram & Twitter). The researcher also advertised the research via Twitter, Instagram and Facebook, using separate accounts created specifically for the project.

The researcher was able to present and advertise the study in a number of forums, including the Luton Collaborative meetings, for the teams in CGL and for the Luton Living Well Open Access group. Advertising the study through these forums was important to inform potential beneficiaries about the hopes for the research to inform service development, connecting with people and starting to create relationships with individuals and teams with hopes that this will aid the dissemination of findings; as well as being a platform to advertise the study to potential participants. Third sector organisations, such as Healthwatch Luton were also contacted and were able to distribute the advertisement materials amongst members of staff and print the poster to display in waiting rooms and reception areas.

Convenience sampling was used at the start of recruitment, with potential participants expressing interest in taking part in the study and interviews were facilitated as and when participants made contact with the researcher. Three participants heard about the study through a Luton Collaborative meeting and seven of the participants were made aware of the study through their involvement with the local drug and alcohol service. When recruitment began, there was hope of implementing a 'snowballing' recruitment strategy by asking participants whether they knew of anyone else who may wish to take part, which can be a fruitful strategy

where recruitment has been identified as challenging with certain populations (Aldridge, 2014). A number of participants said they knew of someone who may wish to take part, however, recruitment of participants using this method did not materialise.

2.5.3 Participants.

Demographic information regarding the participant sample is summarised in Table 8. This information was collected through a demographics questionnaire which participants were given the option to complete (see Appendix H.) Different participant roles, positions and involvement with services are considered in the Discussion, in relation to the impact on the data.

Table 8.

Table Showing Demographic Information of Participants

Recruitment Pathway	Name (chosen pseudonym)	Gender	Age Bracket	Ethnicity	Substance Use (current or historical)	Mental Health Service Involvement (current or historical)
Luton Collaborative	Disgruntled	Male	60+	White British/Irish	Alcohol Cannabis Crack Cocaine	CMHT Drug and alcohol service Third Sector Charity
Luton Collaborative	Anne	Female	60+	White British/Irish	Alcohol	IAPT Drug and alcohol service Third Sector Charity
Luton Collaborative	Robert	Male	60+	White British/Irish	Alcohol	IAPT CMHT Drug and alcohol service

Local drug and alcohol service	Kathy	Female	18-24	White British/Irish	Cannabis	CAMHS IAPT CMHT Crisis Team Inpatient Services Drug and alcohol service
Local drug and alcohol service	Caroline	Female	18-24	White British/Irish	Cannabis Ketamine Cocaine Amphetamines LSD	CAMHS IAPT CMHT Crisis Team Inpatient services Drug and alcohol service
Local drug and alcohol service	Izzy	Female	18-24	Black British – Caribbean heritage	Cannabis	CAMHS Inpatient services Drug and alcohol service
Local drug and alcohol service	Milo	Male	51-60	White British/Irish	Alcohol Prescribed medication Cannabis Cocaine LSD	CMHT Crisis Team Inpatient setting Drug and alcohol service Rehab
Local drug and alcohol service	Jeff	Male	41-50	White British/Irish	Alcohol Prescribed medication Cannabis Heroin Crack Cocaine LSD	IAPT CMHT Drug and alcohol service Rehab
Local drug and alcohol service	Steven	Male	31-40	White British/Irish	Alcohol Prescribed medication Cocaine	IAPT CMHT Crisis Team Inpatient setting Drug and alcohol service Rehab
Local drug and alcohol service	Terry	Male	31-40	Black African	Alcohol	IAPT Drug and alcohol service Charity

2.5.4. Recruitment challenges.

As described in the ethical concerns section there were issues with disingenuous participants which resulted in recruitment being suspended for one month. After this point in time, the researcher made great efforts to meet with sub-teams, from the local drug and alcohol service in order to promote the research. The researcher was relying heavily on staff to be gatekeepers of the research, to share information relating to the project with service-users and staff with lived experience. As recruitment began in August 2021, the impact of the COVID-19 pandemic on staff and service-users during this time presented a significant issue in terms of people's capacity to be involved in research, due to the strain on services. One identified research site withdrew their involvement, as a result. Recruitment was extended by three months in order to try to reach as many potential participants as possible. There were two potential participants who said that they would be able to take part, if the interview could be facilitated in person. Unfortunately, at the time ethical approval applications were submitted, the University was not allowing face to face contact with research participants, due to the risks associated with COVID-19. This restriction was later lifted, but unfortunately, the time scale for the project did not allow for ethics application to be amended and re-submitted in order to allow in-person interviews to be facilitated.

The recruitment challenges have been intensified by the context of conducting research during a global pandemic, as well as being challenged by the restricted timeline to complete and write up the research. If the project had the time and scope of a PhD, it is hypothesised that participant numbers would have been higher.

2.5.5 Qualitative interviews.

Semi-structured interviews provide opportunities to explore opinions and experiences, as well as allowing access into the world of the participant, through interviewer-interviewee inter-subjectivity (Miller & Glassner, 2016). Qualitative interviews have allowed for phenomenological data to be collected about individual experiences, including contextual information that a researcher may not be privy to otherwise. In line with the researcher's critical realist epistemology, the interviews with participants have provided access to social worlds, through researcher-participant intersubjectivity (Charmaz, 2014). Individual interviews were deemed to be most appropriate for collecting phenomenological data, exploring meaning-making and constructions between researcher and participants, as well as addressing the aims of the research (Willig, 2017).

2.5.6 Interview topic guide.

An interview topic guide was used to scaffold each interview, detailing possible lines of enquiry and open-ended questions (see Appendix N.). The interview topic guide was co-constructed with the primary consultant, examples of their advice can be seen in Table 9. Development of the interview topic guide can be seen in Appendix M. and Appendix N.

Table 9.

Table Showing Advice Given by Primary Consultant to Develop Interview Topic Guide

1.	<i>For the first question I wonder if something along the lines of 'Can you tell me your earliest memory of using any substances?' It's possible this is covered in the third question but wondered if this may be a good starting point?</i>
2.	<i>Perhaps the word 'inhibit' could be replaced with 'prevent' as may not be a word everyone will know. Also 'co-occurring' could be replaced with 'joint' or 'dual.' Language that is less academic and/or clinical may be preferred.</i>

3.	<i>I think general questions about anything that could have been better and reframed as 'if there was one thing you could change to make your experience better what would it be?' of course, the participants may decide to suggest more than one but just a thought.</i>
4.	<i>I wonder about a question asking participants about what services, whether it be mental health or substance use, they have found to be most helpful?</i>
5.	<i>Overall, I think the questions make sense and have the flow they need without assuming any specific answers. Having looked at this a couple of times today, I think that's all I have to suggest.</i>

An intensive interview style (Charmaz, 2014) was implemented for each interview in order to facilitate interpretative enquiry. The researcher was encouraging and seeking to learn through understanding the participants' language, emotions, actions and personal meaning-making. It was important for the researcher to put the participant at ease by attempting to join the language being used, once a clear understanding of specific terminology was established (Cronen & Lang, 1994). There were points of interest which guided the interview, referred to by Kathy Charmaz (2014) as 'points of departure', in order to 'spark' thinking in both the researcher and participant (e.g. what are the barriers to accessing mental health support?) Where needed, the researcher used follow-up questions to encourage expansion (Rubin & Rubin, 2005).

Consistent with the GT methodology, the interview topic guide was added to and amended throughout the data collection and analysis processes. Concepts generated from the data led to exploration with the subsequent participants and this in turn shaped the theoretical credibility of the findings. The interviews felt more systematic as data collection went on, however, the researcher was mindful to keep listening for new information and be flexible if there was a deviation from proposed topics or questions.

2.5.7 Interview procedure.

Participants were given the option for interviews to be facilitated online via Microsoft (MS) Teams or over the telephone. Three of the interviews were facilitated over MS Teams and the other six were facilitated over the telephone. There is evidence to suggest that offering choice in methods of data collection is beneficial for participants, especially when the subject matter is deemed to be 'sensitive' (Heath et al., 2018). Unfortunately, due to COVID-19 related restrictions, people who did not have access to a telephone or the internet were unable to take part in the research.

The telephone interviews prevented the researcher from picking up on non-verbal cues and body language, however, as a general observation, it seemed that participants may have felt less inhibited over the phone, perhaps due to not being seen and feeling more at ease (Hanna, 2012). The interviews were facilitated by the researcher in a private room, wearing headphones with good telephone reception and internet connectivity. Participants were asked to be in a private space for the interview. There were a few issues with internet connectivity for a number of participants and two participants received personal telephone calls during the interview. However, it is not believed that these interruptions had any significant impact on data collection. The audio recording for the interview was started from the point of consent and the recording equipment was reliable and produced high quality audio recordings. Facilitating remote interviews was advantageous for the majority of participants and enabled inclusion for people who did not have time or means to travel to an alternative location.

At the beginning of each interview, the researcher introduced themselves as a Trainee Clinical Psychologist, conducting research as part of their training. Personal and professional affiliations with the research topic were shared, as well as

motivations and hopes for the research. As stated, each interview began with the informed consent procedures and the demographic questionnaire was administered, if this had not already been completed. The interviews lasted between 38 and 56 minutes with an average time of 47 minutes. Participants were reminded that they could take breaks at any point during the interview should they need to do so or withdraw their participation at any point. All participants said that they would be happy to be kept up to date with the research and opted to be sent an accessible summary of the findings, as part of the dissemination strategy. Interviews concluded with an opportunity for participants to ask any questions they might have for the research, debriefing, thanking the participant and arranging the gift voucher compensation.

2.5.8 Transcription.

The transcription service utilised for the study has a GDPR policy in place, to ensure confidentiality and the service was asked to sign a non-disclosure agreement (see Appendix I.). Each transcript was imported and coded using NVivo version 12.

2.6 Data Analysis

The data has been analysed using Charmaz' (2014) guidelines for constructivist GT. In accordance with the guidelines, the researcher has listened to the audio recordings a number of times, as well as reading and re-reading transcripts with the view to facilitate full immersion in the data and initial meaning-making processes. Data collection and analysis have occurred in parallel, in order to facilitate concepts emerging inductively from the data, through comparing analysis between the data and developing ideas.

2.6.1 Memoing and reflective processes.

The process of keeping a reflective diary and memoing have been utilised throughout the research study. The reflective diary has a number of entries around NHS ethical approval procedures and barriers to recruitment, with the majority of later entries being around experiences and reflections of facilitating the interviews and data collection process. Entries to the reflective diary were routinely written after each interview and again when reading through the transcription, noting down thoughts, comparisons and ideas. This process has brought clarity to the researcher's ideas, opinions and feelings, as well as being an important tool in developing the research, the collection of data, and analyses (Ortlipp, 2008); extracts can be found in Appendix O.

Memoing has been a crucial part of the development of the grounded theory (Lempert, 2007). It has been used to develop analytical ideas but also to note down reflections when re-reading and coding the transcripts. The memoing process has allowed the researcher to consider alternative conceptualisations of the content throughout the analysis process and organise abstract ideas to work towards developing a theory. Keeping a chronological record of memos allowed the researcher to engage in constant comparison and left footprints to look back on through the analytical trail of changes and developments. An example of how memoing was used in the initial stages of analysis can be found in Appendix P.

2.6.2 Line-by-line coding.

The initial coding of transcripts was done line-by-line as endorsed by Charmaz (2014). This was primarily done using notes relating to actions and processes, also known as 'Gerunds'. It was helpful for the researcher to ask

themselves 'what is happening here?' whilst coding line-by-line, in order to identify which social processes were present and start to think about how the processes could be handled analytically. A constructivist GT methodology allowed the researcher to consider relational processes at play; close attention was paid to language, implicit meanings and how language was used to structure actions throughout initial coding. Through this process, the researcher was able to be immersed in the data. Secondary coding of the interview with 'Milo' by three other peer researchers supported the credibility of the researcher's initial codes. An example of the initial line-by-line coding is available in Appendix Q.

2.6.3 Focused coding.

The initial codes were refined and condensed by focusing on a theoretical direction. The initial codes were revisited, similar and reoccurring codes were merged, codes with comparable meaning were collated. The codes deemed to be making greater contributions to the analysis were promoted to focused codes. It was important for the researcher to keep the research question at the forefront of their mind during the focused coding, keeping the main objectives of the study central to the analysis process. Separate NVivo files were saved at each point of coding (initial, focused and theoretical).

The focused coding process continued throughout data collection, as and when interviews were facilitated and transcribed. The codes were in a continuous process of being refined to ensure they were representative of the new data. Where necessary new initial codes were created where novel ideas were identified in later interviews. Examples of initial codes grouped into focused coding are available in Appendix R. As the analysis process went on, the researcher started to cluster

focused codes into initial categories, and subcategories into higher conceptual categories (see Appendix S.). The focused codes were representative when looking back over the transcribed interviews. The process of focused coding enabled key ideas and central social processes to become clear and started to indicate the theoretical direction of results.

2.6.4 Theoretical coding.

The final stage of coding was theoretical coding. Focused codes constitute the 'empirical substance' of the analysis process, whereas theoretical codes bring together how the focused codes are related, in order to create a more abstract understanding or 'theory' (Glaser, 1978). The researcher asked themselves analytic questions of the data in order to move through the theoretical coding process, such as; 'What larger story do the focused codes tell me?', 'What are the underlying assumptions?', 'What does it mean in practice?'. The researcher started this step by tentatively creating conceptual categories based on grouping focused codes on a theoretical basis, grouping and regrouping them (see Appendix S.) Occasionally focused codes were revisited to change the named and/or reorganise. Memoing was helpful in order for the researcher to consider how renaming a phenomenon changed their relationship to it, also known as symbolic interactionism (Dewey, 1929; Strauss, 1984).

The researcher also utilised post-it mapping to explore the different conceptualisation of ideas. A number of theoretical models were devised using the focused codes, which were reviewed against the transcripts to check how the models held up against the data. This process enabled the researcher to identify points which contradicted the patterns seen through the majority of the data, known

as 'negative cases', which was helpful when holding a critical lens to the theory being posed, in order to edit and improve (Charmaz, 2014). A model was brought to fruition which accounts for and explains the vast majority of the data. This was done through utilising an abductive approach. Abduction is a step further from induction, enabling possible theoretical explanation to form (Peirce, 1878; 1958). This can be conceptualised as a creative, imaginative leap, where the researcher has been able to make the theoretical coding understandable and sensical. Arguably, there can be competing models or explanations that 'fit'. In this case, the researcher moved with the strongest model, which became apparent when tested against the data. The model created is a move towards the development of theory at a conceptual level.

Whilst by the end of analysis, clear social processes were being constructed from the data and making valuable contributions to the literature, the research is unable to claim 'theoretical saturation' based on the number of participants. Therefore, conclusions from the research should be made with caution and further research will be necessary in order to fully address the identified gap. That being said, saturation of data collected for the purposes of the research can be accounted for by the model presented. 'Data sufficiency' (Dey, 1999) and 'conceptual depth' (Nelson, 2017) can also be claimed, as the researcher claims sufficient depth of understanding has been achieved in relation to the theoretical categories. This has been corroborated by members of the research team, to prevent 'shoehorning' data into the researcher's preferred theoretical ideas.

2.6.5 Quality assessment.

The methodological rigour of this research was assessed using Sarah Tracy's (2010) 'Big-Tent' Criteria for Qualitative Quality framework. This is the same tool

used in the systematic literature review to assess the quality of the research presented. It has been selected as most appropriate for appraising quality of qualitative studies (Tracy & Hinrichs, 2017). The review of this research against the eight key markers to assess quality are discussed in the Discussion.

In line with guidance from the University of Hertfordshire, there have been five research supervisory team meetings in order to monitor progress of the research and provide support throughout data collection and analysis.

3. Results

This chapter presents a grounded theory model of the data, in relation to how service provision in Luton impacts the experiences of participants with both mental health difficulties and problems with substance use. The understanding of the findings is subject to the additional layer of inter-subjectivity brought by the reader (Bryant, 2009). Direct quotations from participants are used to evidence the findings (Tracy, 2010).

3.1 An Overview of the Grounded Theory Model

Findings were co-constructed as four categories; 'Navigating Services Working in Silos'; 'Swallowing the Jagged Pill'; 'Doubting Adequacy of Support' and 'Becoming One of The Lucky Ones'. These categories comprise of 11 sub-categories (see Table 10.)

Table 10.

Table Showing Social Processes of the Grounded Theory Model

Category	Sub-category
1. Navigating Services Working in Silos	1a. Falling Through the Cracks
	1b. Battling to Get Support
	1c. Facing Everchanging Services
2. Swallowing the Jagged Pill	2a. Self-Medicating to Cope
	2b. Experiencing Punitive Action
	2c. Feeling Abandoned
3. Doubting Adequacy of Support	3a. Being Labelled
	3b. Disappointing Interactions
	3c. Feeling Disempowered
4. Becoming One of the Lucky Ones	4a. Benefitting from Relationships
	4b. Influencing Change

3.2 Category 1: Navigating Services Working in Silos

Category 1 relates to social processes occurring in services and between the participants and services they have wanted to access or have accessed. Participants spoke of services seeming very blinkered, working in isolation, rather than having a wider and more inclusive view of the multiple agencies involved in a person's care. Barriers impeding more joined-up, systemic approaches are described. The Grounded Theory model (see Figure 2.) illustrates this category at the top of the model, this represents the common experiences of participants, following the initial decision to ask for professional help. All participants described the challenge of having to navigate a complex system at a time when they were struggling with both mental health difficulties and problems with substance use.

The following subcategories were co-constructed in this category; 'Falling Through the Cracks', 'Battling to Get Support' and 'Facing Everchanging Services'. The cogs on the model (see Figure 2.) represent the interactional nature of each; how one social process very much influences the experience of the others. Some participants were able to navigate the complex system of multiple services, resulting in 'Becoming One of the Lucky Ones'. The reasons explaining which aspects of service provision enabled some participants to move to this social process and not others, is discussed throughout the chapter. However, all participants, at some point in time, have been unable to 'Navigate Services Working in Silos', followed by being caught in the social processes of 'Swallowing the Jagged Pill' and/or 'Doubting Adequacy of Support'.

3.2.1 Subcategory 1A: Falling Through the Cracks

This subcategory highlights the experiences of participants when they are deemed not to meet the specific criteria required to access multiple services, which results in getting no help or support at all. Participants spoke about the need for more joined-up working across services, as well as frustrations when hearing contradictory advice from different services or professionals, as well as reflecting on how this has been exacerbated by the COVID-19 global pandemic.

3.2.1.1. Being batted between services.

Participants shared multiple accounts of feeling like they were constantly batted between services; most commonly, between mental health and drug and alcohol services. This experience seemingly related to having co-occurring difficulties which services felt 'the other' service was better equipped to manage. This frequently resulted in the service-user 'Falling through the gaps', when both services were suggesting the other. These happenings were described with a sense of abandonment, helplessness and being misunderstood.

They push you from pillar to post.(Milo)

Look I drink because this is happening, that's happening and it helps me cope with that. So I almost give them permission to say well you need to go and deal with that at a mental health service. And yeah it just batted back and forth for a long long time.(Steven)

It's like a ping pong ball going back and forth saying the same things to the same people over and over.(Terry)

In addition, hearing such contradictory advice was interpreted in different ways by participants, ranging from feeling discriminated against, to staff being misinformed, to services not having adequate resources. A common result, for half of the participants, was feeling frustrated to the point of giving up trying to access support from services.

If you go to the GP and say look that's what I need, I feel can we try that, we've tried everything else. "Ah no sorry we don't do that, [drug and alcohol service], they, that's literally what they're there for, so go tell them that". [Drug and alcohol service] say well we're not a GP, we don't do that, go to a GP and tell them... Do you see that I mean?(Terry)

3.2.1.2 Facing the impact of a global pandemic.

The COVID-19 global pandemic has had a huge knock-on effect on how services have been providing care. A number of participants made reference to how less face-to-face contact with professionals has negatively impacted on their experience of interventions, as well as participants working as members of staff in services, noticing the difficulties around engaging people via remote technology.

You can do what web camera things, but it's not the same.(Robert)

People need face to face, people can't do the online, they haven't got the patience for it and once they've made their mind up they're not doing it, that's it. It's really difficult to try and pull them in, do that stuff as well, the online stuff.(Jeff)

The majority of participants spoke of a venue called 'The Hub' which had been a great source of support and community for people accessing the local drug and alcohol service. Unfortunately, this has now permanently closed since the first lockdown, which participants described as a huge loss:

It shut down in the first lockdown in March and its never opened again.(Milo)

3.2.1.3 Differentiating Luton.

Many participants spoke about their relationship with Luton, many of whom have lived there all their lives. There were mixed feelings about living in Luton, how services are provisioned and how this impacts the wellbeing of participants. Some participants shared their perception of service provision in Luton to be different to other areas or being overrun due to the high population, drug culture in the area and a high proportion of people struggling with mental health difficulties. One participant (Disgruntled) shared his feelings that services in Luton were better than previous areas he has lived.

In Luton the drugs are just everywhere and you're just stuck in that culture...their neighbours are using or if they going into the shop they're using...and they're not being given any help to move to somewhere more appropriate.(Jeff)

Um it's a crack den really. It's... it's a vile place, Luton.(Caroline)

I believe that the services in Luton are better equipped to be able to help people in that instance (mental health difficulties). Um and that's you know that's a big tick in the box for Luton. (Disgruntled)

3.2.1.4 Bridging the gaps.

Wanting joined-up working was expressed with a sense of frustration and desperation by the majority of participants. They described their experiences in relation to substance use issues and mental health difficulties being thought of as distinct difficulties, very much separated by services, whereas lived experience of the two is much more intertwined. Anne expressed how nonsensical it is to 'treat' each difficulty in isolation.

It's no good just trying to deal with the drinking in isolation. It's linked. And you can't sort them in isolation. (Anne)

Similarly, Steven speaks about his experiences of being a service-user, transitioning to working as a member of staff in services. The need for services to work together in order to provide adequate care is again illustrated by the following quotes;

They need to do more like three-way interventions, talk more, work together for the client. (Steven)

I believe that the duty of care links up with some kind of shall we say for want of a better word, marriage of the... the medical services. And it's... it's like they should go hand in hand.(Disgruntled)

Also coming from the data was a sense of confusion about why services are separate and mystery around the barriers that result in people 'Falling Through the Cracks'. This is shown with the two quotes below relating to the lack of transparency around record keeping and not understanding why services are not linked by the same patient record systems.

It's all there...especially someone like me who is so good at engaging...I can imagine there's a linear timeline somewhere, out there on a central database.(Terry)

I don't know if everyone uses the same system, but maybe share the lead systems?(Kathy)

3.2.2 Subcategory 1B: Battling to Get Support

This subcategory described the interactions between participants, professionals and wider services and the fight required for people to access the care and support they needed. These interactions relate to the energy, patience and determination of participants to continually battle, whilst suffering with mental health difficulties and experiencing problems with substance use, which, in a few participant accounts, made the presenting issues worse. These experiences are consolidated

to: 'Waiting too long for support', 'Lacking options', 'Receiving minimal intervention', and 'Feeling the pinch'. The subcategory is broadly illustrated by the quotes below;

It's always been a battle to get support again. (Robert)

It's a structural thing and it's coming from the top and you know there's constantly fighting against it.(Jeff)

3.2.2.1 Waiting too long for support.

All participants described the extensive amount of time they have spent waiting for support, whether that was time spent navigating the system to find the 'right' service, battling to get a referral from a GP to a specialist service or being on a waiting list. This included experiences of having a minimal intervention and then being told that a re-referral could only be made after three months. In addition, participants found that their difficulties worsen over the time they had been waiting, usually resulting in either being unable to engage with support or being told they were '*too complex*' (Milo) for the service. There was a sense of exasperation shared by a couple of participants, relating to the lack of foresight and preventative focus from services, which is illustrated by the quotes below;

Nip them in the bud with the people who've just got to live with it as a problem. Don't wait til the sick person's got a serious problem.(Anne)

Waiting for something like counselling for like nine months...what are they gonna do for those three-months until they can then apply to be put on a

waiting list which will take approximately six months if you're lucky to be actually be seen. People kill themselves.(Terry)

There was a sense of frustration shared by participants about the length of waiting times, as well as narrow and confusing service criteria.

I'm having these problems now, no one to talk to about it now.(Terry)

They'll happily help crack heads, but they don't want to help someone who's smoking a little bit of weed.(Caroline)

It is frustrating because...it's kind of being told you're not crazy enough...or you're not drunk enough.(Terry)

3.2.2.2 Lacking options.

Often, after having to wait for significant periods of time, many participants described the sense of lacking options or having little say in their choice of intervention. It was common for participants to report being offered prescribed medication as their only option, with no alternative discussed.

Antidepressants yeah. No no other, didn't offer anything else at all.(Steven)

Every time I see them for the three-month review, they just bung my medication up even higher.(Caroline)

In addition, there were descriptions of people suffering with substance use problems being placed on a 'script' (prescription), for a heroin substitute, such as Methadone or Buprenorphine, with no offer of additional support. Jeff offered his perspective, as a peer mentor;

They're just stuck there on that script still; they've got no support. (Jeff)

They're given their depot and that's it, they're not actually, there's nothing, there's no other interaction they don't get any phone calls. (Jeff)

There were speculations from participants about why they have not been offered a wider selection of treatment options, including feeling judged for using substances, feeling like a 'hopeless case' (Milo), services lacking resources and funding, and professionals requiring better training.

I don't feel like people should judge us because we've because we've um done substances. (Caroline)

An interesting commonality presented in the data related to fellowship meetings (e.g., Alcoholics Anonymous [AA] and Narcotics Anonymous [NA]). Attending these meetings was described as being a last resort, when other services have denied support. However, the experience of the four participants who mentioned fellowship meetings, reported that these meetings were unhelpful, triggering, and not a viable alternative to support from the local drug and alcohol service.

I'm really really against fellowship meetings. I just don't think they're helpful at all...they are good for people in survival mode. (Jeff)

So many people flock to it out of desperation... Because I'm like, it's a joke I tell myself, but I'm like 'a cult wouldn't say it's a cult'. (Terry)

3.2.2.3 Receiving minimal intervention.

A shared experience amongst all participants was having received a minimal intervention, which they perceived to be insufficient. This ranged from being prescribed only medication (as described above), to having short-term cognitive behavioural therapy (CBT). Experiences ranged from people finding the sessions very helpful, but not having the option to continue after a few weeks, to finding the CBT approach to be surface level and a way of getting people to a place of being 'well enough', to get back to work, for example.

It doesn't matter whether you're better or not, you get six weeks. (Anne)

Even the CBT approach I'm suspicious of. I think that has a political agenda as well to be honest and it all feeds into idealism at the top. (Jeff)

Participants who have been under the care of services for longer periods of time described having minimal contact with professionals and despite being under the care of service, receiving little to no intervention.

[Name] is supposed to be my mental health support worker yeah, I barely hear from her...I hear from [name] like every two weeks.(Caroline)

A phone call from someone once every two or three weeks. "Hi how are you doing?", "I'm not that great, oh yeah I'm just soldiering through." "Ok cool I'll call you in two or three weeks from now. A month from now".(Terry)

3.2.2.4 Feeling the pinch.

The majority of participants appeared to have a degree of empathy and understanding around cuts made to service budgets in Luton over the past five years and how this has affected the quality of care and the timeliness in which interventions are delivered.

They need to be funded more by the Government so they got more money.(Milo)

There's not a lot of money around... there aren't the resources there, um but it's a tricky one that one.(Robert)

There was also a sense that Luton was once very well provisioned, but the changes over the past three to five years, have resulted in a sense of loss and had a heavy impact on the community.

Luton used to be great for recovery and it was a really good place for people to go even to have a cup of tea. They'd have breakfasts on a Sunday and just

to chat and just have that connection. And that's been taken away now. And there's nothing really in the community.(Jeff)

Jeff shared his frustration as a peer mentor and seeing third sector organisations and charities being de-funded, which he would have otherwise signposted service-users to;

The one place in Luton that provides support (specifically) for Muslims has had their funding taken away, when Luton is like 90% Muslim.(Jeff)

3.2.3 Subcategory 1C: Facing Everchanging Services

This subcategory describes the fluidity and seemingly constant changes in how services are set-up; for example, when service contracts go out to tender, changes in commissioning, transformation projects and a high turnaround of staff. These processes were co-constructed as; 'Needing specialist knowledge and skills' and 'Blocking with bureaucracy'.

I mean you can't keep up with all the different changes. It doesn't help people's care...They keep replacing the agency that's providing the care.(Anne)

3.2.3.1 Needing specialist knowledge and skills.

Many participants described feeling they needed specialist knowledge, skills and even be privy to another 'language' in order to navigate the services and access support. This speaks to the inaccessibility of services, if people attempting to access

support are coming up against jargonistic language, complicated processes and needing the skills and resources to ask for support in the 'right way'.

They were talking a different language.(Robert)

Terry described going above and beyond to develop skills to learn specific medical language in order to communicate with his General Practitioner (GP) and access the treatment which he believed to be most appropriate.

I start Googling these things and learning...I learnt that if I go tell the doctor these things, then I would get the treatment...So if you don't know what's wrong with you, and you can't tell the doctor either...I learn words, I find their meanings.(Terry)

3.2.3.2 Blocking with bureaucracy.

Frustration with the needless bureaucracy of service policy and procedures was expressed by all participants. For some this related to service criteria, for others it related to a lack of transparency and accountability held by services. There was a shared sense of frustration about services only offering help to individuals at crisis point, even when the participant met the ambiguous and seemingly everchanging referral criteria.

[Said with sarcasm] And it's never, absolutely never ever, the fault of the organisation that is being contacted for help.(Disgruntled)

Yeah like, there's like barriers and red tape and I feel they are in the wrong places. You have to hit a certain criteria...for you to be eligible for that. You have to be off of your rocker basically.(Terry)

In summary, participants described the turbulent experiences of navigating healthcare systems when suffering from mental health difficulties and problems with substance use. They explained how having co-occurring difficulties results in falling through the gaps in service provision and being forgotten about. A process of continuous battles with professionals and services to fight their case for support, as well as an internal battle to try to not give up when faced with multiple barriers. Having to face the everchanging landscape of services and factors outside of an individual's control resulted in feelings of isolation, frustration and losing motivation to seek help.

3.3 Category 2: Swallowing the Jagged Pill

This category describes the social processes occurring between participants and the system with an inevitability of having a negative experience and being let down. Participants defined how they have had to utilise their own strategies to cope, when they have been unsuccessful in navigating the healthcare system. The subcategory of 'Self-medicating to Cope' demonstrates the process of participants using substances to manage their mental health difficulties. This is frequently met with punitive action from healthcare services, as substance use is conceptualised as '*morally wrong*' (Jeff) or '*complex*' (Milo), resulting in services denying help and participants describing feelings of abandonment. The following subcategories, 'Self-Medicating to Cope', 'Experiencing Punitive Action' and 'Feeling Abandoned' are

represented in the model as being a cyclical process. The '*vicious cycle*', described by a many participants involved; wanting professional help, being denied help, using substances to cope, being punished for using substances, feeling abandoned by services, using substances to cope and the cycle continued.

3.3.1 Subcategory 2A: Self-Medicating to Cope

Participants spoke about how they have had to be self-reliant in times of being unable to access support from services. Commonly, this was managing mental health difficulties through the use of substances, such as alcohol and cannabis. The social process around 'Understanding interaction between substance use and mental health' was important for all participants to address during the interviews. 'Needing help' was highlighted as the social process of wanting to access professional support at a time when they were truly *needing* help, almost at break point.

You'll be all anxious or whatnot, you'll have a couple of puffs [of cannabis] and you're chilled.(Caroline)

I would smoke [cannabis] to literally... to not feel upset...cos that was like my medicine.(Izzy)

This is PTSD. And I end up drinking because of that... Er it's a form of escapism.(Terry)

3.3.1.1 Understanding interaction between substance use and mental health.

All participants described their understanding of the interaction between substance use and mental health difficulties and how this may differ from the view of services and even society as a whole. There was a shared opinion between participants that using substances has always been a means to cope with mental health difficulties. A number of participants described early traumatic histories and adverse experiences which they attributed to developing mental health difficulties in their adult lives.

Mental health come when I was seven-years-old, so I'm pretty god damn sure I weren't using substance then, do you know what I mean. I know what came first.(Caroline)

Where I'm like, no, in all honesty for me alcohol [use] is definitely the symptom of the underlying problems.(Terry)

The majority of participants expressed substance use being problematic, but that usually being the '*quickest fix*' (Steven) or the only option if support from a mental health service has been denied. There were also experiences shared of being told by services that all substance use must cease in order to access support, which is described in more detail in the next section.

Obviously, paranoia, hallucinations, things like that obviously become worse when the person does substances, but it used to be like a World War three if I

couldn't smoke [cannabis], because I didn't know where to regulate anything... If you take that away they're going to be left with a broken person that you're not going to be able to fix. (Kathy)

For some participants it was felt that there needed to be specialist services to offer support for people with both mental health difficulties and problems with substance use as current services do not seem to have a good understanding about the interaction between substance use and mental health difficulties.

The drugs recovery services can't help you because they don't know if it's your mental health making you use. (Milo)

But when someone comes to get help there should be two doors, one for those who have drug use and one for those who don't. (Izzy)

3.3.1.2 Needing help.

All participants described times when they have felt like they were at breaking point and in a vulnerable position, very much needing support from healthcare service. They described being in situations where they were not in a position to ask for help, or even wanting help, but on reflection described really needing help from others.

You can be um in in a place where you are... you've kind of gone into a whirlpool and you're so far in that you can't even speak. (Disgruntled)

Yeah I wanted to die. I was a mess. I was drinking and then that'd lead me into marijuana and cocaine...I was a nine stone shrivelling wreck. Lost all me work jobs cos I didn't go to work. Er wrapped myself around drink...I broke my leg, I took an overdose of Chlorpromazine.(Milo)

Thought I can't... I can't live without that stuff, but I can't live with it any more now either. I've absolutely had enough, I just broke down... And decided after I prayed I thought right, I would kill myself. Like that was... and I felt such a relief when I thought that.(Steven)

I committed...tried to commit [suicide] many times.(Kathy)

The sense of desperation, hopelessness and helplessness in the accounts of these participants illustrates the stark reality of the devastation that the interaction of mental health difficulties and problematic substance use can have on people's lives, especially when these times in people's lives have followed being unable to access services.

3.3.2 Subcategory 2B: Experiencing Punitive Action

Participants described 'Experiencing Punitive Action' from a variety of mental health and drug and alcohol services. This related to a sense of being infantilised, judged and discriminated against by professionals. The underpinning social processes of experiencing punitive action were 'Feeling punished by services' and 'Being told to stop using to access services'.

3.3.2.1 Feeling punished by services.

The majority of participants discussed incidents when they have felt punished by services for not being a 'good patient'. They described this as a result of services being stretched and needing to reduced case load numbers, so acting in an austere manner, lacking compassion, patience and understanding.

I got a letter saying "you've been discharged, we do not want to see you no more". So they sort of just threw you away. Er I think it might have been funding, stressed, but yeah they basically went "you didn't turn up, bye bye".(Milo)

So they'd take away the thing that was helping me most. They'd just taken away like that. Boom.(Anne)

A minority described being given an ultimatum by services to 'get better or else', for example, detention in an inpatient mental health facility being used as a threat.

If you do anything like this again then you'll be here [inpatient unit] for six months and you'll have to take medicine.(Izzy)

However, a minority of participants experienced healthcare professionals' as understanding of their problems with substance use. For example, Steven described needing to be drunk to cope with feeling anxious about leaving the house to go to his psychotherapist appointments and he was not met with judgement or punitive action.

This allowance meant that Steven was able to see his Psychotherapist for around a year and benefitted greatly.

I went to see [name of Psychotherapist] and I would go there and still be drunk cos I had to get... I had to be drunk to get there because of being outside...I used to say to her you can't help me. She'd go "what do you mean?". You can't help me because I'm drinking...one day she just said to me, shut up and sit down. Um and she just showed an interest and really wanted to help.(Steven)

3.3.2.2 Being told to stop using to access services.

Nearly all participants spoke of multiple experiences of being told to stop using substances in order to access mental health services. For these participants, it has felt like a challenging and punitive request, especially as they have described using substances in order to cope with mental health difficulties. If services are asking individuals to stop utilising their own coping mechanisms before being offered any support, it seems inevitable that the individual will feel like they are unable to stop using substances without an alternative coping mechanism.

They all said like if I smoke weed like basically I'm not gonna get no further help.(Caroline)

"Oh we're gonna have to close your case because you smoked [cannabis], once you've stopped smoking then get back to us" and its like this is the

problem. That's like t... telling I don't know like a baby to take their anxiety blanket off.(Izzy)

I tried to explain that to stop smoking they needed to help me because to stop smoking it would deteriorate my mental health, my self-harming would start again, the mood swings would change and no-one would want to deal with me...You need to fix them whilst... I'm not saying you'll be stable taking drugs or alcohol. But they're more stable than what they are off it. (Kathy)

For some participants having to stop using substances before being allowed to access services and stop utilising self-medicating strategies felt like too much of a risk for mental health difficulties to resurface and become unmanageable;

They wanted me to stop [drinking alcohol] before they could talk to me...too much of a risk to me...I can't risk that.(Steven)

A number of participants discussed the rationale behind being asked to stop using substances prior to accessing services. There were mixed opinions about whether this was a fair request or whether it felt restrictive and potentially dangerous. Steven shared his experiences of accessing talking therapy whilst drunk and being able to implement the strategies he learnt in those sessions once he was in recovery.

Even though I was drunk and people say you can't tell a drunk person cos they don't listen, I said all them tools come out when I was sober they were there in my subconscious mind.(Steven)

I'm like well if I could fix myself and stay sober for that long why would I need the counselling after that...it doesn't make sense to see someone who's like constantly hungover and not showing up and this and that. I get that.(Terry)

3.3.3 Subcategory 2C: Feeling Abandoned

This subcategory describes how participants have experienced feeling abandoned by services, receiving support and suddenly discharged, or being denied support from the offset. This section will discuss the social processes between participants and services, these were co-constructed as; 'Feeling alone' and 'Being denied help'.

But they didn't say that in the discharge letter, nothing, it was like that 'finished', you're off; you're on your own now.(Anne)

They just like to leave us in the lurch.(Caroline)

They sort of just threw you away.(Milo)

3.3.3.1 Feeling alone.

A number of participants described feeling isolated and alone as a direct result of the lack of support from services.

Then I was using again then they [mental health services] sort of they went away.(Milo)

In addition, there were reports from participants that even being under the care of services can feel alienating, as opposed to welcoming or containing.

I've actually taken people down there and um to [drug and alcohol service] and it's kind of a most alienating place.(Disgruntled)

3.3.3.2 Being denied help.

Some participants described incidents of being in a mindset of wanting to seek help and navigating the system in order to find support. However, a common experience was feeling that they were in a place of wanting help from professionals, but this was denied as a result of long waiting lists or specific criteria needing to be met. Many participants experienced being told that the service was unable to offer support due to the participants' problems with substance use or, conversely, mental health difficulties. In addition, a number of participants have been told that their difficulties are 'too complex' for the service to address.

They [mental health service] said they can't help me because I'm drinking. And the alcohol and drug services vice versa.(Steven)

"Oh but we think it's really dangerous trying to give you a few sessions it might start opening a whole can of worms and then we're just gonna leave you because we can only do six sessions."(Anne)

In summary, participants described 'Swallowing the Jagged Pill', in terms of having to self-medicate with substances to cope with mental health difficulties, rather than access alternative support from professional services. The social processes involved have complex interactions, including feeling punished or judged by healthcare professionals and facing structural barriers to accessing support. There was a shared sense of feeling abandoned by services and left to fend for themselves, stuck in the vicious cycle of using substances to cope with mental health difficulties, being unable to access support due to substance use, resulting in feeling abandoned and alone.

3.4 Category 3: Doubting Adequacy of Support

The third category 'Doubting Adequacy of Support' relates to the social processes occurring between participants and healthcare professionals, which result in feelings of mistrust, and experiences of disempowerment to occur. The following subcategories were co-constructed under this domain; 'Being Labelled', 'Disappointing Interactions' and 'Feeling Disempowered'. The model (See Figure 2.) presents the subcategories as feeding into one another in a cyclical process.

3.4.1 Subcategory 3A: Being Labelled

This subcategory describes how participants felt that they were being labelled by healthcare professionals, whether in relation to their mental health difficulties or problems with substance use. The majority of participants found this to be a negative and restrictive social process, rather than opening doors to help and support. The underpinning narratives have been co-constructed as, 'Wanting individualised care'. Participants felt that being given a diagnosis or label, impacted on how others

interacted with them, as well as diminishing their sense of self and impacting negatively on the construction of identity.

I've been diagnosed with OCPD [Obsessive Compulsive Personality Disorder] - the personality and that P makes an awful lot of difference.(Robert)

As soon as they hear you've got a bit of mental health then you're crazy.(Caroline)

I was definitely put into a category once I said that I smoke [cannabis].(Izzy)

I'd been labelled as an alcoholic by doctors...and by services then as well. You're an alcoholic.(Steven)

3.4.1.1 Wanting individualised care.

A number of participants described being the recipient of a 'one size fits all' (Terry) approach. There was a feeling that being labelled as an 'alcoholic' or with a specific mental health diagnosis would result in being treated in a particular way by members of staff, seeing the label, rather than the individual. There was a sense of participants wanting to be seen as a person with multiple aspects to who they are, with rich histories, interests and personality.

You can't deal with that the same. Just because your text book says so, doesn't mean that that person's life is that.(Kathy)

You know a lot of the time there's a brush painted (I'm generalising) canvas to everyone that you're an alcoholic and these are your problems. So, there's not enough individual focus I guess is what I'm trying to say... And more personally personalised er approach to individuals.(Terry).

3.4.2 Subcategory 3B: Disappointing Interactions

This subcategory describes how participants felt healthcare professionals are unable to effectively communicate with service-users, other services and family and friends. All participants described at least one disappointing interaction or a lack of effective communication from services. These incidences have been co-constructed as; 'Being misunderstood', 'Lacking transparency', and 'Needing improved training for staff'.

It's just a lack of communication across the board. It's absolutely shocking.(Caroline)

3.4.2.1 Being misunderstood.

A number of participants described being misunderstood by healthcare professionals. Misunderstandings were related to the interaction between substance use and mental health difficulties, as well as misunderstandings based on poor communication or lack of opportunities to foster trusting relationships with staff, to facilitate meaningful communication.

Believe it or not I'm not very good at trying to get my feelings out.(Caroline)

She's a good person but I don't think she understood which fed into that frustration.(Jeff)

Just generally be more understanding, that's what I needed...willing to help.(Steven)

3.4.2.2 Lacking transparency.

There was a sense that healthcare professionals, as well as services as a whole lack transparency. This was described by participants to be in relation to care pathways, policy, procedure, rationale for decision making, as well as owning up to mistakes.

Rather fortunately for the medical profession you know their blunders get buried.(Disgruntled)

It was very like sad in a way because also now because of that I've never actually known what... what was going on.(Izzy)

3.4.2.3 Trusting healthcare professionals to understand.

When asked about how services could be improved, all participants made reference to struggling to trust that healthcare professionals would be able to understand their difficulties. Many participants made reference to specific incidents where they have experienced staff as not understanding and/or able to manage the 'complexity' of co-occurring difficulties. At the heart of this social process, participants described a lack of understanding being communicated, as well as

feeling like they were not seen as the expert in their own experiences. A number of participants felt that they did not have enough time with healthcare professionals to build rapport and a trusting relationship, in order to help members of staff to understand their difficulties.

Learning from a text book and writing down something about something hypothetical is not gonna help the real world.(Kathy)

Sitting there...in your ivory tower and you know you've got no experience and...and you know nothing.(Robert)

3.4.3 Subcategory 3C: Feeling Disempowered

This subcategory describes how the social processes of 'Being Labelled' and 'Disappointing Interactions' work cyclically with the process of 'Feeling Disempowered'. This social process is made up of the following co-constructions: 'Experiencing power imbalance' and 'Feeling judged'. 'Feeling Disempowered' is described by participants as resulting in a relapse or being 'done to' by services, feeling infantilised and having little autonomy in their own treatment, which inevitably puts their recovery journey on hold. Again, this relates a great deal to the manner in which participants have been communicated with by healthcare professionals and services.

No point talking no more because no matter what I say or say how I feel, or do what I feel, or whatever yeah, I'm... I'm in the wrong.(Caroline)

The other issues I had then is the way they speak essentially um not many of them speak as if they're trying to help. A lot speak as if they're trying to talk down...its invalidating.(Kathy)

3.4.3.1 Experiencing power imbalance.

Experiencing the power imbalance may seem like an obvious social process, because of the imbalance of power between a service-user and a member of staff, however, the feeling associated with this, was clearly communicated by a number of participants. When a power imbalance is very much felt and internalised it can have a detrimental impact on the delivery of care and support, especially to participants who already felt like they were in a vulnerable or disempowered position or circumstance. In addition, Robert described experiencing power imbalance in relation to being part of a participation group with a local mental health service. He felt that his contributions were not listened to or taken seriously in the way that he had hoped to impact change.

You get over-ruled. And they make you feel basically like minions; pawns.(Robert)

They're basically patronising towards the person who is... is there, because they have an attitude that seems to say well actually, we know more than you.(Disgruntled)

3.4.3.2 Feeling judged.

All participants described the social process of feeling judged by others. Specifically, feeling judged by healthcare professionals when accessing services. Interestingly, the feeling of judgement was described more commonly in relation to substance use, rather than mental health, perhaps reflecting changing attitudes.

I don't feel like people should judge us because we've... because we've um done substances.(Caroline)

They probably judged it in a moral way. As if, as if it was something bad...

What's wrong, why are you doing this and not really trying to talk about it and understand it.(Jeff)

Terry also speaks to the accessibility of services and how certain groups of people may think that a service is not for them, because of lack of representation in the staff team or people currently under the care of the service. Specifically, Terry was referencing his perception of a lack of Black staff in mental health services.

I'm like this is why people don't come. This is the stigma. I don't see people like me there...That's exactly what's stopping them from coming to access your service.(Terry)

In summary, participants described 'Doubting Adequacy of Support', in terms of feeling labelled by services, which fed into feeling disempowered, which led to interactions with others being disappointing, or not meeting expectations. The social processes involved have complex interactions, including being misunderstood,

feeling disempowered and wanting services to encapsulate a more individualised approach to meet specific needs of service-users. Unfortunately, prior negative experiences of services very much impacted on participants expectations around healthcare professionals' ability to understand their needs.

3.5 Category 4: Becoming One of The Lucky Ones

The final category relates to the social process of 'Becoming One of the Lucky Ones' in terms of being helped by the system. This was described by nearly all participants who are now in or moving towards recovery. The following subcategories were co-constructed within this domain; 'Benefitting from Relationships' and 'Influencing Change'. Participants described that once they had been able to navigate services, become 'one of the lucky ones' and felt helped by a trusting relationship with a professional or peer, they found themselves in a place of wanting to give back and help people still struggling by influencing change in services to be better and do better. This category by the yellow circle at the bottom of the model (see Figure 2); 'Benefitting from Relationships' is the social process that underpins 'Becoming one of the Lucky Ones', whereas 'Influencing Change' is represented by the two upward arrows showing the impact of participants on service development, from the bottom-up.

3.5.1 Subcategory 4A: Benefitting from Relationships

This subcategory describes the reciprocal process of benefitting from relationships, both with professionals and peers with similar experiences. These underpinning ideas are co-constructed as; 'Benefitting from peer support', 'Having a trusting relationship' and 'Being heard'. All participants shared how their experiences

of positive relationships with professionals with and without their own lived experiences of both mental health difficulties and substance use greatly impacted their overall experiences of services and was key in 'Becoming One of the Lucky Ones'.

3.5.1.1 Benefitting from peer support.

The majority of participants spoke of benefitting from peer support, either from the perspective of being a service-user or receiving positive feedback from others in their role as a peer mentor.

He got all the peers to run the groups and stuff. So yeah it was like a Utopia, it was brilliant.(Steven)

They know I'm not talking crap...people open up more when they know you've been there.(Milo)

I met an extremely effective person [name of peer mentor] Um who's still in the industry um and locally um is probably one of the best...he was an ex-user...Been there done that. So it's an understanding.(Disgruntled)

Coming from the data was the feeling that no one can truly understand, relate or offer advice if they have not experienced mental health difficulties and or problems with substance use personally.

Those who don't have experience will never understand.(Kathy)

If they've been on it themselves, got a family member like it, a childhood, a lot people are different.(Caroline)

3.5.1.2 Having a trusting relationship.

This social process describes how participants benefitted from having a trusting relationship with a member of staff and how this is key in helping continuing engagement with a service.

Once you've been dealing with one person for a long time, going to somebody else is a serious difficulty.(Kathy)

People don't just open up that quick when they've got mental health and whatnot.(Caroline)

A number of participants described wanting connection and healthcare professionals to act with kindness, compassion and understanding. There was a sense that these skills might be inhibited if staff working in services are being overstretched, under-resourced and governed by strict policy and procedures.

Don't just do what your boss is telling you to do or what the guidelines are telling you to do. Be a human. Say how can I help like be human to them. Like compassionate.(Steven)

I can't pinpoint exactly what people did apart from they just tried to help me there and they were willing to help and try.(Steven)

Many participants described being helped by the relationship they had fostered with healthcare professionals and the impact that meaningful relationships had on their journey to recovery and overall experiences of services.

But do you know what, [name of support worker] was doing a great job, absolutely great job. I was actually gutted when they took her off me yeah.(Caroline)

He actually really took the time and went out with a coffee for me and listened and he was interested in philosophy as well.(Jeff)

He will try to get onto your level to be able to understand your perspective whereas many others don't.(Kathy)

Cos them three [drug and alcohol service support workers] finally after so many, so many years offered me a bit of hope and were willing to help after it seemed for so long no one was willing to help me.(Steven)

3.5.1.3 Being heard

The value of being heard and truly listened to was given high importance by participants. Feeling listened to and heard by members of staff and peers is related to feeling valued and therefore being able to build a meaningful, trusting relationship. In turn having more trust in interventions offered by services.

He [drug and alcohol support worker] listens, he doesn't invalidate.(Kathy)

She listens to what I say...I'll say things two or three months later, but she's got records of what I said at the time.(Robert)

[Drug and alcohol support worker] actually listened, she just heard me out and said I'm gonna help you. She just give me that hope, she said I'm gonna help you.(Steven)

This was something really practical and really good and everyone felt valued and part of that group.(Anne)

The majority of participants described the importance of being open and honest, this was a reciprocal process, in terms of healthcare professionals being open and honest with service-users and service-users feeling able to be open and honest with services, without the risk of being subjected to punitive action.

She allowed me to be honest... like oh now that was a really good session like I told her how much I smoke [cannabis] and she didn't seem to have an issue with it.(lizzy)

I was just trying to be honest so I'd go to drug and alcohol s.. and they they'd sort of ask you why you drink. Or I would go in there and tell them why I drink.(Steven)

3.5.2 Subcategory 4B: Influencing Change

This subcategory discusses the phenomenon of participants influencing change by helping to develop services, despite having mixed or negative experiences. They conceptualised this subcategory as being underpinned by; 'Giving feedback' and 'Wanting to be involved. Three of the participants are now working in services, as peer mentors, one participant has started their own social media platform offering a space for people to talk about mental health issues. Three participants have been heavily involved in participation groups and the ongoing mental health service transformation project. Another two participants asked the researcher to signpost them to charities and organisations they can volunteer for at the end of the interview, wishing to help others suffering with mental health difficulties.

I wanted to get involved with helping people with their mental health how would I go about that... wanna help kids who have been exposed to like really horrible things.(Izzy)

I'd like to go out there and help homeless people with dual diagnoses.(Milo)

I want people to see that there is a light at the end of the tunnel with this kind of stuff and you know I need to engage.(Terry)

3.5.2.1 Giving feedback.

The social process of giving feedback was discussed with all participants, it seems that giving feedback did not always feel possible or that it was being asked for by services. There was a sense of cynicism shared by a couple of participants

that feedback is only asked for when things had gone well or healthcare professionals felt that they had done a good job.

Um, the good ones did, because they knew that they were good at doing the job.(Kathy)

A number of participants spoke about regretting not giving feedback to a healthcare professional who had really made a difference and helped them on their recovery journey. There was a sense of sadness or regret that they were unable to find these individuals to show their gratitude.

The other guy, the third person I worked with him, so I see him almost daily. He knows how grateful I am but I'd love to see the other two people.(Steven)

3.5.2.2 Wanting to be involved.

The process of wanting to be involved and make a change was apparent within all but one of the participants' accounts. There were two participants who were keen to be involved in service development, but were unsure who to contact or where to start.

Two years um participated in all their meet, all the monthly meetings and all the other activities.(Anne)

I've been involved in [participation project name]...I have to say I've a sense of um in I've kind of tried in knowing that I I've actually participated in that in the early days in helping shape it.(Disgruntled)

One participant felt that after wanting to be involved and contributing to participation groups, their opinions and ideas were overlooked and they believed it to be a tokenistic, 'tick box' exercise.

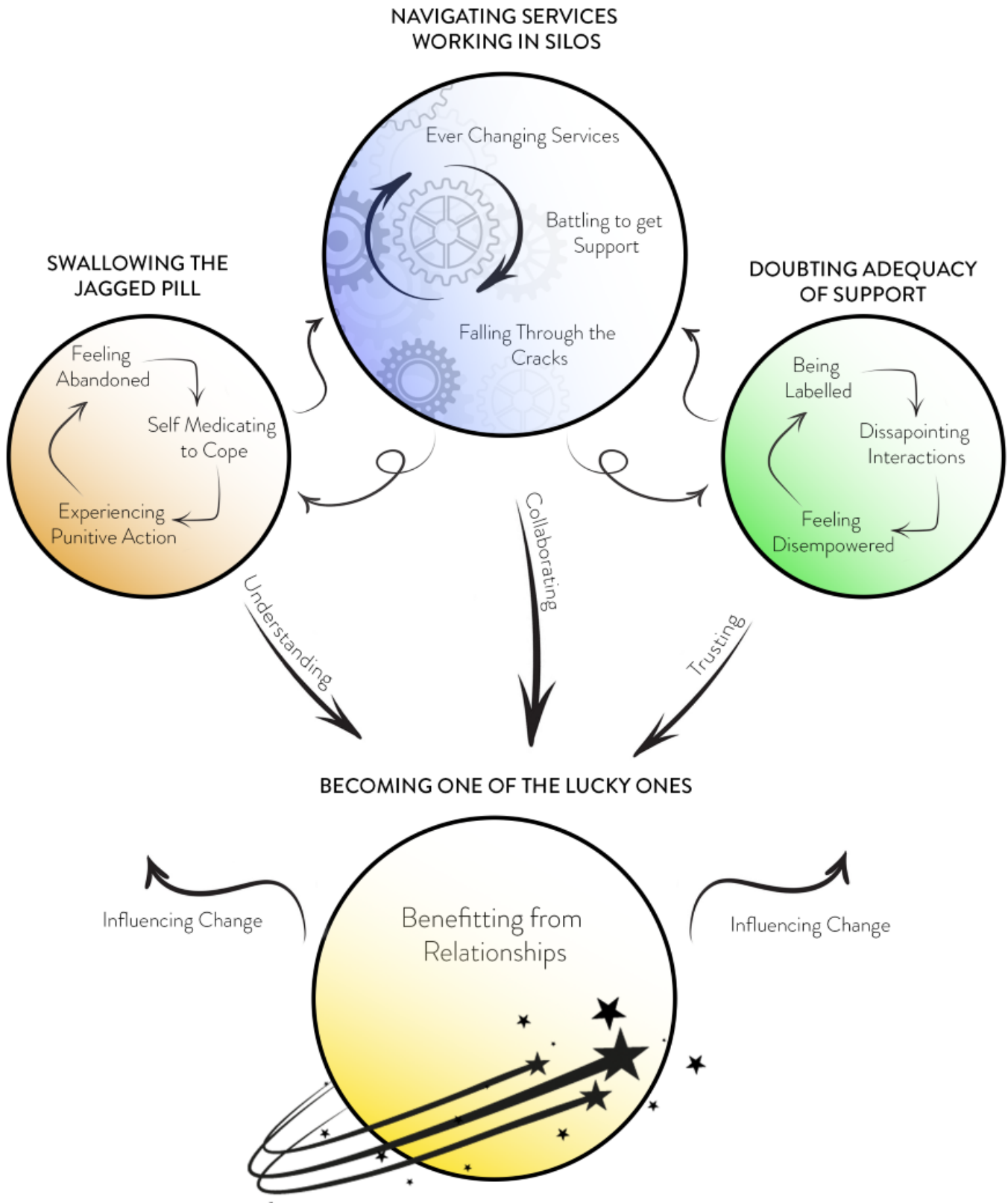
We came up with some really good stuff...I always thought we'd get some feedback. I never heard anything...Sometimes I feel basically that you're just a tick boxes, cross the T's and dot the I's.(Robert)

In summary, 'Becoming One of the Lucky Ones' highlighted the generosity and compassion of participants wanting to give their experience and knowledge to help others through peer support and developing services for the better, underpinned by personally benefitting from positive relationships in their own experiences of services. The discussions around benefitting from peer support give a clear indication that having people with their own lived experience working in services has been instrumental in the recovery of a number of participants. The discourses around being able to make their way through adversity, whether that was conceptualised around service structures, unhelpful interactions with staff or punitive actions, several participants fostered a sense of hope and indicated there is a way to navigate services, but whether this is a positive or negative experience is very much shaped by interpersonal interactions along the way. Experiences of influencing

change were mixed; however, this did not prevent participants from continuing to want to be involved and share their experiences for the benefit of services.

Figure 2.

Figure Showing Grounded Theory Model.



3.6 Relationships Between Categories and Social Processes

Participants have shared commentaries that suggest multifaceted and fluid relationships between all of the categories and social processes presented in the model of grounded theory. The relationships between categories, subcategories and social processes are discussed within the body of the results sections, as well as directionality being indicated by the arrows on Figure 2. While these relationships represent the co-construction of social processes and categories across the dataset, there were prominent differences within the diverse participant group. These differences were due to the nature of their involvement with different services as well as demographic characteristics, such as, age, ethnicity, gender and current level of involvement with services.

4. Discussion

In this chapter the findings of this research will be discussed in relation to existing research in the field and relevant psychological theory. The researcher shares potential clinical implications, as well as methodological issues and areas of further research. The chapter concludes with a summary and final thoughts from the researcher.

4.1 Overview of Findings

This research has found that the way in which services are set up and provisioned has been highly influential on the experiences of people with both mental health difficulties and problems with substance use, living in Luton. These experiences were categorised as social processes between participants and structural issues; 'Navigating Services Working in Silos', service level issues; 'Swallowing the Jagged Pill' and interpersonal interactions; 'Doubting Adequacy of Support'. There were also a number of positive, transformational experiences shared, relating collaborating (joint-working between services), understanding (participants feeling understood) and trusting (developing reciprocal trusting relationship with healthcare professionals). These processes allowed participants to escape the three 'vicious cycles'. 'Becoming One of the Lucky Ones', is the final category, underpinned by social processes related to 'Benefitting from Relationships', through involvement with services. The positive experiences described by participants have had some bearing on participants' endeavours to influence change, using their own knowledge and experience to develop services for the better.

4.1.1 The impact of service provision.

When understanding the Grounded Theory (GT) model, it is necessary to capture the specific 'service provision' that participants have referenced. On the whole, the model comes from participants experiences impacted by National Health Service (NHS) primary care services, such as General Practitioner (GP) contact, the Improving Access to Psychological Therapies (IAPT) service, NHS secondary care services, such as Community Mental Health Teams (CMHTs) and Crisis Teams, NHS inpatient facilities and the local drug and alcohol service. Across the data set there are names of organisations that have come and gone across the service provision landscape. The constant development and re-development of health and social care services in the United Kingdom (UK) spans decades; with a revolving pattern of attempts to integrate services, followed by services being separated and specialised, in a continuing cycle. It appears Luton, much like other areas of the UK, is caught up in a cycle of healthcare service re-structuring, with new reports, plans and reviews constantly emerging. Ways in which 'Re-imagining Luton' can be harnessed to have a sustainable impact and improve service provision for people with both mental health difficulties and problems with substance use will be discussed in 'Clinical Implications'.

As discussed, the way in which mental health services and substance use services are set up varies greatly across different localities the UK. Some areas have NHS drug and alcohol services, others utilise third sector and charity organisations, commissioned by the local authority (e.g., Turning Point, Change Grow Live,) and some areas provide substance use support through integrated services. That being said, the findings from this research may be helpful for locations

in the UK which also have NHS mental health services providing care alongside substance use services commissioned by a third sector or charity organisations.

4.1.2 The impact of participants' context.

In line with the GT methodology, the participants were heterogeneous, with variation in age, experiences with previous service engagement and/or involvement with service participation or employment. Three participants were working as peer mentors, meaning that they have had their own experience of being users of substance use and mental health services, as well as working for the local substance use service in a professional capacity. The peer mentor participants spoke of being able to share their experiences of problems with substance use with service-users, alongside advice and treatment and this being received as more valid and meaningful than from someone without such lived experiences. The value of peer mentoring support is well documented in the literature as being highly effective in substance use services (White, 2009; Tracy et al., 2012). Three participants who have been involved in service-user participation groups and forums, reported mixed experiences. It is hypothesised by the researcher that due to these participants having insight from 'both sides', they have a well-rounded understanding of how services function and are privy to rationales behind decision making. This participant sample, bringing a diverse array of experiences, has brought an original contribution to the evidence base, in understanding how one becomes of the 'lucky ones'.

4.2 Relevance of Findings to Existing Literature

4.2.1 The impact of structural factors.

The experience of 'Navigating Services Working in Silos' is a finding directly related to how services are set-up on a structural level. The primary focus of the UK Government, NHS England and CCGs seems to be 'cost effectiveness' of services and how this is evidenced by meeting arbitrary targets and/or initiatives. This is even more relevant in the context of inflationary pressures facing the wider economy, to which, of course, the NHS is not immune. The Spring Statement (HM Treasury, 2022) alluded to a commitment to increase health spending; however, the amount will be far less than promised in the Autumn Budget and Spending Review (HM Treasury, 2021), because of higher-than-expected inflation. Despite no significant additional funding being announced, the Spring statement goes on to say that the NHS should do as much as it can to improve the value for money of its services and reduce an unwarranted variation in how services are delivered (HM Treasury, 2022). This is only two years after the Spring Budget in 2020, promised to give the NHS whatever was needed to cope with the Covid-19 pandemic. Unfortunately, the tone has very much changed in wanting the NHS to 'do more and prove it', without the appropriate funds.

Difficulty navigating service structures, understanding service criteria and treatment pathways, as well as knowing what is offered by which type of service, are findings that corroborate what is known from existing literature. The lack of clarity appears linked to a lack of continuity and communication between services (Notley, Maskrey & Holland, 2012), healthcare system design flaws (Elison et al., 2016) and, a need for improved visibility and accessibility (Parkman et al., 2017), as well as contradictory information provided by professionals (Edward & Robins, 2012). The experience needing to battle for support, appears to be related to having co-occurring difficulties, and the available support being split between services. This is

not a novel finding, nor is it specific to Luton, but instead mirrors research findings spanning more than ten years. It has been repeatedly highlighted in the evidence base that the separation of mental health and substance use service commissioning and agendas have made effective joint-working almost impossible (e.g., Lawrence-Jones, 2010; BPS, 2012; Searby, Maude & McGrath, 2018). Despite this consistent finding, healthcare services continue to be commissioned in a way that mitigates against joint working.

Participants shared that 'Falling Through the Cracks' between services, tended to result in a reliance on 'self-medicating' and, consequentially, a vicious cycle of not being able to access support. This is consistent with findings from existing research in the field (Edward & Robins, 2012; Elison et al., 2016). A need for more collaboration and joined-up working between drug and alcohol services and mental health services was highlighted by all participants, mirroring recommendations from papers included in the systematic literature review (Edward & Robins, 2012; Klingemann et al., 2019; Notley, Maskrey & Holland, 2012; Matheson et al., 2019; Stott & Priest, 2018). Despite policy suggesting that support for people with co-occurring difficulties should be primarily provided by mental health services (NICE, 2016), this has not been the experience of participants. Despite initiatives being developed in Luton to improve joint-working between services (e.g., 'dual-diagnosis' protocol), more needs to change from a structural level in order for these initiatives to be fully supported and implemented.

Funding for drug and alcohol services in Luton have been cut by £1 million over the past five years (LBC, 2021). This research has brought forth the lived experience of people trying to access support for co-occurring difficulties, sharing great awareness of the lack of resources, staffing issues and long waiting lists. The

outcome of decreased funding has been shown to continue to widen health inequalities and substantial unmet needs in Luton (Ministry of Housing, Communities & Local Government, 2019). Participants reported feeling that service criteria were becoming ever narrower, possibly in an attempt to reduce waiting lists and caseloads. This is in line with reports that the NHS workforce in England is in crisis (The King's Fund, 2022). There was a sense co-constructed with participants, that in order to be deemed 'sick enough' to access support, it was necessary to feel suicidal or act in a dangerous way in order to elicit the attention and support of services. This mirrored findings from the systematic literature review where studies found people had deliberately committed crimes in order to be admitted to specialist facilities to access mental health support and/or substance use interventions (Elison, et al., 2016; Klingemann et al., 2019).

Unsurprisingly, cuts to specialist services result in additional pressures on primary care services such as GPs, who may not have the necessary knowledge or skills to offer the appropriate support. In addition, GP practices are under significant strain with the number of permanent roles reducing by 7% over the last four years (NHS Digital, 2021). A number of participants reported unsatisfactory interactions with primary care services, this corresponds to findings from the systematic review which found that participants reported frequently receiving contradictory or unhelpful advice from professionals (Edward & Robins, 2012). However, based on the findings from this study, the researcher would argue that developing specialised services is not the answer, rather improved joint-working and sharing of knowledge would better serve the needs of this patient group. Specialisation and professionals with specialist knowledge being responsible for the care of people with 'complex' or cooccurring difficulties is likely to lead to more silos and less integration.

4.2.2 The impact of services.

All participants experienced 'Swallowing the Jagged Pill', describing a sense of inevitability of not being helped by services and falling back on using substances to 'self-medicate'. This category speculates that, in some instances, mental health services refuse to provide help, due to a 'zero tolerance' approach to substance use. These experiences tainted a number of participants' perceptions of services and resulted in not seeking further help. For participants who had experiences of working with individual practitioners who had a more lenient, and perhaps more concordant understanding of how substances can be used to cope with mental health difficulties, found that this provided the groundwork for a helpful, therapeutic relationship to be developed. However, proposing that there are 'good practitioners' in a 'bad system' is perhaps far too simplistic to fully understand why certain individuals may hold service guidelines or care pathways less tightly, and most likely corresponds to power and privilege, which will be discussed in more detail later in the chapter, through a Foucauldian lens.

The 'self-medication' hypothesis (Khantzian, 1997; Robinson et al., 2011) fits with the accounts of all participants included in this study. A number of participants spoke of initial experiences of drug and/or alcohol use fostering a preferred identity and the sense of belonging to a specific social group, corroborating what is already known in the existing literature (Chorlton, & Smith, 2016). However, the medicating effects were often reported as short lived and reflected on as not being helpful long-term, resulting in participants becoming stuck in the vicious cycle of using substances. This provides evidence for the need for services to facilitate preventative outreach projects, giving people the opportunity to become involved in meaningful activity in the community, aiming to instil a sense of belonging. Self-

medicating to cope was also linked to long waiting times and inflexible service criteria (Staiger et al., 2011; Notley, Maskrey & Holland, 2012). Participants reported feeling that they had little option but to utilise tried and tested coping strategies (substance use) to manage mental health difficulties, which was conceptualised as the less risky option.

Findings from this research indicated that services and, in turn, healthcare professionals have a limited understanding of the interaction between mental health difficulties and problems with substance use. The co-construction of understanding from this research suggests that the local substance use service works with more of a 'harm-reduction' approach, whereas, mental health services, tend to take more of a 'zero tolerance' approach to substance use. Such divergent philosophies, are highly likely to impede joint-working across services. In addition, the dominant societal discourse, around substance use and mental health difficulties, will inevitably impact the focus of commissioning and service structures. For example, 'addiction as a disease' has been at the forefront of research in the field for many years. In turn, this research establishes the basis for the National Institute for Health and Care Excellence (NICE) guidelines (NICE, 2011; 2016; 2019), and clinical practice, which further cements the supremacy of the biomedical narrative around substance use.

4.2.3 The impact of healthcare professionals.

The category of 'Doubting Adequacy of Support' related to the experience of service provision on a more relational level. It is important to bear in mind that the experiences of healthcare professionals and members of staff working for mental health services are not captured in this research, other than the three peer mentors. Recent reports evidence that funding cuts (Kmietowicz, 2021), diminishing resources

(Bannister, 2021), long waiting lists (Punton, Dodd & McNeill, 2022), staffing issues (Black, 2021), ongoing consequences of the COVID-19 pandemic (Schofield et al., 2022) and limited training opportunities (Noblett, Lawrence, & Smith, 2015), may impact on the social processes underpinning participants feeling unable to trust that healthcare professionals will offer adequate support. This finding speaks to the importance of healthcare professionals having the necessary capacity to understand individual service-user difficulties and nurture therapeutic relationships. This is reliant on adequate funding for services to employ enough staff with the necessary skills and experience.

Participants described most disappointing interactions to be underpinned by perceiving that healthcare professionals lacked understanding about the complex interplay of substance use and mental health difficulties. This echoes findings from the systematic literature review (Klingemann et al., 2019; Notley, Maskrey & Holland, 2012). Communicating clear expectations has been found to be key in improving the service-user-healthcare professional relationship (Parkman et al., 2017). In addition, the finding of participants perceiving judgement from healthcare professionals was similar to experiences of discrimination described across many of the papers included in the systematic literature review, including a fear of not being listened to due to 'addict' or 'mental health difficulty' label, or judged for 'self-medicating' (Notley, Maskrey & Holland, 2012). 'Disappointing Interactions' impacted the social process of how honest participants felt they could be with healthcare professionals and how willing they are to foster trusting relationships (Edward & Robins, 2012).

Participants described experiencing a 'one size fits all' approach when working with healthcare professionals, after experiencing being labelled with 'addiction', 'mental health problems' or 'dual-diagnosis'. The importance of

individualised care is clear from the experiences shared by participants, particularly a greater need for services to support with psychosocial issues, housing and employment. This reflects recommendations from the literature included in the systematic review (Edward & Robins, 2012; O' Sullivan, Boulter & Black, 2013; Parkman et al., 2017; Matheson et al., 2019). The concept of 'bending the frame' (Winiarski, 1991), may be helpful when thinking about how professionals can work flexibly within services with structured care-pathways and rigid policies. When working with people with co-occurring difficulties, it is important to tailor support and tackling potential barriers to engagement together. Such an approach would increase the possibility of fostering trusting relationships with healthcare professionals, increasing the chances of 'Becoming One of the Lucky Ones'.

4.2.4 The impact of relationships.

One of the key findings from this research has been how the combination of collaborative working between services, better understanding of service-users with co-occurring difficulties and trusting relationships on an individual level have led to 'Becoming One of the Lucky Ones'. This was co-constructed as 'unusual' or 'lucky', perhaps speaking to the cohort of participants that took part in the research. However, the findings shine a light on the importance of relational aspects of service provision, in helping service-users navigate experiences of distress and move towards recovery.

All participants reported that they had benefitted, or feel that they would benefit, from peer support. This finding perhaps connects to incidences where participants have felt judged by healthcare professionals and the benefit of peer support is more likely to be judgement free. The value placed on peer support by

participants very much reaffirms the findings from the systematic literature review; peer support has been found to be integral in adding meaning, purpose and value to an individual's sense of self and identity. (Edward & Robins, 2012; Matheson et al., 2019; Parkman et al., 2017; Stott & Priest, 2018). Based on the findings from this research and existing literature in the field there is no denying peer support should be championed as an integral aspect of treatment for people with mental health difficulties and problems with substance use (Lawrence-Jones, 2010; Pawsey, Logan & Castle, 2011; De Ruyscher et al., 2017). In addition, peer support roles disrupt traditional power imbalances between 'patient' and 'doctor', allowing the system to evolve. Given the high value of the peer support workers and other peer roles, this needs to be better reflected in their pay and being monetarily rewarded.

Participants described specific healthcare professionals where a trusting relationship had been developed, which subsequently had a positive impact on their recovery journey. 'Benefitting from the Relationship' was co-constructed as wanting more of an equilibrium in a therapeutic relationship, stripping away job titles and labels and seeing one another as a human being in need of help or trying to be the helper. Again, this speaks to a more level playing field, creating less of a power imbalance. A strong therapeutic relationship was identified as an important factor in recovery from both mental health difficulties and problems with substance use, in all papers included in the systematic literature review, corroborating this finding (Edward and Robins, 2012; Klingemann et al., 2019; Matheson et al., 2019; Notley, Maskrey & Holland, 2012; O' Sullivan, Boulter & Black, 2013; Parkman et al., 2017; Stott & Priest, 2018). The majority of participants expressed a wish to help others through involving themselves in service development endeavours. Arguably, this finding illustrates the philanthropy of the participants who took part in the study,

perhaps influenced by positive experiences of 'Benefitting from the relationship', as well as more challenging experiences, resulting in a hope to influence change so that things will be better for others. However, this finding does not negate the need for services to be improved and this should not fall on the shoulders of people who use those services.

4.3 Better Understanding the Findings Through a Theoretical Lens

The researcher will draw on the work of Michael Foucault (Foucault, 1965; Foucault, & Gordon, 1980), to consider power and knowledge at a structural level. Foucault's insights are especially useful to conceptualise the social processes and findings of this research, as they bring a wider structural lens to the social processes and emerging discourse; much of which is linked to control (surveillance), trust and acts of resistance. The post-structural ideas of Complexity Theory are also considered, specifically the concept of Complex Evolving Systems (CES; Mitleton-Kelly, 2003) to inform a greater understanding of agency at an individual level. In line with Foucault's work (Foucault, & Gordon, 1980), Eve Mitleton-Kelly's ideas explain the impact of learning and memory on agency and how this can influence system development. Her perspectives on 'agency' and 'social order' will be reflected on when discussing the overall findings of the research, providing a richer understanding on how individual action can prevent or promote system change and development.

Looking back and understanding how civilisations throughout history have treated people with mental health difficulties, has been helpful in understanding why current structures, on the surface, appear confusing, difficult to navigate and, at times, not at all helpful for the people they are meant to serve. To this end,

Foucault's writings on power relations, particularly in relation to the treatment of 'madness' over time and how Western societies have operated to 'correct', bring about order and maintain hierarchy in order to uphold political agendas, may shed light on these findings. In Foucault's work 'Madness and Civilization' he speaks to the treatment of the 'mad' in 14th-19th century Europe and posits how we can learn from events, such as 'the great confinement', and draw conclusions relevant to power relations and institutions existing in society today.

The researcher understands Foucauldian theory as suggesting that, over time, the 'mad man' has been portrayed as a moral outcast and locked away in asylums to prevent society having to 'look in the mirror' and come to terms with their own morality. Even today, substance use and mental health difficulties are conceptualised by some as a moral failing or weakness of character. Regardless of the physicality of asylums being destroyed, comparable power relations between 'doctor' and 'patient' still exist, maintaining structures which control, restrict and victimise 'moral offenders', or those that violate 'specific social norms' (Foucault, 1965). This can be linked to participants' experience of power imbalance; power and powerlessness acting in tandem. However, as Foucault himself expressed, where there is power there is resistance (Foucault, & Gordon, 1980). This act of resistance is interpreted by the researcher as the power from nurturing and 'Benefitting from Relationships', leading to 'Influencing Change' on services, from the bottom up.

CES theory (Mitleton-Kelly, 2003) would suggest that social systems (e.g., the NHS) are reflexive and conscious of what has gone before (e.g., asylums). For example, a system wanting to change and improve allows members of a social system to become active and intentionally change the expected conclusions. CES theory suggests that interplay between structural values, beliefs and existing practice

(services) and agency of individual parts (service-users) organise and reorganise social systems. Unlike Foucault's thinking, CES theory suggests that individuals have greater agency in changing systems and escaping inevitable negative outcomes, which directly relates to 'Influencing Change'. Influence from service-users on service development, very much changes the power relations of traditional top-down, hierarchical approaches in healthcare systems.

Looking through a Foucauldian lens, the powerful act of 'surveillance' is present at all levels; politically, organisationally and between service-user and clinician, through processes such as management, audits and targets, all created to remain congruent to the norm. The assessment of 'effectiveness' is rife in clinical settings and this does not exclude service-users' assessment of clinicians. Unsurprisingly, these processes tend to reduce the possibility for collaboration, trust, innovation and adaptability of a system. Complexity theory provides insights into management strategies focused on enhancing relationships from a human-focused perspective, which can lead to more creative and adaptable organisations (Mitleton-Kelly, 2003). On an individual level, members of teams in organisations who feel they belong and are contributing to a greater purpose or goal, were more able to be flexible when working with service-users and compassion fatigue is less common (Regine & Lewin, 2003). Recommendations to this effect are discussed in 'Clinical Implications'.

In some of his last lectures, Foucault considered the concept of trust, in relation to power (Foucault, 1983-1984). He suggested that trust is not a linear phenomenon and it is not possible to bring it about through political discourses that preach collaborative working and commitment to an organisation. Instead, trust must be nurtured through reciprocal action; giving and receiving (Foucault, 1983-1984).

Trust plays an important part in enabling connectedness, therapeutic relationships and collaboration between healthcare professionals and service-users. In clinical settings, the relational aspects of practice, as well as the somewhat unpredictable, risky nature of the work requires trust so that reflective, responsive and safe environments can exist (Webster & Watson, 2002). However, trust is easy to damage and the techniques of surveillance employed by systems, can clash with service-user and healthcare professionals' expectations of autonomy (Watson, 2002).

CES theory is helpful in thinking about how to operationalise recommendations, based on the issues, brought to light looking through a Foucauldian lens. CES poses that connection between individuals making up human systems, is not a constant but much more fluid and variable over time (Mitleton-Kelly, 2003). The quality and diversity of interactions between agents of the system (such as between service-users and healthcare professionals) can impact on how successfully knowledge is transferred. Changes to actions and behaviours based on feedback are likely to vary according to the degree of 'connectivity' between individual parts of the system, as well as specific contexts and the political landscape (Mitleton-Kelly, 2003). Mitleton-Kelly would suggest that 'far-from-equilibrium conditions' is the point at which an organisation can either lead to a stagnant system, with loss of morale and productivity, or give rise to a new way of being, discovering new ways of working and evolving. For the latter to be possible, feedback processes (such as this research) are key for informing such transformation, as they provide a starting point to make sense of fluidity in complex systems. It is possible for a natural unity to come from a defined common purpose and effective processes of sharing and producing knowledge (Mitleton-Kelly, 2003).

4.4 Clinical Implications

4.4.1 Clinical Implications: Commissioners (UK Government, NHS England, Bedfordshire, Luton, Milton Keynes (BLMK) CCG/Integrated Care System (ICS), Luton Borough Council)

The findings from the study bring into question problems with substance use being conceptualised as a 'public health issue'. If drug and alcohol services were provisioned by the NHS, this may reduce barriers to joint-working with NHS mental health services. For example, access to the same patient record systems, shared Trust policy and procedures, more opportunities for collaborative meetings and possibly, closer physical proximity (e.g., working in the same building) would improve the cohesiveness of joined-up working. The researcher would advocate for commissioning of services to be done in a manner to promote joint-working of mental health and drug and alcohol services, as opposed to creating specialist services, which would inevitably perpetuate 'silo-working'. The logistics of changing the funding stream (from PHE, to the NHS) for drug and alcohol services, would obviously be a challenge. However, this has been done in the past and there is evidence of cohesive, effective joint-working at this time (e.g., Cooper et al., 2006; Vick & Kipping, 2009).

In the meantime, joint-working between existing services in Luton must be put at the forefront of the 'Re-imagining Luton' agenda. In order to implement successful and sustainable joint-working between mental health services and the drug and alcohol service, oversight and leadership will be key. It will be important for a shared purpose, goal and values to be instilled *between* services, when providing care for people with co-occurring difficulties. A leadership style that can complement the unpredictability that comes with working with the everchanging health and care

needs of the local population. If leaders are able to create an environment that is flexible and attuned to the unpredictable nature of the service, this will foster a space for healthcare professionals to feel less restricted and develop, as part of the system. This would also counter fears of constant assessment or needing to 'bend the frame' and fight against the system (Regine & Lewin, 2003). In practice, improving communication between services could be facilitated by setting up regular joint meetings, as well as opportunities for teams to get to know one another, prioritising relationships as the foundation for effective working.

4.4.2 Clinical Implications: Services and Healthcare Professionals in Luton

Appropriate funding from NHS England and PHE is required to allow for highly skilled, adequately staffed workforces. As the findings from the research indicate, healthcare professionals who have large caseloads, and inadequate training are unable to foster therapeutic relationships with services users, which have been shown to be key in promoting recovery. The success and importance of training programmes in 'dual-diagnosis' for staff in mental health and drug and alcohol services is evidenced in the literature (Cooper et al., 2006; Hughes et al., 2008; Schulte et al., 2010). The researcher recommends all staff in mental health services and drug and alcohol services undertaking training on 'dual-diagnosis'. Allowing people with lived experiences of co-occurring difficulties to co-produce or consult with professionals to develop the training programme is essential (Hawkins et al., 2017).

The effectiveness and importance of peer support for individuals with mental health difficulties and problems with substance use corroborates findings in existing

research. Being connected with someone who has been through something similar, allows one to not feel alone in their own subjective experience (Merleau-Ponty, 1962; Yalom & Leszcz, 2005). The local drug and alcohol service have already made huge steps to integrate people with lived experience into the workforce. Employing 'peer mentors' does not appear to be on the agenda for the local mental health services. Perhaps with more effective joint-working, services will be able to learn from each other and have a better understanding of the practical steps to better integrate peer support. In addition, there is a need to widely advertise participation opportunities within drug and alcohol services and NHS Trusts, as some participants were not aware that these opportunities existed.

An operational 'dual-diagnosis' protocol has been designed to give a clear framework within which Luton mental health services and the local alcohol and drug services can operate together to provide comprehensive support. However, this protocol is relatively new (verbally ratified in 2019) and the effect of which has not yet been seen by the participants included in this study. Based on the findings of the research, the following recommendations to further integrate mental health services and the drug and alcohol service are detailed below;

- Facilitate 'dual-diagnosis' training for all staff (developed by individuals with lived experience)
- Develop additional 'Dual-diagnosis' practitioner roles to work across both mental health and substance use services
- Peer support opportunities in mental health services
- Specific 'Dual-diagnosis' pathway across services
- 'Dual-diagnosis' specific assessment proforma
- Champion a harm-reduction approach

- Improve accessibility and visibility of services (outreach programmes)

The researcher will be presenting the findings and clinical implications to the collaborative involved in 'Re-imagining Luton' later in the year. It is hoped that the specific recommendations will inform the final version of the 'Luton's Collaborative Mental Health Strategy (2022-2024)'. It has not been possible to include a copy, due to ongoing developments.

4.4.3. Clinical implications: The profession of clinical psychology.

This research is useful for the profession of Clinical Psychology and other healthcare professionals in highlighting the impact of structural issues, service issues and relational experiences with healthcare professionals. The profession of Clinical Psychology tends to try to separate itself from Psychiatry, however, there is no denying the reality of the profession being born through oppressive systems (Foucault, 1965). The researcher suggests that mental health services, including the profession of Clinical Psychology, continues to perpetuate oppressive cultural logic. Therefore, it is necessary for Clinical Psychology to champion services engaging with people with lived experience and implement sustainable initiatives that champion meaningful co-production and access to peer support. Due to the importance of trust, understanding and collaboration it is vitally important for Clinical Psychologists to work alongside service users, as well as family members, carers and other healthcare professionals. It is the researcher's opinion that Clinical Psychologists must acknowledge their 'outsider' position and consult with people with co-occurring difficulties to know how best to assist in collective action to improve service provision (Dywer & Buckle, 2009). Arguably, as individuals with a degree of power and status with professional networks, it is imperative that Clinical

Psychologists draw attention to gaps in service provision as well as the continuing discrimination and stigma faced by people with problems with substance use and co-occurring mental health difficulties (Lister, 2004).

Improving joint-working between Luton mental health services and the drug and alcohol services will require substantial organisation and practice changes, in order to fully embrace service user participation and co-production initiatives. It will be important for all professions to work together, to deliver on improving outcomes for service-users with co-occurring difficulties, at a time of such financial pressures calls for creativity and greater effectiveness from available resources. Arguably, Clinical Psychologists are well placed to involve service-users in decision making, as well as making connections with community resources (BPS, 2012). Clinical Psychologists are skilled in leadership and working effectively within teams, understanding the process of change in services and implementing innovation within systems.

In addition, Clinical Psychologists have the power to influence narratives in teams and perhaps advocate working transdiagnostically in a way that fits with the preferred story of the person with co-occurring mental health difficulties and problems with substance use. This research has highlighted that the primary function of substance use by participants was a mechanism of coping with mental health difficulties, and the majority of participants also reported experiencing a traumatic life event. Therefore, the need for services to be trauma-informed and trauma responsive, working in a way that is relationship-focused is particularly important for this client group. Clinical Psychologists can advocate for and help develop trauma responsive systems to ensure that services do not respond to this client group in a punitive manner. This can be achieved by engaging in practices such as, offering

reflective practice to members of staff, working collaboratively and transparently, offering choice and championing autonomy, as well as reviewing policies and procedure to ensure that are trauma informed. Karen Treisman has created resources for organisation that include the assumptions, principals and values of a trauma informed organisational culture (Treisman, 2021). A framework such as this, can be drawn on to firstly identify the current values, principals, commitments of a service to better understand their baseline, their readiness to change, their strengths and use this information to inform plans to develop the service that is trauma responsive.

4.5 Evaluation of the Research

This section describes the strengths and limitations of this research using the 'Big-Tent' Criteria for Qualitative Quality (Tracy, 2010). This framework was chosen due to providing clear ideas of 'gold standard' qualitative methodological approaches (Tracy & Hinrichs, 2017). It is also hoped that by using the same quality appraisal tool as used in the systematic literature review, clearer comparisons can be made between the quality of this research and the quality of existing literature in the field.

4.5.1 Strengths and limitations.

This research has many strengths. It is deemed to be a worthy, relevant topic of research. On a national scale, recent recommendations from Carol Black's report (Black 2021), as well as the Health and Social Care Bill (2022) champion joined-up services and a reduction in the variation in care provision across the country. However, the direct experiences of service-users do not necessarily take the forefront in the aforementioned report and legislation. In addition, appropriate

guidelines and policy (NICE, 2016; 2019) which clearly state the importance of joint-working, do not appear to be implemented in Luton, due to a number of identified barriers. Therefore, this research allows the lived experiences of participants to be brought to the foreground and the findings are hopefully used to shape service provision, going forward. The findings are persuasive due to the first-person accounts of service-user experiences, which might not have been heard or shared without this study.

The research is rigorous in nature as it employed a constructivist GT methodology, including constant comparison of the data. This paved the way for a robust analysis process in the development of categories from the data. Supervision from the research team has also been key in upholding rigour and allowing the researcher to consider biases and potential blind spots throughout the analysis processes. Arguably, the research meets the criteria of sincerity based on personal reflections and transparency around why the research topic was chosen and hopes for the research to improve service provision. A reflective diary was instrumental in reflecting on the subject matter, as well as utilising supervision. Barriers to recruitment and challenges that have cropped up for the researcher have been clearly documented, again indicating sincerity of the research. In addition, a clear analysis audit trail has been provided to plainly show the steps that were taken by the researcher. In addition, the GT methodology has strengthened the coherence of the study, in turn enhancing the credibility of the findings and clinical implications (Birks & Mills, 2015).

The research is resonant, with a clear plan on how the findings of the study will be shared with relevant parties, including those involved with the 'Re-imagining Luton' project. The findings and clinical implications will be made accessible to

multiple audiences, including participants, service-users, policymakers, commissioners and healthcare. This research has made a significant contribution to the literature, based on the originality in bringing a structural focus to service-user experiences of healthcare services. The GT model speaks to the current dominant political and social discourses about mental health difficulties and 'addiction', which existing research has not commented on. It furthers understanding of the stigma and discrimination faced by users of services that have both problems with substance use and mental health difficulties, and how power operates to maintain these relations. This research has been conducted in line with procedural and situational ethical standards. This includes the researchers' considerations for disseminating the research findings to as many people as possible, in an accessible manner.

It is important to acknowledge a number of limitations in the study. A number of challenges to recruitment pathways were due, in part, to the COVID-19 pandemic. This has undoubtedly impacted on the diversity of the sample, which is relevant in a GT study like this one. In addition, the interviews took place via remote online technology or over the phone which, unfortunately, meant that individuals who did not have access to the internet or a telephone were unable to take part. It would be beneficial to conduct research with a participant sample who are homeless or do not have readily available access to the internet or a telephone, to compare experiences. Due to the relatively small sample, the model is perhaps most relevant to the group of participants included in the study. However, further research could test this model with a more diverse sample in Luton, and across other areas of the UK, in order to widen understanding about the social process depicted in the model. Member-checking can be one way in which qualitative researchers can increase the rigour of

their research. Unfortunately, due to the timescale of the project, it was not possible to undertake member-checking with participants in this study with regards to whether they felt that the model was representative of their experiences. Ideally, participants would have been asked whether and to what extent the categories felt aligned to their experience, based on the process devised by Albas and Albas (1988), which is similar to member-checking used in other qualitative methodologies. However, this process could be carried out when testing the model in future research.

Recruiting most participants from the local drug and alcohol services may have biased the research towards those who have already received some support. Proportionally, the sample of participants is not representative of Luton as a whole, based on age and ethnicity. As discussed, a number of the participants have been involved with services either in a professional capacity or by participating in service development initiatives. Advantages of recruiting participants with these unique multifaceted perspectives include hypothesised greater knowledge of the 'inner workings' of services, including how services are commissioned and service pressures, as well as personal experiences of accessing professional support from the service and what was helpful for them as a service user and what was detrimental. However, it is important to also hold in mind that this group of participants might have felt more aligned to or felt loyal to the services they have been or are part of, and therefore, others from the target group who have not moved on to roles such as these might have reported quite different experiences. This should be held in mind when considering the GT model. Therefore, further testing of the GT model with a wider, more diverse samples in a variety of localities in the UK will be necessary. Future research could aim to recruit through alternative avenues, such as community spaces or religious organisations.

A larger scale study would give way for a more conceptual level understanding of the phenomenon of how service provision impacts the experiences of people with co-occurring mental health difficulties and problems with substance use to be explored. In order to study a complex evolving system effectively, research should take place over a longer period of time in order to track the evolving and co-evolving characteristics and better understand how the system is functioning. A longitudinal study would be beneficial in shedding light on service development and the impact on experiences over time. This may improve understanding around how service provision can be utilised to improve experiences of people with both mental health difficulties and problems with substance use. Further research could involve conducting interviews with healthcare professionals in mental health and drug and alcohol services in Luton and conduct a discourse analysis to identify patterns and shared aims, with the hope of improving joint-working (Mitleton-Kelly, 2003). More generally, further research will be needed in order to further develop the beginnings of the theory offered, to better understand how services provision impacts the experiences of people with co-occurring mental health difficulties and problems with substance use. Specifically, it would be useful to apply the model to localities where the drug and alcohol service is provisioned by the NHS, to see whether joint-working with mental health services is improved, along with the overall experiences of service-users being better.

4.6 Conclusion

This study has contributed to the understanding of how service provision impacts the experiences of people with both mental health difficulties and problems with substance use. The model and theoretical offerings in this research can only be

claimed to be representative of the experiences of the ten participants taking part. That being said, the researcher is confident that this model is the robust beginnings of theory development to explain how service provision impacts the experiences of people with co-occurring mental health difficulties and problems with substance use more widely. The research goes beyond existing literature about the experiences of people with both mental health difficulties and substance use, which does not focus on the direct impact of wider structures, discourses and political agendas, which all affect how services are provisioned.

The GT model presented presents dynamic interactions of social processes and mechanisms that help to explain how and why individuals might remain 'stuck' within service provision, and why some can benefit and, consequently, move forward with recovery. The importance of relational interactions has been highlighted as key to making support beneficial to those accessing services. It is hoped that this research clearly highlights the value of utilising shared lived experiences, in order to develop and improve service provision. The findings acknowledge power relations working at a structural, service level and interpersonal level, whilst highlighting the processes that can help and hinder recovery from co-occurring mental health and substance use difficulties. The findings have led to recommendations for anyone working with this group, as well as the UK Government, NHS England and commissioners, who have such a powerful influence on the way services are provisioned and how they can be changed for the better.

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Appendices

Appendix A.

Table Showing Key Search Term Used in Initial Systematic Literature Review Searches

Concept	Search Terms
1. Service-user experiences	(experienc* OR impact OR "first hand" OR "first-hand" OR "first person" OR "first-person" OR "service-user" OR "meaning making" OR "meaning-making" OR access*)
	AND
2a. Mental health difficulties	("mental health" OR "mental illness" OR "mental disorder" OR schiz* OR psychosis OR depression OR anxiety OR bipolar)
	AND
2b. Substance use	("drug addict*" OR "substance addict*" OR "dual-diagnosis" OR "dual diagnosis")
	AND
3. Service provision	("mental health team" OR "mental health service" OR "community care" OR "drug and alcohol service" OR "substance misuse service")

Appendix B.

Table Showing Critical Evaluation of Studies Included in the Systematic Literature Review using Tracy's Eight 'Big-Tent' Criteria (Tracy, 2010)

1. Edward, K. L., & Robins, A. (2012). Dual diagnosis, as described by those who experience the disorder: using the Internet as a source of data.

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	The topic of the research is: <ul style="list-style-type: none"> •Relevant •Timely •Significant •Interesting 	Gap identified in the literature and clear aims	Y
Rich rigor	The study uses a sufficient, abundant, appropriate, and complex: <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes 	Used Scott's (1990) quality criteria for assessing documents used when identifying data sources (Authenticity, credibility, representativeness, meaning) A research member checked and reviewed the data at multiple stages of the research – texts were read several times by different members of the research team, leading to formulation of themes. Comments of data saturation	Y
Sincerity	The study is characterised by: <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	Very little to no comments of reflexivity of the researchers Acknowledgement that the researchers were not able to access the sites identified that were inaccessible to the public, requiring membership	N

Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit(non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Definitions of terminology used are adequate (resilience, dual-diagnosis and quality of life)</p> <p>Direct quotes were taken from the narrative data to support themes that came from the Content Analysis</p> <p>Internet as a source of data – able to access rich global perspectives and discussions where individuals may be more able to honestly express opinions</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalisations •Transferable findings 	<p>The countries hosting the websites have very different healthcare systems which may limit cross-cultural applicability related to the relatively small sample of data, which may limit significance of findings</p>	N
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	<p>Clear implications for mental health nursing practice stated at the end of the paper – the role of mental health nurses in influencing treatment outcomes and being aware of barriers that the client group faces</p> <p>States how the study will inform future research relating to building existing evidence base further and developing technology-based interventions</p>	Y
Ethics	<p>The research considers</p> <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics 	<p>Acknowledgement that confidentiality and anonymity need to be carefully considered when using the internet as a data source – if the data</p>	Y

	<ul style="list-style-type: none"> •Exiting ethics (leaving the scene and sharing the research) 	<p>is publicly available can it be used for research purposes?</p> <p>University Human Research Ethics committee consultation undertaken – exempt from needing ethical review due to collections of non-identifiable data being used with negligible risk</p> <p>The research suggests that consent was 'implied' due to public availability</p> <p>Consideration around anonymity – pseudonyms were used</p>	
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	<p>Clear thread throughout, relevant review of literature, gap identified and clear aims for future research and application</p>	Y
Other comments			

2. Elison, S., Weston, S., Dugdale, S., Ward, J., & Davies, G. (2016). A Qualitative Exploration of U.K. Prisoners' Experiences of Substance Misuse and Mental Health Difficulties, and the Breaking Free Health and Justice Interventions.

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	<p>The topic of the research is:</p> <ul style="list-style-type: none"> •Relevant •Timely 	<p>The researcher does not clearly identify gap in the literature, which they are</p>	Y

	<ul style="list-style-type: none"> •Significant •Interesting 	<p>hoping to fill with the study</p> <p>Relevant research, highlighting application of findings to prisons and healthcare services</p>	
Rich rigor	<p>The study uses a sufficient, abundant, appropriate, and complex:</p> <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes 	<p>The study provided valuable insights into the difficulties that substance using prisoners have faced in terms of accessing services</p> <p>Inherent subjectivity of the qualitative approach is a strength. However, some may perceive the recollection of autobiographical experiences to be unreliable and overly subjective</p> <p>UK, majority male, self-selecting sample of participants, it cannot be assumed that the experiences and opinions are generalisable to the general prisoner population, in the UK or globally</p>	Y
Sincerity	<p>The study is characterized by:</p> <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	<p>Clearly states the researcher's intention relating to their epistemological position – not seeking an objective truth, but to capture prisoners' own understandings of their experience</p> <p>Declaration regarding conflict of interest</p> <p>No funding received for the project</p>	Y

Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit(non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Definitions of terminology and concepts used are adequate (self-medicating, prevalence of 'dual-diagnosis' in prison populations)</p> <p>Direct quotes were taken from the interview data to support themes from thematic analyses</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalizations •Transferable findings 	<p>Adds to evidence base around difficulties for people in accessing support for their substance use and mental health difficulties</p> <p>Highlights clinical implications of requirement to work towards collaborative, inter-agency working</p>	Y
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	<p>Adds to evidence base around substance use being more prevalent when individuals have experienced traumatic childhood events. Mental health difficulties are conceptualised as reactions to adverse life events</p>	Y
Ethics	<p>The research considers</p> <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics •Exiting ethics (leaving the scene and sharing the research) 	<p>Informed consent gained from each participant</p> <p>No incentive or compensation was offered to participants</p> <p>No mentioned or consideration of contextual power dynamic between interviewee and interviewer</p>	Y

		<p>No other prison staff present during the interview – private space. However, member of staff present in next room in case assistance was required</p> <p>Approval for study granted by the Ministry of Justice National Offender Management Service</p> <p>Week long training/induction required for lead researcher before undertaking interviews in the prison</p> <p>Data protection and efforts to maintain confidentiality stated clearly, removal of identifiable information, pseudonyms used</p>	
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	<p>Clear thread throughout, relevant review of literature, however the researcher does not clearly identify gap in the literature. Clear aims for research and implications for healthcare provision are highlighted</p>	Y
Other comments			

3. Klingemann, J., Welbel, M., Moskalewicz, J., Nicaise, P., Priebe, S., Matanov, A. & Bird, V. (2019).

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for
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			quality Y/N
Worthy topic	The topic of the research is: •Relevant •Timely •Significant •Interesting	Gap identified in the literature and clear aims Interesting to use to separate samples from different countries and bring clinician and service-user perspectives together in the analysis	Y
Rich rigor	The study uses a sufficient, abundant, appropriate, and complex: •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes	Interviews were informed by the framework set out in the COFI study (comparing policy framework, structure, effectiveness and cost-effectiveness of functional and integrated systems of healthcare) unified study protocol and interview guidelines (Giacco et al., 2015) An attempt was made to obtain a diverse sample of participants - high level of homogeneity of the data collected across the UK and Poland Consistency of coding across transcripts – emerging themes discussed between the teams – new codes were communicated and approved across the teams Memoing utilised by both teams throughout analysis	Y
Sincerity	The study is characterized by:	Very little to no comments of reflexivity of the researchers	N

	<ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 		
Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Definitions of terminology and concepts used are adequate, although medicalised and pathologising</p> <p>Direct quotes were taken from the interview data to support themes from thematic analyses</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalizations •Transferable findings 	<p>High level of homogeneity of the data – validates results across countries</p> <p>Clinician and patient samples showed high level of consistency when describing their experiences and accounts</p>	Y
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	<p>Clear implications for mental health services stated at the end of the paper – need for screening instruments in the process of assessment of alcohol use disorder, training mental health professionals in how to treat alcohol use disorder and how to support motivation and adherence to treatment. More collaboration between services needed</p> <p>States how the study will inform future research relating to comorbidity of</p>	Y

		mental health and alcohol use	
Ethics	The research considers <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics •Exiting ethics (leaving the scene and sharing the research) 	Data protection and efforts to maintain confidentiality and anonymity, removal of identifiable information Ethical approval obtained in both countries Study funded by European Commission 7th Framework Programme and co-financed by Polish Ministry of Science and Higher Education	Y
Meaningful coherence	The study <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	Clear thread throughout, relevant review of literature, gap identified and clear aims for future research and applications	Y
Other comments			

4. Matheson, C., Hamilton, E., Wallace, J. & Liddell, D. (2019) Exploring the health and social care needs of older people with a drug problem.

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	The topic of the research is: <ul style="list-style-type: none"> •Relevant •Timely •Significant •Interesting 	Gap identified in the literature and clear aims Highlights need for policymakers and service providers to better understand health	Y

		and social care need of older people	
Rich rigor	The study uses a sufficient, abundant, appropriate, and complex: <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes 	<p>Rationale given for using mixed-methods design</p> <p>Clear sampling frame to recruit participants not currently under the care of services</p> <p>Participant inclusion criteria was over the age of 35 years, arguably not a typical older person population</p> <p>30 qualitative interviews were conducted analysis using thematic analysis, little detail of analysis</p> <p>High proportion of the sample lived alone, which is not representative of the drug users accessing services. Younger males were overrepresented in the sample</p> <p>Questionnaire used for data collection designed by research team, informed by literature and 'expert by experience' working group. Tested by peer researchers prior to data collection. Despite this the measure was not validated.</p>	Y
Sincerity	The study is characterized by: <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	<p>Very little to no comments of reflexivity of the researchers</p> <p>Transparency around challenges in obtaining a representative sample and efforts to overcome these</p>	N

Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Definitions of terminology and concepts used are adequate</p> <p>Findings support previous research looking at health and social care needs for older people</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalizations •Transferable findings 	<p>Increased risks of overdose due to poor mental health and isolation in this population was highlighted</p> <p>A high proportion of the sample lived alone, reducing effectiveness of Naloxone programmes. Transferable learning can be applied to other settings with regard to this vulnerable group having additional health and support needs.</p>	Y
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	<p>First mixed methods study of older people with a drug problem covering diverse geographical area</p> <p>Adds to evidence base for 'older' population of drug users not in treatment and presents practical recommendations to improve services and outreach work</p>	Y
Ethics	<p>The research considers</p> <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics 	<p>Ethical approval was granted by the North of Scotland Research Ethics Committee</p> <p>Funded by Scottish Government Drug Policy Unit</p>	Y

	<ul style="list-style-type: none"> •Exiting ethics (leaving the scene and sharing the research) 	Participants were given £10 supermarket voucher as honorarium	
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	Clear thread throughout, relevant review of literature, gap identified and clear aims for future research and recommendations	Y
Other comments			

5. Notley, C., Maskrey, V. & Holland, R. (2012)

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	<p>The topic of the research is:</p> <ul style="list-style-type: none"> •Relevant •Timely •Significant •Interesting 	The researchers undertook a systematic literature review in order to identify a gap in the literature. Clear aims for the study based on identifying a gap in existing literature.	Y
Rich rigor	<p>The study uses a sufficient, abundant, appropriate, and complex:</p> <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes 	<p>Diverse sample of participants achieved through purposive sampling</p> <p>Neither themes of data analysis were discussed, only lead researcher conducted analysis</p> <p>Relatively small sample, selection bias is inherent</p> <p>'Over-sampling' of Portuguese population</p>	Y

		<p>living in Norfolk – specialist translation services available to the research team</p> <p>Focus groups may have limited individual discourse and disclosure</p>	
Sincerity	<p>The study is characterized by:</p> <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	<p>Acknowledgement about the importance for interviews and focus groups to take place in neutral venues, anonymous, non-stigmatising locations</p> <p>Participant inclusion criteria relating to self-identifying as problematic drug users with mental health problems</p> <p>Reflections relating to participants being wary of sharing personal information</p>	Y
Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Definitions of terminology and concepts used are adequate</p> <p>Findings support previous research looking at barriers to treatment</p> <p>Direct quotes were taken from the interview data to support themes from thematic analyses</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation 	<p>Findings support previous research looking at barriers to treatment</p> <p>Views expressed may be transferrable to other out</p>	Y

	<ul style="list-style-type: none"> •Naturalistic generalizations •Transferable findings 	of treatment drug using populations	
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	Add to evidence base for 'hard to reach' population of drug users not in treatment and presents practical recommendations to improve services	Y
Ethics	<p>The research considers</p> <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics •Exiting ethics (leaving the scene and sharing the research) 	<p>All participants gave full written informed consent before taking part</p> <p>Reviewed by Cambridgeshire REC</p> <p>Participants received £10 supermarket voucher as an honorarium for taking part and travel expenses were reimbursed</p> <p>Grant received from the Norfolk drug and alcohol team – affiliation could potentially impact perspective of researchers to show current service provision in good light</p>	Y
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	Clear thread throughout, relevant review of literature, gap identified and clear aims for future research and recommendations	Y
Other comments			

6. O'Sullivan, M., Boulter, S. & Black, G. (2013)

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	The topic of the research is: <ul style="list-style-type: none"> •Relevant •Timely •Significant •Interesting 	Gap identified in the literature and clear aims	Y
Rich rigor	The study uses a sufficient, abundant, appropriate, and complex: <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes 	Gives rationale for qualitative research methodology Interview schedule prepared with questions devised from existing knowledge of the literature and reviewed by co-researcher and psychologists within the service References social identity theory	Y
Sincerity	The study is characterized by: <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	Transparency about seeking to examine personal lived experience and how participants make sense of those, without a pre-identified framework being placed over the data Consideration made regarding the over-representation of black men in forensic services, and this being seen in the participant sample Reflective about the position of the researcher, having worked in the unit –	Y

		<p>maintained sensitivity to context</p> <p>Consideration of power dynamic in interviewer and interview roles</p>	
Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Data was subject to credibility checks, such as checking themes by the remaining authors at all stages of analysis, demonstrating investigator triangulation.</p> <p>In vivo theme labels used to stay close to the data</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalizations •Transferable findings 	<p>Generalisability is limited to the group studied, results can be extended through theoretical generalisability</p>	Y
Significant contribution	<p>The research provides a significant contribution:</p> <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	<p>Clear recommendations for services: Need for person-centred planning and recovery-oriented care when treating this population</p> <p>Highlighted importance of service-users readiness to change</p>	Y
Ethics	<p>The research considers</p> <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics •Exiting ethics (leaving the scene and sharing the research) 	<p>Potential participants identified by clinical teams who acted as gatekeepers, reflection by researchers that only service-users reflecting a particular view point may have been selected</p> <p>Participants were briefed on research and consent form, then given one week to decide whether</p>	Y

		<p>they would like to take part. Written consent was then obtained</p> <p>Pseudonyms used to maintain confidentiality</p> <p>Ethical approval gained from the local research ethics committee. R&D approval was obtained from the North Central London Research Consortium</p>	
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	<p>Clear thread throughout, relevant review of literature, gap identified and clear aims for future research and recommendations</p>	Y
Other comments			

7. Parkman, T., Neale, J., Day, E. & Drummond, C. (2017)

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	<p>The topic of the research is:</p> <ul style="list-style-type: none"> •Relevant •Timely •Significant •Interesting 	<p>Gap identified in the literature and clear aims. Most research in the area is quantitative or epidemiological</p>	Y
Rich rigor	<p>The study uses a sufficient, abundant, appropriate, and complex:</p> <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) 	<p>The paper states that the researchers did not seek to convey empirical generalisability beyond the sample, however themes and patterns have the potential to be</p>	Y

	<ul style="list-style-type: none"> •Context(s) •Data collection and analysis processes 	<p>transferrable to other settings</p> <p>Diverse sample, varying ethnicities, genders and ages</p> <p>Rigorous analysis using Iterative Categorization (Neale, 2016) according to the principles of the Framework (Ritchie & Spencer, 1994)</p>	
Sincerity	<p>The study is characterized by:</p> <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	<p>Very little to no comments of reflexivity of the researchers</p>	N
Credibility	<p>The research is marked by:</p> <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	<p>Direct quotations were used to support key findings</p> <p>Previous research conducted in the area has been referred to support findings</p>	Y
Resonance	<p>The research influences, impacts, or moves particular readers or a variety of audiences through:</p> <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalizations •Transferable findings 	<p>The paper makes reference to other countries having similar evidence to suggest that people attend emergency departments, rather than specialist services for alcohol related concerns, which may make the findings transferable globally</p> <p>The paper states that the researchers did not seek to convey empirical generalisability beyond</p>	Y

		the sample, however themes and patterns have the potential to be transferrable to other settings	
Significant contribution	The research provides a significant contribution: <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally •Methodologically •Heuristically 	Clear recommendations for services: patients wanted help relating to psychosocial support and mental health problems rather than alcohol treatment	Y
Ethics	The research considers <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics •Exiting ethics (leaving the scene and sharing the research) 	<p>If eligible, the hospital would ask the patients' permission to pass their contact information to the researcher, the researcher phoned them to conduct a screening interview. Written information about the study was then provided, with verbal explanations and gained written informed consent from all participants</p> <p>Participants were interviewed in their own home</p> <p>Some participants drank alcohol before or during the interview, all were deemed 'sober enough' to engage with the interview – no comments made on how this could have impacted on capacity to consent</p> <p>Pseudonyms were used to protect anonymity</p> <p>Participants were given a £15 voucher for their time</p>	Y

		<p>Research funded by Alcohol Research UK, part funded by NIHR</p> <p>Ethical approval for the research was secured from a UK NHS research ethics committee</p>	
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	<p>Clear thread throughout, relevant review of literature. Clear aims for future research and implications for healthcare provision are highlighted</p>	Y
Other comments			

8. Stott, A. & Priest, H. (2018)

Criteria for quality (end goal)	Various means, practices and methods through which to achieve	Comments	Achieves criteria for quality Y/N
Worthy topic	<p>The topic of the research is:</p> <ul style="list-style-type: none"> •Relevant •Timely •Significant •Interesting 	<p>Gap identified in the literature (recovery as a process) and clear aims</p>	Y
Rich rigor	<p>The study uses a sufficient, abundant, appropriate, and complex:</p> <ul style="list-style-type: none"> •Set of theoretical constructs •Data and time in the field •Sample(s) •Context(s) •Data collection and analysis processes 	<p>Clear and thorough description of narrative analysis</p> <p>By only analysing transcripts of recorded interviews, the study neglected possible benefits of using wider narrative material such as diaries, photographs or films</p>	Y

		The research excluded people who recover outside of services, replicating a shortcoming of much research in this area	
Sincerity	The study is characterized by: <ul style="list-style-type: none"> •Self-reflexivity about subjective values, biases, and inclinations of the researcher(s) •Transparency about the methods and challenges 	Clearly states epistemological position of the researcher (social constructionist) Memoing used through analysis process Evidence of reflexivity of the researcher in terms of situating the narratives and the researchers' purpose for hearing the stories and reflection on researchers' lenses	Y
Credibility	The research is marked by: <ul style="list-style-type: none"> •Thick description, concrete detail, explication of tacit (non-textual) knowledge and showing rather than telling •Triangulation or crystallization •Multivocality •Member reflections 	Direct quotations were used to support key findings Participant verification of narratives were not used, limiting the extent to which the study can claim to be empowering of its participants	Y
Resonance	The research influences, impacts, or moves particular readers or a variety of audiences through: <ul style="list-style-type: none"> •Aesthetic, evocative representation •Naturalistic generalizations •Transferable findings 	The study is the product of its particular context, generalisability of findings is limited	Y
Significant contribution	The research provides a significant contribution: <ul style="list-style-type: none"> •Conceptually/theoretically •Practically •Morally 	Originality in exploring recovery narratives of a population which has been overlooked by previous research	Y

	<ul style="list-style-type: none"> •Methodologically •Heuristically 	<p>The narrative methodology enables the study to draw links between personal stories of recovery and wider social influences, allowing comment on the implications for services; practical and material support, need for multi-agency working. Need for mental health services and drug and alcohol services to integrate</p>	
Ethics	<p>The research considers</p> <ul style="list-style-type: none"> •Procedural ethics (such as human subjects) •Situational and culturally specific ethics •Relational ethics •Exiting ethics (leaving the scene and sharing the research) 	<p>Treatment was completely unaffected by participants decision to take part</p> <p>No inducements to take part were offered</p> <p>Informed consent was gained before each interview, including explanation around right to withdraw and procedures to protect confidentiality and anonymity</p> <p>Pseudonyms were used to maintain anonymity</p> <p>Ethical approval obtained by NHS Research Ethics Committee and the Research and Development department at the local authority</p>	Y
Meaningful coherence	<p>The study</p> <ul style="list-style-type: none"> •Achieves what it purports to be about 	<p>Clear thread throughout, relevant review of literature. Clear aims for future research and implications for</p>	Y

	<ul style="list-style-type: none"> •Uses methods and procedures that fit its stated goals •Meaningfully interconnects literature, research questions/foci, findings, and interpretations with each other 	<p>healthcare provision are highlighted</p>	
<p>Other comments</p>			

Appendix C.

A Letter Stating Favourable Opinion from The London - Brent Research Ethics Committee



**Health Research
Authority**

London - Brent Research Ethics Committee

80 London Road
Skipton House
London
SE1 6LH

21 July 2021

Dr Jade Weston
Doctorate in Clinical Psychology
Health Research Building, College Lane Campus
University of Hertfordshire
AL10 9AB

Dear Dr Weston

Study title:	Falling Through the Cracks: Using Constructivist Grounded Theory to Explore How Service Provision Impacts Experiences of Those with Co-Occurring Mental Health Difficulties and Problems with Substance Use
REC reference:	21/PR/0892
Protocol number:	TBC
IRAS project ID:	298969

Thank you for your letter of 16 July 2021, responding to the Proportionate Review Sub-Committee's request for changes to the documentation for the above study.

The revised documentation has been reviewed and approved on behalf of the PR sub-committee.

Confirmation of ethical opinion

On behalf of the Research Ethics Committee (REC), 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.

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 publicly accessible database within six weeks of recruiting the first research participant. For this purpose, 'clinical trials' are defined as the first four project categories in IRAS project filter question 2. Failure to register is a breach of these approval conditions, unless a deferral has been agreed by or on behalf of the Research Ethics Committee (see here for more information on requesting a deferral):

<https://www.hra.nhs.uk/planning-and-improving-research/research-planning/research-registration-research-project-identifiers/>

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.

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.

Should you wish to provide a substitute contact point, make a request to defer, or require further information, please visit:

<https://www.hra.nhs.uk/planning-and-improving-research/application-summaries/research-summaries/>

N.B. If your study is related to COVID-19 we will aim to publish your research summary within 3 days rather than three months.

During this public health emergency, it is vital that everyone can promptly identify all relevant research related to COVID-19 that is taking place globally. If you haven't already done so, please register your study on a public registry as soon as possible and provide the REC with the registration detail, which will be posted alongside other information relating to your project. We are also asking sponsors not to request deferral of publication of research summary for any projects relating to COVID-19. In addition, to facilitate finding and extracting studies related to COVID-19 from public databases, please enter the WHO official acronym for the coronavirus disease (COVID-19) in the full title of your study. Approved COVID-19 studies can be found at: <https://www.hra.nhs.uk/covid-19-research/approved-covid-19-research/>

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
- Final report
- Reporting results

The latest guidance on these topics can be found at <https://www.hra.nhs.uk/approvals-amendments/managing-your-approval/>.

Ethical review of research sites

The favourable opinion applies to all NHS/HSC sites taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" above).

Approved documents

The documents reviewed and approved by the Committee are:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Copies of materials calling attention of potential participants to the research [Participant Recruitment Poster]	0.1	24 May 2021
Copies of materials calling attention of potential participants to the research [Link to YouTube video advertising study to potential participants]	0.1	24 May 2021
Covering letter on headed paper [Cover Letter Detailing Amendments following REC feedback]	0.2	15 July 2021
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [Professional Indemnity Cert]	0.1	24 May 2021
Interview schedules or topic guides for participants [Interview Topic Guide]	0.1	24 May 2021
Interview schedules or topic guides for participants [Participant Debrief Sheet]	0.2	15 July 2021
IRAS Application Form [IRAS_Form_18062021]		18 June 2021

Letter from sponsor [Sponsorship in principle letter]	0.1	24 May 2021
Non-validated questionnaire [Participant Demographics Questionnaire]	0.1	24 May 2021
Participant consent form [Participant Consent Form]	0.1	24 May 2021
Participant information sheet (PIS) [Participant Information Sheet]	0.2	15 July 2021
Research protocol or project proposal [Research Project Protocol]	0.1	24 May 2021
Summary CV for Chief Investigator (CI) [Chief Investigator Summary CV]	0.1	24 May 2021
Summary CV for student [Student CV]	0.1	21 June 2021
Summary CV for supervisor (student research) [Chief Investigator CV]	0.1	24 May 2021
Summary of any applicable exclusions to sponsor insurance (non-NHS sponsors only) [Sponsor Insurance Letter]	0.1	24 May 2021

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:

<http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

HRA Learning

We are pleased to welcome researchers and research staff to our HRA Learning Events and online learning opportunities– see details at:

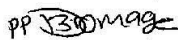
<https://www.hra.nhs.uk/planning-and-improving-research/learning/>

IRAS project ID: 298969
correspondence

Please quote this number on all

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

Yours sincerely



Zainab Yate
Vice Chair

Email: brent.rec@hra.nhs.uk

Enclosures: "After ethical review – guidance for researchers" [\[SL-AR2\]](#)

Copy to: Ms Ellie Hubbard

Appendix D.

Email Correspondence Confirming Ethical Approval from CGL Research Oversight Group

From: [REDACTED]
Sent: 09 August 2021 15:58
To: Laura Aggett [Student-LMS] [REDACTED]
Cc: [REDACTED]
Subject: RE: Research Meeting - Starting recruitment (non-NHS)

Hi Laura,

Many thanks for bearing with us.

I forwarded on your responses to the Research Oversight and Tori (cc'd) has confirmed they are satisfied the feedback has been addressed. I can confirm your application has now been approved and you can move forward in commencing your study.

Do let me know if you have any questions, and please do keep us in the loop with progress and any outputs.

All the best,

[REDACTED]
Research Assistant

M: [REDACTED]
Change Grow Live, 2nd Floor, 39-41 Thomas Street, Manchester, M4 1NA

For external research requests, please visit: <https://www.changegrowlive.org/about-us/resources/research>



www.changegrowlive.org



Appendix E.

Letter Confirming Sponsorship in Full From the University of Hertfordshire



John M Senior
BSc MSc DSc PGCE CEng FIET FRSA FHEA
Professor of Communication Networks
Pro Vice-Chancellor (Research and Enterprise)

Dr J Weston & Ms L Aggett
Department of Psychology, Sport & Geography
School of Life & Medical Sciences

18 August 2021

Dear Dr Weston and Ms Aggett

Re: UNIVERSITY OF HERTFORDSHIRE SPONSORSHIP IN FULL for the following:
RESEARCH STUDY TITLE: Falling Through the Cracks: Using Constructivist Grounded Theory to Explore How Service Provision Impacts Experiences of Those with Co-Occurring Mental Health Difficulties and Problems with Substance Use
NAME OF CHIEF INVESTIGATOR (Supervisor): Dr Jade Weston
NAME OF INVESTIGATOR (Student): Ms Laura Aggett
UNIVERSITY OF HERTFORDSHIRE ETHICS PROTOCOL NUMBER: LMS/PGT/NHS/02968
HEALTH RESEARCH AUTHORITY REFERENCE: 21/PR/0892

This letter is to confirm your research study detailed above has been reviewed and accepted and I agree to give full University of Hertfordshire sponsorship, so you may now commence your research.

As a condition of receiving full sponsorship, please note that it is the responsibility of the Chief Investigator to inform the Sponsor at any time of any changes to the duration or funding of the project, changes of investigators, changes to the protocol and any future amendments, or deviations from the protocol, which may require re-evaluation of the sponsorship arrangements.

Permission to seek changes as outlined above should be requested from myself before submission to the Health Research Authority (HRA) Research Ethics Committee (REC) and I must also be notified of the outcome. It is also essential that evidence of any further NHS Trust or other site permissions is sent as soon as they are received. Copies of annual reports and the end of study report as submitted to the HRA also need to be provided. Please do this via email to research-sponsorship@herts.ac.uk

Please note that University Sponsorship of your study is invalidated if this process is not followed.

In the meantime, I wish you well in pursuing this interesting research study.

Yours sincerely

Professor J M Senior
Pro Vice-Chancellor (Research and Enterprise)



University of Hertfordshire
Higher Education Corporation
Hatfield, Hertfordshire
AL10 9AB

Telephone +44 (0) 1707 284000
Fax +44 (0) 1707 284115
Website www.herts.ac.uk

Appendix F.

Participant Information Sheet



Participant Information Sheet

An invitation to take part in research...
Falling through the cracks: using constructivist grounded theory to explore how service provision impacts experiences of those with co-occurring mental health difficulties and problems with substance use

What are the aims of this research?

The purpose of the interview is to explore your experiences and opinions regarding the provision of mental health support for individuals with both mental health difficulties and problems with substance use. There will be discussion about your experiences of accessing mental health support and other services. Ideas to improve the current service provision will hopefully be identified and fed back to the re-imagining Luton project.

What would this involve?

The lead researcher for the project, Laura, would arrange a time to meet with you for the interview. This would be over remote video technology of your choice (Microsoft Teams, Zoom, WhatsApp video) or over the telephone. Laura will interview you for about 50 minutes; this is to allow you time and space to talk about your experience. You will only be invited to talk about what you feel willing and able to. The audio from the interview will be recorded using a Dictaphone, you will be asked to sign a consent form to say that you are happy for the interview to be voice recorded.

What will you do with the information I give you?

All information collected is strictly confidential. Information will be stored in a locked filing cabinet that is only accessible by Laura. Encrypted documents and on password protected folders on encrypted devices. Personal identifiable information will only be accessed by Laura. Information that could identify you, such as your name and other details, will be removed or changed. We will ask you to choose your own pseudonym so that your real name will not be used.

The interview will be need to be audio recorded. This is because it is then transcribed for analysis later on in the research. These recordings will be accessed by Laura and Dr Jade Weston (supervisor on the research team, University of Hertfordshire). The interview recording will be sent to an independent transition company, using your pseudonym. They must follow our rules about keeping your information safe. No one other than Laura will know your real name. Those who do not need to know who you are will not be able to see your name or contact details. 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.

How will you use this information?

The results of the research will be written up in a report for Laura's Doctorate in Clinical Psychology. This may contain anonymised quotes from the interview. The research will be written up for submission to peer-reviewed academic journals and conferences, so that other health professionals can learn from the research.

Are there any situations when information I tell you will be shared?

Disclosure of any personal information from the interview would only occur in exceptional circumstances, such as if you revealed information that may indicate a risk to yourselves or others. No information that you provide around current or historic use of illegal substances will be shared with the police.

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.
- We need to manage your records in specific ways for the research to be reliable. This means that we will not 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?

- at www.hra.nhs.uk/information-about-patients/
- or contacting the University of Hertfordshire's Data Protection Team on dataprotection@herts.ac.uk
- by sending an email to the Laura la19abi@herts.ac.uk

Are there any potential benefits in taking part?

There are not any direct benefits in taking part in the research, however there will be a space to share your experiences, as well being able to voice your thoughts and ideas about how service provision can be improved for people with co-occurring mental health difficulties and problems with substance use. Sharing your experiences and suggestions could inform service structures and provision through the re-imagining Luton project. Talking about your experience with someone who is impartial may be helpful in making meaning from the experience. Also, contributing to research in an area which is lacking, which may have implications for people accessing services in the future.

Are there any potential risks in taking part?

There are no known risks, however, there is a chance that the interview may bring up difficult emotions for some (e.g. during or after the interview). Laura has experience in providing emotional support to people who are experiencing distress, and will be sensitive to this in her interview technique and delivery. For example, if Laura feels you are becoming distressed, she may ask you to pause for a moment and check you are not feeling too anxious. As stated above, Laura may ask clarifying questions but not questions which will involve asking details about specifics of an event. You will be reminded that you should only talk about the experiences that feel you feel willing to talk about, and in a way that feels manageable for you. You are free to request to take a break at any point during the interview. If you no longer want to continue with the interview, you can stop whenever you wish.

What happens after the interview?

Following the interview, you will have no further involvement in the study. You will be offered a leaflet with some relevant support networks should participant like further support. If you feel you would like further support from either Resolutions or Pathway 2 Recovery or a mental health service following the interview, Laura will be able to put you in contact with the respective team, with your consent.

Following the end of the project, a summary of the findings will be documented and made available to those who took part, if you would like.

What happens if I agree to take part but then later change my mind?

You can withdraw from the interview at any time point, including during the interview and up to 14 days after the interview. You can withdraw for any reason, and you do not have to tell Laura the reason you would like to withdraw.

Who is in the research team?

Name	Role	Email
Laura Aggett	Lead researcher for the project Trainee Clinical Psychologist, University of Hertfordshire	la19abi@herts.ac.uk
Dr. Jade Weston	Clinical Psychologist and Senior Lecturer, University of Hertfordshire	j.weston4@herts.ac.uk
Dr. Tori Snell	Consultant Clinical Psychologist, Change Grow Live National Psychology Lead	Tori.Snell@cgl.org.uk

What do I do if I am interested in taking part?

1. Participation is entirely voluntary, so we first encourage you to **have some time and space to think** about whether you would like to take part. If you have any questions, or would like more information, you can email Laura, or if you would prefer, you can email to arrange a time to talk with her over the phone.
2. If you decide you would like to take part, **please email Laura: la19abi@herts.ac.uk**

Please note that there is no guarantee that all those who apply to take part will be interviewed.

This research is being conducted as part of Laura's Doctorate in Clinical Psychology, sponsored by the University of Hertfordshire. It is supported by Resolutions and the wider Change Grow Live (CGL) group. The research team work in accordance to professional code of conduct including ethical practice.

Although we hope it is not the case, if you have any complaints or concerns about any aspect of the way you have been approached or treated during the course of this study, please write to the University's Secretary and Registrar at the following address:

Secretary and Registrar
University of Hertfordshire
College Lane
Hatfield
Herts
AL10 9AB

Thank you very much for reading this information and giving consideration to taking part in this study.

University of Hertfordshire **UH** Ethics Committee

This is an official notification by student of the University of Hertfordshire in respect of a study involving human participants.

Title of study: Falling through the cracks: using constructivist grounded theory to explore how service provision impacts experiences of those with co-occurring mental health difficulties and problems with substance use

Protocol Number: LMS/PGT/NHS/02968

Approving Committee: Health, Science, Engineering & Technology ECDA

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

If you have any queries concerning this document, please contact me Laura Aggett, Trainee Clinical Psychologist, la19abi@herts.ac.uk or my supervisor Dr Jade Weston, Clinical Psychologist and Senior Lecturer j.weston4@herts.ac.uk

Appendix G.

Participant Consent Form

CONSENT FORM

Falling through the cracks: using constructivist grounded theory to explore how service provision impacts experiences of those with co-occurring mental health difficulties and problems with substance use

PLEASE COMPLETE SECTIONS IN BLUE

	PLEASE TICK
1) I confirm that I have been given a Participant Information Sheet for the above study. I am aware that it states the aim, methods and design, the names and contact details of key people, the potential risks and potential benefits and how the information collected will be stored and for how long. I have had the opportunity to consider and information, ask questions and have these questions answered.	
2) I understand that my participation is voluntary and that I can withdraw at any time, without having to provide reason, and that my job role and legal rights will not be affected. I also understand that I can withdraw up to 14 days after the interview.	
3) I understand that my interview will be audio recorded over remote technology	
4) I understand that when a report is written and published about the study, quotes/sentences from my interview may be used, but all identifying information will be removed or changed. I give permission for publication of these anonymised quotes.	
5) I have been told how information relating to me (data obtained in the course of the study, and data provided by me about myself) will be handled; how it will be kept secure, who will have access to it, and how it will or may be used.	
6) I understand that my participation in this study may reveal findings that could indicate that I might require further advice and support. In that event, I will be signposted to the appropriate service and/or emailed a list of contact details for support following the interview.	
7) I understand that if there is any revelation that could put others at risk, the University may refer the matter to the appropriate authorities.	
8) I give my agreement to take part in the above study.	

PARTICIPANT:	NAME:	
	CHOSEN PSEUDONYM:	
	DATE:	
	SIGNATURE:	
LEAD RESEARCHER:	NAME:	
	DATE:	
	SIGNATURE:	

This is an official notification by student of the University of Hertfordshire in respect of a study involving human participants.

Title of study: Falling through the cracks: using constructivist grounded theory to explore how service provision impacts experiences of those with co-occurring mental health and problems with substance use

Protocol Number: LMS/PGT/NHS/02968

Approving Committee: Health, Science, Engineering & Technology ECDA

The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

If you have any queries concerning this document, please contact me Laura Aggett, Trainee Clinical Psychologist, la19abi@herts.ac.uk or my supervisor Dr Jade Weston, j.weston4@nhs.net

Appendix H.

Participant Demographics Questionnaire

Participant Demographics Questionnaire

Name.....

If you would like to be kept up to date with the progress of the research and receive a summary of the results please leave your contact details below;

Telephone contact number

Email address

Would you be happy to give feedback on the results of the research?

- Yes
- No

Question 1. How do you define your gender?

- Male
- Female
- Non-binary
- Other (please state)

Question 2. Which age bracket do you fall under?

- 18-24
- 24-30
- 31-40
- 41-50
- 51-60
- 60+

Question 3. How do you define your ethnicity?

- White – British/Irish
- White – Any other white background
- Dual heritage (please state)
- Black or Black British – Caribbean
- Black or Black British – African
- Black or Black British – Any other Black background
- Asian or Asian British – Indian
- Asian or Asian British – Pakistani
- Asian or Asian British – Bangladeshi
- Asian or Asian British – Any other Asian background
- Chinese
- Other ethnicity (please state)

Question 4. Most frequently used substance (historically or otherwise)?

- Alcohol
- Prescribed medication (opioids, sedatives, benzodiazepines)
- Cannabis
- Cocaine/amphetamines
- Heroin
- Other (please state)

Question 5. Have you accessed any mental health services (historically or otherwise)?

- Improving access to Psychological Therapies (IAPT, Total Wellbeing)
- Community Mental Health Team (CMHT) or Crisis Team (CRHT) or Pathway 2 Recovery (PR2)
- Inpatient Setting (e.g. Coral Ward, Crystal Ward, Jade Ward, Onyx Ward)
- Third sector organisation (e.g. Turning Point, Resolutions)
- Other (please state)

This is an official notification by student of the University of Hertfordshire in respect of a study involving human participants.

Title of study: Falling through the cracks: using constructivist grounded theory to explore how service provision impacts experiences of those with co-occurring mental health and problems with substance use

Protocol Number: LMS/PGT/NHS/02968

Approving Committee: Health, Science, Engineering & Technology ECDA

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If you have any queries concerning this document, please contact me Laura Aggett, Trainee Clinical Psychologist, la19abi@herts.ac.uk or my supervisor Dr Jade Weston, j.weston4@nhs.net

Appendix I.

Signed Non-Disclosure Agreement with Transcription Company



Non-Disclosure Agreement with Transcription Company

This non-disclosure agreement is in reference to the following parties:

Laura Aggett (discloser)
and
Lesley Beadsley (transcriber)

- The recipient agrees to not divulge any information to a third party with regards to the transcription of audio recordings, as recorded by the discloser. The information shared will therefore remain confidential.
- If the recipient is able to identify and knows the participant in the recording, the recipient agrees to cease transcription, inform the disclosure and destroy any copies of the recording.
- The recipient also agrees to destroy the transcripts as soon as they have been provided to the discloser.
- The recipient agrees to return and/or destroy any copies of the recordings they were able to access provided by the discloser.

TRANSCRIBER TO COMPLETE:

SIGNED:

NAME: Lesley Beadsley t/a Alltypes Secretarial Services

DATE: 10th November 2021

<p>University of Hertfordshire UH Ethics Committee</p> <p>This is an official notification by student of the University of Hertfordshire in respect of a study involving human participants.</p> <p>Title of study: Falling Through the Cracks: Using Constructivist Grounded Theory to Explore How Service Provision Impacts Experiences of Those with Co-Occurring Mental Health Difficulties and Problems with Substance Use</p> <p>Protocol Number:</p> <p>Approving Committee: Health, Science, Engineering & Technology ECDA</p> <p>The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority</p> <p>If you have any queries concerning this document, please contact me Laura Aggett, Trainee Clinical Psychologist, 07894573212 la19abi@herts.ac.uk or my supervisor Dr Jade Weston, Clinical Psychologist and Senior Lecturer, j.weston4@herts.ac.uk</p>



Appendix J.

Participant Debrief Sheet

Participant Debrief Sheet - Contacts for further support

Information for participants after taking part in the research...
Falling through the cracks: using constructivist grounded theory to explore how service provision impacts experiences of those with co-occurring mental health difficulties and problems with substance use

Retelling accounts of your experiences accessing mental health support may have been distressing for you. We hope that some of the resources will be helpful should you find yourself needing some extra support.

The professional code of conduct and ethical approval for this study means that Laura Aggett cannot personally support individuals with support beyond the remit of the study. This is why we have created this debrief sheet with a list of contact details for further support. However, if you feel you would like further support from either Resolutions, Pathway 2 Recovery (PR2) or a mental health service following the interview, Laura can put you in contact with the respective team or make them aware that you would benefit from additional support.

- **GP or local Psychological Therapy Services**
For advice if you are feeling low in mood, anxious or other emotional difficulties
- **ResoLUTIONs Recovery Hub: 01582 965123**
- **Mind (BLMK): 01582 380002**
Offers a range of services to support better mental health across Bedfordshire, Luton and Milton Keynes
- **Total Wellbeing Luton: 0300 555 4152**
8am - 8pm Monday to Friday and 9am - 4pm on Saturday
- **Bedfordshire Wellbeing Service: 01234 880400.**
9am - 5pm Monday to Friday
- **The Samaritans: 116 123**
24-hour crisis line for people contemplating harming themselves
- **Saneline: 0300 304 7000**
6pm - 11pm practical information, crisis care and emotional support

Please note: *This debrief sheet should not be considered equivalent to consultation with a professional*

University of Hertfordshire UH Ethics Committee

This is an official notification by student of the University of Hertfordshire in respect of a study involving human participants.

Title of study: Falling Through the Cracks: Using Constructivist Grounded Theory to Explore How Service Provision Impacts Experiences of Those with Co-Occurring Mental Health Difficulties and Problems with Substance Use

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The University of Hertfordshire Health, Science, Engineering and Technology Ethics Committee with Delegated Authority

If you have any queries concerning this document, please contact me Laura Aggett, Trainee Clinical Psychologist, 07894573212 la19abi@herts.ac.uk or my supervisor Dr Jade Weston, Clinical Psychologist and Senior Lecturer, j.weston4@herts.ac.uk

Appendix K.

Participant Recruitment Poster

24/05/2021 | Version 0.1 | Protocol Number: LMS/PGT/NHS/02968

University of
Hertfordshire **UH**

HELP US IMPROVE ACCESSABILITY OF
MENTAL HEALTH SERVICES

PARTICIPANTS WANTED!

- Have you suffered with mental health difficulties?
- Have you struggled to get help due to alcohol and/or drug use?
- Have you received support from mental health and/or drug and alcohol services in Luton or Bedfordshire?



Would you like to be involved in a research study interested in hearing your experiences and opinions about mental health and/or drug and alcohol services? If you meet the following criteria, it would be great to speak to you:

- ◆ Aged 18 years or over
- ◆ Experience of problems with substance use
- ◆ Experience of a struggling with your mental health
- ◆ Experience of seeking mental health support in Luton/Bedfordshire
- ◆ Willing to take part in an individual interview

If you would like more information please email Laura Aggett (Trainee Clinical Psychologist) at la19abi@herts.ac.uk or send a direct message (DM) via Instagram: [mrp_dclinpsy](#) or Twitter: [@FallingThruGaps](#)

Appendix L.

URL to Participant Recruitment Video

<https://youtu.be/sBpMVLn9uug>



Appendix M.

First Drafted Version of Interview Topic Guide

Interview Topic Guide (version 1)

	Topic
10 minutes	Introductions <ul style="list-style-type: none">- Information sheet- Consent form/Demographics Questionnaire- Any questions?
15 minutes	Experiences of co-occurring difficulties <ul style="list-style-type: none">- How have your experiences of substance (mis)use impact on your life?- How have your experiences of mental health difficulties impacted on your life?- What are your experiences of have <i>both</i> substance (mis)use and mental health difficulties (which came first)?
15 minutes	Access to mental health services <ul style="list-style-type: none">- What have been your experiences of trying to access mental health support?- Do you know of anyone who has had similar/different experiences?
15 minutes	Ideas for improving service provision <ul style="list-style-type: none">- What barriers do you think there are currently that are inhibiting individuals with substance (mis)use difficulties access mental health support?- Do you have any ideas with regard to how mental health services could be improved for individuals with co-occurring mental health and substance (mis)use difficulties?- How would you like to see this research shape service provision?
5 minutes	Endings <ul style="list-style-type: none">- Anything else you would like to discuss?- Any questions?

Appendix N.

Final Version of Interview Topic Guide

Outline Interview Topic Guide

	Topic
10 minutes	Introductions <ul style="list-style-type: none">- Information sheet- Consent form/Demographics Questionnaire- Any questions?
15 minutes	Experiences of co-occurring difficulties <ul style="list-style-type: none">- Can you tell me your earliest memory of substance use?- How have your experiences of substance use impacted on your life?- How have your experiences of mental health difficulties impacted on your life?- What are your experiences of substance use <i>and</i> mental health difficulties (which came first)?
15 minutes	Access to mental health services <ul style="list-style-type: none">- Can you describe your experiences at times when you have tried to access mental health support?- Which services have been the most helpful in your experience?- Do you know of anyone who has had similar/different experiences?
15 minutes	Ideas for improving service provision <ul style="list-style-type: none">- If there was one thing you could change to make your experience better what would it be?- What barriers do you think there are preventing individuals with substance use difficulties from being able to access mental health support?- Do you have any ideas regarding how mental health services could be improved for individuals with mental health and substance use difficulties?- How would you like to see this research shape service provision?
5 minutes	Endings <ul style="list-style-type: none">- Anything else you would like to discuss?- Any questions?

Appendix O.

Three Extracts from the Researcher's Reflective Diary

Recruitment Site Backs Out (26/08/21)

I am feeling incredibly frustrated by the numerous obstacles that keep appearing as I go through the NHS ethical approval processes. Today, [research site name] withdrew confirmation of capacity and capability, going back on what had been agreed. It seems that a Clinical Director initially 'signed off' on the capacity and capability for the service to act as a recruitment site. However, despite the prospective research being discussed at length with the Service Manager, the Clinical Lead had not been informed and has withdrawn capability and capability confirmation. This feels like a huge blow, as I will now be restricted to recruiting participants from Luton, as opposed to wider Bedfordshire, which will impact on the diversity of the sample. The rationale from the service for not wanting to take part was that people accessing the service are 'vulnerable' and the research has potential to distress participants. This has prompted reflection on who we deem to be 'vulnerable' and what 'vulnerable' really means. Too often healthcare services infantilise and/or fragilise people under their care, limiting choice and autonomy. The role of the recruitment sites identified would be to advertise the study to potential participants, by displaying the recruitment posters, and allowing people to choose whether they would like to take part.

My initial thoughts were that the service does not want to be involved in case negative comments are made about the service. However, the purpose of the research is to improve experiences of people using services, so my perspective is that knowledge is power and all information is helpful in making changes for the better, for services, staff and service-users. Perhaps the response was coming from a place of wanting to 'protect' people accessing the services, but given the opportunity, people surely have the right to decide whether or not they want to take part in the research. It is likely that COVID-19 has created additional strains on the service that withdrew their involvement, and I understand that it is a particularly difficult time to be asking services to become involved with additional things, such as research, alongside managing their routine endeavours. I have taken this set back quite personally, as it feels that I have gone to great measures to ensure that any potential risks to participants would be minimised, going through rigorous processes of risk assessment, as well as the study being given approval from the REC. I have to try and not let this dampen my spirits, moving forward to concentrate on my remaining recruitment site and think about how I can harness their resources to advertise the study as widely as possible.

Disingenuous Participants (16/12/21)

I have done two interviews this morning but I'm slightly concerned about the authenticity of the participants, and I don't know what to do. The stories were both similar and they were both overly positive about services (surprising!) One person said they self-referred to the [name of service] which seems unlikely that would be

possible and also did not seem to have a good understanding about what support a CMHT offers. The other person said they were in a private rehab unit in [place name]. I have a general feeling that the stories are not authentic and I am sure that certain parts have been fabricated. I have no idea what to do in this situation. They both said they had found the advert on LinkedIn, but I have not advertised through that platform. They have both requested Amazon gift vouchers to compensate their time involvement. Both people did not have a camera on, during the MS Teams interview and their accounts did not always make sense. However, when their eligibility was screened and my information sheet was sent, they confirmed they met the criteria.

After contacting Jade and speaking to the rest of the research team at University, I am feeling reassured. The sudden influx of interest from potential participants, should have alerted me to something untoward, but I was just so relieved that there was interest in taking part in the study! It was helpful to hear the perspectives of Jade and others in the research team, and that I was not alone in thinking that the accounts shared in the interviews seemed implausible. I felt annoyed being advised to still honour the agreed voucher compensation, but I suppose there is no concrete way to prove the participants were authentic or not. Following further advice from HRA, I have deleted the interview recordings. It feels very frustrating that a great deal of my time has been taken up arranging and facilitating interview that have turned out to be unusable sources of data. I have contacted all the other participants that had come forward around the same time, and explained that I would be suspending data collection for the time being and was transparent with my reasoning. Again, I had arranged dates and times for to facilitate interviews with these people, which took time and effort. Looking back over email correspondence, it seems that the emails were all formatted in a similar way, possibly created through an online email generator. They all said they wanted to take part in the study or share their experiences but never made specific reference to topic of the study in their initial email. The emails were very short and had no subject headings. This has been a painful experience, especially with a topic so close to my heart.

Participant Interview (25/01/22)

I really enjoyed facilitating the interview, it felt very natural and free flowing. Initially [participant name] seemed quite anxious and said that he had not had any time to prepare. I tried to reassure him that I would not expect any participants to prepare for the interview and I was only interested in hearing about his experiences of services to date. We soon settled into the conversation, however, at times I was swaying from the interview topic guide. We spoke about philosophy and politics (Marxism) for a large portion of the interview, as this was a particular interest of his and something that he studied at university. I wonder whether other participants would be so interested in the political landscape and how this impacts service provision? Part way through the interview, I had a sudden panic that I was not in 'researcher mode' and things had turned into a chat, which was not particularly relevant to the research question. I was able to apologise for going off track with the interview and (hopefully) gently guided the conversation back to the next section of the topic guide. I feel like I still have a long way to go in developing my interviewer skills – in such a relatively small window of time it can be difficult to prioritise the interview topic guide. I

suppose I am far more use to a therapeutic space where I would spend time building rapport, but within a 50-minute interview timeframe that is not possible. I wondered how [name of participant] perceived me and whether sharing my more personal reasons for conducting the research may have impacted on him seeing me as an 'insider', as opposed to a professional or researcher. They asked me a number of questions towards the end of the interview about how the research findings would be disseminated as they were keen to see real change in services. They were completely legitimate questions which I was happy to answer, but it did make me question my researcher position and also that he wants the researcher to be impactful, not just published in a journal somewhere for academics to read.

Appendix P.

Example of Memo Use During Initial Stages of Analysis

Transcript Extract ('Milo')	Memo
Yeah anything you need answering I will tell you one hundred percent the truth. I've got um I've been through all these sort of systems. I have been the lucky one I came out the other end but it ain't been easy sailing as it is.	Expert position Open Lucky
And in the 1970s it weren't so looked down upon then and it was things like oh give him half a lager, give the boy half a lager he's he's in the pool team.	Situating historically - suggesting change since
I think there's always been things wrong with me.	Pathologizing language re: self
the alcohol was always there	Alcohol as a friend
I opened up the car door, jumped out	Suicidal or something else?
getting on the underground was a bit of a traumatic thing for me	General anxiety or fearful of specific life experiences?
But it didn't come out of me til I was sort of in my thirties I suppose.	Mental health difficulties being innate
Oh they put me on um Olanzapine, cos only a psychiatrist could do that. While my GP I was certain messing around with stuff; wasn't working.	Being done to
Not really that's... well yeah but um in the end I was still miserable,	Medication not helping
Mr [participant surname] we found your file in the back of er a cabinet. It looks like you've slipped through our fingers for many years. So all of a sudden I got a social worker. They got the debt collectors off my back; er I was bidding then, I was living in temporary accommodation and they got me an extra point in my bidding ladder through my mental health. So they had their uses. But then I had about four social.. five social workers within about seven months. They were coming and going and then they took them away from me.	Matter of fact about service errors Was there a relationship there? Life problems arising alongside the MH and substance use problems The social workers were taken away from me - powerless
One day I was having a really bad day I didn't turn up for meeting, I got a letter	None attendance leading to discharge

saying you've been discharged, we do not want to see you no more.	
So they sort of just threw you away.	Threw away by services
Now I'm a [job title].	Change in identity - confidently claiming new identity
So they didn't just say you haven't got it, go and get experience, they've offered me.	Support from others - different to previous experiences of services

Appendix Q.

Data Analysis Audit Trail: An example of process from initial Line-by-line coding to focused coding (extract taken from the transcript of the interview with 'Steven')

PARTICIPANT:

Transcript	Initial coding	Focused coding
<p>Um it just continued with the GP because er the panic attacks didn't go away. Um they were they were getting more and more severe. I was starting to drink more. I actually went to the doctors er I was around fifteen/sixteen and explained to him. And er he said to me he said do you drink alcohol. And I said yeah. I said it stops it, it makes it better. And he said yeah which was correct. But in the long term he said you drink, so that alleviates it and takes you a bit high. He said the next day you've got a big low, he said the panic will get worse. I took that in and understood it erm I was probably it was twenty years ago now, I was probably given more tablets but by that by that age the panic attacks got that bad that the tablets were doing nothing. I just used alcohol still. But I still at sixteen, I still wasn't dependent um I was using it, til the worse gone and I was using it every day, not sparingly. I was using it when I needed it, but it was like random.</p> <p>Ok. Yeah.</p> <p>Know what I mean I'd I'd go out. It was more or less, it was nearly every night. But um but I worked and stuff then. So I'd go to work, then I'd finish work. I'd just feel uneasy, I wouldn't feel ok until I'd had two or three beers. And um it was..</p> <p>I guess, like, it sounds like there wasn't there wasn't really an alternative to helping you cope with your mental health.</p> <p>Looking back, maybe um talking therapies or something may have helped. But um they they, my memory of it went literally just have some tablets. There was no other support at all. Yeah.</p>	<p>Having more severe panic attacks Drinking to cope Having more severe panic attacks Being honest about drinking with GP Drinking more to cope Getting advice from GP Understanding advice Being prescribed medication Having to drink to cope Using alcohol to cope Being in control, not dependent</p> <p>Drinking every night Feeling uneasy, drinking to manage Feeling okay after beers</p> <p>Wanting talking therapy Lacking options Being given only medication</p>	<p>Self-medicating to cope</p> <p>Being open and honest</p> <p>Praising services</p> <p>Being prescribed drugs Self-medicating to cope</p> <p>Self-medicating to cope</p> <p>Lacking options Being prescribed drugs</p>

<p>Ok. And then how did things progress from there in terms of your mental health and substance use. So when I was twenty I moved to [place name] um the drink the drinking got really bad then I moved to somewhere I didn't know anyone, the anxiety was more.. I was still aware of why I was drinking. It was still to control my mental health problems, my anxiety, it was it was a tool. Um when I was twenty one I moved to [place name]. Somewhere in this the the drinking actually developed into a real problem.</p> <p>Ok. And I lost, I'd lost the reason that I drank. I'd I'd forgot why I'd started. I'd been labelled as an alcoholic by doctors. Oh you're an alcoholic and and by services then as well. You're you're an alcoholic. And erm I'd go to the doctor about my mental health, they'd tell me I'm an alcoholic. And in the end, that cemented that I was an "alco". I'd forgot about mental health issues. I was an alcoholic that needed a drink and all through my time in [place name] I'd I um I went on one treatment centre in [place name] literally for I didn't understand addiction either. Literally thought if they detox. cos I I by this time in my mind I was just an alcoholic, there was no other issues. So I thought if I have a detox, when they let me out everything will be fine, because. And obviously it wasn't. I would come out from a detox. The mental health would go through the roof and my only answer I knew was to drink again. And but each time this happened I didn't recognise the mental health I would just drink again.</p> <p>Mmm. And I just got stuck. Then through my whole twenties more or less til my late twenties as I was an alcoholic that just had to stop drinking, there was no other problems. I'd forgotten forgotten my mental health, um things until I was about twenty six and er I had a massive seizure in my head I had bleeding on the brain, I was in a coma..</p> <p>Oh my goodness, that's terrible. Um they detoxed me. I got moved back to Luton and it was then that I remembered.. I had a broken hip and a broken collar bone as well so I couldn't move about, I couldn't go and drink and I remembered about</p>	<p>Moving to new area</p> <p>Using alcohol to manage anxiety</p> <p>Drinking becoming a problem</p> <p>Forgetting why drinking began Being labelled an alcoholic Wanting help for mental health difficulties Being denied help Internalising label of alcoholic Wanting to be 'cured' Forgetting mental health difficulties Wanting detox to solve all problems Experiencing mental health difficulties resurface Being trapped in vicious cycle</p> <p>Being stuck Needing to stop drinking Forgetting about mental health problems Having seizure and coma</p> <p>Being detoxed Being 'done to' Remembering the reason for drinking</p>	<p>Sharing early experiences Self-medicating to cope</p> <p>Being labelled Self-medicating to cope Being misunderstood Being labelled Wanting help Self-medicating to cope Accessing substance use services Being vulnerable</p> <p>Self-medicating to cope</p> <p>Feeling hopeless Being labelled Self-medicating to cope Breaking point</p> <p>Accessing substance use services Being done to</p>
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<p>my mental health issues, they all come back and I thought oh yeah it was like a light switched on..</p> <p>Really. Ah that was why I drank. I remembered why I drank and what I was using it for. And this was when I started going to a lot of services in Luton regarding my mental health. They were telling me they can't help me because.. I started inevitably started drinking again.</p> <p>Mmm. They said they can't help me because I'm drinking. And the alcohol and drug services vice versa.</p> <p>Yeah. They can't help me because it's mental health.</p> <p>Mmm. And it was very very back and forth and then I'd lose hope and go off drinking for a year, not contact any services, get even worse. Then I would go back to services just to have that happen again.</p> <p>Wow. That sounds, Yeah. that sounds terrible. And yeah the cycle that you got into kind of when you were in [place name] being told you're an alcoholic. Yeah literally just being constantly labelled you're an alcoholic. I forgot the issues which caused me to first ever pick up an alcoholic drink.</p> <p>Mmm. I'd forgotten why I first done it.</p> <p>Yeah and then coming back to Luton almost kind of maybe I don't know memories of being there before and things coming back or.. Maybe yeah. It just it just all come back to me and when when I was first in Luton I was sort of, my mum was in a third floor Flat er I I couldn't I had a broken hip so I couldn't walk, my memory was where I'd hit my head that hard my memory was shot I couldn't talk very well, um I couldn't physically get to a shop to get drink. So the mental health come back to me, but as soon as I could get to a shop and get drink, I did. And um yeah but luckily I kept in my head why I was</p>	<p>Wanting to access mental health services Being denied help Feeling helpless Drinking to cope Being denied help from all services</p> <p>Feeling let down by service criteria Losing hope Revolving service door Feeling frustrated</p> <p>Being labelled an alcoholic Having understanding of the underlying issues of alcohol use</p> <p>Forgetting the reason for drinking</p> <p>Feeling restricted</p> <p>Being overwhelmed by mental health difficulties Buying alcohol as soon as possible Getting alcohol to cope</p>	<p>Self-medicating to cope</p> <p>Wanting help Being denied help Breaking point Self-medicating to cope Being denied help</p> <p>Being denied help</p> <p>Feeling hopeless</p> <p>Being frustrated by service structure</p> <p>Being labelled Understanding interaction between mental health and drug use Self-medicating to cope</p> <p>Feeling disempowered</p> <p>Self-medicating to cope</p>
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<p>getting that drink, it was no longer because I was an alcoholic. Cos I was detoxed. I wasn't an..</p> <p>Of course. I wasn't physically dependent on alcohol any more. It was beca.. I knew why I was doing it because it helped with my mental health.</p> <p>Yeah it was still a coping strategy. Yeah yeah.</p> <p>And what you mentioned before about um mental health services saying that you have to be abstinent for them to help you and then drug and alcohol services saying need to sort out your mental health before you come to us.. Yeah. And ..</p> <p>I was just trying to be honest so I'd go to drug and alcohol s.. and they they'd sort of ask you why you drink. Or I would go in there and tell them why I drink. Look I drink because this is happening, that's happening and it helps me cope with that. So I almost give them permission to say well you need to go and deal with that at a mental health service. And yeah it just batted back and forth for a long long time.</p> <p>Especially as you knew that drinking alcohol was to help you cope with your mental health and then for them to say you need to give up that coping mechanism before we can help you.. Exactly yeah.</p> <p>Doesn't really seem to make sense. In my mind it was the only thing keeping me safe</p> <p>Yes. and they wanted me to stop that before they could talk to me and and I it.. too much of a risk to me. But I can't I can't risk that. Er yeah.</p> <p>Yeah. And were you e were you ever able to kind of have that conversation or was it quite black and white from their side and you need to do this.. Very er like</p> <p>..otherwise they're not going to help. Yeah. Very, we can't help you, go here. Um which like I said just sent me back out there, again.</p>	<p>Knowing reason for drinking Being in control Medicating with alcohol</p> <p>Being honest with services</p> <p>Explaining cycle of using alcohol to cope with mental health Being batted between services</p> <p>Being kept safe by alcohol Being told to give up coping strategy Feeling too risky to stop drinking</p> <p>Being denied help Being sent back to alcohol</p> <p>Giving up seeking help</p>	<p>Understanding interaction between mental health and drug use</p> <p>Self-medicating to cope</p> <p>Being open and honest Understanding interaction between mental health and drug use Being batted between services</p> <p>Self-medicating to cope Having to stop using to access services</p> <p>Being let down</p>
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<p>Yes. For another year that I'd just give up. I'd just.. By the time I finally got help I'd like the guy, I work with the guy now who actually listened to me in the end. I work with him in the same office.</p> <p>Oh really. And he said the first time he met me he said you were just, I've never seen someone that broken. He said you just had no hope in you at all. He said and all you needed was a bit of hope. Someone to listen to you and hear what you were saying. And um yeah it really destroyed me.</p>	<p>Being listened too finally</p> <p>Being seen as broken Having no hope Needing to be given hope Needing to be listened to and heard Feeling destroyed by alcohol Feeling destroyed by services</p>	<p>Being let down</p> <p>Being heard</p> <p>Being labelled Feeling hopeless Needing help Being heard</p> <p>Needing help Being let down</p>
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Appendix R.

Data Analysis Audit Trail: An example of initial codes grouped under focused codes (NVivo)

Battling with services to get support	Being batted between services	Benefitting from peer support	
Acknowledging challenges through recovery journey	Being batted back and forth between services	Acknowledging importance of peer support and lived experience of staff	Having experienced staff support
Banging on services doors for support	Being pushed away	Acknowledging people will open up if they have had similar experiences	Having lived experience makes a difference
Battling for support	Being pushed to other services	Assuming the experts know best	Having relationships based on lived experience
Battling to access care	Being put under the crisis team	Being around the right people	Having something to offer
Battling with services for support	Being referred for autism ax	Being away from familiarity	Highlighting own life experience
Being worried to cut ties with services	Being referred to a psychiatrist	Being down to earth	Interacting with others
Fighting against the system	Being referred to different services back and forth	Being involved as a service-user	Involving others in participation
Fighting for appointments	Being referred to mental health service	Being involved in more activities, SMART groups	Joining peer led aftercare
Fighting to be seen	Being referred to MH service	Being open about experiences with clients	Joining together with others with shared experiences
Finding access difficult	Being referred to Open Access	Being unable to trust people without lived experience	Joining webinars
Making progress together	Being told by both services to go to the other	Believing we all have issues	Knowing more than others without lived experience

Perceiving progress as a struggle	Being told by services 'nothing we can do'	Connecting, chatting with others	Learning to cope with panic
Pleading for intervention	Being told disorders are too much for service to handle (Total Wellbeing)	Ending up working for services by mistake	Making friends
Pleading for second chance	Being under care of crisis team	Enjoying interaction	Meeting others
	Being under care of MH team	Enjoying talking to others	Needing mentors
	Experiencing revolving door	Experiencing peer mentors as excellent	Needing people with lived experience
	Feeling pushed from pillar to post	Experiencing support as experiential	Needing someone to relate to
	Going around in circles with services	Feeling connected to others	Relating to group facilitator
	Going back and forth	Feeling supported by people with life experience	Seeing service as Utopia - peer led
	Going through multiple services	Feeling understood by staff with lived experience	Sharing others experiences

