In and Out: People with lived experience, carer & professional perspectives on avoiding admission to mental health hospitals, and how discharges could be safely made more quickly

"Managers and commissioners think that everybody understands mental health services; what they are like, what's available, what phone lines are available, like the fact that Safe Havens exist. They take all these things for granted. But your average person in the street probably knows their GP, they know about A&E, you know, they might potentially have heard of CAMHS. But that's probably it."

(professional)

the coalition
Surrey Coalition of Disabled People

IMHN
INDEPENDENT MENTAL HEALTH NETWORK
SURREY & NE HANTS

Acknowledgements

The research team would like to thank the people with lived experience, carers, professionals, and the steering group that worked with us on this research project. We would particularly like to pay tribute to the people who so generously shared their lived and carer experiences with us.

Contents

List of Abbreviations

A&E	Accident & Emergency (Also known as ED)
AMHP	Adult Mental Health Professionals
CMHRS	Community Mental Health Recovery Service
CQC	Care Quality Commission
CTO	Community Treatment Order
CTR	Care Treatment Review
ED	Emergency Departments (Also known as A&E)
GP	General Practitioner
GPIMHS	General Practice Integrated Mental Health Service
IAPT	Improving Access to Psychological Therapies
JSNA	Joint Strategic Needs Assessment
LOS	Length of stay
LTP	NHS Long Term Plan (Also known as ‘The Plan’)
Meds	Medications
MHA	Mental Health Act (Also known as ‘The Act’)
NHS	National Health Service
PCNs	Primary Care Networks
The Coalition	Surrey Coalition of Disabled People

Glossary

Admission	The decision is made for the individual to stay in a mental health hospital as an inpatient, and the process of them entering the service
Carer	An adult who provides care for another adult outside of their job role. An adult who provides care under a contract, or as voluntary work is not regarded to be a carer (as defined by the Carers Act (2014)
Commissioner	A person who works in the mental health service in charge of making decisions about the running of the services
Community mental health services	Mental health services available in the community before the individual is admitted as an inpatient, or after they are discharged from being an inpatient in a mental health service
Discharge	The process of the individual leaving the mental health hospital where they were an inpatient, and entering the community
Independent hospital	A mental health hospital which receives private funding, not under the NHS
NHS hospital	A mental health hospital which is funded by the NHS
Person with lived experience	A person who is using health services e.g., an individual who is a patient in a mental health ward Sometimes referred to in this report as an ‘individual’, ‘patient’ or ‘service user’.
Sectioned	An individual being admitted to a mental health hospital as an inpatient against their will because they are a risk to themselves or others
Stakeholder	Peoples and organisations with an interest in the current research e.g., Surrey Heartlands
Statutory sector	Government-run services involved in mental health care e.g., police, ambulance

Stay	The time spent in a mental health hospital as an inpatient.
Third sector	Mental health services which are non-governmental and not-for-profit e.g., charities, voluntary sector, community groups

1 Introduction

About us: The Coalition

Surrey Coalition of Disabled People (The Coalition) is a not-for-profit organisation which is run and managed by Disabled people for Disabled people. Members live across Surrey and North-East Hampshire. The Coalition promotes the rights of disabled people to have equality of opportunity and to live independently. The Coalition’s work and activity is divided into 5 broad areas:

1) Co-production, service monitoring and consultation activity
2) Technology and innovation
3) Mental health and emotional wellbeing
4) Wider determinants of health
5) Campaigning and influencing

Peer researchers and our role in the project

The Peer Researchers began their roles with The Coalition in June 2022. Alex Hird, the lead Peer Researcher, is completing a PhD at Aberystwyth University on crisis houses. Kirsty Smith, the Trainee Peer Researcher, graduated from Roehampton University in September 2022 with a BSc in Psychology and Counselling. Both Peer Researchers have experience of mental ill-health. Their research has been supervised by Dr Dawn Benson, a sociologist with a specialism in disability studies and inclusion and safety investigation in health and social care sectors. She is also the parent of adult disabled children and has experience of caring for someone who has been admitted as an inpatient to a mental health hospital.

Dr Dawn Benson
Research Supervisor

Photo of Dawn smiling, wearing a black top and a white cardigan. Dawn has woodlands behind her in the picture

Alex Hird
Lead Peer Researcher

Photo of Alex smiling, wearing a black and white striped top. Alex has woodlands behind her in the picture

Kirsty Smith
Trainee Peer Researcher

Photo of Kirsty smiling, wearing a pale green shirt. Kirsty has a white wall behind her in the picture

The Steering Group

The research team worked with a steering group made up of people with lived experiences, carers, and professionals. They held online meetings with the group to gather their insights into the research questions, data collection methods, and outputs.

Steering group members:

- People with lived experience of admission
- Carers
- Professionals
- Service commissioners

Who funded the project and who requested it

Funding was allocated by the Winter Pressures Group. Surrey Heartlands commissioned the project to better understand:

- What support could help individuals, their families, and carers to safely avoid an admission to hospital for a mental health crisis
- What support could enable people to get well more quickly and for admissions to be shorter
- How discharge arrangements could be improved

This was to be explored through pro-active outreach research, such as interviews and surveys.

The purpose of the research was to find ways that admissions to mental health hospitals could be avoided; stays in hospital could be shortened; and discharge arrangements be improved. A key aim of the research was to identify alternatives to admission, by shaping future service developments and reducing the demand on Emergency Departments (ED) by gathering insights of the reasons why people attend an ED.

Core outputs:

- A research report with recommendations that have been co-designed
- Some creative summaries, such as an animated video

- Blogs/vlogs and any explainers to make sure that the research and recommendations are accessible.

Why we did the project

To help us to understand the issues which influence unexpected admission to mental health hospital and the process of discharge, for people who live in Surrey, we looked at what work had previously been done and what is known about both admission and discharge. Several themes were identified from a review of academic articles, media articles, and television documentaries.

Literature review

The purpose of the study is to explore factors which contribute to emergency admission and delayed discharge from mental health hospitals, and to identify opportunities for improvement across services within Surrey.

This literature review covers national policy and planning on mental health specifically with regard to crisis and inpatient care (The NHS Long Term Plan), the Mental Health Act (MHA) (in both its current form and details of proposed reform) and the Care Quality Commission (CQC) findings of the application of the Act as one of their regulatory responsibilities.

The review also considers the system and financial imperative relating to people moving through the inpatient system, often referred to as ‘flow’ and references the commissioning model of delegated commissioning with Surrey where commissioning of all inpatient bed use for the system. UK and national research into emergency admission and discharge from mental health hospitals will also be considered.

The review concludes by looking forward at opportunities for the findings of this research to be included within the Mental Health Improvement Plan within Surrey which includes the crisis and inpatient offer as major focus and the opportunity nationally to feed into the call for evidence from NHS (National Health Service) England towards a proposed 10 year plan.

The NHS Long Term Plan, first published 7 January 2019 made a renewed commitment to improve and widen access to care for children and adults needing mental health support, including during crisis. This commitment came with increasing funding at a faster rate than the overall NHS budget (by at least £2.3bn a year by 2023/24) and a commitment to making it easier and quicker for people of all ages to receive mental health crisis care, around the clock, 365 days a year, including through NHS 111 and building on the work of the former ‘Five Year Forward View’.

The NHS Long Term Plan (LTP or ‘the plan’) outlined a whole section (3.95 – 3.101) on ‘emergency mental health support’ quoting a CQC survey where only ‘14% of adults surveyed felt they were provided with the right response when in crisis, and only half of community teams were able to offer an adequate 24-hour, seven-day crisis service' (CQC, 2015) and the planned expansion of services for people experiencing a mental health crisis as a result of this. The plan committed to ensuring 'a 24/7 community-based mental health crisis response for adults and older adults is available across England by 2020/21', including 'intensive home treatment as an alternative to an acute inpatient'. As well as 'no acute hospital is without an all-age mental health liaison service in Accident and Emergency (A&E) departments and inpatient wards by 2020/21, and that at least 50% of these services meet the 'core 24' service standard as a minimum' and by '2023/24, 70% of these liaison services will meet the 'core 24' service standard, working towards 100% coverage thereafter'.

This was underpinned by a statement of commitment that within the next ten years:

- The NHS will provide a single point of access and timely, universal mental health crisis care for everyone.
- Anyone experiencing mental health crisis can call NHS 111 and have 24/7 access to the mental health support they need in the community.
- Clear standards will be set for access to urgent and emergency specialist mental health care.
- Post-crisis support for families and staff who are bereaved by suicide will be available (recogniing that these bereaved families and staff are likely to have experienced extreme trauma and are at a heightened risk of crisis themselves)

The plan also outlines the increase in the spread of provision and signposting of alternative more suitable forms of support for those in crisis such as sanctuaries, safe havens and crisis cafes recognising these are 'commissioned through the NHS and local authorities, provided at relatively low costs, high satisfaction, and usually delivered by voluntary sector partners.'

The plan further mentions a 'Clinical Review of Standards' aiming to make recommendations 'for embedding urgent and emergency mental health in waiting time standards' with the expectation 'that everyone who needs it can expect to receive timely care in the most appropriate setting, whether that is through NHS 111, accessing a liaison mental health service in A&E, or a community-based crisis service' to take effect from 2020.

The plan's section on 'inpatient care' (3.102) starts with the statement that 'for people admitted to an acute mental health unit, a therapeutic environment provides the best opportunity for recovery', citing the Crisp Commission as evidencing the 'wide variation in the quality and capability of these acute mental health units across the country' (The Independent Commission on Acute Adult Psychiatric Care, 2016).

A goal carried over from the prior Five Year Forward View was to continue to work with units with longer lengths of stay to reduce this to the national average of 32 days in the hope that this would contribute to 'ending out of area placements by

2021'. The plan also references capital investment from the forthcoming Spending Review being needed to upgrade the physical environment for inpatient psychiatric care as recommended by Professor Sir Simon Wessely's Mental Health Act review.

Discharge is only referenced from this perspective within the plan. The final section within the plan concludes with a set of milestones covering integrate models of primary and community mental health care, increase in numbers of accessing IAPT (Improving Access to Psychological Therapies) services by 2023, NHS 111 to be the single, universal point of access for people experiencing mental health crisis by 2023 and increasing alternative forms of provision for those in crisis, including non-medical alternatives to A&E and alternatives to inpatient admission in acute mental health pathways. Surrey is one of only 7 integrated care systems to have implemented the 111 'press two for mental health support' crisis line (as highlighted by the Health Service Journal on 3 October 2022).

The Long-term Plan (LTP) also references the independent review of the Mental Health Act, chaired by Professor Sir Simon Wessely (Department of Health and Social Care, 2018). CQC describes 'The Mental Health Act 1983 (MHA) as 'the legal framework that provides authority for hospitals to detain and treat people who have a mental illness and need protection for their own health or safety, or the safety of other people and also provides more limited community-based powers, community treatment orders and guardianship'. The CQC is an executive non-departmental public body of the Department of Health and Social Care of the United Kingdom established in 2009 to regulate and inspect health and social care services in England. One of the CQC roles is the to check that patients' basic human rights are maintained while they are being cared for or treated under the Mental Health Act'.

The aforementioned Wessely review referenced within the LTP examined rising detention rates, racial disparities in detention and concerns that the Act is out of step with a modern mental health system and provided 150 recommendations covering four principles to underpin improving legislation and practice:

- Choice and autonomy – ensuring service users' views and choices are respected.
- Least restriction – ensuring the Act's powers are used in the least restrictive way.
- Therapeutic benefit – ensuring patients are supported to get better, so they can be discharged from the Act.
- People as individuals – ensuring patients are viewed and treated as rounded individuals.

Following the review, the Government published a white paper on 'Reforming the Mental Health Act' on 13 January 2021 containing proposals to reform the Mental Health Act 1983 (as amended in 2007) in England and Wales. The Government subsequently responded to the consultation on the white paper proposals details of the draft Mental Health Bill, published in June 2022, with the inclusion of most of the review 150 recommendations. The Queen’s Speech in May 2022 included an announcement on draft legislation to reform the Mental Health Act. Lord Kamall, The Parliamentary Under-Secretary of State for the Department of Health and Social Care stated that scrutiny would “commence at the earliest opportunity” and the government’s ambition is “to introduce the Bill in the new year on 28th June 2022.

Within the draft Bill are several amendments to the Mental Health Act 1983:

- Autism and learning disabilities are not conditions for which a person could be subject to compulsory treatment under section 3.
- Changes to the criteria for detention by setting out two new tests with a higher risk threshold.
- A new definition of “appropriate medical treatment” to require that the treatment must have a reasonable prospect of alleviating, or preventing the worsening of, the patient’s mental disorder.
- A new duty on the clinician in charge of the patient’s treatment to consider certain matters and take several steps when deciding whether to give treatment to a patient under Part IV of the Act.
- A requirement for the clinician responsible for overseeing the patient’s care as a community patient, to be involved in decisions regarding the use and operation of the Community Treatment Order (CTO)
- A new power for Mental Health Tribunal to recommend that the Responsible Clinician reconsider whether a particular CTO condition is necessary, in cases where the Tribunal has decided not to discharge a person from a CTO.
- A new statutory role, the nominated person to replace the current Nearest Relative role in the Act.
- Quicker expiry of the initial detention period under the Act and more frequent review and renewal of the detention.
- Extend the amount of time patients can apply to the Mental Health Tribunal and make automatic referrals more frequent.

(Above taken from: CBP-9132.pdf (parliament.uk))

CQC produce an annual report, ‘Monitoring the Mental Health Act’ devised from their monitoring activity of how providers are caring for patients that includes whether patients' rights are being protected. The 2020/21 report indicated that through the MHA monitoring activity they found:

1. **The workforce is under extreme pressure**
   The pandemic has placed additional stresses on staff, patients and carers. Many patients and carers have told us that they appreciate the extra efforts made by staff to mitigate the effects of lockdown restrictions and there has been some good practice. But staff are now exhausted, with high levels of anxiety, stress and burnout, and the workforce is experiencing high levels of vacancies. The negative impact of working under this sustained pressure poses a challenge to the safe, effective and caring management of inpatient

services and to the delivery of care in a way that maintains people's human rights.

2. **Community services are key to reducing levels of detention in hospital**
   Not getting the right help at the right time can lead to symptoms worsening and people needing inpatient care.
3. **Urgent action is needed to address longstanding inequalities in mental health care**
   We remain concerned that Black or Black British people are more likely to be detained under the MHA, spend longer in hospital and have more subsequent readmissions than White people.

Given the national policy drivers under the LTP and prior the Five Year Forward View, the scrutiny from CQC and planned changes to the Mental Health Act from consultation, what is the research evidence telling us about emergency admission and discharge, particularly where research includes those with lived experience?

Mind's website describes the current Mental Health Act 1983 and its current use, including the rights of those subject to the Act. [1] It states that the Act covers the rights of people in England and Wales including 'Assessment and treatment in hospital' and 'Pathways into hospital, which can be civil or criminal'.

The website helpfully outlines the difference being detained in hospital against your wishes (or 'sectioned') known as being a 'formal patient' as opposed to going voluntarily into a hospital for treatment, where Mind indicates that this is half of all patients. Different sections of the Act are used according to need and also give an indication as to how long you may need to stay in hospital. The main sections are 2, 3, 5(2) and 5(4).[2]

The joint strategic needs assessment (JSNA) is an assessment of the current and future health and social care needs of the local community and as such is usually an excellent source of data but this is currently being rewritten within Surrey with publication due November 2022.

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[1] Mind is a national organisation that offers 'advice and support to empower anyone experiencing a mental health problem' and 'campaigns to improve services, raise awareness and promote understanding'.

[2] Detention under section 2 is used for a mental disorder, for short term assessment and/ or medical treatment and is necessary for you own or others protection and health and safety for up to 28 days. Section 3 is used when treatment cannot be given anywhere other than hospital and lasts for up to six months, renewable by a responsible clinical. Section 5(2) and 5(4) are used where there may be a need to detain you formally if you are a voluntary patient for 72 and 6 hours respectively. According to the NHS (2019) in the United Kingdom, involuntary hospitalisation is implemented only in emergencies, when a person is in grave danger of harming themselves or others and when one displays signs of mental disorder in public, as stated in Warrant 135 and 136 respectively (NHS, 2019).

Mental health crisis definitions are many and varied that include those both defined by services, the risk-based definition defined by the NHS above (regarding the MHA and admission) and by the person themselves, as well sometimes in collaboration with their families and professionals around them. For example, the Joint Commissioning Panel for Mental Health (2013) offer a service definition: ‘Crisis brings the service user to the attention of crisis services for example through the relapse of an existing mental health condition. This results in a substantial impact on the life of the service user and their social network’.

This makes the numbers of people experiencing crisis hard to ascertain at any given time, other than by collecting numbers of people accessing crisis related services (which we know will not always incorporate everyone) including being admitted to an inpatient setting. However, it would follow that if crisis were an exacerbation of mental health issues, e.g. relapse, then it might follow that the greater the mental health issues within any given population the greater the likelihood of crisis occurring regardless of definition.

The number of mental health issues in the public has been significantly exacerbated by the Covid-19 pandemic. Stress and anxiety from the crisis have increased (Holmes et al, 2020), and social distancing may have increased social isolation (Armitage & Nellums, 2020). Pearce at al (2020) conducted a study that examined pre- and post- UK government’s lockdown orders responses by a nationally representative sample to a mental health screening instrument in 2017–2019. The responses indicated mental health problems prevalence were significantly higher in late April 2020 and more pronounced among females and younger age groups (Pierce et al, 2020).

Anxiety about personal health and worries about the health of family members with existing medical conditions may also be common (Shevlin et al, 2020) and exacerbated by the high death rate reported.

Research suggests this is compounded by the economic downturn and worries over financial insecurity (Fernandes, 2020). This all indicates a significant and increased burden upon population mental health and as such, Holmes et al (2020) state that tracking and understanding the mental health burden of the Covid-19 crisis has been identified as a public health research priority.

For Surrey, data is used across the system as to the number of people who have/are experiencing crisis who access a range of services including to make sure services are responsive and delivering the right support at the right time, to ensure that the system is delivering against the LTP targets and the Mental Health Improvement Plan[3] locally (within which crisis was a significant workstream) and for practical measures such as making sure the number of beds is right.

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[3] Plan under review currently.

Prior to considering literature on admission and discharge, it is worth considering why bed numbers and admission and discharge from these beds is important for the system before considering, most importantly, why this also true for individuals and their families.

Any inpatient bed capacity is geographically located and delivered by the local mental health trust. Any bed capacity needed beyond this fixed capacity usually is commissioned from the independent sector (either within or out of area) at additional cost per day, either directly by mental health commissioners or the task is sometimes delegated to the local mental health trust. Delegated commissioning is the process within Surrey and there are significant bed pressures and spend currently that is subject to system work. The Mental Health Foundation identifies mental illnesses as the second largest strain on healthcare resources in the UK because they are more prevalent and chronic than other illnesses and spend on beds (per bed and overall) is the highest cost.

Developing more beds to meet the needs of the population is often complex and time bound. This is also often financially fixed due to the need for capital to increase capacity and the time taken to build and new inpatient beds. The Capacity Unit completed an analysis 'Exploring Mental Health Inpatient Capacity' in 2019 and found that 'since 1987/88, the number of mental health beds in England have fallen by 73 per cent from around 67,100 to 18,400' and that 'mental health bed occupancy currently exceeds 90 per cent'. They also found that:

- 'Thresholds for admission to a mental health bed have increased; the level of mental ill health of people admitted to hospital in 2018 was higher on average than individuals admitted in 2013'.
- 'Patients discharged in 2018, although deemed clinically fit for discharge, were on average less well than patients leaving hospital in 2013'.

Within this context the use of available bed capacity and overspill into 'paid for' beds outside of the NHS capacity is subject to demand, via admissions and discharge, often described as 'flow'. Flow can be described as 'the ability of healthcare systems to manage patients effectively and with minimal delays as they move through stages of care' and 'efficient patient flow alleviating the burden on staff, thus improving clinical safety and patient outcomes' (NHS Improvement 2017). Tlap et al (2020) noted that poor patient flow negatively affects staff, patients and overall quality, with Aiken (2002) indicating that leads to not meeting patients' individual needs. Knock on effects include overstretched staff leading to medical errors and readmissions (Baker et al 2009) and ultimately dissatisfaction, prolonged patient length of stay (LOS) and worse health outcomes according to Colleen (online).

The literature search for this project regarding admission found research that focused on increasing rates of admission and reasons for this, patient's perspectives were predominantly negative and focused on involuntary admission, admission alternatives and routes and admission for specific cohorts, such as those with complex emotional needs and those from ethnic minorities.

The number of people admitted to a psychiatric hospital on a compulsory basis in England and Wales per head of population increased by over 50% in the decade to 1995 and then rose by 13% from 26,632 to 30,092 during the decade to 2010–2011 (Department of Health, 2011) and rates of detention in psychiatric hospital 'have more than doubled in England since 1983 and risen faster than almost anywhere else in Europe during the past decade' (Sheridan-Rains, 2019).

A 2020 study (Sheridan-Rains, 2020) looking to understand increasing rates of psychiatric hospital detentions in England tested 'seventeen hypotheses related to social, service, legal and data-quality factors' and found the following were supported by evidence:

- Changes in legal approaches to patients without decision-making capacity but not actively objecting to admission.
- Demographic changes
- Increasing psychiatric morbidity
- Reductions in the availability or quality of community mental health services changes in police practice may have contributed to the rise in detentions.

Some research also indicates that as the bed numbers dramatically reduce, bed availability may lead to more detentions citing the following potential reasons:

- Offer of inpatient admission may be delayed until illness becomes more acute.
- Relapse and re-detention may be more likely if patients are discharged prematurely because of bed pressures.
- Patients may not accept voluntary admission if the only available beds are far from home or because levels of disturbance in inpatient wards have increased, as only the most severely unwell, mainly non-consenting patients are admitted (Keown et al, 2011)

Keown et al (2011) went as far as to suggest a causal relationship after finding that the association between bed reductions and detention rates at local level in England was strongest with a 1-year time lag, i.e. increases in detentions follow bed cuts. Some psychiatrists report a perceived need to (unlawfully) detain patients who could have been voluntarily admitted to secure prompt access to a bed. Despite the assertion made by Priebe et al (2010) that involuntary hospital admissions are typically longer and more costly than voluntary admissions with Clibbens et al (2018) noting that long psychiatric hospital stays are unpopular with services users, harmful and costly.

The research into patient perspectives of being admitted is predominantly negative. Frueh et al (2005) describe compulsory psychiatric admissions as 'very stressful events in the lives of patients and their caregivers'. Sheehan et al (2008) found that patients experience detention in hospital as inherently coercive with Priebe et al (2010) finding that 3 months after detention, many patients still disagreed with the decision to detain them and that this experience only limited improvements in health and social circumstances following detention. A prior study also by Preiebe et al (2009) found that patients understood detention as unjustified even 12 months later.

A 2016 study by Wright et al considered user involvement as a key tenant in recent policy and practice in both admission to and discharge from acute inpatient mental health wards as ‘care transitions’. Waring et al (2015) state that care transitions involve a multitude of health and social care professionals working within and across different organisational boundaries, with Gilburt et al (2008) the complexity of these transitions ‘given the potential for high emotion and coercive practice’. Wright et al (2016) argues that given all the evidence, mechanisms for service user involvement appear to be crucial in this process.

Werbeloff et al (2017) conducted a study to consider admission to acute mental health services after contact with crisis resolution and home treatment teams (CRTs) and found that ‘past use of mental health services and a diagnosis of non-affective psychosis, which are markers of severity of mental illness, and older age, which is a marker of chronicity, are all risk factors for future relapse after interactions with CRTs’. Lloyd Evans et al in a 2018 national survey found CRT implementation and local acute care system contexts varied substantially although access to CRTs for working-age adults appears to have improved, compared with a similar survey in 2012, despite no evidence of higher staffing levels.

Given the LTP direction in subsequent years it is hoped that crisis resolution and home treatment teams are more widespread although the Lloyd Evans et al (2018)’s study indicated that the ‘national mandate and policy guidelines (Five Year Forward View) have [had] been insufficient to implement CRTs fully as planned’.

Research highlights specific cohorts at risk of admission including those from ethnic minorities and those with personality disorder diagnosis.

Barnett et al (2019) examined compulsory detention in ethnic minority and migrant groups in the UK and internationally and aimed to expand upon existing systematic reviews and meta-analyses of the rates of detention for ethnic minorities and found that ‘BAME [Black, Asian and Minority Ethnic] and migrant groups are at a greater risk of psychiatric detention than are majority groups, although there is variation across ethnic groups’.

Lewis et al (2019) study looked into ‘mental health presentations to acute psychiatric services: 3-year study of prevalence and readmission risk for personality disorders compared with psychotic, affective, substance or other disorders’ and found:

> Individuals with personality disorder in this study had on average 18.3 bed days in the 3-year study period, equating to approximately 6 days per year. Although they spent fewer days in hospital than those with psychotic disorders

> and affective disorders, they were admitted to hospital more frequently than patients in affective, substance and self-harm groups. Having a personality disorder was also associated with more short-term readmissions, consistent with Shoka et al (2017).

This is unsurprising given the known high involvement of this group with mental health services including having extensive histories of outpatient and inpatient care (Bender et al, 2001), comorbidity of other mental health conditions such as mood, anxiety and substance use disorders are also high (Quirk et al, 2017) as well as higher risk of suicidal behaviours and self-harm (Bolton & Robinson, 2010) resulting in significantly higher risk of mortality for this than the general population (Fok et al, 2012). Some personality disorders evidence crisis-prone, risky and impulsive behaviours which can result in frequent presentations to emergency departments and admission to inpatient hospital units (Borschmann & Moran, 2011).

Readmission is also a researched factor. Donisi et al (2016) found readmission rates are high internationally, ranging from 33% at 3 months post-discharge to 41% at 1 year (Wheeler et al, 2011). Tulloch et al (2016) found the strongest predictor of early readmission is previous psychiatric hospitalisation. Keown et al (2011) state that relapse and re-detention may be more likely if patients are discharged prematurely because of bed pressures. A rapid literature review into early discharge by Clibbens et al (2018) found that early discharge was neither provided to all inpatients nor limited to the Crisis Resolution and Home Treatment (CRHT) service model internationally, that early discharge interventions required collaborative working, discharge planning was not associated with unplanned readmissions and had a small effect on length of stay, although professionals and service users were positive about early discharge and service users asked for peer support. Overall review found that the limitations in the scope, detail, and quality of the evidence about early discharge leave an unclear picture of the components of early discharge as an intervention, its effectiveness, cost-effectiveness, or outcomes.

Discharge appeared to be less well researched with many papers citing this to be the case. Many studies focus upon the experience and safety of discharges including risk following discharge, most prominently risk of suicide (although cited as rare). Tyler et al (2019) noted that ‘transition from acute mental health inpatient to community care is often a vulnerable period in the pathway, where people can experience additional risks to their mental health and psychological wellbeing’. Gillard et al (2022), in their research into peer support suggested patients need particular support at discharge given suicide rates in the first 3 months after discharge are approximately 100 times higher than in the general population (Chung et al, 2017). Meehan et al (2006) studied suicide in mental health inpatients and within 3 months of discharge and found the first 7 days after discharge from hospital were a ‘critical period’ of post-discharge care when people with mental health problems are at increased risk of suicide.

Waring et al (2015) considered the occupational and organisational boundaries to safe hospital discharge and concluded that hospital discharge relies upon the coordination of multiple actors working across occupational and organisational boundaries and that attention to the sociocultural boundaries that influence communication and coordination can help inform interventions that might support enhanced discharge safety. Waring et al focuses upon contemporary thinking in patient safety developed within the fields of social psychology and human factors.

Loch (2014) considered negative outcomes of psychiatric hospitalisation posing the question, ‘is it safe to go home?’ The list of negative outcomes included both rehospitalisation and suicide (as described elsewhere in this review).

Tyler (2019) aimed to identify the evidence base for interventions to support continuity of care and safety in the transition from acute mental health inpatient to community services at the point of discharge from 45 papers conclusion that interventions reviewed are spread across a spectrum ranging from addressing a single problem within a single agency with a single solution, to multiple solutions addressing multi-agency problems and recommending that future research attempts to improve homogeneity in outcome reporting.

Research by Wright et al (2016) noted service users found discharge to be a chaotic, stressful and emotionally charged time and that despite this, strategies to reduce hospital admissions have received a large amount of research attention (including innovations for more collaborative or user-focused approaches) this isn’t the case for hospital discharge.

2 Executive Summary

In Spring 2022, Surrey Coalition of Disabled People (The Coalition) was asked to undertake a research project to better understand:

- What support could help individuals, their families, and carers to safely avoid an admission to hospital for a mental health crisis
- What support could enable people to get well more quickly and for admissions to be shorter
- How discharge arrangements could be improved

The research was carried out under the supervision of a principal researcher and 2 peer researchers with the support and direction of a stakeholder representative steering group.

A participatory approach was taken to the collection and analysis of data through pro-active outreach research methods including interviews and surveys.

The purpose of the research was to find ways that admissions to mental health hospitals could be avoided; stays in hospital could be shorten; and discharge arrangements be improved. A key aim of the research was to identify alternatives to admission, by shaping future service developments and reducing the demand on Emergency Departments by gathering insights of the reasons why people attend an ED.

Aims

This Surrey-based participatory project engaged with local people who have had an admission, their carers, and professionals, to understand their experience of admission to and discharge from UK inpatient mental health services. The factors which contributed to emergency admission and delayed discharge were explored, to identify opportunities for quality improvement across the services.

Objectives

- Engage with local people with lived experience of admission, their carers, and professionals
- Apply qualitative participatory methodology and data collection methods to foreground the voices of people with lived experience of admissions and their carers by drawing upon methods and analysis which include a systems approach, interviews and surveys
- Explore the experiences of people with lived experience of admissions and their carers at and around the time of unplanned admission to and subsequent discharge from a mental health hospital in the UK
- Identify opportunities to improve efficiency and quality of mental health services in Surrey

- Recruit participants who lived in Surrey at the time of their hospital admission and/or discharge

Observations

Summary

The amount of information we gathered in this research far outstretched our expectations. Participants were incredibly candid and generous in sharing their experiences with us.

What stands out is that opportunities to learn about how to improve the experiences of admission and discharge to mental health hospital largely hinge on improving community early/rapid response intervention and providing front line services in and out of hospital, with the resources to enable effective and compassionate communication between people with lived experience, carers and professionals.

What support helps to safely avoid an admission to hospital for a mental health crisis

The type of support which is needed for individuals, their families, and carers to safely avoid admission to hospital depends upon their history of mental ill health.

The research heard from people who had a history of accessing mental health services. They were able to talk about what would support them to avoid re-admission to hospital. They were also able to reflect upon their early experiences of mental health distress and what might help those who have no history of accessing mental health services. Carers and professionals also provided valuable insight about the type of support which could help avoid admission to hospital for a mental health crisis.

How new mental health conditions can be managed better at home

Managing a new mental health condition at home is something participants reflected upon as difficult. They told us that front line response to initial symptoms is usually through general practice. However, they viewed general practice as a place from which they were referred to mental health services, not as a provider of mental health services. Participants reported that people with lived experience who present to general practice with mental health symptoms are unlikely to recognise what they are experiencing as mental ill health. They viewed appointment time constraints and triage arrangements in general practice as obstacles to effective consultation with their general practice professionals. They also felt that general practice professionals struggled to link people with lived experience to timely and effective mental health services.

Understanding the systems and resources available to front line clinicians was outside of the scope of this research. The experiences of people with lived experience, their families and carers and mental health professionals highlighted the need to further explore the barriers which front line clinicians experience in helping people with lived experience to access effective early intervention. Early intervention was identified as the most effective support in safely avoiding admission to hospital and presentation at the emergency department. Partnership and collaboration between agencies which includes carers and people with lived experience was considered essential to creating a climate in which everyone feels secure about what is happening, what will happen, when things will happen and why and how decisions are and will be made.

How known mental health conditions can be managed better at home

Managing a known mental health condition at home was considered to be the most important and difficult thing for people with lived experience to do.

There were multiple challenges around establishing continuity in care; finding and maintaining support and timely intervention when it was needed; keeping people in touch with each other; and having shared language and expectation around the steps to be taken, roles and responsibilities and the difference between contact and intervention.

People with lived experience and carers told us about the challenges of maintaining a positive life experience whilst being mindful of the emergence of patterns of behaviour, situations, anniversaries etc which might contribute to a deterioration. Having a sustainable plan for when things deteriorate was described as a solution to complicated and vulnerable risks.

What helps people get well more quickly and have shorter stays in hospital

The research very clearly tells us that people with lived experience, carers and professionals believe that timely, consistent and accessible community based intensive intervention, prior to, and, at the time of crisis, is what keeps people most well. When admission is the only option there are 6 factors which contribute to or delay discharge and recovery. Action to mitigate those factors was considered essential in enabling people to get well more quickly and support shorter hospital stays.

1. Rapid and unexpected admission
2. Lack of information about what to expect on admission and contact arrangements
3. Containment and punishment
4. Inaccessible settings and services

5. Isolation, exclusion & paternalism
6. Unresolved trauma associated with the stay

Factors included rapid and unexpected admissions, lack of information about the practicalities of admission and establishment of lines of communication between carers and professionals. Rapid admission was also aligned with feelings of containment and punishment. People who have had an admission reported feeling they did not feel cared for but they did feel confined, and that the physical spaces were often sterile and threatening and they felt they were under surveillance. We were told that individuals felt frightened, unsafe and not in a place where they could be healed. The notion of confinement was pervasive when participants described their experience of stay in hospital. There was a strong sense from all participants that hospital is a place to be held, while pharmacology is established, but not a place where healing happens.

People who had experience of an admission told us about how inpatient settings were not inclusive, in that physical health needs and, in particular, the needs of autistic people and people with learning disabilities, were often not met. The experience of being an inpatient in an environment which is hostile to the sensitivity of those people who are neurodiverse was more harmful than therapeutic.

Above all, we were told that the lack of partnership between professionals and people with lived experience and their carers made them feel isolated and excluded from important decisions about their health and care. The systems felt paternalistic and contributed to distress and trauma for both the individuals and their carers. We heard that practices around restraint sometimes felt indiscriminate and unnecessary, and that after a hospital stay participants felt they needed some form of debrief and trauma therapy. Participants acknowledged that in the current system, with inaccessible and scarce community-based services there were no obvious alternatives to their own admission to hospital. However, they were able to identify system changes which could improve their recovery and reduce their admission.

How discharge arrangements could be improved

The feedback we received about discharge was mostly focussed upon the often unexpected timing.   People who have had an admission reported feeling abandoned and unprepared for discharge. Carers were alarmed at the general lack of preparation and communication about upcoming discharge. They described a lack of coordination between agencies which would ensure continuity of care, handover between hospital and community services and planning for suitable accommodation. Concerns were raised about being discharged without medication and information about how to get medication. Perhaps the most disturbing findings were around individuals being told they were discharged without any warning and after a stay in an environment where they had become institutionalised, they, without warning or support, were expected to find their own way home. In some cases that meant traveling across counties, on public transport to sometimes empty homes, with empty fridges and sometimes fridges with rotten food and rancid bins.

Summary

This research looked at the experiences of people who had experienced admission, their families and carers and professionals of mental health from community life through the process of an admission to hospital and discharge back to community. The touch points in the process were around accessing timely and effective intervention. However, it was this idea of intervention that was missing. The dominant discourse throughout the research was of support. This was in the absence of therapy or intervention. It is clear from the stories we were told that people perceive there to be a lack of organised, reliable, and accessible early intervention from qualified mental health clinicians.

We heard that participants feel the current volume of crisis has outstretched resources. Crisis is being normalised to the point that when people present in a state of need there is rarely any therapeutic option available to them. Frontline mental health services are often staffed by non-clinicians and individuals feel frightened because they are not getting the clinical intervention they feel they need. They are often left feeling abandoned and that clinicians are often out of their reach or invisible in the system.

3 About the research

Aims

This Surrey-based participatory project will engage with local people with lived experience of admission to a mental health hospital, carers, and professionals, to understand their experience of admission to and discharge from UK inpatient mental health services. The factors which contribute to emergency admission and delayed discharge will be explored, to identify opportunities for quality improvement across the services.

Objectives

- Engage with local people with lived experience of admission to a mental health hospital, carers, and professionals.
- Apply qualitative participatory methodology and data collection methods to foreground the voices of people with lived experience of admission to a mental health hospital and their carers by drawing upon methods and analysis which include a systems approach, interviews, and surveys.
- Explore the experiences of people with lived experience of admission to a mental health hospital and carers at and around the time of unplanned admission to and subsequent discharge from a mental health hospital in the UK.
- Identify opportunities to improve efficiency and quality of mental health services in Surrey.
- Recruit participants who lived in Surrey at the time of their hospital admission and/or discharge.

Who we wanted to talk to

Inclusion criteria:

- Experience of admission and discharge to a mental health hospital in the UK since 2017.
- Cared for someone admitted to hospital for a mental health crisis since 2017.
- Over 18 years old at the time of admission.
- Live(d) in Surrey at the time of admission.

Exclusion criteria:

- Admitted to hospital for a mental health crisis before 2017.
- Cared for someone who was admitted to hospital for a mental health crisis before 2017.
- Under 18 years old at the time of admission.
- Live(d) outside of Surrey at the time of admission.

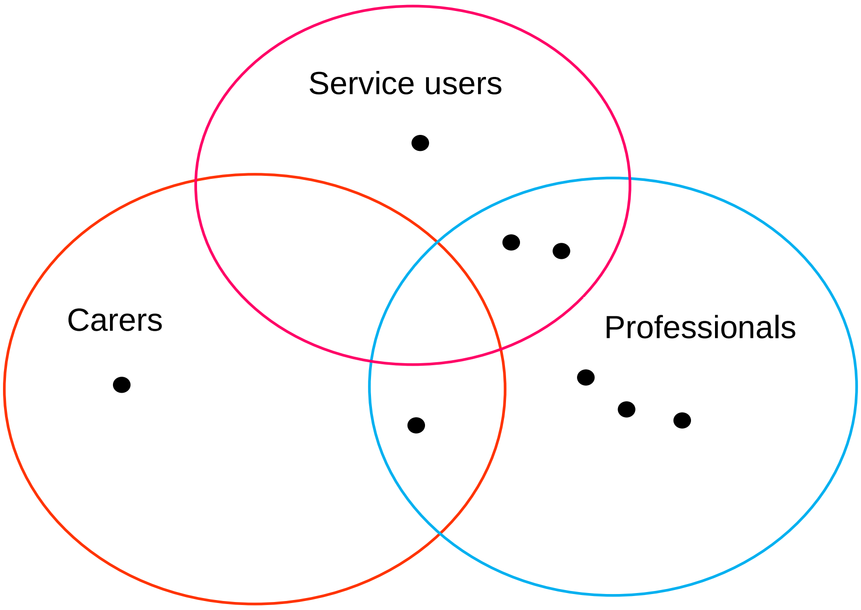
- Admitted through Prison Mental Health Services.

What we did

This project was designed and conducted around the principles of the social model of disability and participatory research. **The social model of disability** views society and attitudes towards people who have impairments as disabling. Under the Equality Act (2010), many mental health conditions are considered to be ‘a disability’. This means people who have mental health conditions are disabled people. **Participatory research** places an emphasis upon building equity in the relationships and power dynamics between researchers and participants. The recruitment of peer researchers who identify as people who have lived experience of accessing mental health services, provided the project with authentic insight into the perspectives of the participants and their carers. A steering group was established early in the project to foster co-production. This was achieved by inviting representation from stakeholders.

The steering group

The steering group included people with lived experience of admission to a mental health hospital, carers, and professionals, both paid and voluntary, from across health and social care, policing, the third sector and commissioning.



How we included disabled people

We used different methods to include disabled people, their carers and the professionals who work with them, in the research. One of the methods was to ask people who we know and work with to tell other people and connect us to those people who met our research inclusion criteria. This is called a snowballing approach and it was our main way of contacting relevant statutory and third sector organisations across Surrey. By doing this we were able to reach people with lived experience of admission to a mental health hospital, cares, and professionals. In some cases, there was overlap in the contributions of individual people. For example, some professionals also had personal experience of admission to a mental health hospital. This enriched the data because the participants naturally engaged in the process of analysis. This was encouraged as a feature of co-production.

We also made posters to get the attention of participants. The research steering group helped us to design and to distribute the posters.

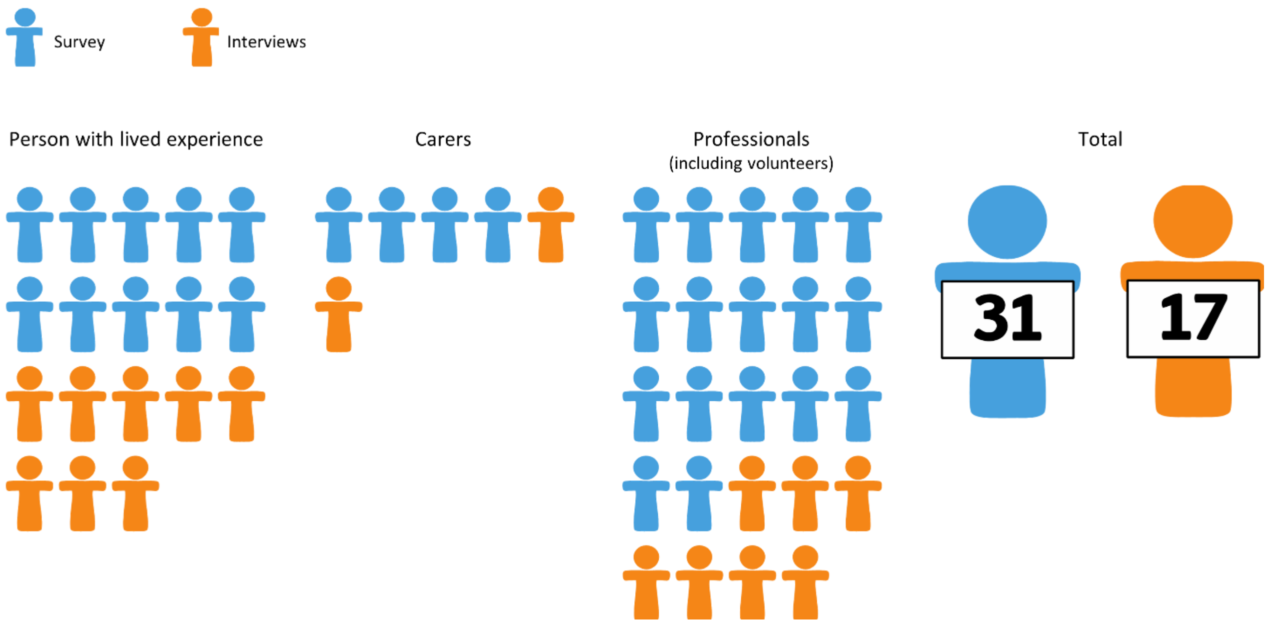
We produced a series of short video updates which were displayed on YouTube and promoted through social media such as Instagram, Twitter and Facebook. We also held 2 ‘drop in’ events at a psychiatric hospital and at a supported accommodation facility in Surrey.

We worked with the research steering group to co-produce 2 surveys for people with lived experience of admission to a mental health hospital and their carers (see appendix 1) and mental health professionals and volunteers (see appendix 2). The surveys were managed online from Thursday 4 August to Sunday 4 September 2022. There was a total of 31 responses (17 professionals,10 people with lived experience of admission to a mental health hospital and 4 carers), some of which led to in depth interviews.

Collecting the data

Our main method to collect data (stories and experiences) was by interviewing individual people. The interviews were conducted over a period of 3 weeks (Tuesday 30 August to Monday 20 September 2022) online, in-person and by phone. We interviewed 17 people. Of them, 6 were people with lived experience of admission to a mental health hospital, 9 were professionals, and 2 were carers. 2 participants’ roles overlapped; they completed surveys as professionals and had personal lived experience of admission. The interviews varied in duration and were audio and video recorded so they could be transcribed to ensure accuracy of the data.

The research participants



4 What we found out

This section of the report is arranged in two sections, which focus on admission to and discharge from mental health hospitals. The findings are arranged around research participants' statements. The volume of data was significant because the participants were incredibly generous with their time and stories. We could not include everything that was said, but we have selected quotes which represented the experiences which were disclosed to us. In this section, we added some explanations to help pull the themes and the experiences together.

4.1 Admission to mental health hospitals

The experiences of emergency and planned admissions to mental health hospitals were closely linked to experiences of community-based mental health care. When, people with lived experience of admission to a mental health hospital, carers, and professionals told us about their experiences of admission to hospital, they connected their experiences between community mental health services, general practice and their hospital admission. Their stories reflected three distinct themes around:

1) Relationships
2) Respect and partnership
3) Accessibility

Relationships

We explored the importance of and experiences of relationships between people with lived experience of admission, their families and carers, and professionals.

Relationships was a prominent theme when participants described their experiences and observations of hospital admission and community-based services. It describes the interactions between professionals, people with lived experience of admission, and carers. It also describes the interactions and communication across professional teams, and the imperative of designing and delivering services and care within a multidisciplinary team. The headline findings regarding relationships are:

Headline findings

- Communication
- Getting the right help at the right time
- Holistic approach
- Boundaries and Professionalism
- Too ill to know

What people told us about communication

> “This is really the fundamental thing, it's [the] connection … between community agencies, carers, family, loved ones, friends. People who know the individual, people who've worked with the individual in a different context than perhaps a clinical context and the clinical sphere so that when they are taken in as an inpatient, there's some kind of information flow both ways so that people know what's going on who needs to know.” (professional).

Participants told us about inconsistent communication from professionals to people with lived experience of admission to a mental health hospital. What became clear was that successful communication was often a result of an individual professional, not the system. One person with lived experience of admission to a mental health hospital told us about her General Practitioner (G), who…

> **“…**rang each day … until I saw somebody.”

The stories we heard were about recognition, from all participants, that the landscape is fragmented. That staff are often trying their individual best, but that the complexity of mental health provision, in a space which is organised around a system which puts acute medical services at the front line, makes it increasingly difficult for people with lived experience and professionals to communicate. Where participants did not use the word multidisciplinary when they told us about the problems around communication, it was implied, as they often referred to the need for professionals, from across all the agencies, to communicate with each other and include individuals and their carers and families. The professionals who contributed to the research also observed the benefits of effective multidisciplinary working.

> “We’ve seen really good outcomes when hospitals have called for multidisciplinary teams to kind of gather around because they're getting a really full picture, holistic picture and I think they're able to then make very patient oriented care.” (professional).

Patient-orientated care is something participants repeatedly raised concerns about when discussing how admission was often a surprise to them, indicating that their experience of community services was not working. This person with lived experience of admission to a mental health hospital said,

> “I just couldn't understand why I was being admitted to an inpatient unit because it didn't make sense because I felt that things were going quite well and that I was managing quite well as an outpatient.”

We were told that the lack of effective communication around any deterioration, which led to an unexpected admission, was a form of trauma for people with lived experience of admission to a mental health hospital and their carers, and often placed strain on other relationships for them. For example, disappearing from work or university courses made it difficult for them to pick up their lives when they were later discharged.

> “I was trying to communicate with my supervisors and it was quite embarrassing … I didn't really understand what was going on… saying to them, I think I'm going to be off sick for six weeks.” (person with lived experience of admission).

People with lived experience of admission focussed upon the need for better communication about their mental health as they tried to stay well at home with the support of their own GP or community mental health teams and they also focussed upon communication when a decision had been made about admission to hospital. There was recognition that no one could tell them how long they would be in hospital, and more information about what they should and should not take with them was often discussed.

> “I asked what do I bring? And they … did not really know. They were like, oh well, bring clothes and pyjamas and, you know, probably some slippers and a toothbrush, but I wasn't told. Like you shouldn't bring XYZ …You know I wasn't told [what] I should expect from an inpatient admission” (person with lived experience of admission)

People with lived experience of admission and carers compared the communication about what to expect to that of acute hospital admission and raised the need for standardised information. Carers were particularly concerned that there is no standardisation across the services to provide information to them when their loved ones are admitted to hospital. They told us that this can cause them anxiety and makes it difficult for them to provide good support to the individual. This carer was very clear about what is needed,

> “So they need to, you know, on admission for anybody. They need to actually have … something that they provide to carers about your rights … that gives you a contact detail for somebody who leads for carers at the mental health trust? So, if you're not getting answers, you've got somewhere to go to”

Carers talked about being frightened and feeling a complete loss of control, as if their loved ones had been removed from them and the mixture of emotion this brought, because, in some cases, they felt they could not provide safety, but they could not be sure that the mental health services were actually keeping their loved ones safe. This raised interesting questions for the research team around what constitutes safety when considered in the physiological and psychological sense. Ultimately, when carers and people with lived experience felt informed and included in communication and decision making, they were much more comfortable.

Getting the right help at the right time

> “Paramedics took me to A&E. The junior doctor sent me home by not realising paracetamol levels continue to rise. I saw my care co-ordinator the next day and was sent back to A&E. A doctor took my bloods. The results were so sky high that they put me on the liver transplant list. After then being on a ward for a while I was transferred to hospital on a Section 3.” (person with lived experience of admission)

Getting the right help at the right time is as much about individuals and their carers and families knowing where to go to get the right help and the availability of specialist services and skilled staff. One person with lived experience of admission talked about how although their GP is not a mental health specialist, they knew her well and that was valuable.

A common theme across people with lived experience of admission and carers was to ensure there is someone who can recognise a deterioration and escalate to appropriate services.

> “And I guess that's part of the role of community teams, primary care, GPs, everyone really to get a better understanding of that person and to make them more accountable … taking responsibility for their own recovery and their own care, understanding what works, what doesn't work for them” (professional)

However, this was not always seen to be happening. For some people with lived experience there was a lack of consistency in who provided the care;

> “Nobody ever really gets to really know her. And she never really gets to know them. And you're always explaining things all over again, somebody new. And it's absolutely exhausting.” (carer).

Carers and people with lived experience of admission talked about having to repeatedly pass information to different people and how it negatively affects them. They also highlighted how this increases the risk of important information being missed out, while also delaying appropriate treatment. Similarly, understanding patterns in behaviour can ensure that the appropriate level of treatment is provided.

> “We did that [reducing unnecessary ambulance call outs] by identifying … people who regularly … [have] call outs and trying to meet their needs better in the community.” (professional).

Knowing what the appropriate level of treatment is can be difficult, especially if the healthcare professional does not have all the relevant information about the person with lived experience.

> “They [professionals] hold the power. And I … think that's really hard … they know the system and, uhm, they're there as professionals, as experts, you know, it's like they've got the degrees, whatever it is, and we're in a mindset that you know, when you go to the doctor, when you go through GP or whatever, you know, you go to them because you trust them to know what's best for you, and you explain your situation.” (professional).

Getting the correct diagnosis and treatment plan in place early was recognised across the participants as a feature in reducing excess trauma on the individuals. However, there was apprehension around the reality of having regular reviews.

> “When people are misdiagnosed but the professional who's responsible for that diagnosis, or the team, won't acknowledge that they won't review it … that whole persons treatment plan is totally skewed in the wrong direction.” (professional).

It was suggested that some people with lived experience needed more care than they could be currently given in the community, and they often found it difficult to access the help they needed.

> “Sometimes [it] feels like people are very busy guarding their front doors and the reality is, some people need an admission.” (professional).

In such cases it was stated that

> “People also end up in A&E if they feel that the support they receive from the community mental health team is inadequate or if they feel misjudged or uncared for by the practitioner.” (professional).

The continuation of care, post-admission, was also highlighted as a concern,

> “Lack of the right support for people, crisis support not being replaced by long term support, problems not being addressed in hospital during stay, ineffective or no follow up plans, partner agencies not working together, long waiting lists

> for support, limits on types of support available, no safety plan or support networks in place, stigma and failures in mental health care." (professional).

One professional suggested that such admissions and escalations could be avoided with,

> "More support and care in the community, more person-centred approaches. more support in primary care settings so people are diagnosed/treated before they get more unwell." (professional).

The overall impression was that timely intervention whilst living at home in the community is a key factor in reducing crisis and unexpected admission to mental health hospitals.

Holistic approach

The holistic approach involves providing support for the whole person, not just their mental health needs. Often it can be that the individual has problems elsewhere, be they emotional, mental, spiritual, environmental, occupational, social or physical and these need to be considered as part of a holistic solution.

> "All the problems filtered down eventually into health, environmental problems, transport problems, logistics, housing. Uh, uh, ecology, economy, everything filters down and the ill-est people end up in residential care of some sort or another. They're admitted because they can't take it anymore." (professional).

In order to be able to successfully rehabilitate people with lived experience it was suggested by a professional that a multi-disciplinary team could work together to address these issues,

> "We've seen really good outcomes when hospitals have called for multidisciplinary teams to kind of gather around because they're getting a really full picture, holistic picture and I think they're able to then make very patient oriented care."

Outside of the hospital setting, one of the groups the professionals were keen to work together with to address some of the issues was the police service.

> "A more joined up approach. So, at the moment it's very siloed so the police officers will do their element of the mental health facts and detain and they'll pass over to the, if we had a more holistic joined up approach, I think we would reduce admissions."

One of the suggestions made was that the police are given further training on mental health issues, however it was noted that the impact of COVID cannot be underestimated regarding the affect it has had on all services, not just healthcare, and also on people's mental health.

> "But certainly, some of the stuff that we do, is to try and give them (police) a better understanding about that person's trauma history because a lot of their

> responses to these people can actually escalate their behaviour. You know, putting them in handcuffs. ‘Why have you put that person in handcuffs?’ ‘Well, they were trying to run away.’ ‘Did you ask them not to run away? Did you ask them to actually sit down? Let's have a sit down and have a chat.’ I think people can over respond because they panic that this situation needs containing and actually a lot of time. Just talk to the person, you know, and we're all the same. We've all got issues, we all got problems and that we're not all that dissimilar and I think we need to just take a step back sometime.” (professional).

> “Better education for officers and for, I guess for other colleagues and in different services so we can understand what we're being presented with I think one of the - and to go back to the covid point, one of the things I will say is that none of the services were prepared for the increase in demand. So, none of us prepared with more resources, none of us prepared with better services or more joined up services. And actually, when we saw the increase, there was a lack of ability to deal with it.” (professional)

Again, the holistic approach would ensure the impact of implications of COVID on people’s mental wellbeing, social, physical and emotional health was considered.

> “I don't think that the numbers of admissions, the number of police contacts regarding mental health have increased since the since the start of the pandemic. Uhm, all of our data is suggesting that, so whether that be the impact of social isolation, the impact on, the unfortunate consequences the COVID the pandemic has had on families, uhm, I don't know. I can't answer that one, but I certainly, we certainly feel, and it's my conversations with other services, we certainly feel that it is linked to the to the pandemic in some way.” (professional).

People with lived experience themselves often reported a number of wider issues “coming together” to trigger their mental health crises.

> “I had, yeah, several things coming together, several life events coming together, and it was too much, and it triggered relapse. Yeah. So, yeah, life stressors, as you say. I had a bad holiday. My son was starting secondary school. I started a different job. I was changing medication. Yeah, it was a whole muddle.”

One respondent shared how it can become a vicious cycle, with things “spiralling” and the interaction of a number of factors resulting in a crisis.

> “Went downhill quite rapidly each time. Started going to the Safe Haven every night in lead up. Started making bad decisions, things at home spiralled out of control so it was more and more miserable to be at home (unpaid bills, mess everywhere, no clean clothes, no food in, mice)”

A number of survey responses reported similar issues, and highlighted issues around poverty and feeling adrift from society and the community.

> "Feeling adrift, using unhelpful coping strategies, isolation, lack of finances"

> "Poverty, loneliness and fragmented care are the main drivers"

It was suggested that outside of the hospital and healthcare system, the wider community might have a meaningful role in supporting individuals.

> "It would be incredible if …local businesses and community took investment in their community and invested in really good community spaces." (professional).

Being part of the wider community was discussed with a distinct sense that greater awareness about mental health is a positive thing, especially in terms of reducing stigma. Making mental health awareness part of ordinary life was a desire of people across the whole participant group.

Boundaries and Professionalism

> "In the end I spent most of my time in my room; drawing and writing. But then the staff read my writings and were laughing about it in the office reading what I wrote. I said to them, 'that wasn't funny what I wrote' and he said, 'oh but there was one bit which was funny you wrote about staff.' And I was like, thinking 'it wasn't funny to me." "I showed them some of it, not all of it. I was just trying to get across how I was feeling to them because they don't talk to you. And I thought this one member of staff would be all right to share it with, but I was wrong. I didn't share anything again with them." (person with lived experience of admission).

Boundaries and professionalism are about the skills of professionals, and goal setting with people with lived experience. People with lived experience of admission have spoken about times when professionals laughed at things they shared with them or asked them personal questions in public settings. It is about trust between people with lived experience and professionals. People with lived experience of admission and carers recognise it can be difficult for professionals to maintain distance while providing care in an encouraging and positive way. People with lived experience of admission also acknowledged that professionals have mental health needs too and that high workload demands and responsibilities outside of their skill set can make the professional and the people with lived experience vulnerable.

> "I had one woman. She was, essentially just used me a little bit as like, I don't know, it felt like her therapy a little bit." (person with lived experience of admission).

We heard that individuals often felt they should be grateful for whatever support they got. This was in stark contrast with professionals who were careful to ensure individuals had realistic expectations about what service could be available to them.

> “And setting I think setting clear boundaries. OK, you need to say, ‘I can give you this amount of time, but then I need to go and do so and so. I can come back at this point.’ So it's setting clear boundaries and clear goals.” (professional).

Stories which described experiences of where boundaries were crossed were usually around individuals feeling that service providers had been intrusive, not accepting being told that they were not in the right physical or emotional space to engage in conversation which was driven by a professional. This went further in one story where we were told about how a participant, who was a registered nurse professionally, had an emergency admission, when experiencing mental health distress, and…

> “…the paramedic reported me to the Nursing Midwifery Council to say that I wasn’t fit to practise.” (person with lived experience of admission).

We were told how the case against the individual was dropped but that the incident caused them significant distress at a time when they were already unwell. This example talks to the idea that mental ill health can affect anyone, including health and social care professionals.

Too ill to know

> “My state wasn't threatening, it was just that I needed to be admitted. Yeah, I was beyond the point of knowing that.” (person with lived experience of admission)

Being too ill to know that you need mental health intervention can be a barrier to accessing much needed help. We were told that the lack of general awareness about how to get mental health help makes it more difficult. That for people who have not previously experienced mental health distress it is not necessarily obvious that they are in mental health crisis or where to go to get help. , and professionals talked about there being a lack of understanding about what different services do.

> “Our daughter - like many with her illness - does not know when she is ill which results in her not taking medication.” (carer).

We learned that mental ill health can inhibit people from engaging with services. People with lived experience of admission, carers and professionals felt that there is an assumed responsibility on people to seek help and be willing to engage with services even at a time when their mental health symptoms are preventing them from doing so.

> “And there's that trade-off in terms of responsibility. But you can't ask somebody with broken legs to run a race. They can't look after themselves properly if they're terribly mentally ill and yet that seems to be the system that we're being encouraged to take responsibility for our health and well-being.

> Hence, people smoke a lot, drink a lot, eat lot uh, distract themselves." (professional)

> "So, you've got comorbidity and early mortality just because we can't take responsibility for ourselves if we're not well enough. It took me several years to realise I'd become seriously ill. And all the time I was getting bounced [from service to service]. So, - and I'd seen that happen - but when it happens to oneself, that awareness is lost because we're in the jumble of complex trauma and the stress disorders, anxiety and depression that go along with it." (person with lived experience of admission)

This story about complex trauma is something which was connected to diagnosis and how diagnosis can be the ticket to specialist help. It also linked to the layers of what one participant referred to as gatekeepers who acted as a barrier to mental health doctors (psychiatrists) and clinical psychologists.

> "I had somebody who, she had personality disorder diagnosis. I didn't think she had personality disorder, but obviously I'm not qualified to review anyone's diagnosis. It didn't seem like a good fit and she was in crisis regularly and she was having episodes of dissociation and kind of almost like psychotic episodes when she was really in extremely in crisis. And professionals would just be going, 'oh you know, that's all personality, it is all personality' and just telling her to follow her safety plan and to ring the crisis line and she was not capable of doing that and she was not in touch with reality at times. You know, she was seeing people that other people couldn't see, she was having hallucinations and tactile hallucinations and she was in so much distress and you can't just tell somebody in that state, 'just follow your safety plan'. I mean, like that ain't gonna work." (professional).

This story of being too unwell to recognise that illness exemplifies the concerns of participants that mental ill health is often viewed as something an individual has control and options over. Furthermore, this professional talked about how…

> "… if people were ready to take what's there and what's offered to them it would reduce admissions because they would be in a better place. Uhm, but a lot of people don't want to. They choose other things: drugs, alcohol, and then that adds a whole another layer to the presentation and their distress." (professional).

When things deteriorate to a point where carers raise concerns and got help which then led to an admission to a mental health hospital for their loved ones, there was usually a story like this one of trauma,

> "I think actually … it ended up with the community mental health team attending with the police and the police removing her son from the house and doing sort of a court protection order to temporarily remove him and then that

> was obviously very distressing for her and her husband and then because she wouldn't let [the] community mental health team in the house.” (carer).

There was a general sense that the stigma which surrounds mental health has led to a system which separates mental health medicine from front line health services and makes mental ill health difficult to recognise for individuals, carers and many professionals.

Respect and partnership

Respect through partnership was a prominent theme when participants described their experiences and observations of admission and community services. This theme describes respect between professionals, people with lived experience, and carers. It also describes involvement of people with lived experience and carers, and power dynamics between professionals, people with lived experience, and carers.

Headline findings:

- Listening to the person with lived experience
- Humanising the person with lived experience
- Being done to

Listening to people with lived experience

> “Sometimes the doctors listen to you so you feel a bit better. I had a doctor at [her local hospital] so I went there for a lot of times over the years and had a doctor, there who just didn't listen at all, so it was just going round in circles really.” (person with lived experience of admission).

> “There are so many young people who just need someone to listen to them and to care.” (professional).

Listening to people with lived experience was a theme which emerged through conversations with people with lived experience of admission, carers and professionals. Participants talked about not feeling listened to and professionals talked about the need to demonstrate value in the voice of the person with lived experience.

> “I tried to access support as I knew I was struggling but my GP was not really listening.” (person with lived experience of admission).

This example suggests there may be more to this issue around being listened to and that could be related to the parity of esteem between mental ill health and physical ill health. Front line health care is primarily accessed through general practice and participants talked about excellent interactions with their primary care practitioner but many, like this participant, were concerned that their mental health was not a priority for their GP. This idea of not being listened to or being heard was articulated well by a professional who was concerned that issues are being minimised against a backdrop of complexity and sinking services.

> “It's almost like they're just trying to provide a tick box quick solution like, ‘do this, you'll be fine’ and the young people are like uh no my situation in my life is more complex than a quick fix and ‘you have not listened to me.’” (professional).

Although these experiences were expressed in the context of being listened to, they were underpinned by awareness that individual professionals are constrained by the resources available to them.

> “When people kind of, you know – they’re given all the standard advice and that's not working and you kind of sit there and you can feel the desperation, you know, from them, and you know from their mum or dad or their partner or whoever is there who is genuinely scared that the person they love is going to die and they are just given what feel like kind of quite cliched lines about how to keep themself safe and told, ‘you'll be fine’, you know. And it's just like, ‘no this doesn't feel OK. They're clearly not OK’, but they're just sent on their way.” (professional).

Professionals appear to be just as frustrated as people with lived experience about their lack of power to help in community settings. We heard stories which suggest that distress is largely normalised.

> “I still can't leave the house, but nobody seems to find that important, even though it is out of character.” (person with lived experience of admission)

This lack of intervention was cited as being instrumental to some people seeking inpatient services in the hope that they would offer a solution to their desire for therapeutic intervention.

> “I don't find them [the home treatment team] particularly helpful. They're a distraction for half an hour, but, and they don't really do anything. You know, I've told them ‘I'm in crisis’ sometimes, and they have just left me and then I've ended up being picked up by the police that night or something drastic has happened which they were told about.” (person with lived experience of admission).

> “They [supported living] didn’t support me anyway. They just weren’t kind and when I asked for support, they didn’t give me support.” (person with lived experience of admission).

This notion of support is something which might be helpful to explore across people with lived experience and provider perspectives. It was clear in the research that people with lived experience of admission were looking for something tangible but rarely felt they found it in either community or inpatient settings.

Humanising the person with lived experience

> “For my role, working with … I think it's about showing that person that you're validating what they're going through and you're understanding, you're taking a very non-judgmental approach.” (professional).

Humanising the person with lived experience is about their comfort during the admission process. People with lived experience of admission and professionals talked about not feeling listened to by professionals and being treated like a problem. People with lived experience of admission and professionals also talked about the opportunity for a shift toward trauma informed care.

> “When I wasn't under the home treatment team, [I was seeing someone from an advocacy charity] she's been amazing. She's been so lovely. We just went and had coffee and chatted for an hour and they're just like one of the first people that have treated me that I wasn't just a problem. Like I was an actual person.” (person with lived experience of admission).

Although many of the stories we were told were about when things did not go well, we were also told about what did go well and what would improve services and experiences for people with lived experience, carers and professionals. Some of the ideas around improvement were linked to diagnosis and formulation of care. The need to have resources to recognise trauma and develop services which are trauma informed was a message from across the participant groups.

> “If there could be a whole shift in culture around becoming truly, truly trauma informed I just really think that services would be so much more compassionate and person-centred, that people would feel cared for. They would feel listened to and they would be involved and empowered to kind of, like help make those decisions about their care or what it is that they need. So, maybe they would not so much get to that point of like, ‘I'm desperate, nobody’s listening to me, nothing is working for me.’” (professional).

The foundations of accurate diagnosis to inform formulation was also linked to beliefs that diagnosis is resource led. Similarly, there was a narrative which suggested that some diagnostic labels are seen as a sentence and that they cannot be challenged.

> “There's a lot of stigma around personality disorders in services and if somebody disagrees with their diagnosis of a personality disorder it’s almost seen by professionals as being proof that they have a personality disorder.” (professional).

This notion of being able to challenge professionals was extended to topics around services users being seen as challenging. This was often linked to stories about interactions with ambulance crews and police officers. This was not only about the perspective of police officers but of the impression that engagement with police must mean an individual is in some way deviant.

> “It [Section 136] takes place in a public place … it’s the only place that 136 can be used, then the person is essentially, can look like they're criminalised because they're being detained by police officers.” (professional).

> “I think my aim would be for the person to spend the least amount of time with police officers as possible. For their own access to care. And for their own dignity. Uh, and I would add, you know, I would want an ambulance response to be short and so they can get there quickly and I'd want a mental health assessment always to be available so we could hand that over as quickly as possible.” (professional).

We heard many accounts of positive interactions with the police especially when they had been involved in the process of transfer to a mental health hospital or a 136 suite.

> “They [the police] listen to you. They're compassionate. They are good at listening. They get things moving. You know they make decisions quickly and contact the right people, they know what to do. And they never make you feel like you you've put them to any kind of trouble wandering off in the middle of the night, you know, they just deal with it in a professional way and it makes you feel much better about things, really.” (person with lived experience of admission).

These descriptions of the police providing support were largely positive, but not always, and there is a suggestion in the stories that there may be some inconsistency. This extends beyond the police, who were often linked to experiences of being admitted to hospital under a section of the Mental Health Act, to the transfer arrangements when being admitted to out of county hospitals.

> “Uhm, when they took me to [another county] It was, uh, it was like a converted car. So, the seats at least were comfortable. But quite often it's like a van. Uh, with like cold metal framework with hard seats. They don't even always have water on board. And then there's usually about four or five staff with you, so it feels quite threatening sometimes.” (person with lived experience of admission).

People with lived experience of admission in particular reported mixed experiences of feeling cared for and feeling as though they were bad, and to be feared.

Being done to

> “I had a friend round when they turned up, my daughter let them in. She said, ‘Oh, [your care coordinator]’s here’ and then about three other people followed behind her. So they just turned up. They don't pre-warn you.” (person with lived experience of admission)

Being done to is about people with lived experience and carers being unaware of what was going to happen during their admission and with regard to community support teams. People with lived experience of admission spoke about being left alone for periods of time during admission and not being told what was going on.

Professionals talked about opportunities for input of the person with lived experience in their care.

> "Giving that person control and giving them some sort of input into what happens to them. Instead of just saying 'you're going to hospital, this is going to happen to you', 'What do you want to happen to you?' " (professional).

The power inequality between professionals and people with lived experience was an impassioned subject. The examples were many, and covered feelings of intrusion and inconvenience. For example, professionals assuming the person with lived experience would be available to see them without an appointment.

> "I've just been offered a support worker as a new scheme, but I don't know what it's called. And I don't know why it's been set up, where it's been set up and what the criteria for referral are 'cause I've been referred to them and I wasn't told that [I] was being referred to them. They just turned up out of the blue on the phone to offer me an appointment, which I took." (person with lived experience of admission).

More extreme examples were around absolutely no indication that an admission to hospital was immediate.

> "You just have to go there and so you just grab a few clothes and go, you know? They don't give you any time." (person with lived experience of admission).

Feeling disempowered rather than cared for was something which people with lived experience of admission identified with as contributing to distress at a time when they were often already experiencing high levels of distress.

> "They [professionals] hold the power. And I think that's really hard because they hold the power because they know the system and, uhm, they're there as professionals, as experts, you know, it's like they've got the degrees, whatever it is, and we're in a mindset that you know, when you go to the doctor, when you go through GP or whatever, you know you go to them because you trust them to know what's best for you, and you explain your situation and you hope and you trust them to know what's best, and do what's best and help you." (professional).

Power imbalance is about decisions being made by professionals. People with lived experience of admission spoke about professionals making decisions about their admission, which people with lived experience disagreed with or were uncertain about.

> "They decided that the admission was necessary and that I would be sectioned. You know, even though I did say I'd go in voluntary." (person with lived experience of admission).

People with lived experience of admission also spoke about feeling that professionals have more knowledge on the subject than themselves.

> “So, although I don't understand and I'm really scared and I really don't want it, you know, it might be that they're right. And this might be a good idea in some way, but I still couldn't get my head round [it]. But how has this happened and why is this a good idea now?” (person with lived experience of admission).

> “I think just knowing a little bit more about why stuff happens is quite important, because it's kind of like, well, someone made this decision for you. Uhm, and like, you know, from your perspective, they've made it for you because they have more knowledge than you about it.” (person with lived experience of admission).

Although people with lived experience of admission viewed intervention in these contrasting ways, they agreed that being informed and included in decision making was something they wanted and something which helped in their recovery.

Accessibility

Headline findings

- Accessing support
- Eligibility criteria
- Waiting lists
- Accessing medication
- Consistency
- Staffing & Skills

Accessing support

> “I think if there were, if there was more support back out in the community as well, I think that would be a really key part of potentially medical professionals decision because I think if they knew there were services out in the community that were able to jump into gear from the get go, there probably would be less of a concern about discharging, as well a reduction in pressure across the services, but I don't quite know how that's achieved.” (professional).

The inaccessibility of mental health support was a prominent theme when participants described their experiences and observations of admission and community services. It describes obstacles to accessing community services, including logistical and person-specific obstacles, such as distance.

> “[The service] is about 4 or 5 miles from where I live. So, it’s ok because I drive, so I can get there.” (person with lived experience of admission)

> “I haven't accessed the [service]. It's too far away.” (person with lived experience of admission)

Signposting to services appear to depend upon having already been linked into a service with professionals who help identify services and facilities.

> “Most things I kind of found by myself … So most things are kind of found through my own kind of looking at things.” (person with lived experience of admission)

The professionals focussed more on the availability of inpatient beds in county.

> “There's not enough beds for mental health. People are getting placed outside the county rather than in county.” (professional).

This linked to concern about the lack of services in general; what was described as a reliance on policing to deal with people in mental health crisis because of a shortage of mental health services.

> "I think they [police] get frustrated with the fact that other services put people at risk, and so they're having to keep people safe, sometimes from the lack of services that are available." (professional).

Beyond hospital there was concern about the lack of suitable housing to be discharged home or housing suitable for community-based care.

> "so, there's limited accommodation for people to access when they're ready for discharge from admission, which then means that they stay in their bed for a lot longer, which then means that there's a blockage in the assessment suite." (professional).

> "Housing was the main issue, and she needed a care home who could meet her needs." (carer).

Accessibility was described in multiple different ways, but location and availability were important factors. Online support was discussed. People with lived experience of admission talked about a lack of privacy when using online services in their homes, and about a preference to speak to people face-to-face.

> "I sometimes virtually call them … and that's ok but it can be difficult for me to talk freely at my home because [of] other people around." (person with lived experience of admission).

> "Because my husband moans at me for wasting petrol – he doesn't understand that it's easier for me to talk when I go there [service] rather than talk when everyone's around." (person with lived experience of admission)

> "I used to have telephone calls. I prefer to be in person." (person with lived experience of admission).

The option of online support was clearly valued but only as an option and not as an alternative to face to face.

Eligibility criteria

> "It can be really great to get have early intervention, is one way of saying it, but like it's really hard for anyone to access that. Like you almost have to be admitted to hospital to be taken seriously." (professional).

People with lived experience of admission, carers and professionals told us about how services are designed around a criterion of eligibility. Professionals and people with lived experience of admission spoke about severity levels having to be high for support to be offered, and how some people fall between criteria.

> "I think our thresholds are so high now for secondary services, they have to be really, really quite high risk" (professional).

Professionals and people with lived experience of admission spoke about being unable to access services due to the severity of their mental ill-health.

> “It was being in crisis that brought me back into the criteria because yeah, you have to be, with depression, obviously you have to be in a severe state to go back under the CMHRS [Community Mental Health Recovery Services]” (person with lived experience of admission)

Professionals and people with lived experience of admission also spoke about a lack of consistency between services regarding their eligibility criteria.

> “I wouldn't meet the threshold for the eating disorder service. But then some of the IAPTs (Improving Access to Psychological Therapies) were saying ‘no, this is not something we could take on’, but then one of the IAPTs said they would. I think it was [local] talking therapies or something. So there's still an aspect of falling in between services for people.” (person with lived experience of admission)

This presents a significant concern and is perhaps a point for commissioners and clinicians to discuss around diagnosis and formulation as a critical mechanism for unlocking services.

Waiting lists

> “They're on waiting lists forever and ever and that, like the services want to help them, but they just can't because there's such a long list.” (professional).

Waiting lists describes people with lived experience being unable to access timely mental health support. People with lived experience of admission spoke about mental health crises escalating while waiting for such support. Professionals spoke about the inter-relationships between waiting times and workloads, and the impact that waiting times have on their ability to meet various needs.

> “If it was more readily available and there weren't really long waiting lists or certain criteria to be able to be seen by mental health services of various kinds before a hospital admission, [that] would be really helpful.” (professional).

People with lived experience of admission spoke about time limits on available support, and the interaction between waiting times and unsuitable mental health support.

> “Sometimes they’re [service] just so – on about distracting yourself and all these skills you can use and stuff, and I know that, but sometimes it’s just cool to able to offload what’s going through my head, and they don’t give you time for that. It seems the service is very pressurised as well because you have to wait. You wait sometimes, 10, 15 minutes – sometimes longer to get through

> to then just be told “well, go and distract yourself.” (person with lived experience of admission).

The involvement of other services was mentioned in regard to time spent waiting for admission to be completed.

> “And I was with the police for about over 24 hours. They kept changing over a lot.” (person with lived experience of admission)

Waiting times have been linked to an escalation in mental health distress for people with lived experience and to an increase in presentations at Accident and Emergency Departments, and admissions to hospital.

> “At the time I was keeping track of it and then it kind of - just rapidly escalated I guess, like everything just was way too much and then I was waiting for responses from CMHRS and loads of different [support services]. Sort of trying to reach out to like everyone at once. But then obviously there was a big waiting list and stuff like that. So, I then kind of didn't get much back. And then, things just started getting a little bit worse and in a really bad place.” (person with lived experience of admission).

Professionals identified workload and talked about professional and volunteer burnout.

> “The pressures on mental health workers and volunteers has been increasing and in the past decade or so this increase has resulted in carrying higher caseloads than are manageable. That has in turn resulted in increased waiting times and a largely unseen burden on support workers in a variety of services.” (professional).

There was a sense that system overload is pushing mental health practice into other professional areas such as policing.

> “[The police] can't access an assessment suite and that person is sitting within a very public environment of A&E, um for let's say 8 hours. They're seeing many people in public with [police] officers detained with them, which can't be right.” (professional).

> “The more time we spend, uh with a person detained, for example, means that those [police] officers who have to stay with the person under [Section]136 cannot [be] deployed. So there is a potential impact on police response to other crime.” (professional).

> “I've just written a report that shows that the amount of hours that police have spent on [Section] 136 detentions in 2021- 22 was almost doubled [than] the previous year.” (professional).

Pressure on emergency departments in general hospitals

> “I've had very different experiences in A&E. Some have been OK. I haven't had to wait for long, been dealt with all right. Given us [a] bed in a separate room, so where it's quiet. Other times - once I waited 16 hours to see anybody at all. Haven't even seen a Triage or anything in 16 hours. I was crawling the walls. I couldn't even sit down and I just kept leaving and they said, they’d get the police and bring me back here, but still nobody saw me to assess me and you just keep going round and round.” (person with lived experience of admission).

> “Depending on how ill I was, the process was quick if sectioned. Although very long in A&E departments.” (person with lived experience of admission).

When explaining what it is like to have a crisis at night-time and weekends participants explained that most of their interactions involved emergency departments and the police. It also usually meant very long and uncomfortable periods of waiting around for decisions and arrangements to be made.

> “I also went there a few times when I needed like patching up and things I'd just be walking by, and I could pop in if I was in a bit of a state and they [service] could like call the paramedics. They [community service] were quite useful because they weren't just like, ‘yeah, go to A&E’ because after a couple of A&E trips I was like, ‘I do not want to go back to A&E’. They were really helpful with that and then I've only been to their young adult [service] once. I think that I wasn't in a good space to go there. So I think it was mostly my fault I guess because sometimes if I'm around other people that are also going through a tough time, I tend to absorb whatever they're kind of going through, and then I just try and do I what I can to fix whatever they're going through so then I end up just offering advice and then I go home and I think about it and get upset. So, I haven't gone back since.” (person with lived experience of admission).

Out of hours crises is about the services that are available outside of regular working hours. People with lived experience of admission and professionals have spoken about the distress that out of hours care can create due to the environment and wait times.

> “I think having access to that kind of, not just in office hours as well, and I know that, you know, [community services] now or [service] and things like that, but there's no substitute for being able to actually be in person with somebody and actually see them or speak to somebody on the phone where you can have like a proper conversation. Uhm, but yeah, I think having somebody that you can actually see is really, yeah, just really helpful.” (professional).

> “There needs to be a parity of service across, uhm, a full day, not just 9am to 5pm or 8am to 4pm. So that will give the police more opportunity to divert the use of [Section] 136. So, access to AMHP [Approved Mental Health

> Professionals] services consistently out of hours, more service provision out of hours." (professional).

Participants shared their frustration at the lack of the right mental health care at the time it is needed. This raised a question about terminology and qualification of front-line mental health staff to deal with people who are in crisis.

> "People whose problems are considered to be of low or medium severity tend to be referred respectively to primary responses in the community or to secondary outpatient services after a long wait, and even longer to be re-assessed and gain access to a suitable level of treatment." (professional).
>
> "You can't get hold of anybody at night. You can ring and there's someone who answers the phone, but they're stuck in the base so no one can visit at night which means after about 6pm, maybe in the evening, you're not going to get a home visit until 10 or 11 the next morning. So, it's just not really good enough. I know it's all you know, lack of resources but still not good enough." (person with lived experience of admission).
>
> "For intensive therapy, waiting lists are long and opportunities are small" (professional & person with lived experience of admission).

There was a desire to unpack the difference between professionals who can listen and those who can provide treatment. Issues of qualification, skills, experience and authority were touched on in regard to providing treatment, recognising an escalating situation and clinical condition, and being able to prescribe and reconcile medication.

Accessing medication

> "The logistics of I've run out of meds [medications], and then the practicalities that people have to go through to try and get that reinstated at short notice can be really stressful. And then also if they've actually run out and therefore, they're feeling the physical effects of not taking the medication that they're meant to be taking and then that's difficult. And then if you've got both at the same time, then that's really, really hard." (professional).

The barriers to accessing medication were usually identified as being system issues around information transfer between different agencies and departments. Carers spoke about the lack of monitoring around medication regimes and getting timely access to prescribers.

> "And the way that their GP might then respond to them as well, sometimes it's great and sometimes it's not so great and sometimes you know it, it might just be something as simple as a difficult interaction with the receptionist at the GP practice where it's come across as being that they've been fobbed off or they've been dismissed and then they feel like, 'well, nobody cares about me and this is really bad. What am I going to do 'cause I can't get meds?'" (professional).

We were told by professionals that they have concerns about how often individuals are blamed for not being engaged in their own care or disengaging with services.

> “Accessing medication can be a real driving factor [of admission] for a couple of reasons. It can lead people to feel stressed out and insecure about their situation if they know their prescription’s ran out and they, for whatever reason, can't get access to get their prescription refilled. It can be stressful trying to deal with their GP, trying to get access to their GP, trying to speak to their GP” (professional).

When individuals are too unwell to take responsibility or be assertive when confronted with inflexible systems, they struggle to maintain medication regimes and risk running out of medication which can lead to a mental health crisis and possible hospital admission.

Consistency

> “Consistency and monitoring is what I think we need” (carer).

Consistent treatment is about the same treatment being offered to individuals across mental health services. It is about connected support and monitoring for individuals. Differences in approaches between professionals is also spoken about.

> “Her psychiatric care has been extremely patchy over the years.” (carer).

> “There's a range of factors where admissions could be prevented, including when people are discharged after inpatient care but don't get the connected support.” (professional).

> “And so lack of trust so it does need you see a constant person already be always there; to be always reassuring and someone she can build trust with and because that's never happened, she's now almost closed down completely. It's very, very difficult to get anybody to accept any help.” (carer).

Needing a constant person is about consistency within mental health care to improve trust, and to enable information flow. People with lived experience of admission , carers, and professionals have spoken about changeability within mental health support. Needing a constant person is about familiarity between people with lived experience and professionals, and connections between mental health services, people with lived experience , and carers.

> “This social worker, was able to make a connections with the hospital when she was in, she, the social worker, attended meetings on our behalf 'cause if we couldn't get there, she was a link and she fed information to the hospital staff about, you know, advise them really on what should be happening” (carer).

> “And people say it's like being in [a] washing machine, you’re tumbled in the blades. You know? I've met people with five different key workers. But the key

> workers don't know each other. They all think that they're the [only] one who's handling the case.” (professional).
>
> “At the moment I've got a care coordinator. He's the third one I've had since lockdown because I have had a bit of an unsatisfactory experience with them, and I've asked to change several times. Uhm, so we're still getting to know each other a bit, really.” (person with lived experience of admission).
>
> “I'm lucky. I've got a good care coordinator who is quite accessible. I can always text her or e-mail her and I normally get a response quite promptly” (person with lived experience of admission).

Participants recognised that staff retention is a challenge across health and social care services and that improving retention and consistency of care across individual professionals is not going to be easily improved.

Staffing and skills

> “I think it's quite stressful working in the community and high caseloads. Again, lack of experience, I think lack of senior management. I think the managers now move on up. As a Trust, I think they're encouraged to sort of move up the ranks quite quickly, which then leaves quite junior members of staff being put in place.” (professional).

Staffing was a prominent theme when participants described their experiences and observations of admission and community services. It describes the interaction between staff shortages and high workloads in mental health services. It also describes training opportunities, and inter-service connections and service-community connections.

Staff shortages combined with high workloads result in increased stress levels within mental health services. Shortages is about the changeability of professionals working in mental health services. Professionals have spoken about the progression of professionals within their roles and varying levels of experience. People with lived experience of admission have acknowledged low staff levels and staff leave resulting in hand over to different professionals. Staffing is also about the demands and pressure that professionals working in mental health services are under.

> “There's such a high turnover of staff as there always has been, but I think certainly over the last few years I've seen, … a lot of teams are running on agency, a lot of teams are running on sort of quite junior members of staff that aren't that confident with their care planning” (professional).
>
> “The manager roles very much changed and that sort of then filters down to the staff that there’s a lot more put on them. So instead of having ‘right, you've got a caseload of 30. this is your role. This is one day a week. You'll do rapid response or something like that.’ They end up ‘oh God we’re short staffed.

> You've got to do this, you got to cover this' and people just sort of lose confidence." (professional).
>
> "There's a lot of other jobs you could be doing that are less stressful really, which is a shame because most people go into mental health and nursing, social work to help people, but if they themselves [are] feeling quite stressed it can be quite difficult to sort of maintain that and sort of carry on. So, I certainly seen a lot of people leave to do completely different things due to the workloads." (professional).
>
> "My care coordinator been on long-term sick leave. I saw her a few times in March. Then she went on long-term sick. She's just come back for two weeks to hand over her clients to other people because she's leaving, so it's not been very good at all." (person with lived experience of admission).
>
> "They're [the Home Treatment Team] seriously understaffed." (person with lived experience of admission).

Despite recognised staff shortages, participants were keen to consider how improvements could be made across the system. Improving consistency through strengthening of cross and multidisciplinary working and information transfer through personal and systems of communication was high on their list.

> "They [staff] weren't very productive because it was different people all the time, so you just feel like you're going over old ground all the time" (person with lived experience of admission).
>
> "There was an arrangement or sort of joint working arrangement between Surrey County Council and The Trust, and they split that and so now the mental health social workers just sit in Surrey County Council but there isn't any sort of joining up, proper joining up or sort of multi-agency conversations" (carer).

The way that information travels across all the statutory services is complex. It sits with a sociotechnical system which is far from perfect and means there is always going to be a risk of missed information and repetition. People with lived experience of admission have acknowledged the involvement of a range of professionals in mental health care who have different knowledge of the situation of the person with lived experience, and professionals have spoken about a lack of connection between mental health services.

> "Admission can be fraught with difficulty. Information doesn't travel too well because of a lack of connection between the different parts of the system" (professional).

In terms of repetition of information there remains some uncertainty about whether individuals were more bothered by being asked the same questions repeatedly or the lack of a single person taking responsibility for their care.

> “It's all documented on the computer. Why do they need to ask these questions? And then you have to go through all again the next morning with the ward doctor and then the junior and then you go through it all again with them and then a couple of days later, you go [on] rounds so you've got the consultant, so you have to go through it all again, because none of them talk to each other” (person with lived experience of admission)

Carers and professionals shared their concerns about the safety risks associated with record systems which do not interact.

> “I gave them [the police], the NHS, the local contact point, the crisis line, who she was and the answer came back: ‘they've never heard of her.’ She's been under them for years.” (carer).

These concerns about records extended to up-to-date care plans.

> “The amount of people that I've seen that haven't got up-to-date care plans, crisis contingency plans or sort of wellness and recovery plans in place would sort of concern me.” (professional).

Participants were strident in their individual and collective voice that agencies must find better ways to work together and share their knowledge to provide joined-up care to people with lived experience. Carers spoke about a recent lack of conversations between and merging of different agencies involved in community mental health care.

4.2 Discharge from mental health hospitals

This section focuses on stay in and discharge from mental health hospitals.

Participant’s stories reflect distinct and overlapping themes around:

1. Unmet needs
2. Containment not recovery
3. Transparency and clear communication
4. Limited staff resources
5. Discharge and transition not supported

Unmet Needs

Participants from all groups (people with lived experience of admission, carers and professionals) felt that needs of the person with lived experience were not sufficiently met during and leading up to their discharge from mental health hospital.

Headline findings

- Parity of esteem
- Basic needs
- Boredom & isolation
- Discharge & flow

Parity of esteem

> “We've always felt that they [mental health hospitals] ignore the physical illnesses the patient might have or believes they've got. You just feel that the physical person is being ignored and they're only concentrated on the medication and that's it. And if you get any extra help? Well, you're lucky” (carer).

Individuals with learning difficulties, learning disabilities and physical disabilities reported not feeling supported in mental health hospital. They described how unsuitable ward environments and procedures impact them. Experiences from autistic individuals were highlighted, as well as symptoms of physical disability being mistaken for symptoms of mental illness.

> “I just think my physical disability was almost a barrier to my [mental health] progress and feeling of value as a person and that's something that's actually not being addressed [by services].” (person with lived experience of admission)

> “So, I've got a mild cerebral palsy and the way that affects me is - it's my thumb, mainly my right arm; a bit in my left. I have tremors … and so any kind of, uh, shaking or jerkiness, uhm, was put down to anxiety, which was so frustrating.” (person with lived experience of admission)

> “We had to do a lot of writing in groups and I can't write unless I'm sat at the table and with lots of things to lean on [due to mild cerebral palsy]. And we used to sit in these kind of chairs which had arms, but you know, people would write on their laps and I just can't do this worksheet - I can't do this activity [sat like this]. So I'd just be sent out in the corridor with the table so that I could do it and I had to walk back in and then we’d debrief and then I'd be sent back out into the corridor and then I wasn't always called back in, so I had to just come back in when I'd finished and they might have already started up again and so I really felt like I was just not valued. I felt like my presence didn't matter in that group and I was just like extra. Uhm, I didn't

> really need to be there when I was out there. And no one really cared about my kind of treatment and I just felt like a spare part” (person with lived experience of admission).

These experiences exemplify the lack of parity between physical and mental health provision in mental health hospital settings. People with lived experience of admission told us that this was a barrier to their recovery and may have affected their length of stay. It made them feel marginalised and discriminated against and impacted their relationship with their care providers and other people with lived experience.

One person with lived experience of admission described how having the lack of inclusion around their needs as a disabled person because they had cerebral palsy and an eating disorder, complicated their care. They may have been involvement from a speech and language therapist and dietician for this person with lived experience, but if there was, that expertise did not appear to have been shared with ward staff. Therefore, causing barriers to being included in the day-to-day activities on the ward.

> “Eating with a knife and fork, that could be really difficult [due to their mild cerebral palsy] and it's quite messy and I choked on some foods. Things like melons, cucumber. Uhm, apples were quite difficult, but we had no kind of say in what we could and couldn't have so I had a few choking episodes. Uhm, and it was all down to ‘you’re anxious about eating’. You know any kind of difficulty I was having with a knife and fork; it was like, well, ‘why are you having difficulty today? You weren't having an issue yesterday’ and it wasn't addressed at all.” (person with lived experience of admission)

This emphasises how individuals lost their sense of agency as inpatients. This is most apparent in terms of the experiences of autistic people.

> **“**I think the lady with autism. She wasn't listened to at all, believe it or not, and she's quite vocal and they weren't accepting her diagnosis as autistic. They were saying it was EUPD [Emotionally Unstable Personality Disorder]. With autism, it needs set routines and you need set things. And if you're told that you've got that half an hour, you can go out for half an hour. Somebody going to sit, go out with you for half an hour. And that doesn't happen and you're not told when it's gonna be. I'm like, I can come to you and say, ‘look I know I’m supposed to go out with you at 12:30. However, I can't do that until such and such a time because they haven't got the staff’, they’re not, she wasn't able to go out and it's the lack of getting it into her head that she didn't, 'cause she wasn't told. Another time or another, there wasn't it wasn't an ending it, so it was just ‘it might be later, might be later” (professional).

Professionals were keen to raise their concern about the increasing number of neurodiverse individuals in inpatient settings for whom the systems of care are not compatible with their needs.

> “We seem to be having more and more patients who are on the autistic spectrum, … and it's particularly hard for them because the ward environment is not good. It's noisy, it's light, it's bright and they like to know where they are and what's happening when.” (professional).

Basic needs

> “The toilet and the shower bit – because it only had these – you know saloon doors you get on an Old styled Western? It was like those and anyone, staff could just walk in. This is going to sound terrible! I didn’t have a shower in the two weeks I was there because I felt too exposed and embarrassed to have one because of those flimsy little doors. All I did was have a wash every day at the sink quickly – as fast as I could” (person with lived experience of admission).

The basic needs of people with lived experience, such as showering, eating, and wearing clean sets of clothes were not met and would go unnoticed by staff for stretches of time, particularly if people with lived experience had no visitors. Participants felt the meals provided were unpalatable, and that some diets were not catered for in the mental health hospital. On discharge, some individuals returned home to poorer conditions, and carers mentioned practical difficulties preparing the individual’s house for their return, such as late notice of discharge and access to the property.

> “I was frequently sleeping in the same clothes for up to a week because I didn't have visitors to bring me anything. You don't have any kind of toiletries, clean clothes, clean underwear, nothing like that. And then frequently the staff don't even notice. They just let you sort of rot in your own rotten clothes.” (person with lived experience of admission)

> “I wouldn't have fed it to a pet. It was that bad. And I'm not fussy I’ll eat anything, especially when I've got no alternative, you know? It was absolutely shocking food.” (person with lived experience of admission).

> “You get in, you've got no milk or food or anything in the house 'cause, you've been away for two months, so everything is rotten on the sides, and it's just far too much for you to cope with. But that's just been the norm really is that you just got kicked out and left to fend for yourself.” (person with lived experience of admission).

Most of the experiences we heard were of poor standards, but they were dispersed with examples of excellent care and mindful organising by individual professionals.

> “She [the social worker] organised a deep clean of her flat and got everything sorted ready for her when she came out, so we felt greatly relieved.” (carer).

> "In previous times you didn't know whether you could get in, whether we've got the key, who's got the key, whether there was any electricity, whether the fridge [had] defrosted … whether there was any food for her? That side of things over the years has been absolutely awful, but this last time it was managed reasonably well, though we didn't know actually which day [she was being discharged]" (carer).

Social care agencies having the home and care package of a person with lived experience ready was dependent upon good communication between the hospital team and the home team and when that happened the results were celebrated.

> "I got moved into another room which had, uhm, no hose, so the shower didn't work. So, I had cold showers for about six months. Uhm, that was really difficult." (person with lived experience of admission)

> "[At discharge, I felt] worried about … what kind of state everything would be in at home… I could of done with practical help to tidy, and organise bills." (person with lived experience of admission)

Good effective communication between agencies and people with lived experience and their families and carers was said to support recovery.

Boredom & isolation

> On why other people with lived experience start fights: "They're bored and frustrated… Staff are in the office. You have to knock on the door. They don't always answer, they ignore you. it's very frustrating. Boredom is a terrible thing." (person with lived experience of admission)

Boredom caused by lack of meaningful occupation was discussed by participants, mostly people with lived experience of admission who remembered being frustrated that activities were regularly cancelled or not clearly communicated to people with lived experience. Boredom was cited as a contributing factor in aggression and not supporting healing and recovery.

> "Having more to do as well would be a good thing because most of the time I'm just sat around bored." (person with lived experience of admission).

> "A lot of the time things were cancelled." (person with lived experience of admission)

> "And at weekends they have no activities at all and if you've got no leave, those weekends feel so long." (person with lived experience of admission).

> "I had a good experience in 2018 at [mental health hospital] I was in for a month and I made rapid progress because there was a lot of activities and a lot of therapy sessions that went on during that month, that meant I got better quite quickly." (person with lived experience of admission)

> “it's a matter of trying to fill up your day without being bored.” (person with lived experience of admission).

> “I don't think it was very long [in hospital], I think it was only like a couple of days. But it felt a lot longer than it was 'cause there's nothing to do.” (person with lived experience of admission).

Much of the retrospective focus was that weekends in particular were periods of boredom which contributed to anxiety and distress. Access to art and occupational therapy was cited as something which made a positive contribution to recovery. However, many of the people with lived experience of admission told us that there was little for them to do to occupy their time. They were also keen to explain that they expected inpatient stay to include opportunities to talk with professionals and address their worries through talking therapy, and just to have someone who cared about them.

> “I think sometimes patients feel that they're not known because [they’re] just being observed [and that] doesn't tell you everything does it?” (professional).

> “I didn’t like the staff very much. They don’t really talk to you. They just kind of just hover around and don’t seem to do anything…. They don’t make an effort to talk to you at all. It makes me wonder how they can write their notes up about you at the end of each shift when they change over, because sometimes they hadn’t talked to you at all. They didn’t make much of an effort to check in with you and stuff like that.” (person with lived experience of admission).

> “I was told when I was better, I could go out for a walk with member of staff, but they walked 10 foot ahead of me, talking to their friend and I had to trail behind. … I was really upset, cause I was looking forward to getting out and because I like walking anyway. But you’re just like a kid behind your parents.” (person with lived experience of admission).

Participant’s felt they were observed, rather than engaged with or listened to. Staff were not visible on the ward. They were either in the office or concentrated on louder people with lived experience. Positive interactions were reported from non-medical members of staff.

> “I was probably quiet but I was left alone. Whereas the ones that are kicking off all the time would get, they [staff] would be bothering about them more.” (person with lived experience of admission)

We heard from many of the participants that they felt staff were not engaging meaningfully with them as inpatients. The sense was that there may be a variety of reasons, including lack of skill and high workload.

> “They’re [staff] busy chatting in the office and doing stuff. They just don't seem to be that visible and spend that much time, actually quality time, chatting to

> you and that's what people need.” (person with lived experience of admission).

Services users were keen to offer suggestions to help improve the experience of others through more personal meaningful interaction between people with lived experience and staff.

> “I think the staff could do better and I think they could be a bit more proactive in engaging with people and I think that's something they need to work on” (person with lived experience of admission).

> “The staff make all the difference 'cause they can change the whole atmosphere [of the ward] by coming around and talking to people.” (person with lived experience of admission).

The roles and responsibilities of different staff appear to influence the amount of time they have to engage with people with lived experience. The more qualified mental health nurses have high levels of leadership and management responsibilities and less time to engage, they also have the higher level of skill in supporting meaningful discussion around mental health. Healthcare assistants make up a large part of the hospital workforce and they have more available time but less skills, training and experience in meaningful mental health engagement.

> “You have an allocated nurse, but they don't really spend any time with you, they just oversee your care on the ward, If you get a charge nurse or whatever, then you don't really see them.” (person with lived experience of admission).

Beyond barriers around skills and time there was also a sense that there may be compassion burnout across the clinical workforce and that staff are doing their best in an incredibly demanding period in the history of the NHS.

> “At my [voluntary] admission [to an independent mental health hospital] I was taking a tour around with my mum and the person doing the tour was so disinterested. Uhm and she [the tour guide] took me to the kitchen and the chef came out and kind of said, ‘Hello’. And she was just really, kind of, really human. And she had a joke with me and she said that she liked my jumper that had a rabbit on it. And she asked me about my life and stuff, and she said that she ran a baking group with the ward. Then she [asked], you know, did I like baking and that kind of thing and you know, a real kind of light-hearted conversation. And she would do that every time.” (person with lived experience of admission).

If compassion fatigue is a contributory factor (and more work would need to be done with staff to determine if this is right), then that may account for the lack of inclusion in decisions of care which we were told about from people with lived experience of admission, carers, and professionals.

> “There was a multi-disciplinary meeting going on that the young person hadn't been invited into but they were talking about her care and this young person was 21, so in all intents and purposes should have been involved in that conversation so [my colleague from an advocacy charity] was able to step in and say, ‘hey come on, we need to be hearing from her’ .... The young person was trying to talk then during the meeting and [my colleague] said it was as if people just weren't listening.” (professional)

Discharge & flow

> “If someone’s admitted and they haven't got accommodation, that needs to be flagged up at the moment they get admitted. There's so many people just medically fit for discharge and they haven't got any accommodation and it's not safe for them to just put them in at bed and breakfast, et cetera, so that that needs to be flagged up in order to make a timely discharge.” (professional).

Delayed discharges were reported as often being caused by difficulties finding suitable accommodation, such as supported accommodation and care homes, for people with lived experience. Professionals told us that bed flow is highly dependent on people with lived experience having suitable accommodation to be discharged to. This was strongly associated with autistic people and people with learning disabilities. Lack of accommodation impacts bed flow in Surrey as potential inpatients are unable to be admitted or assessed if beds or suites are full.

> “There is an issue around bed flow in Surrey. There's limited accommodation for people to access when they're ready for discharge from admission, which then means that they stay in their bed for a lot longer, which then means that there's a blockage in the assessment suite.” (professional)

> “I think the main thing [contributing to delayed discharges] for me is accommodation, which we've got a severe lack of everywhere.” (professional).

> “The person might be medically fit for discharge, but the placement hasn't been found, so the person is just being held on the ward even though they're well enough to be in the community.” (professional).

> “If somebody got nowhere to go, they can't leave.” (professional).

> “Sometimes you think somebody is going to be discharged and then it doesn't happen because they decided they're not going home, they are going to supported accommodation, but then maybe they don't meet the threshold for supported accommodation, so weeks down the line they're back into [a] private landlord or they're back into homelessness.” (professional).

> **“**I think it's important that people are when they're discharged, they're discharged appropriately, … so it's about discharging appropriately. Where are they going? What care’s in place? What's the next step?” (professional).

> “Housing was the main issue [at discharge]. She needed a care home who could meet her needs… She could have been discharged months before if there was dedicated support to find her a place in a care home.” (carer).

The systemic barriers to timely, efficient, good quality discharge in Surrey that were identified include internal and external multidisciplinary care planning during a hospital stay. Being ready by identifying all potential needs and resources to meet those needs at home in the community after discharge so that discharge can be initiated in conjunction with community teams, families and carers.

> “I think [out of area placements] can have [a] huge impact on people if they don't know the area. They don't care when they're in hospital. When they come out of hospital and there's no placement in the area where they want to go. It is really sad 'cause they know that area, they've lived in that area, but why should they be shot off to somewhere where they don't know?” (professional).

The same concerns about planning for discharge apply to out of county placements but the imperative is likely to be greater. Conversely, we were told about the risks associated with premature discharge.

> “The reasons for [readmissions], sometimes it was misjudged. It was too early. It looked like it was going to be OK, but it wasn't. You know, something might have happened that triggered it. I mean nobody is fully recovered when they leave hospital. They're just past the crisis point really.” (professional).

Premature discharges may impact an individual’s recovery; they feel like they’re not ready to leave or their mental health deteriorates quickly after discharge – which may lead to a readmission. Limited number of hospital beds was mentioned as a contributory factor to premature discharge.

> “One of the other gentlemen ended up back in hospital 'cause he really wasn't well. I don't think he was supported enough too. If he had a CTR [Care Treatment Review] in place and things in place to start off with, none of that would have happened. I think he got sent out possibly far too quickly.” (professional).

Any issues around discharge seemed to come back to planning and involvement of internal and external multidisciplinary teams to be sure the decisions are the right ones at the right time for the wellbeing of the individual.

Containment not recovery

Whilst participants recognised the need for a place which can be a safe space in a crisis, there was a strong sense that mental health hospitals are not places for recovery but places where unwell people are contained until pharmacology can improve their safety.

Headline findings

- Restraint
- No therapies during stay
- Containment and Pharmacology
- Harm

Restraint

> “I know they have to hold you down. I know there's a means of giving you an injection 'cause they have to be safe, although I wasn't threatening and all I kept saying, ‘just let me put my underwear on’ and they wouldn't let me do that. So, they injected me in my bottom with no underwear on knowing my past history related to rape. I was pinned against a wall … I think the trust broke down, as I say with the injection, when you're just saying, ‘please [let me] put my underwear on’ and they know you're in there 'cause you were raped [as a teenager] and they don't let you do that - the trust breaks down … there was five of them pinned me to a wall, male and female. And they said they had to do it that way for their safety.” (person with lived experience of admission).

People with lived experience of admission talked about being subjected to the use of force by staff and not understanding why. They felt that least restrictive options were not considered.

> “I went to [an independent mental health hospital] and had a terrible experience there. I was restrained and injected with tranquillizers four times in four days, which I didn't think was good practice. They didn't make any attempts to go for another path.” (person with lived experience of admission).

Unresolved trauma associated with restraint during stay and at the time of admission (particularly when the police were involved) was exacerbated by a lack of debriefing. When participants told us about trauma, they were also telling us that they felt they needed an opportunity to discuss what had happened – either to them personally or to someone else. This linked to the most common theme in this research around lack of therapeutic intervention.

No therapies during stay

> “There aren't many treatment options when you're on the ward, you know, you can't engage in any meaningful psychological interventions.” (professional).

Many participants told us that therapeutic interventions were offered on wards. This is at odds with the expectations of people with lived experience and new members of staff. No therapies during stay was identified as not getting to the root of the problem and associated with extended stays and readmissions.

> “I think a lot of times people are under the misconception that because they're in hospital they're gonna get intense therapy and that's not what it's about.” (professional).

> “I had a good experience in 2018 at [mental health hospital] I was in for a month and I made rapid progress because there was a lot of activities and a lot of therapy sessions that went on during that month, that meant I was, I got better quite quickly.” (person with lived experience of admission)

> “I thought that when you went into a psychiatric hospital for care, it would involve maybe 1:1s each day with a member of staff just talking through where you're at but there's nothing like that.” (person with lived experience of admission).

> “There was nothing therapeutic. It was a holding pen, I suppose, until the medication helped me and I got better. But I didn't feel that there's any therapeutic interventions. I've had more therapeutic interventions with the psychiatric nurse at [mental health service], you know, going actually for a session, it's what I, as I say, I genuinely thought as a nurse that that's what you did that that when you're in a hospital like that either a psychologist or the nurse or somebody would interact with you each day, but it didn't happen.” (person with lived experience of admission).

> “What I used to think when I was new at this, was that when people went to be in psychiatric inpatient they were going to get therapy and that they would come out better than they were when they went in, and that they were gonna go to a place that was going to be really safe and where they were going to be really cared for and looked after and where, you know, their psychological needs would be met. And their emotional needs would be addressed and that they could do some actual work on what was going on for them psychologically, so that when they came out they could cope better. And what I've realised is that for the majority of people, that is not their experience and it kind of seems like it is more like it's a place where you're not going to be able to end your life.” (professional).

> “I always assumed inpatient care was going to be holistic and therapeutic and it isn't. It's a holding pen.” (person with lived experience of admission).

This description of hospital as a ‘holding pen’ was used repeatedly by participants. It supports the theme which emerged around containment which in turn was linked to pharmacology

Containment and Pharmacology

> “It was a holding pen, I suppose, until the medication helped me and I got better.” (person with lived experience of admission).
>
> “These places aren't very pleasant, you know, and people don't like being there and they're very risk averse. They're not a natural environment. As I say, we feel policed anyway on the ward. We don't feel nursed and so it's about containment.” (person with lived experience of admission).

Wards used as a contained environment to prevent suicides of or further harm to people with lived experience and to change medications. Mixed responses were reported about the involvement of people with lived experience around their medication. Negative side effects of medication impacted their engagement with recovery, such as refusing their medication.

> “Sadly, it's [admission] about kind of containment in a crisis, being safe in a crisis.” (professional).
>
> “You feel more policed than nursed I mean a lot of the time you're just being kept corralled around where you should be.” (person with lived experience of admission).
>
> “It's very important for somebody to know, ‘are they going to be seen today or are they gonna be seen tomorrow?’ ‘Is it gonna be in the next hour or is it gonna be at the end of the day?’ Because yeah, you're kind of in a very powerless situation, aren't you? You're contained in this environment and often you were under section, so you don't have any recourse against that until the tribunal date or the managers’ meeting date.” (professional).
>
> “Sadly, it's [admission and stay] about kind of containment in a crisis, being safe in a crisis.” (professional).
>
> “You feel more policed than nursed I mean a lot of the time you're just being kept corralled around where you should be.” (person with lived experience of admission)
>
> “Being on a psychiatric ward, you're just sitting around waiting for the pills to work really” (person with lived experience of admission)

People with lived experience of admission were keen to identify practice and individual practitioners who they felt had an approach which helped them and made them feel like partners in their own care.

> “From the meds. point of view, they were really good because they had their like own prescriber there as well as like other people that were around and

> [the prescriber] was really good, because he actually like chatted to me a little bit more rather than you know, ‘oh, we see you've been on these meds. Uh, why don't we just up your dose and just keep upping them until you do something?’ but yeah, he was a little bit more nicer and a little bit more open to, you know, ‘do you have any ideas as to what might help?’ because you know, [the prescriber] was like, ‘I know lots of people do their own research on what meds that they want to be on’. So he like, asked that and stuff.” (person with lived experience of admission).

When shared decision making was experienced there were still difficulties, as is explained by this next participant story.

> “So I had not been on any medication before I was admitted. I started to feel a bit - it wasn't down - I was feeling very, very uncomfortable in my body and just scared by the situation. And I was talking about how I was, you know, having trouble with eating and that I was just feeling really stressed out at all times. So, the consultant said in my ward round that he was going to recommend a type of medication, and I kind of agreed to it. And then by the evening when it was meant to be taken, I decided actually no, I didn't want to take it, but the nurse that was on said ‘it's been prescribed by the consultant. If you don't take it… we'll section you’ and I still didn't understand [what that meant]. So, I literally thought, if I don't take this medication, I'm not gonna have as much say of my treatment. And all the other myths that come with sectioning, I thought I'll never be able to go to America. I thought, I'll never be able to be a teacher. I believed these things which I now know not to be true. So I thought, ‘OK, I'll just take this medication’. And it made me really unwell, it made me very sleepy and it made me very agitated so I couldn't stop moving and it made my thoughts go all over the place, 'cause it was an antipsychotic medication, and I didn't have any real symptoms of depression. I didn't have any experiences of psychosis at all and [now] I think I was just anxious and stressed because I [had been] put in an inpatient unit and my life had been completely disrupted. Uhm, so because I'd got this stressed on that medication and it wasn't working, they started adding in things like benzos, so there was diazepam… and then lorazepam and then … there was another one that I took every evening and it began with ‘P’ and it was like another kind of sedative.” (person with lived experience of admission).

This highlights the system constraints within organisations and across nursing and medical approaches. It also raises complexity in socio-technical and medico-legal systems. People with lived experience of admission often told us they felt that mental health medicine felt more akin to punishment and the judiciary than healthcare.

Harm

People with lived experience of admission felt threatened by staff (intimidation, shouting and swearing) and by other people with lived experience (theft, fights, manipulation, and violence). People with lived experience did not feel safe from themselves either with references to self-harm or suicide whilst in mental health hospitals. Some began to self-harm. Self-harm was described by one professional as contagious in hospital, particularly amongst women.

> “I think the worst thing that happened to me, I was asked to fill in a questionnaire [on a] tablet and they said be honest about it, which I was, and then a few days later somebody asked me if I'd like to revise what I wrote. So, I felt very threatened.” (People with lived experience of admission).

> “So, I've never self-harmed before my admission, and I haven't self-harmed since. My feeling is that it was partly to do with the medication that I was on, kind of making my thoughts, you know, all over the place. And it was partly to do with being in an environment where I was around that going on a lot and that just became like the norm. The staff felt like I was just copying other patients for attention and whether there's truth in that - there may be, but I don't know. But they [staff] were very angry with me whenever it happened. I remember one incident really clearly - there were building materials [around the independent mental health hospital] and I'd cut my elbow and it had bled more than I could kind of cope with. So, I pressed my alarm and someone came and they were just shouting and swearing like ‘why have you done that? Why have you done that? That is disgusting’ and I was just apologising, and they were retching and they were like, ‘this is disgusting.’ And I was still bleeding, and they were like, ‘we need to clean this up.’ And they went and got me a mop and then they said ‘you need to clean this. Why have you done that?’ And so, as I’m cleaning and as I was doing it, you know the bleeding kind of got less by itself, and then I had to go down to the nurses station and I already knew I was being told off. This other [staff member] was just retching at me. Uhm, and I went and I just said to the nurse that ‘I'm really sorry. I don't know what's going on. Really sorry. I know you're really busy. Like, I'm just really sorry’. He wouldn't even look at me. He was just snarled [and said], ‘If you were sorry, you wouldn't be doing this. You need to stop copying other patients. We don't have time for your attention seeking behaviour’, and kind of threw a plaster at me and then uhm kind of, you know, shoved me out of the room. That was probably the most extreme example of how it was handled, but it was basically … like [that] every time.” (People with lived experience of admission).

The stories we were told about staff responses to self-harm raises questions about the clinical skills and qualifications of the staff and the availability of professionals who understand the nature of self-harm in this context.

> “We had discovered that this young person had been able to swallow a whole load of batteries and was meant to be observed every 15 minutes, but it was kind of every two hours. … Our team member [from an advocacy charity] walked in, and the young person disclosed, ‘so about an hour ago I swallowed

> batteries’ but they clearly weren't looking well either. So, there were all these issues that had been sat there for close to an hour without anyone coming in to get them the critical care that they needed in that moment.” (professional).

Not responding to critical physical health risks in a timely and appropriate way is something which was discussed by people with lived experience of admission, carers and professionals. From the data, the research is not able to clearly interpret the causal factors. However, there is good evidence in the stories that skills of the staff, workload, and a normalisation of crisis may be contributory factors.

> **“**The episode I'm aware of took place in the [mental health hospital] and crucially involved somebody who was there as a voluntary patient. And the regime is different for voluntary patients so when they said, ‘can I go out?’ They're allowed out. But that person was a huge risk patient and was an inpatient. And unfortunately, although citizens intervened, reported to the police, the police intervened, that person was let out the same day again because she wanted to complete suicide and she did.” (professional).

We were told about the impact which suicide of others had on people with lived experience of admission and professionals.

Another kind of harm is that which happened between people with lived experience.

> “You don't take much in with you of any value. it's just not worth it. especially being in dormitories. …You're vulnerable then to people taking your stuff.” (person with lived experience of admission)

> “As a vulnerable person, she encounters people who manipulate her. She’ll trust them and then they steal her possessions or do something dreadful, you know, and so it goes on.” (carer).

> “I got bullied quite a lot [by other patients] when I was in hospital… I got hit twice in there.” (person with lived experience of admission).

> “The women kept screaming at night and they seemed to argue a lot more. There was a lot more tension on the ward, there were arguments at mealtimes, any excuse to have a row really. It was dreadful.” (person with lived experience of admission)

We were told that staff were also abused physically and racially, and that staff and people with lived experience began to adopt protective behaviours.

> “The last time I was on the ward it was a constant shouting of racist abuse at the staff and they just didn't deal with it, they just sort of let it go over their heads because they heard it so many times before, but it was quite unpleasant for me to sit there and hear the staff being abused like that.” (person with lived experience of admission)

> “During my stay I saw a lot of really, really difficult things. I saw people self-harming. I experienced people running away. Times where you know, other patients were kind of concerned for their lives? Uhm, there were kind of lots of, lots of, kind of really distressing self-harm behaviours, but there was also quite a lot of like emotional manipulation of staff and of other patients, including myself.” (person with lived experience of admission).

People with lived experience of admission and carers communicated a sense that accessing mental health services is a balancing act between the benefits from certain harm and the almost inevitable harms which come with the systems.

Transparency and Clear Communication

Lack of transparency around treatment and discharge procedures.

Headline findings

- Getting the process right
- Having a plan

Getting the process right

> “This time I was discharged with a care package from social services of people to come round to my house, but I never knew exactly [when]. They said they'd ring me up and I'd be out somewhere, and they’d ring me up and say, ‘oh, we're at your house’ and I'm like, ‘well, you didn't tell me you were coming’, you know, and this went on for about a week, two weeks. People kept turning up or ringing me, saying ‘we're outside’. I didn't want them. I didn't want them in my house and so I ended up cancelling the whole care package where I probably could have done with some help, but it just was so badly organised and nobody told me what was going on or what the care was for.” (person with lived experience of admission)

Reports of the involvement of people with lived experience during their admission, stay and discharge varied. We heard stories about sudden discharges and services users not understanding what the service provided offers.

The researchers were told that carers experienced little communication following a discharge, which meant they were unable to prepare for it.

> “We've always been phoned by - I can't remember the special title for a social worker who has that duty. It's a legal duty because of the sectioning, it seems. When she's sectioned, they have to inform you that something happened. That she’s in hospital and they're supposed to ring you again just before a discharge, but I have to say that doesn't always happen and again I can't quote chapter and verse as to which times it hasn't happened, but on more than one occasion it hasn't happened. Not in recent times. We've been alarmed to find that she's been discharged and is at home and we didn't know.” (carer).

The importance of discussing uncomfortable topics with people with lived experience was raised by professionals.

> “It might [be] because some things they don't need to hear, but I think they should be hearing them whether they like it or not? Maybe just - for lack of a better word - Suck it up. You did do that, and this is your consequence. They're not knowing the consequences.” (professional).

> “On all three discharges, nobody explained the meetings, you know the big meetings they have and you go in the room, but nobody ever talked to me about that. I remember the first admission going to this board room. There's a big table and everyone’s around it, but nobody really had prepared me. I didn't know what it was about. I was just told to go in. My husband was there, and I panicked and left. And I remember the next day saying to the Doctor - Junior doctor, ‘can I talk to someone about my discharge?’ And the Doctor said, ‘you had your chance yesterday.’ That was his comment. So, it just left it until they did the meeting again at a later date. The second time I was told I could go home that day. It was a big meeting, but nobody again really explained the meeting and then last time, the doctor was really actually very good and he actually got some people to leave the room because I just found it overwhelming. There were medical students, … there's this sea of faces, but he was really good at putting me at ease and explaining things and that was helpful. But again, I was discharged that day.” (person with lived experience of admission)

Discharge meetings in hospital were raised, with the suitability of the number of attendees or the size of the space in which the meeting takes place were discussed. These factors may impact the engagement of people with lived experience and they may want to raise issues after their meeting. People with lived experience of admission reported not understanding what meetings are about or when they would happen which meant they were unable to prepare for or properly engage with them.

> “They tell you [you’re discharged] and then you just go. There's no point hanging around [as] somebody else will be using your bed as soon as you're out the door anyway.” (person with lived experience of admission)

Professionals stressed the importance of working with individuals from the start of their admission to hospital.

> “It's involving the patient in the process, so it's about that care planning, you know, what do they want to happen in hospital? What would be helpful? Giving them some sort of control and say about what happens in their treatment.” (professional).

Professionals were eager for people with lived experience to understand the realities of recovery, and that support was in place to anticipate possible deterioration.

> “Presuming … I'll out the other end safely, efficiently, effectively and my problem is reduced. Will I be able to go round the loop again if I need it? And that's really the big issue. I think there's a big barrier and what you'll find is to reassure a person that they can fall back. It seems to uphold their progress onwards. So just having the capability, the reassurance, ‘OK if you have any problems or this reoccurs, contact us, come back.’” (professional).

Having a plan

> "Nothing was ever discussed with me. Nobody ever said, 'this is what's going to happen'. I mean, obviously I realise I was very unwell at first and those conversations may have taken place, but certainly when I was more aware of things - I don't recall anybody sitting down and saying, 'this is where you're at. we think that you'll probably need another 10 days, and then we'll review you and then we'll see it from there' in the same way I would do [as a nurse] with somebody with a physical illness: 'You've had your op. 10 days ago, you're doing really well. We'll be looking at this, [this and this.] What do you think? What's your home setup?' That never happened." (person with lived experience of admission).

> "I would ask that like inpatient admissions for medical problems that you actually have a discharge summary, you don't get them in psychiatric care, I've never had one, so I've never had something saying, 'X was in for this and she's come out for that, this is the plan'. It's almost like because it's mental health, you shouldn't see it, but you should see it. Really. It's just as important, and probably more important really 'cause you've got something, if there's a problem, to show somebody who comes around to your home." (person with lived experience of admission).

The difference in care planning between mental and physical health conditions were highlighted by people with lived experience of admission.

Discharge dates were not provided early enough for professionals and making sure the person with lived experience understands why they were admitted was associated with extended stays in hospital.

> "And I think discharge planning is done quite late in the process when someone is admitted to the ward. It can be a week or so before anyone considered to bring all the other services that are involved with that person into looking at why that person is admitted." (professional).

> "The first thing that springs to mind is setting a discharge date upon admission. I think that's really important. I've seen so many people just, you know, weeks and weeks later they're still on the ward. Well, why they still on the ward? What's the purpose of this admission? So timely discharge would be to set a date. 'Right, we are agreeing for you to be admitted for two weeks because we need to change your medication', so for two weeks that is an adequate time to do that or for whatever reason that person is admitted." (professional).

The researchers were told about making sure care plans were realistic and viable:

> "And making sure that you know if you're gonna be offering something, if there's a care plan put in place then that actually is [a] viable care plan? Don't say that you can offer someone an hour a day to talk to if it's actually not

> possible. So it's got to be measurable, it's got to be achievable. All these things that care plan’s put in place when that person is admitted is actually going to happen.” (professional).

It was reported that information flow surrounding discharge was affected by a lack of integrated services and collaborative working.

> “People withhold information that they should have disclosed, such as when they're gonna discharge them. There is no discharge plan available for workers outside of clinical situations to continue the work or support the work that's been done consolidated. So, you know, admission can be fraught with difficulty. Information doesn't travel too well because of a lack of connection between the different parts of the system. Uh, you know, a lot of discharge work can be done even before admission if it's a planned admission. And the whole idea of the care plan could worked out with the individual.” (professional).

People with lived experience of admission raised not having their own copies of their care plans.

> “I don't remember seeing my care plan when I was on the ward, but I'm sure I have one. I don't remember physically having a copy of it, which is what good practice says you should have.” (person with lived experience of admission).

Limited staff and resources

Limited number of staff on the ward and limits on their roles impacted stay and the involvement with other agencies which may be of benefit to recovery.

Headline findings

- Staff resource and skills
- Collaboration

Staff resource & skills

> “We had discovered that this young person had been able to swallow a whole load of batteries and was meant to be observed every 15 minutes, but it was kind of every two hours. … Our team member [from an advocacy charity] walked in, and the young person disclosed, ‘so about an hour ago I swallowed batteries’ but they clearly weren't looking well either. So, there were all these issues that had been sat there for close to an hour without anyone coming in to get them the critical care that they needed in that moment.” (professional).

It was identified that limited resources meant only those exhibiting riskier behaviours were prioritised and admitted to hospital. Limited staffing meant activities were cancelled, regular observations for high-risk people with lived experience were reduced, or other people with lived experience had to support their peers in the service, which was distressing.

> “We've just shrunk down to just the kind of top layer of people coming into hospital because that's all the provision that is available.” (professional).

> “I do a very low-level contact with the carers, so I kind of bring them and explain the [transition from hospital to community] service. I'll also signpost them to sources of support in the community, but that's as far as I go.” (professional).

We heard stories from people with lived experience of admission about the ways in which understaffing affected their stay in hospital, such as supervised access to the garden and therapeutic activities being cancelled.

> “But they don't, there's nobody down there [in the mental hospital’s garden]. They don't have the staff to have somebody down in the garden, they have to be monitored everywhere. And uhm, you know perhaps a higher staffing level would be better.” (person with lived experience of admission)

> “The unit [at the independent mental health hospital] was regularly understaffed and the programme of therapeutic activity couldn’t run properly. I had to administer first aid to a fellow patient because the staff had been inadequately trained.” (person with lived experience of admission)

A person with lived experience of admission reported having to administer first-aid to a fellow person with lived experience and convince others not to abscond from the hospital. These impositions were distressing for the individual.

> “I often felt like I had to either be involved in a couple of incidents where someone had self-harmed and there were just no staff around to kind of deal with that situation and so I had to kind of assist or all of the staff were dealing with someone who was having an acute episode and there were no staff for the rest of the group. So, you know, people would take the opportunity to run away and it was kind of convincing them to stay and it was just very, very stressful.” (person with lived experience of admission).

Collaboration

> “She had at that time [in 2021] a fantastic social worker. The first time ever we thought we got somebody that really absolutely understood and had experience of people like my daughter before and really understood the issues. And she, this social worker, was able to make a connection with the hospital when she was in, she attended meetings on our behalf if we couldn't get there, she was a link and she fed information to the hospital staff about, you know, advise them really on what should be happening. And that that was a huge contribution towards the success.” (carer).

Participants emphasised the need for more integrated care between services (and if applicable, involvement from families and carers), as well as clearer communication from service providers about how support was delivered.

Positive and negative experiences were reported on the involvement of care co-ordinators whilst being an inpatient.

> “When people have a care coordinator whilst they’re an inpatient, the care coordinator kind of goes, ‘well, they’re an inpatient so I don't need to worry about them’. Uhm, but it's meant - from my understanding - it’s meant to layer, you know? So, it's kind of like, you've always got your care coordinator and then if you need them, you've also got the home treatment team and then if you need more you've also got, you know, the day service or you've also got inpatient. But it seems to me that care coordinators basically check out when somebody goes in as an inpatient and then they have to pick it all up when they come back out again. So, there's not that continuity even if they might have a discharge planning meeting, but, like, that's not the same.” (professional)

This professional highlights the possible positive outcomes of supportive care following a discharge. They illuminate motivation and empowerment of people with lived experience involvement in their care.

> “I think it's about how helping people to have hope. And to not just feel like they're just they're being spat out of a system, but that they're moving on to something. they've got [to] help them to, sort of problem solve and to take ownership of their situation but feel like they're being supported to do that and not that they're powerless.” (professional)

> “How are carers being looked after? Does the integrated care system produced for carers? You’re gonna have somebody discharged into effectively their care. I know it says the GP is on the care plan, but the carer is the one at home who's gonna feel the brunt, but if there are problems, you know, did they get the right support plan? You know, so there are questions … about having integrated systems that really work well for everybody and everybody has contributed to them. And the reflective practise in the end has to include feedback from patients and carers.” (professional).

Other professionals highlighted the importance of including the employer of the person with lived experience (if applicable). We heard stories of supportive employers who arranged for extended time off following their employee’s discharge and visited their employees in hospital.

> “[For inpatient services] not to be an island, to have vibrant relationships that are systematic with the coroner, with the CQC [Care Quality Commission], with all the agencies in your community, including employers, [they’re] always left out.” (professional).

Inclusive reaching out to employers and providing guidance on how to support employees will support recovery and contribute to the movement of change around eradicating stigma associated with mental health and hospital admission.

Discharge from mental health hospital

Mixed experiences were reported at discharge and around and transitioning to community-based services or returning to their homes.

Headline findings

- Barriers to discharge
- Institutionalisation
- Including carers
- The whole person

Barriers to discharge

> "As far as working in discharge is concerned. At times it can be very rewarding, at times it can be very frustrating. Frustrating because of waiting for funding, trying to find the right sort of placement." (professional).

We heard how waiting for funding reportedly impacted both professionals and the discharge experiences of people with lived experience.

> "It [my discharge] just came around almost quite suddenly. There wasn't really any planning. And then suddenly it was my day to be discharged. So, I just packed up my bags and then kind of left. Halfway through the day, my dad came, picked me up and drove me back to my home. And that was kind of it. I know I was meant to have some daily patient treatment as kind of a - what is the word? Uhm, not follow up, but sort of like as a step down. Uhm, but I was just told that my funding hadn't come through. And so, I would find out about that within kind of eight weeks. So it was, you know, kind of eight weeks of not knowing what was going to happen and then going, you know, transitioning straight into outpatient again. Uhm, so there wasn't a whole lot of planning. And also, around the time of my discharge there were another group of patients with very complex needs, so there wasn't a lot of time for people to have 1:1s in the end, and kind of plan my discharge. Uhm, so, I kind of felt like I was completely thrown into back into the outside world and it was a really, really difficult experience." (person with lived experience of admission)

Little or no discharge planning was reported by people with lived experience of admission, with reference to delays in getting medication preventing discharge.

> "I went to a ward review and it was agreed that I could be discharged. They were late getting my medication, so, I got a taxi home, and they paid for a taxi for me to come home, and my daughter went back and collected the medication at 6 o'clock, so they could do that better. They could get the medication ready earlier when they know they're discharging you because

> there's nothing worse than being discharged than having to wait around for medication to be ready. I resented that a bit, but they, as I say they let me go ‘on the condition that my daughter picked up my medication 'cause I have to discharge you with at least a week’s medication otherwise I won't discharge you’.” (person with lived experience of admission).

> “Hours waiting around for meds – despite being legally discharged I was not allowed to leave. … often last-minute discharge with no planning whatsoever.” (person with lived experience of admission).

The following participant experienced a quick discharge but was unaware of simple procedures like leaving the hospital.

> “They met with me in the morning and then I was discharged quite quickly after that. … They were like, ‘yeah, so we'll put that in place’ and then like my housemate was there and then they [staff members] kind of left and then I was like, ‘so can I go now? Like, can I just walk out?’ And then I went round and I checked with the nurse and she was like, ‘yeah, yeah, you can go.’ So I was like, ‘OK’. I walked home, which was probably not a good idea 'cause I had like loads of stitches and stuff, but I just wanted to leave. So, they didn't check how it was getting home or anything like that.” (person with lived experience of admission).

Institutionalisation

> “Sometimes you haven't been out at all. Or you've been just walked to the shop and back with a member of staff or something like that, and then suddenly you were expected to travel for about an hour and a half, two hours, to get home on public transport. Uhm, it's unrealistic to expect it to go well really. No wonder I keep getting re-admitted.” (person with lived experience of admission).

Institutionalised refers to the difficulties some individuals might face after being discharged from hospital. Some tasks, such as returning home using public transport, people with lived experience of admission reported struggling with, as well as coping with the poorer state of their homes on their return.

> “Normally you’re discharged like when I was at [my local hospital], which was most of the times I've been admitted whilst I've lived in this flat. I mean, at the moment, it was a bus and two trains to get home from. This is when you're discharged, you know. A bus and two trains to get home. You get in, you've got no milk or food or anything in the house 'cause, you've been away for two months, so everything is rotten on the sides, you know, and it's just far too much for you to cope with. But that's just been the norm really is that you just

> got kicked out and left to fend for yourself.” (person with lived experience of admission)

Difficulties being at home following discharge were reported by people with lived experience of admission with words such as ‘lost’ and ‘a drift’. We heard that relationships were impacted from both the individual’s time away in hospital, and what they had experienced there.

> “I felt very lost in my home. It was hard going back to work because everybody had moved on in a way and they hadn't seen the things that I'd seen… at home, suddenly I was on my own for periods of time. And I couldn't manage, but it was just really like – sorry, I always feel like I'm back there [in the mental health hospital] - and it was just really jarring to be on my own 'cause there's been so many people around all the time and I kept hearing the alarms, and it wasn't the alarms it was the oven going off or the microwave going off. But you know, I always felt like I was on high alert. You know, the silence was really difficult.” (person with lived experience of admission)

The importance of communication and structure set by services following discharge from hospital was considered to ease transition.

> “I remember getting a taxi to my flat. I remember feeling a drift in my flat and not really knowing what to do. I didn’t know when I would see a care co-ordinator and I was just waiting for a call.” (person with lived experience of admission).
>
> “My outpatient team were really quick at kind of picking things up again and they made a whole plan of how my appointments were going to be and set me up a timetable. You've got this person, on this day, at this time and you know, every day there was something in the timetable - either a phone call or a meeting with someone and where it was going to be and that was so helpful because from going from an inpatient unit where everything was timetabled and structured. Even when things didn't happen like, for example, there was lots of time where groups didn't run because there weren't enough staff, for example. But you always kind of knew what their expectations were and where you're going to be. And to have a timetable given to me by [at] discharge [was] so helpful for the transition out. Uhm, even if I just knew I had a 10-minute phone call on that day. And that went on for three weeks and it gradually reduced. So, I went from almost kind of daily phone call appointments to uhm, you know, a couple a week and then, you know, kind of transitions back into regular outpatient appointments. And that that was really helpful.” (person with lived experience of admission)

Including carers

> “We have had very different experiences in being able to contact mental health wards to discuss our daughter’s treatment and progress. Sometimes it is because when she is very unwell, she becomes paranoid about us and refuses permission for staff to discuss her with us. When she is well, she has no problem with this. Sometimes a ward manager or nursing staff will be very open to discussions with us, but more often they are too busy to take the time and it is very frustrating.” (carer).

Carers reported that they were offered little support to deal with their loved one’s admission, stay, and discharge from hospital. Many reported frustrations with their loved one’s refusal to consent to share details about their treatment, especially when it concerned the same carers having to correspond with agencies such as the family courts or preparing the home of the person with lived experience for their return.

> “At the moment, she's coming off all her medication [unsupervised], but nobody [from mental health services] was going to tell the family that. And yet we supervise contact with her son.” (carer).

> “The business about knowing the situation that the patient has left behind them and what they will encounter when they go back, I mean, that is critical with somebody who's obviously not been looking after themselves. Well, I know in the past there has been absolutely no concern whatsoever. It's just been left to us.” (carer).

Carers felt that their knowledge of the person with lived experience was not appreciated by staff, which may lead to readmissions if the pattern of behaviours observed by carers is not valued by staff and preventative care is not implemented.

> “Her sectioning also led to children social services getting involved. And … the family courts basically to assess her capacity to parent and also her partner's capacity to parent because he has a learning disability. Uhm, so we were sort of all in the family court for the months while she was also sectioned and what we sort of experienced there was that the mental health team at [the mental health hospital] were not interested in sort of engaging or talking to the family at all. In fact, I think we had about 15 minutes with the Doctor after making a formal complaint … 'cause they weren't speaking to the family at all [asking] about for our insight into how it led to this sort of sectioning. And how we felt she would probably best benefit from treatment, and I think, unfortunately, that also meant that we weren't empowered as a family either to ask the right questions and we didn't know that she could be put on a Community Treatment Order (CTO), given the pattern of her deciding to come off medication, then refusing to be on medication. So, we're now in a situation 2 ½ years down the line where exactly the same thing is happening again and

> she wasn't put on a community treatment order, so the only option is for her to go to be sectioned once she becomes such a significant risk of harm to herself or to others that she's sectioned. And that's really sad because she doesn't live with the son anymore, he lives with his dad and his dad divorced her." (carer).

> "I think that basically carers, family carers - even though we're the ones that pick up the pieces - are completely disregarded, certainly in the Surrey mental health system. And you have to explain yourselves over and over again. You have to sort of fight to get answers. You have to fight to even contribute your insight." (carer).

> '"It's to their [staff's] agenda, it's setting what they want to talk about and they're quite defensive as well and not really wanting to hear from the family or have any empathy really." (carer).

Some family and carers were not contacted or involved during the stay of the person with lived experience in hospital:

> "My family didn't really get involved. They weren't contacted at all and they weren't involved in anything. And to be fair, they didn't try to make contact. But all of the other patients had a lot of family coming in and having family meetings on the unit and all of their people would come to carers group. Or they'd have conversations on the phone if they lived further away and that just didn't happen at all for me." (person with lived experience of admission).

Some people with lived experience of admission reported their families and carers were contacted despite refusing consent. The following statement raises the suitability of contacting an elderly relative living at a considerable distance.

> "My mother [who lives 100+ miles away and is over eighty years old] was [contacted] this time actually. They kept bringing her up and asking her things. I don't know why, because I had refused consent for a family member to be given any details about my treatment, but yet she was still contacted, so I wasn't very happy with that." (person with lived experience of admission)

> **"**It's about identifying who the carers are and who the carers are in that patient's perception as well. I think a lot of people are perceived as carers that that patient doesn't actually want to be involved but involve them." (professional).

Likewise, concerns were raised by people with lived experience of admission about the capabilities of carers and families to keep them safe during a mental health crisis:

> "[The person with lived experience of admission] was really worried to go back home to mum, stepdad, sibling and partner … because she didn't feel they

> could actually act if she was unsafe, if that makes sense … She felt that if she ended up in a crisis moment again, they weren't going to be able to cope with her. So, she was trying to say that, yet the conversation [with staff] kept being like, ‘Oh well, she's got enough people at home’ and so our team member [from an advocacy charity] was able to say, ‘but actually you're not hearing that. She's really concerned that actually they are at home… They're not gonna be able to help. So, what can we do about that?’” (professional).

Concerns over the impact caring for someone has on carers were highlighted. We heard that carers felt their wellbeing was not considered by services and relied on carer support groups.

> “I was on a call with Action for Carers’ support group, and it was just horror story after horror story of how little the system really wants to hear about you or support you. … like people who've been … [caring for their] son or daughter for 20-30 years. And it's just extremely sad and the toll that takes physically and mentally, you know, on carers. And that is not taken into account at all by the mental health system- how has your loved one's inpatient stay impacted you? Her husband? Her son? The family?” (carer).

The whole person

> “It's the psycho, social, medical or whatever it is, you know all these things are needed together. Medication helps some people, talking therapies helps some people, but social support also helps some people, so it's getting the right balance of those things for each individual.” (professional).

This statement from a professional highlights different ways individuals could be treated for mental ill health and stressed the importance of a tailored treatment plan.

These sentiments were echoed by another professional who supports women with learning disabilities and difficulties:

> **“**My ladies have got various needs and wants and being able to do and stuff, so it depends on the individual, I think. I think we just label mental health as like mental health, it isn't. Everybody is an individual. And I think we need to look at the person rather than the label.” (professional).

People with lived experience of admission highlighted the ways in which their time in mental health hospitals affected other aspects of their lives, particularly their roles as partners and parents. Body image concerns following discharge from hospital were also referred to.

> “For me being able to carry on as a mum and a wife is just so important, whereas by the time you've got to, say out of the psychiatric hospital, it took a good year to really get back to normal. And then also the weight problems because of the diet in hospital when you're feeling rough anyway, and I've always liked exercise. You've got so many different things to contend with and you're feeling so vulnerable” (person with lived experience of admission).

This carer emphasises the need for looking at ‘the bigger picture’ of the lives of people with lived experience:

> “Given she's lost her home, she's lost her marriage, she's lost access - properly access to her son, you would think that [the treating psychiatrist had] looked at the big picture” (carer).

As well as stressing the importance of discussing the responsibilities of looking after oneself, particularly if dependants are involved, they reported a hesitancy from staff to do so.

> “I don't know how much things have been explained to her, but - you know, the reason she needs to keep on her medication regime is 'cause you need to have contact and be a mum to your son. And every professional seems to be afraid of, sort of saying that sort of thing to her, so they don't; they just talk about the medication.” (carer).

Considering the context of the life of people with lived experience, as well as a step-by-step individualised discharge strategy with integrated and coordinated care was critical for professionals.

> “Timeliness includes having, appreciating the context of the individual that you're admitting. It's not the same for everybody… Now that's what should happen for everybody is the separate pathway, should be their personal pathway, judging their health conditions and their social context, their abilities, their overall well-being and the things that contribute to it. Making the assessment, then seeing how that changes at points during their treatment until it's approaching the time for discharge. Tracking the assumptions, discharge assumptions, making sure they still all applicable. So, the barriers are you might not know enough about social contexts 'cause you've got a clinical focus. So, what you need then is integrated care and coordinated care. So, coordinate with all the different people who've dealt with this person.” (professional).

5 Research observations

Summary

The amount of information we gathered in this research far outstretched our expectations. Participants were incredibly candid and generous in sharing their experiences with us.

What stands out is that opportunities to learn about how to improve the experiences of admission and discharge to mental health hospital largely hinge on improving community early/rapid response intervention and providing front line services in and out of hospital, with the resources to enable effective and compassionate communication between people with lived experience, carers and professionals.

What support helps to safely avoid an admission to hospital for a mental health crisis

The type of support which is needed for individuals, their families, and carers to safely avoid admission to hospital depends upon their history of mental ill health.

The research heard from people who had a history of accessing mental health services. They were able to talk about what would support them to avoid re-admission to hospital. They were also able to reflect upon their early experiences of mental health distress and what might help those who have no history of accessing mental health services. Carers and professionals also provided valuable insight about the type of support which could help avoid admission to hospital for a mental health crisis.

How new mental health conditions can be managed better at home

Managing a new mental health condition at home is something participants reflected upon as difficult. They told us that front line response to initial symptoms is usually through general practice. However, they viewed general practice as a place from which they were referred to mental health services, not as a provider of mental health services. Participants reported that people with lived experience who present to general practice with mental health symptoms are unlikely to recognise what they are experiencing as mental ill health. They viewed appointment time constraints and triage arrangements in general practice as obstacles to effective consultation with their general practice professionals. They also felt that general practice professionals struggled to link people with lived experience to timely and effective mental health services.

Understanding the systems and resources available to front line clinicians was outside of the scope of this research. The experiences of people with lived experience, their families and carers and mental health professionals highlighted the need to further explore the barriers which front line clinicians experience in helping their people with lived experience to access effective early intervention. Early intervention was identified as the most effective support in safely avoiding admission to hospital and presentation at the emergency department. Partnership and collaboration between agencies which includes carers and people with lived experience was considered essential to creating a climate in which everyone feels secure about what is happening, what will happen, when things will happen and why and how decisions are and will be made.

How known mental health conditions can be managed better at home

Managing a known mental health condition at home was considered to be the most important and difficult thing for people with lived experience to do.

There were multiple challenges around establishing continuity in care; finding and maintaining support and timely intervention when it was needed; keeping people in touch with each other; and having shared language and expectation around the steps to be taken, roles and responsibilities and the difference between contact and intervention.

People with lived experience and carers told us about the challenges of maintaining a positive life experience whilst being mindful of the emergence of patterns of behaviour, situations, anniversaries etc which might contribute to a deterioration. Having a sustainable plan for when things deteriorate was described as a solution to complicated and vulnerable risks.

What helps people get well more quickly and have shorter stays in hospital

The research very clearly tells us that people with lived experience, carers and professionals believe that timely, consistent and accessible community based intensive intervention, prior to, and, at the time of crisis, is what keeps people most well. When admission is the only option there are 6 factors which contribute to or delay discharge and recovery. Action to mitigate those factors was considered essential in enabling people to get well more quickly and support shorter hospital stays.

1. Rapid and unexpected admission
2. Lack of information about what to expect on admission and contact arrangements
3. Containment and punishment
4. Inaccessible settings and services
5. Isolation, exclusion & paternalism
6. Unresolved trauma associated with the stay

Factors included rapid and unexpected admissions, lack of information about the practicalities of admission and establishment of lines of communication between carers and professionals. Rapid admission was also aligned with feelings of containment and punishment. People who have had an admission reported feeling they did not feel cared for but they did feel confined, and that the physical spaces were often sterile and threatening and they felt they were under surveillance. We were told that individuals felt frightened, unsafe and not in a place where they could be healed. The notion of confinement was pervasive when participants described their experience of stay in hospital. There was a strong sense from all participants that hospital is a place to be held, while pharmacology is established, but not a place where healing happens.

People who had experience of an admission told us about how inpatient settings were not inclusive, in that physical health needs and, in particular, the needs of autistic people and people with learning disabilities, were often not met. The experience of being an inpatient in an environment which is hostile to the sensitivity of those people who are neurodiverse was more harmful than therapeutic.

Above all, we were told that the lack of partnership between professionals and people with lived experience and their carers made them feel isolated and excluded from important decisions about their health and care. The systems felt paternalistic and contributed to distress and trauma for both the individuals and their carers. We heard that practices around restraint sometimes felt indiscriminate and unnecessary, and that after a hospital stay participants felt they needed some form of debrief and trauma therapy. Participants acknowledged that in the current system, with inaccessible and scarce community-based services there were no obvious alternatives to their own admission to hospital. However, they were able to identify system changes which could improve their recovery and reduce their admission.

How discharge arrangements could be improved

The feedback we received about discharge was mostly focussed upon the often unexpected timing.   People who have had an admission reported feeling abandoned and unprepared for discharge. Carers were alarmed at the general lack of preparation and communication about upcoming discharge. They described a lack of coordination between agencies which would ensure continuity of care, handover between hospital and community services and planning for suitable accommodation. Concerns were raised about being discharged without medication and information about how to get medication. Perhaps the most disturbing findings were around individuals being told they were discharged without any warning and after a stay in an environment where they had become institutionalised, they, without warning or support, were expected to find their own way home. In some cases that meant traveling across counties, on public transport to sometimes empty homes, with empty fridges and sometimes fridges with rotten food and rancid bins.

Summary

This research looked at the experiences of people who had experienced admission, their families and carers and professionals of mental health from community life through the process of an admission to hospital and discharge back to community. The touch points in the process were around accessing timely and effective intervention. However, it was this idea of intervention that was missing. The dominant discourse throughout the research was of support. This was in the absence of therapy or intervention. It is clear from the stories we were told that people perceive there to be a lack of organised, reliable, and accessible early intervention from qualified mental health clinicians.

We heard that participants feel the current volume of crisis has outstretched resources. Crisis is being normalised to the point that when people present in a state of need there is rarely any therapeutic option available to them. Frontline mental health services are often staffed by non-clinicians and individuals feel frightened because they are not getting the clinical intervention they feel they need. They are often left feeling abandoned and that clinicians are often out of their reach or invisible in the system.

6 Recommendations

We are looking for Surrey-based adults (18+) with experience of admission to, and discharge from mental health hospital to develop recommendations from the In and Out Project’s findings.

Professionals (including volunteers) with experience of supporting individuals during an admission and discharge are welcome to join too.

Meetings will be held online (by Zoom).

Please contact us if you would like to join the recommendations group.

E-mail: research@surreycoalition.org.uk

Phone: 07379 486 479 (Kirsty) / 07599 693 182 (Alex)

For more information about The Coalition’s research project, please visit: https://surreycoalition.org.uk/imhn/blogs/research-blogs

#InAndOutProject

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8 Appendices

Appendix 1.	Service users and Carer’s Survey
Appendix 2.	Professionals Survey
Appendix 3.	Participant Consent Form
Appendix 4.	Participant Information Sheet
Appendix 5.	Debriefing Sheet

Appendix 1. Service users and Carers Survey

Admission to and Discharge from Inpatient Mental Health Hospitals

If you require assistance with this survey or in an alternative format, please contact Kirsty Smith at research@surreycoalition.org.uk / 07379486479.

Please read the attached Participant Information Sheet (pages 13-17) before starting this survey.

Survey closes on Sunday, 4 September 2022 at 11:59PM.

This survey is for adults (18+) living in Surrey who have been admitted to and discharged from a mental health hospital since 2017, and their carers. Please note that the hospital does not need to be in Surrey but must be in the UK.

Surrey Coalition of Disabled People are working on a research project for Surrey Heartlands which is looking at what can lead to an admission, and how to better support safe and timely discharge. With your help in this survey, we hope to identify opportunities to improve mental health services in Surrey.

Please answer the questions below from your own point of view. You can skip any questions which make you feel uncomfortable. This survey is anonymous, meaning no one will know who has completed it, unless you provide your contact details at the end of this survey. Even in this case, your details will not be shared outside of the research team.

Please base your answers on the admission which you can remember the best, or the most recent one.

Thank you for taking the time to help with this research.

Definitions

Admission – Going into hospital for treatment

Carer - Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support

Discharge – Coming out of hospital after treatment

Hospital - Inpatient services, wards, mental health units, PICU, A&E

Inpatient - The patient is formally admitted to stay on a ward/unit for an extended period of time e.g., more than 24 hours

Service User - A person who is using inpatient mental health services e.g., an individual who is a patient in a mental health ward

Question 1

We are aware you may have experience as a service user and carer. Please answer this survey from the point of view you feel most comfortable with.

Are you answering this survey as:

☐ A service user (meaning you have been admitted to and discharged from an inpatient mental health hospital since 2017)

☐ As a carer (meaning you have cared for or supported someone who has been admitted to and discharged from an inpatient mental health hospital since 2017)

Question 2

How many times have you/the person you cared for been admitted to an inpatient mental health hospital since 2017?

Question 3

Before admission, were you or the person you cared for or supported in contact with any mental health services?

E.g., Safe Haven, Community Mental Health Team, Home Treatment Team, Mary Frances Trust, Catalyst, Talking Therapies

☐ Yes

☐ No

☐ Unsure

Tell us more:

Question 4

What do you remember about the time leading up to your/their admission?

E.g., Things that happened, who you contacted and how they responded, what was worrying you

Question 5

What can you tell us about the hospital experience?

E.g., Which hospital/hospitals you/they were admitted to, how long the process took, if you/they were transferred from one hospital to a different one

Question 6

What happened on the day you/ they were admitted to hospital?

E.g., What happened, who was involved, how long did it take, how did you/they get there, were you/they sectioned or was the admission voluntary

Question 7

Do you think the admission was needed?

☐ Yes

☐ No

☐ Unsure

Tell us more:

Question 8

What helped/ could have helped your/their recovery during the inpatient stay?

E.g., your involvement in treatment planning, timely meetings, preparation for admission and/or being transferred

Question 9

What do you remember about the time leading up to being discharged from the hospital?

E.g., Things that happened, discharge plans, involvement in discharge plans, time to prepare, home leave, carers visiting, medication, accessing groups/therapies

Question 10
What do you remember about your/their discharge from the hospital?

E.g., What happened, who was involved, how long did it take, were you given a plan, were you on medication, involvement of home treatment teams

Question 11

What do you remember about the time after your/their discharge from hospital?

E.g., Who and what was important to you, housing, finance, activities, safety, benefits, friends

Question 12

Do you feel the discharge from hospital happened at the right time?

☐ Yes
☐ Too early
☐ Not soon enough
☐ Unsure

Tell us more if you wish to:

Is there anything else you would like to share about your experience of being an inpatient or a carer of an inpatient?

Would you like to take part in a follow-up conversation to discuss your answers in more detail? This will either be in-person, over the telephone, or over Microsoft Teams/Zoom.

☐ Yes

☐ No

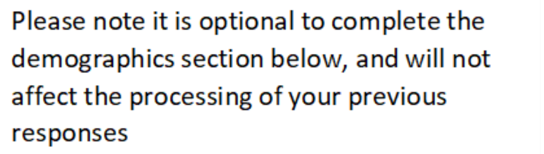
If yes, please provide your preferred contact details and the best time to contact you:

Email/Phone number:

If you would like to be entered into a prize draw to win a £20 Amazon voucher, please leave your email below:

Thank you for taking the time to complete this survey.

Participant Demographics



Please note it is optional to complete the demographics section below, and will not affect the processing of your previous responses

Ethnicity

Please tick which ethnicity you are, or write it in the box provided

Asian or Asian British
Indian
Pakistani
Bangladeshi
Chinese
Any other Asian background

Black, Black British, Caribbean or African
Caribbean
African
Any other Black, Black British, or Caribbean background

Mixed or multiple ethnic groups
White and Black Caribbean
White and Black African
White and Asian
Any other Mixed or multiple ethnic background

English, Welsh, Scottish, Northern Irish or British
Irish
Gypsy or Irish Traveller
Roma
Any other White background

Other ethnic group
Arab
Prefer not to say
Other
Please state:

Age

Please tick which age group you are in
18-24 65+
25-34
35-44
45-54
55-64
65+
Prefer not to say

Is the gender you identify with the as your gender registered at birth?

Yes

No

Prefer not to say

Sexuality

Please tick the sexuality you best identify with, or write it in the box provided

Heterosexual (attracted to people of the opposite gender)

Gay (attracted to people of the same gender)

Bisexual (can experience attraction to people of more than one gender)

Asexual (little or no sexual attraction to others of any gender)

Pansexual (can experience attraction to any person, regardless of that person's gender, sex, or sexuality)

Other

Please state:

Prefer not to say

Disability status

Would you consider yourself to be disabled?

Yes

No

Religion/faith

Please tick the religion you best identify with, or write it in the box provided

Christianity

Islam

Hinduism

Buddhism

Judaism

Atheist (you do not believe in God)

Agnostic (you believe the existence of a God is unknown)

No religion

Other

Please state:

Prefer not to say

Appendix 2. Professionals Survey

Admission to and Discharge from Inpatient Mental Health Hospitals

If you require assistance with this survey or in an alternative format, please contact Kirsty Smith at research@surreycoalition.org.uk / 07379486479.

Please read the attached Participant Information Sheet (pages 8-12) before starting this survey.

Survey closes on Sunday, 4 September 2022 at 11:59PM.

This survey is aimed at Surrey-based mental health workers (including volunteers) that support people with mental ill-health who may be at risk of a hospital admission or who have experienced admission and discharge from hospital, since 2017.

Surrey Coalition of Disabled People are working on a research project for Surrey Heartlands which is looking at what can lead to an admission, and how to better support safe discharges. With your help in this survey, we hope to identify opportunities to improve mental health services in Surrey.

Please answer the questions below from your own point of view. You can skip any questions which make you feel uncomfortable. This survey is anonymous, meaning no one will know who has completed it, unless you provide your contact details at the end of this survey. Even in this case, your details will not be shared outside of the research team.

Please provide an overview of your experience with admissions or discharges, and your views on how the experience can be avoided or improved.

Thank you for taking the time to help with this research.

Definitions

Admission – Going into hospital for treatment

Carer - Anyone who cares, unpaid, for a friend or family member who due to illness, disability, a mental health problem or an addiction cannot cope without their support

Discharge – Coming out of hospital after treatment

Hospital - Inpatient services, wards, mental health units, PICU, A&E

Inpatient - The patient is formally admitted to stay on a ward/unit for an extended period of time e.g., more than 24 hours

Service User - A person who is using inpatient mental health services e.g., an individual who is a patient in a mental health ward

Question 1

Please briefly outline your role:

E.g., Volunteer, service you are based in, private or public sector, general duties

Question 2

What is your knowledge of the admission process within the service/s you work in?

Question 3

What do you think could prevent or reduce admissions to mental health hospitals?

Question 4

What is your knowledge of the discharge from hospital process within the service/s you work in?

Question 5

What factors contribute to optimum discharge?

Question 6

What factors contribute to readmission?

Is there anything else you would like to share about your experience of being a mental healthcare worker?

Would you like to take part in a follow-up conversation to discuss your answers in more detail? This will either be in-person, over the telephone, or over Microsoft Teams/Zoom.

☐ Yes

☐ No

If yes, please provide your contact details and the best time to contact you:

Email/Phone number:

Thank you for taking the time to complete this survey.

Participant Demographics

Please note it is optional to complete the demographics section below, and will not affect the processing of your previous responses

Ethnicity

Please tick which ethnicity you are, or write it in the box provided

Asian or Asian British
Indian
Pakistani
Bangladeshi
Chinese
Any other Asian background

Black, Black British, Caribbean or African
Caribbean
African
Any other Black, Black British, or Caribbean background

Mixed or multiple ethnic groups
White and Black Caribbean
White and Black African
White and Asian
Any other Mixed or multiple ethnic background

English, Welsh, Scottish, Northern Irish or British
Irish
Gypsy or Irish Traveller
Roma
Any other White background

Other ethnic group
Arab
Prefer not to say
Other
Please state:

Age

Please tick which age group you are in
18-24 65+
25-34
35-44
45-54
55-64
65+
Prefer not to say

Is the gender you identify with the as your gender registered at birth?
Yes
No
Prefer not to say

Sexuality
Please tick the sexuality you best identify with, or write it in the box provided
Heterosexual (attracted to people of the opposite gender)
Gay (attracted to people of the same gender)
Bisexual (can experience attraction to people of more than one gender)
Asexual (little or no sexual attraction to others of any gender)
Pansexual (can experience attraction to any person, regardless of that person's gender, sex, or sexuality)
Other
Please state:
Prefer not to say

Disability status
Would you consider yourself to be disabled?

Yes
No

Religion/faith
Please tick the religion you best identify with, or write it in the box provided
Christianity
Islam
Hinduism
Buddhism

Judaism
Atheist (you do not believe in God)
Agnostic (you believe the existence of a God is unknown)
No religion
Other
Please state:
Prefer not to say

Appendix 3. Participant Consent Form

Surrey Coalition of Disabled People
Astolat, Coniers Way, Burpham, Guildford, Surrey GU4 7HL

In and Out: Surrey-based Service User and Carer Perspectives on Admission to and Discharge from Inpatient Mental Health Services

PARTICIPANT CONSENT FORM

Before you decide to take part, you must read the accompanying **Participant Information Sheet.**

This form is to confirm that you understand what the purposes of the research project are, what will be involved and that you agree to take part. If you are happy to participate, please initial each box to indicate your agreement, sign and date the form, and return to the researcher.

Please do not hesitate to ask questions if anything is unclear or if you would like more information about any aspect of this research. It is important that you feel able to take the necessary time to decide whether you wish to take part.

1. Taking part in the study	
I have read and understood the participant information sheet, or it has been read to me. I have been able to ask questions about the study and my questions have been answered to my satisfaction.	
I consent voluntarily to be a participant in this study and understand that I can refuse to answer questions and I can withdraw from the study at any time, up until 11 September 2022, without having to give a reason.	
I understand that the interview will be recorded for the purposes of transcription.	
2. Use of information in this study	
I understand that the information I provide will be used for reports, presentations, and short films (which will available online)	
I agree that my information can be quoted in research outputs.	
I understand that all information I provide will be kept confidential and stored securely, and that only the researcher will have access to it.	

Name of Participant	Date	Signature
Name of Researcher	Date	Signature

Appendix 4. Participant Information Sheet

If you require assistance with the participant information sheet or in an alternative format, please contact the researchers.

Surrey Coalition of Disabled People
Astolat, Coniers Way, Burpham, Guildford, Surrey GU4 7HL

Researchers:
Dr Dawn Benson
Alex Hird research@surreycoalition.org.uk | 07599 693 182
Kirsty Smith research@surreycoalition.org.uk | 07379 486 479

In and Out: Surrey-based Service User and Carer Perspectives on Admission to and Discharge from Inpatient Mental Health Services

PARTICIPANT INFORMATION SHEET

You are being invited to take part in a research project about service user and carers' experiences of admission to and discharge from mental health hospitals. To help you decide if you want to take part, it is important for you to understand why the research is being done and what it will involve. Please read the following information carefully and ask us if there is anything that is not clear or if you would like more information. Your decision about whether to participate in this project will no way affect any services you receive.

Thank you for reading this.

Definitions

- Service user: A person who is using health services e.g., an individual who is a patient in a mental health ward
- Carer: an adult who provides care for another adult.
  An adult who provides care under a contract, or as voluntary work is not regarded to be a carer (as defined by the Care Act 2014)

- Hospital: inpatient services, wards, mental health units
- Inpatient: the patient stays there overnight

What is the purpose of the project?

The purpose of this study is to explore factors which contribute to emergency admission and delayed discharge from mental health hospitals, and to identify opportunities for improvement across services. This research project is being carried out by researchers from Surrey Coalition of Disabled People for Surrey Heartlands. The findings will be disseminated as a report, presentations, and short films (which will be available online).

Why I have been asked to take part?

You are being asked to take part if you:

- have been admitted to or discharged from a mental health hospital in the UK since 2017, or you cared for someone who experienced this.
- are over 18 years old.
- lived in Surrey at the time of your/their admission.

Taking part in this research is entirely voluntary.

If you decide to take part, you will be given this information sheet to keep and you will be asked to sign a consent form. **Please note that if you change your mind then you can withdraw from the study until 11 September 2022**. You will not be asked to give a reason for doing so. To withdraw from the study please contact the researchers. Unfortunately, after this date the research will have been prepared for analysis and write-up, and we will not be able to extract your information from the study.

What will happen to me if I take part?

You will be asked to participate in an online survey, and an **optional** follow up research conversation. The survey will take about 10 minutes of your time, with the follow-up conversation lasting around 45 minutes. The follow-up conversations will be held in-person/over the phone/over Zoom or Microsoft Teams.

Will I be recorded, and how will the recorded media be used? With your permission, the research conversations will be recorded and then transcribed. The transcripts will be anonymised. Once transcribed, the recordings will be destroyed. The transcripts and consent forms will be held securely, and not retained for longer than necessary.

What are the possible disadvantages and risks of taking part?

There are no foreseeable risks associated with this study and it is hoped that you enjoy taking part. However, if you become uncomfortable discussing your experiences, we can step out at any point and you will be referred to an appropriate source of support.

Will my taking part in this project be kept confidential?

All personal information about you (e.g., name, contact details) will be kept confidential. Information held electronically will be and held securely in Surrey Coalition of Disabled People's IT system and paper documents, such as your consent form, will be stored securely in a lockable cabinet.

The data for this project will be in the form of anonymised quotes from surveys and research conversations. Participants who are quoted will be given a pseudonym, and any personal information about them such as their job will be anonymised so that they cannot be identified from the quote. Only the researchers, Dr Dawn Benson, Alex Hird and Kirsty Smith, will have access to your personal details and data.

In accordance with the terms and conditions of funded research, it is possible that the research data (not personal contact details data) collected within this project may be required to be deposited in an approved data repository for archiving and sharing. All data will be fully anonymised before it is deposited, and no individual will be identified in the archived data.

Please note that in exceptional circumstances confidentiality may have to be breached in cases where a person is considered to be at risk or if required by law.

What happens immediately after data collection?

You will be debriefed and will have the opportunity to ask further questions regarding the study should you wish to do so.

Who has reviewed the project?

This project has been reviewed by the In and Out steering group which consists of a service user, a carer, a clinical professional, and staff from the Independent Mental Health Network (IMHN) and Adult Social Care.

Does the project conform to GDPR guidelines?

This research is being conducted in accordance with the General Data Protection Regulation guidelines. The data controller for this project will be Surrey Coalition of Disabled People.

In the unlikely event that you have cause for complaint, please contact Helen Anjomshoaa, Operations Manager at Surrey Coalition of Disabled People on helen@surreycoalition.org.uk or at the address above.
If you remain dissatisfied with the response, you may wish to contact the Information Commissioner's Office (ICO). Contact details, and details of data subject rights, are available on the ICO website at: https://ico.org.uk/for-organisations/data-protection-reform/overview-of-the-gdpr/individuals-rights/

Appendix 5. Debriefing Sheet

Surrey Coalition of Disabled People
Astolat, Coniers Way, Burpham, Guildford, Surrey GU4 7HL

Researchers:
Dr Dawn Benson
Alex Hird research@surreycoalition.org.uk | 07599 693 182
Kirsty Smith research@surreycoalition.org.uk | 07379 486 479

In and Out: Surrey-based Service User and Carer Perspectives on Admission to and Discharge from Inpatient Mental Health Services

Debriefing Sheet

Thank you.

If you have been affected by this research, you may wish to contact your GP or the following organisations:

- **Mind**
  0300 123 3393 (Open Monday to Friday, 9am-6pm)
  www.mind.org.uk
- **Samaritans**
  116 123 (Open 24/7)
  www.samaritans.org
- **Shout**
  Text ‘Shout’ to 85258 (Open 24/7)
  www.giveusashout.org
- **Action for Carers Surrey Helpline:**
  0303 040 1234 (Open Monday to Friday, 9am-5pm),
  www.actionforcarers.org.uk

Please feel free to contact Alex Hird and/or Kirsty Smith if you have any questions or comments regarding this study.

If you require assistance with the debriefing sheet or in an alternative format, please contact the researchers.

To cite: Benson, D. Hird, A. & Smith, K. (2022). People with lived experience, carer & professional perspectives on avoiding admission to mental health hospitals, and how discharges could be safely made more quickly, Surrey Coalition of Disabled People. Available from: surreycoalition.org.uk

Surrey Coalition for Disabled People (The Coalition)
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