



IN AND OUT

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

CONTENTS

- 4 Background
- 6 Research aim
- 7 Research objectives
- 9 Research observations summary
- 10 What support helps to safely avoid an admission to hospital for a mental health crisis
- 11 How new mental health conditions can be managed better at home
- 12 How known mental health conditions can be managed better at home
- 13 What helps people get well more quickly and have shorter stays in
- 15 How discharge arrangements could be improved
- 17 Recommendations



““

I didn't find them (community service) particularly helpful, but not because they weren't. It's just when you ring, the person who's assessing you is probably less experienced than the person I'm used to dealing with when I have problems so I spent a long time talking through things for them to then say I need to escalate this to the next level, which I knew would be the case. So I didn't go... in the end, but for me it just for me it created more of a tier of complexity 'cause when I'm like that, I need more than what that junior person can offer.

””

(person with lived experience)

““

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)



““

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)

““

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)

““

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)

BACKGROUND

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 unnecessary admission to hospital for a mental health crisis?
- What support could reduce length of stay?
- How discharge arrangements could be improved?

BACKGROUND (continued)

The research was carried out under the supervision of a principal researcher and two 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 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.

RESEARCH PARTICIPANTS

The research participants included people with lived experience, carers and professionals as shown below:

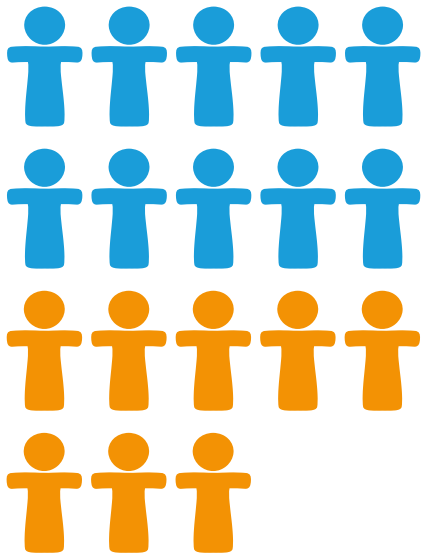


Survey

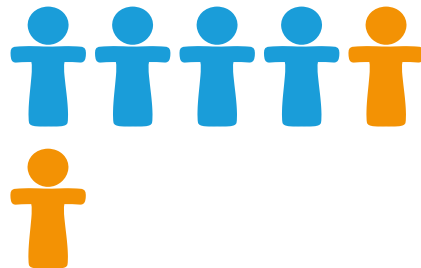


Interviews

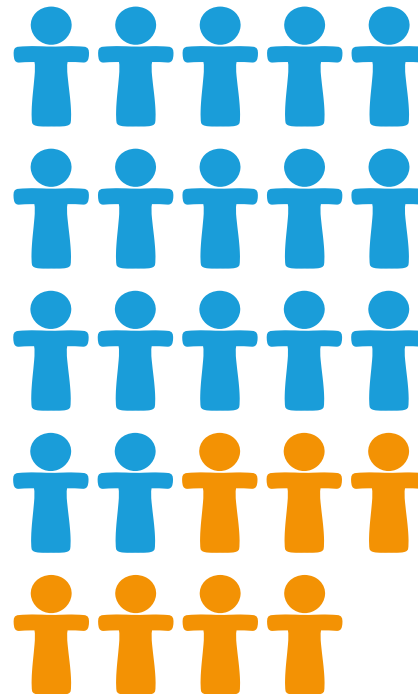
Person with lived experience



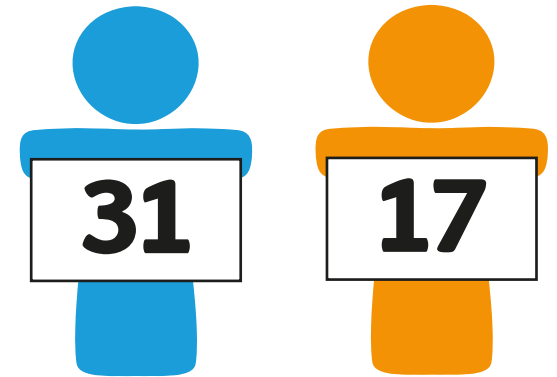
Carers



Professionals
(including volunteers)



Total





RESEARCH AIM

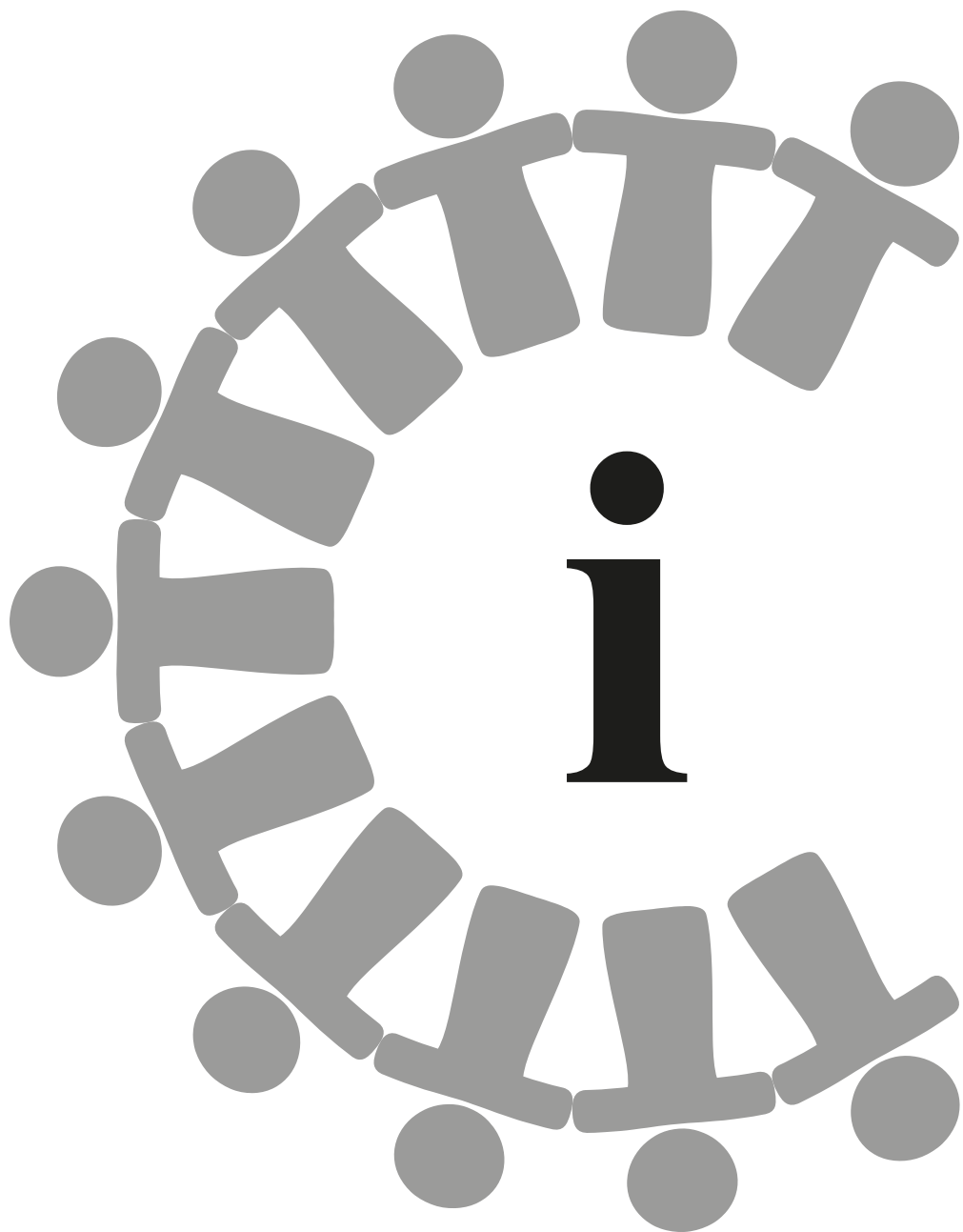
This Surrey-based participatory project engaged with local people who have had an admission, their carers, and professionals, to understand their experience of admission to and discharge from UK inpatient mental health services.

The factors which contributed to emergency admission and delayed discharge were explored, to identify opportunities for quality improvement across the services.



RESEARCH OBJECTIVES

- Engage with local people with lived experience, their carers, and professionals
- Apply qualitative participatory methodology and data collection methods to foreground the voices of people with lived experience and their carers by drawing upon methods and analysis which include a systems approach, interviews and surveys
- Explore the experiences of people who have had an admission 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



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 individual people with lived experience, 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 patients 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 patients 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 who had an experience of an admission, 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 six 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 and 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 with lived experience 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 people with lived experience felt frightened, unsafe and not in a place where they could be healed. The notion of confinement was pervasive when people with lived experience 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 an 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 people with lived experience and their carers. We heard that practices around restraint sometimes felt indiscriminate and unnecessary, and that after a hospital stay people with lived experience felt they needed some form of debrief and trauma therapy. People with lived experience 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 with lived experience 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 with lived experience, 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 overstretched 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.



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