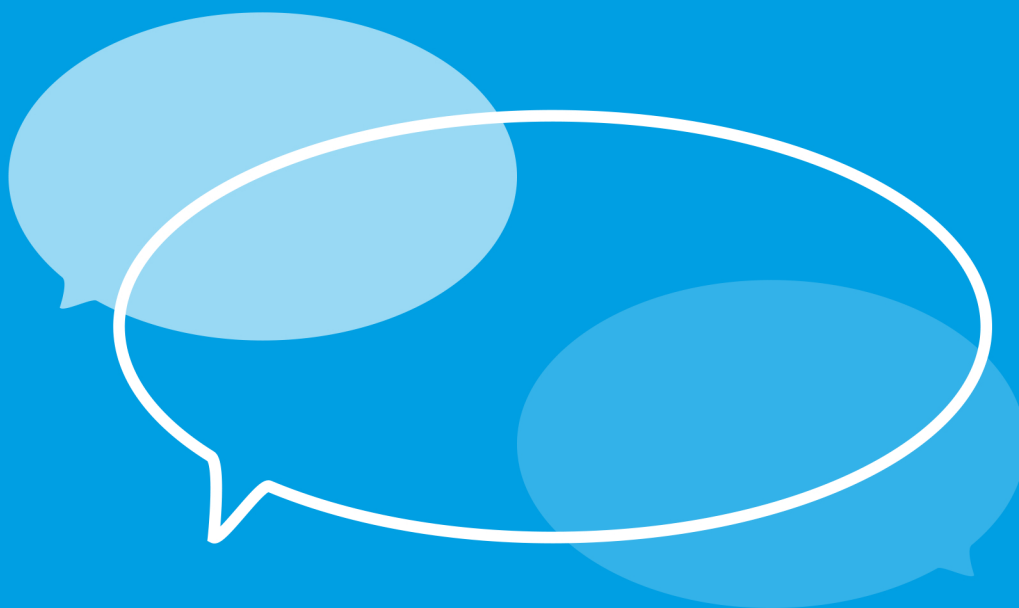


No Voice, No Choice? Making the Mental Health Act more person centred

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Foreword



When the Mental Health Act was introduced in 1983, it was assumed that people severely affected by mental illness were not capable of taking an active role in their care or treatment. While attitudes to mental health, the deprivation of liberty, and the principles of

involving people in their care have evolved significantly (partly due to the campaigning of our members and beneficiaries) over the past 35 years, the Mental Health Act has not.

The Act remains the only piece of healthcare legislation which assumes that people cannot make meaningful choices due to the nature of their illness. Nevertheless, there are encouraging signs that this may change. The past decade has seen increasing recognition of the legal and practical importance of involving people in treatment decisions.

In the midst of this shifting healthcare landscape, the Prime Minister announced in October 2017 that there would be a review of the Mental Health Act, chaired by Professor Sir Simon Wessley. This is a once-in-a-generation opportunity to reform this vital legislation, and to make a vast difference in the lives of people who rely on the Act when they are at their most vulnerable.

This research can help inform the changes that are needed to ensure that the Mental Health Act is better at including and involving the people who are detained under it, as well as their families, friends, and carers. Time in hospital should be a step towards recovery, not a place where people feel entirely detached from society and the rights they have as part of it. This report shows that this is too often the case.

Our report is also an important example of what can be achieved in partnership, when organisations are committed to meaningful change and share their expertise in order to work towards a common goal.

The Mental Health Act can only be truly reformed if people come together to create solutions, listening to and learning from each other's perspectives, and using their connections to develop practical reforms which work at every level. This research has therefore brought together clinicians, service users, and carers so that they can share their visions of how the Act might be changed, both legislatively and in practice.

We will be working hard to develop practical materials and tools which empower service users and clinicians to address some of the issues which emerged from the

research, as well as calling for legislative change to ensure that any new Act puts service users and those who love them at its heart.

Times have changed a great deal since 1983, and this legislation has not stood the test of time. This report is one of the first steps towards building a reformed Mental Health Act that's fit for the 21st century.

I am deeply grateful to Adelphi Research UK for the hard work that they have put into this crucial project and to Janssen-Cilag Ltd for the financial support they provided.

A handwritten signature in black ink, reading 'M. Winstanley'.

**Mark Winstanley, Chief Executive,
Rethink Mental Illness**



Executive Summary

- The research has highlighted a range of key insights and associated recommendations. However, as the sample was relatively small, the findings are indicative rather than representative and we recommend further validation ahead of implementation.
- Service users who had been detained under the Mental Health Act told us they had minimal involvement in decision making and their choices were largely disregarded.
- Changes to the Nearest Relative provision within the current legislation would be welcomed to give service users the right to select who they think is suitable and appropriate.
- Very few service users and carers involved in the research were aware of the option to make and record Advance Decisions regarding their care as part of the Mental Health Act although there was a clear appetite for these.
- Although Healthcare Professionals (HCPs) said they assess service user capacity to make decisions there appears to be no formal or consistent approach to doing so.
- There were significant gaps in the information provided to service users and carers regarding their rights whilst detained. Information on treatment options and a lack of consistency in terms of what was received and how it was explained.
- Time pressures and shortage of staff (nurses in particular) were cited as a key reason for the inconsistency of information provided.
- Differences in the attitude and approach of HCPs to service users were also reported to have a fundamental impact, both positive and negative, on the quality of care received.
- Independent Mental Health Advocates (IMHAs) were perceived by both service users and healthcare professionals to be an invaluable resource to guide service users through the system.
- The research uncovered a feeling that detention under the Mental Health Act takes a standard, 'one-size-fits-all' approach with little focus on the service user themselves.
- Many service users described their experiences as similar to being imprisoned rather than being cared for with a complete loss of any sense of control over their lives.

Key Recommendations

The research has highlighted a number of key areas worthy of consideration to ensure that the rights of people detained under the Mental Health Act are protected and overall care is improved.

These suggestions include:

- Greater overall involvement of service users in their care via mandatory access to IMHAs within 48 hours of admission (currently, service users have a right to access advocacy, but not within set timeframes).
- The standardisation of information provided to include more information on rights to tribunals and appeals, along with details of medicines and potential side effects.
- A change to legislation on the appointment of the Nearest Relative, to give service users the right to choose their own representative.
- Inclusion of Advance Decisions as a routine component within the care pathway and legislative changes that give legal weight to Advance Decisions.



Background

IMHAs: Independent Mental Health Advocates

A person who is trained to work within the framework of the Mental Health Act to support people to understand their rights under the Act and participate in decisions about their care and treatment.

Research Objectives

The objective of the research was to identify any limitations to the way care for those detained under the Mental Health Act is executed and to provide practical suggestions for changes to legislation and practice. The research was designed to address three overriding questions:

- What are the current approaches to decision making and involvement of service users and their carers from detention to discharge?
- What are the current limitations or frustrations with the way the Act is executed including awareness of Advance Decisions and the Nearest Relative provision?
- How might the care under the Mental Health Act be improved through changes to legislation and practice?

Sample and Methodology

A qualitative sample of 24 participants took part in the research: 8 people who had previously been detained, 3 carers, 13 HCPs, including psychiatrists, community and hospital based mental health nurses, social workers and IMHAs.

The sample was not intended to be quantitatively representative; however, a mix of gender identities, sexual orientation, a spread of ages and representation from Black and Minority Ethnic Groups (BAME) were included.

Fieldwork took place between 15th November and 15th December 2017. Further details on the methodology and organisations involved can be found in the appendix to this report.

Research Limitations

The findings from this research are based on a relatively small qualitative sample and are therefore indicative, rather than representative, of the wider population. Further validation of the themes in a quantitative sample is recommended.

As the service users, carers and IMHAs were recruited via the Rethink Mental Illness network, some of the respondents may have been more engaged than would be expected had recruitment taken place independently of the charity.



Key Findings

MDT: Multi-Disciplinary Team

This is a group of healthcare and other professionals who are members of different disciplines or professions e.g. psychiatrists, social workers, nurses, each providing specific services to the service user. The activities of the team are often brought together using a personalised care plan.

HCPs: Healthcare Professionals

In the context of this report, HCPs include psychiatrists, social workers, and mental health nurses based in either the hospital or the community as well as Independent Mental Health Advocates (IMHAs).

Choice and Involvement in Decision Making

We explored how much choice service users were provided with at different stages of detention and asked them to give us a rating of how involved they felt in the decision making process.

The majority of service users we spoke to felt that they had minimal involvement in their care and their choices were largely disregarded when detained under the Mental Health Act.

Capacity for decision making was assumed to be lacking for the majority, and there was no formal process for assessing capacity.

This lack of involvement extended to decisions regarding the location of detention, treatment choices, prescribing decisions and use of injections versus other treatments. Perceived involvement at discharge was slightly better, carers in particular reported that they felt that it was in the unit's interest to engage at that point in order to ensure discharge of the service user into the community went ahead unhindered.

Many of the service users and carers involved in the research felt that the treating psychiatrist took complete control of treatment decisions when they were detained. Feedback from service users and carers we spoke to indicated that psychiatrists assumed that the majority of people detained had limited mental capacity and therefore their opinions and views were rarely sought.

“...I know I was very unwell but amongst the psychotic thoughts were also some rational thoughts and opinions that no-one sought to unravel...”

Service user

A key frustration for many service users was that they felt it was too easy for one physician to make decisions about their treatment. Some of the service users we spoke to felt that decisions about treatment, especially when initially detained, should be broadened to include the other community based HCPs who are more familiar with their needs and involved in their care.

In addition, carers or family members reported that they were rarely involved in the decision making process unless they had actively insisted on involvement or made a fuss.

“...I kicked up a fuss when he was given some medication that resulted in some side effects we weren't expecting or told about. They know now not to make decisions without involving me...”

Carer

Assessing Capacity for Decision Making

We uncovered a clear disconnect between the service users' perspectives on their involvement compared with the HCPs. From the feedback we heard, there appears to be no formal or consistent approach to assessing capacity for making decisions; it seems to be based on the physician's judgement and experience.

On the one hand, some HCPs cited a 'three star' approach which involved the service user, the family member and the multi-disciplinary team (MDT) working together on a care plan. However, HCPs stated that they ultimately have a responsibility to make decisions on behalf of the service user if they feel that the service user lacks insight or capacity, in order to safeguard service users and others.

On the other hand, the psychiatrists we spoke to stated that they often make decisions on treatment independently, without question or consultation, as they believe the majority of service users lack capacity to make informed decisions and, furthermore, they consider decision making their responsibility.

The majority of HCPs said they do check capacity for decision making in people when they are first detained

under the Mental Health Act. Some HCPs stated that they consider patients to have capacity if they agree to take medication in the way prescribed.

HCPs further reported that if a patient does not consent to the medication suggested, the doctor will usually request a second opinion but can proceed without it. However, the service users we spoke to suggested that this was not the case and some had experienced the administration of medication against their will and without any prior explanation.

“I refused to take it orally. I said if you can’t explain why I need to take this medication I’m not taking it. So I was injected in my lower back against my will fifteen times”

Service user

The current approach to assessing capacity for decision making for those detained was mainly based on a physician’s experience and judgment. This lack of formal assessment may impact on the consistency of care delivered.

Involvement in Review Meetings

HCPs told us that MDT reviews for people detained under the Mental Health Act take place on a regular basis, although service users and carers suggested that their involvement is infrequent and they often feel disconnected from the discussions taking place.

The HCPs also told us that the weekly care plan meetings and ward rounds are the key forums for decision making. IMHAs are sometimes involved in these care planning meetings if a service user has requested them to be present, but we heard from the service users we spoke to that access to advocacy support was scarce.

HCPs also mentioned that the service user, carer and care-coordinator should be invited to the weekly reviews. However, the inference from some of the HCPs was that service users are not routinely involved in discussions and this was validated by the service users themselves.

“Decisions are made by the professionals really because sometimes they’re not in any state of mind to make decisions”

Mental health worker

“We have to involve the patients as part of the CPA....the weekly review by the MDT takes place which, ideally, they should attend as well as their care-coordinator and their carer or family member”

Psychiatrist

“In terms of the actual say you have, you don’t have any say; you’re lucky if the doctors see you”

Service user

“I didn’t have much involvement at all. At some points I was too ill but as I got better there was still that assumption”

Service user

Suitability of the Nearest Relative Mechanism

Nearest Relative is a legal term used in the Mental Health Act. The Nearest Relative mechanism uses a hierarchical list to determine a person that is involved in a service user’s care. The Nearest Relative has some rights when someone is, or may be, detained under the Mental Health Act.

The Nearest Relative can request assessments for their relative, that they be discharged, and some information on a patient’s treatment. The Nearest Relative mechanism can sometimes lead to inappropriate people being involved in the care and treatment of people detained under the Mental Health Act.

The majority of HCPs we spoke to during the research felt that it was very uncommon for the Nearest Relative mechanism to cause any issues. However, they did state that they can ‘work around’ the definition of the Nearest Relative if the appointed relative is deemed, in practice, to be inappropriate. We heard from the HCPs that they have the ability to have the Nearest Relative discharged in order for someone else to be appointed.

“I don’t think there’s a simple solution but as professionals you’ve got a duty of care, if you have got concerns you need to raise that and act towards discharging that Nearest Relative, which I have done”

Forensic social worker

The majority of service users we spoke to felt that the Nearest Relative provision worked well. However, some service users felt that there were issues because a relative was allocated without consideration of any 'closer' relatives or because the relationship with the Nearest Relative had previously broken down or was destructive.

All of the service users we spoke to felt they should have the right to choose their own Nearest Relative. Some service users and carers were aware of the legal process required to discharge the Nearest Relative, but it was felt to be both complicated and time consuming.

“...this one's stuck in stone that it should be your eldest relative on your maternal or paternal side and I just think that's stupid; you should be able to choose who's your Nearest Relative...”

Service user

There was also dissatisfaction expressed by some service users regarding the potential for the psychiatrist to override any requests for a change to the assigned Nearest Relative. Some service users expressed frustration because they felt that the psychiatrists may be unaware of issues such as existing family problems. For these service users this frustration resulted in a lack of confidence in the treating physician.

There is a clear need to review the Nearest Relative mechanism within the current legislation, to give service users the right to select their representative.

Awareness and Appetite for Advance Decisions

Advance Decisions refer to the way a person can state how they would like to be treated in the future if they are unable to decide for themselves.

We asked service users and carers if they had been given the opportunity to make an Advance Decision about their treatment but very few were aware that this is possible. However, there was a clear appetite for them.

“...I think certainly when a person recovers from a mental illness there is absolutely no question that they would then have the capacity to then make decisions in advance on how they would actually wish to be treated...”

Service user

Those who knew about Advance Decisions had previously been made aware by Rethink Mental Illness or another mental health charity and not by a HCP.

Some of the mental health workers interviewed felt that the ability to make Advance Decisions should be promoted amongst service users. They felt that IMHAs should play a key role in raising awareness of Advance Decisions with HCPs.

Although awareness was low, there was a clear appetite for Advance Decisions amongst service users. They were welcomed by the majority and some suggested that the decisions should be recorded.

However, there was scepticism whether Advance Decisions would be respected in practice and a fear they would be easily overturned by clinicians without changes to legislation.

Many of the service users we interviewed felt that there should be a more robust process to both collect, record and implement Advance Decisions as well as an enhanced review process for overturning Advance Decisions.

The psychiatrists we spoke to acknowledge the benefit of Advance Decisions in principle, although many felt that their responsibility is to act in the best interest of the service user at the time and that information provided as an Advance Decision may not always be appropriate to follow.

Some HCPs feared that the current healthcare systems and processes were insufficient to support Advance Decisions, and they cited other issues that can disrupt the process. HCPs suggested more joined up communication and record sharing between community care, social care and the hospital would need to be considered if a change of policy in this area were to be implemented successfully.

“I think it's great to have it, but it's easily over ruled, they want to give you this treatment and that's what they are going to do”

IMHA

These findings suggest a more formal and regulated approach to capturing and implementing Advance Decisions should be investigated.

Quality and Consistency of Information Provided

We asked what information was provided to people detained under the Mental Health Act.

It was clear from the service users we spoke to that there were significant gaps and inconsistencies in the information provided when initially detained.

The majority of service users reported they were provided with basic information packs when they were first detained. These covered the minimum legal information requirements regarding the section they had been detained under and the likely length of their detention.

Other information was provided regarding ward procedures and in some cases medications. Both service users and carers told us that it was not in an easy to understand format.

Many of the service users we spoke to recognised that they lacked insight at this stage of their detention and, therefore, had limited ability to retain information. This issue was also recognised by HCPs. Both parties were aware of the need for repeated conversations to ensure that information was understood, however, this appeared to happen infrequently.

“We are given loads of information but whether it actually means anything or we can actually do anything about it is another thing. I mean you can be given a random sheet, which is a tick box thing for any nurse but whether it’s actually true and informative is something else”

Service user

From speaking to HCPs, service users and carers, there was a marked discrepancy between what information HCPs believed was being provided and what service users and carers themselves experienced.

Service users we spoke to had not been given information on their rights to a tribunal or information on independent mental health advocacy. Most of the people we spoke to were not offered access to an IMHA at all.

We also heard of service users’ dissatisfaction with the limited information provided on the benefits and side effects of medications prescribed in a format that was easy to understand.

Improvements to the quality of information provided on treatments and rights for those detained under the Act would enable a more informed choice and improve engagement in care.

Challenges for Healthcare Professionals

During the research, HCPs explained what information *should* be provided to service users. This included the legally required information on why the person has been detained and the Section of the Act but many said it should include information on ward services, a summary of processes for care reviews and appeals and information on how to access the advocacy service.

The inference from the HCPs who took part in this research was that what actually happened varied considerably; the circumstances, exact nature of the service user’s illness, its presentation, and a multitude of other factors such as time of day/night when detained. Previous history of detention or living situation all impacted the actual approach taken and the quality of information provided.

Furthermore, time and resource pressures for HCPs, particularly the number of nurses available and the use of agency staff, also appeared to have a significant negative impact. The result of this pressure appeared to be a highly inconsistent approach, with service users and carers feeling disconnected and a widespread perception that information provision was patchy.

“I keep saying they should, they should, they should because I’m not convinced it happens all the time”

IMHA

“They should be given choices about what types of interventions are available; they should be given that verbally and in written form, it should be explained to them quite carefully so hopefully they can be part of the decision making”

Community Psychiatric Nurse

The Carer’s Perspective

We also spoke to carers about the information they received when their loved one was detained. The information pack provided was focused on the service user’s needs, but there was no equivalent for the carers on the care pathway process and how they could support their loved one.

As a result, the carers we spoke to attempted to supplement their understanding by seeking out information online or from other carers. The carers described how they were forced to try to work out for themselves who could provide them with what they needed to know, their legal rights and how to have their voice heard.

We heard how subsequent detentions became easier for carers to navigate 'the system' as they had a greater understanding based on previous experience. They believed that, with time, they were better equipped to understand the system and 'play the game' to influence and optimise the care of their loved one.

These findings suggest there is also a need to improve information provided to carers to optimise the support they can give to people detained under the Act.

"I was very 'green' the first time he was sectioned. I didn't know what was going on, what I was entitled to know. I've learnt more each time it's happened"

Carer

Limitations and Frustrations with the Current System

We explored some of the frustrations with the care received by service users when they were detained under the Mental Health Act.

The majority of service users and carers we spoke to reported that their experiences were significantly affected by changes in the designated care team or individual HCPs.

The impact of changes was reported to be positive in some instances where carers or service users had actively requested changes to the care team to improve a relationship or situation. For other users, changes in the care team had taken place that detrimentally affected trust and overall care.

"The first time the psychiatrist didn't get my views, she spoke to me like I was a little kid. She was extremely unhelpful and uncaring. The last time the psychiatrist was amazing and the nurses were lovely. I had a fantastic key nurse as well so that was really good"

Service user

Staff Availability and Resource Challenges

We heard from many service users that pressure on nurse time and resources resulted in substandard care for many.

Service users told us that basic information regarding their personal circumstances, including their medical history, was not always captured on their notes. Service user rights whilst detained e.g. to a tribunal or access to an IMHA were not consistently communicated or repeated sufficiently to ensure understanding.

HCPs also reported that overstretched resources impacted on the quality and consistency of care especially at nurse handovers. The widespread use of agency staff was also perceived by service users as a key factor.

In addition to problems at nurse handover, HCPs also told us that insufficient resource negatively impacted time available for staff to interact with service users in a meaningful way. In turn, had a detrimental effect on awareness and uptake of support services such as IMHAs.

"While you know what to do, if there is only a few of you, you just can't do it"

Community Psychiatric Nurse

Staff availability and pressure on nurse's time were also felt to contribute to a lack of stimulation during detention, with many service users saying that they were often left alone for long periods with little to do. One service user reported the cigarette break as being the highlight of the day as it gave her something to do.

It was felt this lack of time and resource impacted the capacity of HCPs to engage with service users in non-medicated ways or provide access to alternative therapies, further fuelling service users perception of a 'medication-led' culture.

In addition to the frustration experienced by the service users we spoke to, we also heard from many of the HCPs that lack of resources impacted their ability to

undertake their role as they wanted to.

“The ratio of patients to staff is a problem”

Community Psychiatric Nurse

Many of the HCPs we spoke to acknowledged that shortage of beds was another key contributing factor to service users sometimes not being detained locally. They also described how this lack of choice regarding the location of detention could have a significant impact on the ability of relatives to support their loved one.

“We are having an absolute nightmare because of the shortage of beds nationally”

Community Psychiatric Nurse

When we asked the HCPs and other professionals what one thing they would change to improve the experiences of people detained under the Mental Health Act they universally responded that more time with service users and consistency in the resources they had available to them was needed.

“I think time is the thing that seems to be in short supply, but that then equates to staff and staffing levels”

IMHA

Appeals and Tribunals

Despite being entitled to them, for many service users we heard that opportunities for appeals and tribunals and a review of detention were limited, if not impossible.

Some service users claimed that the prospect of a tribunal taking place was highly unlikely and that this was well known amongst service users, despite it being part of their rights under the Mental Health Act.

Some HCPs also said that it could take weeks before a review was undertaken depending on staff availability.

The Role of Mental Health Advocacy

IMHAs were perceived to be invaluable for those service users who had been able to access their support. Service users perceived IMHAs to be truly independent and to engender greater levels of trust than either HCPs or family members thereby providing vital help to guide service users through the system.

However, there was both a lack of awareness of mental health advocacy and also significant problems accessing support, with some service users stating that they rarely saw an IMHA despite repeated requests.

In addition, awareness of the IMHA service amongst the carers we spoke to was very limited, although all were interested in learning more about advocacy and felt it could play an important supporting role.

Through our discussions with HCPs and IMHAs it was clear that there were some areas of tension between the two parties and that this tension may be acting as a conscious or subconscious barrier to providing awareness and access for service users.

Some service users we spoke to believed that HCPs were not always supportive of IMHAs and felt that clinicians did not want IMHAs to interfere.

The HCPs we interviewed were broadly supportive of the role that IMHAs could play in providing support for service users, although many did not spontaneously mention advocacy when describing the process of detention and care under the Mental Health Act.

For some HCPs, IMHAs were perceived to be ‘troublemakers’, and they questioned their legitimacy or qualifications. Others acknowledged the benefit of the IMHA role but felt there needed to be improved education and awareness of what they do.

“In some cases advocates could be very difficult as well and they kind of create a degree of mistrust and animosity against the service”

Psychiatrist

Culture and Environment for Care

We explored how the current culture and overall environment impacted the experiences of service users detained under the Mental Health Act.

There was widespread feeling that detention under the Mental Health Act is not tailored to individual circumstances and there can be little focus on the service user themselves.

Many people we spoke to expressed frustration and anger at the lack of appreciation of their specific circumstances and the blanket approach to applying the Act.

Whilst many of the service users recognised that they lacked capacity and insight when first detained and appreciated that there was a need to focus on keeping them and others safe, we heard that this did not change as the service user’s mental health improved.

“I felt a lot of things were done to me rather than with me”

Service user

Some service users recalled experiences where rules routinely applied on the ward served to strip them of their overall control of the situation and further contributed to perceptions that the system was draconian and not centred around the person requiring care.

“I was reflecting back on it and I realised how weird it was that I had to earn back my shoes”

Service user

“These people, doctors, who are supposed to be fair had control over my clothes, shoes, bedding. Everything”

Service user

Many of the service users interviewed expressed frustration at the perceived complexities of being in a system they did not understand and the difficulties of navigating through it. A specific area of concern was the tribunal process and understanding how it worked, how to initiate it and their entitlements within it.

In addition, some service users found it difficult to understand which professionals they could access for support, and at what stage. A lack of information and contact with HCPs contributed to overall levels of confusion and limited understanding of the system for many of the service users we spoke to.

“If I could, I’d have put ‘utterly powerless’ because I just can’t express enough to someone who’s never been in that situation how little say you have. A sectioned person has less legal rights than a prisoner or that’s what it feels like at the time”

Service user

Furthermore, even when service users requested information on prescribed treatments, details were often not provided, which further contributed to feelings of suspicion and distrust.



Many service users described their experiences as similar to being imprisoned, with complete loss of control over their lives.

“I feel very strongly that these psychiatric hospitals are supposed to be rehabilitation centres and they’re not, they’re prisons where they pump you full of drugs”

Service user

“Personally, I think that’s wrong. If you’re not forensic then you shouldn’t be put on a forensic ward. I hadn’t committed a crime”

Service user

The Impact of Repeated Detention

The experience of repeated detentions under the Mental Health Act served to shape attitudes and expectations of the service users we spoke to. Some service users indicated that they started to 'play along' with the system; they knew what was expected of them, what they needed to say and how they needed to respond in order to be allowed to return home.

Others stated that they became more demanding of their overall care and, as a result, started to understand their rights and to ask for and expect more.

“I reached a point where I realised that if I wanted to get out I had to do what they wanted me to do”

Service user

Experience gained by carers from their loved ones' repeated detentions proved either galvanising or dispiriting. We heard how some carers had become somewhat resigned to how the system worked; over time they began to accept that the experience would be poor, they had lowered their expectations and learned to expect not to be kept informed.

Others we spoke to had used their experiences to ensure they were better informed for any subsequent detentions and used the opportunity to build relationships with the relevant HCPs.

“We were encouraged at one point to make a complaint but you know, it's very difficult because you're still working in the system, you've still got to exist within that”

Carer

The circumstances of detention, including whether it was planned or unplanned and the time of day or night, appeared to have a significant impact for some of the service users we spoke to.

A planned detention provided service users with some level of reassurance and feeling of being somewhat 'in control' of what was happening to them, even if they were being detained unwillingly.

For service users where the detention was unplanned, for example in the middle of the night when service provision was more limited, the ability to communicate with others, including carers, was quite significantly impacted.

A lack of choice in the location of detention was mentioned frequently by a number of the service users

we spoke to, with many stating they were unaware of where they would be detained until they were admitted.

Furthermore, it was clear from the research that limited time and resources further exacerbated the overall quality of care received.

“I don't really remember very much... I was detained, I think, in A&E and I didn't have any choice. I was very scared...But the last time I was detained, I refused so they sectioned me but they gave me a night at home so I had time to pack and get ready to be out into hospital”

Service user

“It's all a very strange experience, especially not knowing where you're going and then arriving and not knowing where I was, was quite unpleasant”

Service user

It appears the lack of resources and current culture of 'one size fits all' is at odds with a patient-centred approach to care for people detained under the Act



Recommendations

The research has highlighted a number of key areas where specific actions could be taken to ensure that the rights of people detained under the Mental Health Act are protected and overall care is improved.

There is a widespread feeling among service users that detention under the Mental Health Act is not tailored to individual circumstances, and that there is little focus on the service user themselves. The lack of person-centred care is a clear source of frustration to service users and carers with many expressing anger at the lack of appreciation of their specific circumstances.

The following suggestions go some way in addressing this, but a more fundamental change in attitudes to involvement of service users in their care whilst detained under the Act is needed.

Formalising Mental Health Advocacy

Awareness of mental health advocacy and uptake of the services of IMHAs among the service users and carers we spoke to was limited. Furthermore, we heard from some of the HCPs that their own experiences of advocacy were relatively narrow and not always positive which led to questions regarding the legitimacy or qualifications of IMHAs.

Therefore, we propose the development of clearer guidelines with regard to the role of IMHAs including formalisation and clarification of their role and the process through which advocacy is provided.

We also suggest service users are given more involvement in their care via mandatory access to an IMHA within a clearly defined time period e.g. 48 hours of admission.

To ensure any changes introduced have maximum impact we suggest that there is a need to create greater awareness, understanding and trust of advocacy amongst HCPs, service users and carers. We also suggest increasing the number of available IMHAs.

Change to the Nearest Relative Mechanism

Although it was rare for the Nearest Relative mechanism to cause any problems for either service users or HCPs, the service users we spoke to were keen to see changes regarding how the Nearest Relative is determined, in particular, to give service users the ability to select who they think is suitable and appropriate.

We suggest changes to legislation which governs Nearest Relative is considered to give service users the right to choose who should represent them.

Moreover, we suggest further exploration of the role of the consultant or lead HCP when making changes to the person named as Nearest Relative, including the possibility of introducing an independent review to sanction any changes.

In addition, we propose that the named Nearest Relative should be provided with clear information and support, including an understanding of their own legal rights.

Access to Advance Decisions

The findings from the research suggest that there is both a clear appetite for Advance Decisions and a need to explore a more formal and regulated approach to capturing and implementing them in order to reflect the wishes of service users.

We recommend inclusion of Advance Decisions as a routine component within the care pathway, and further recommend that options for giving legal weight to Advance Decisions are explored in detail.

The underlying principle should be that Advance Decisions are fixed and cannot be overturned except in exceptional circumstances.

Once Advance Decisions are documented these should be captured electronically on a patient's record and noted before treatment is given.

Improved Information Provision

The need for improvement in the information provided to service users and how it is communicated was clearly highlighted. There were significant gaps in information highlighted by both service users and carers.

In addition, HCPs with limited time were often unable to have repeated conversations with service users to ensure that information was received and understood. Furthermore, we heard from some service users that there was a lack of information provided on prescribed medication.

We suggest provision of standardised, co-produced information packs to both carers and service users upon detention. A consistent format that is adopted nationally should be explored.

We suggest a review of the information provided to ensure it goes beyond the minimum legal requirements. We propose information on tribunals, review meetings, the workings of the ward, and details of the nurses and other HCPs involved in care should also be included as standard.

Moreover, we recommend that the standardisation of information on medicines provided and their potential side effects is considered as part of improving the Act. We propose that information regarding prescribed treatments should be more readily available and easier for lay persons to understand.

Furthermore, we suggest that the legislation should include a requirement for HCPs to record and take responsibility for whether the service user has been given and has understood the information provided; this would move away from the current 'box-ticking' approach.

In addition, a national communications charter, similar to that successfully implemented in Australia, could be considered as part of the solution.

Next Steps

This research has highlighted a number of issues with the Mental Health Act as a result of what we heard from service users, carers, HCPs and other professionals.

Whilst the insights offer a clear foundation on which to build, there is a need to explore the recommendations further and validate what was said in the interviews.

The Mental Health Act Review offers an opportunity to ensure that this further research and exploration takes place.

“I think there should be more person-centred care, more so than blanket rules...It should be individualised to your care with a say on what you're allowed to have and not have”

Service user



Glossary of Terms

Term	Definition
Mental Health Act:	<p>The law which sets out when a person can be admitted, detained and treated in hospital against their wishes. It is also known as being 'sectioned'.</p> <ul style="list-style-type: none"> • For this to happen, certain people must agree that the person has a mental disorder that requires a stay in hospital. The person is then given an assessment and treatment if needed. • This is only done when the person is considered to be putting their own safety or that of others at risk. • The person detained can be given treatment even if they don't want it. • There are different sections of the Mental Health Act that have different aims. • Certain rights exist under the Mental Health Act, including the right to appeal and the right to get help from an advocate. • The Mental Health Act is over 30 years old, and is currently being independently reviewed. The Review is specifically concerned with: <ul style="list-style-type: none"> - Rising rates of detention under the Act - The disproportionate number of people from black and minority ethnic groups detained under the Act - Processes that are out of step with a modern mental health care system
Section 2 of the Mental Health Act:	<p>Allows a person to be admitted to hospital for an assessment of their mental health and to get any necessary treatment. It lasts for a maximum of 28 days and cannot be renewed. People who need to stay in hospital after 28 days will be transferred to a Section 3.</p>
Section 3 of the Mental Health Act:	<p>Allows a person to be admitted to hospital for treatment. It lasts for 6 months, but this can be renewed.</p>
Part 3 of the Mental Health Act	<p>A number of different sections of the Mental Health Act which govern when a person in contact with the criminal justice system can be sent to receive mental health treatment. It governs court orders, transfers from prison to mental health units, and the powers of the Secretary of State for Justice over people who are detained under some sections of Part 3.</p>
Community Treatment Order (CTO):	<p>Can be used when someone is discharged from detention in a hospital under the Mental Health Act to ensure they undergo supervised community treatment.</p>
Independent Mental Health Advocate (IMHA):	<p>A person who is trained to work within the framework of the Mental Health Act to support people to understand their rights under the Act and participate in decisions about their care and treatment.</p>
Service User:	<p>A widely accepted term in the fields of health and social care. It usually means anyone who is receiving care from health and / or social services.</p>
Advance Statement:	<p>Advance statements are non-legally-binding expressions of wishes or feelings about how someone would like to be treated (usually relating to medical treatment), and their beliefs or values, which should be taken into account under the Mental Capacity Act, but do not have legal weight. For example, someone might want clinicians to know they follow a particular religion.</p>
Advance Decision:	<p>Advance decisions can be used to refuse medical treatment in the future, including life-saving treatment. Most mental health-specific Advance Decisions (except those relating to Electro-Convulsive Therapy and Neurosurgery) can be overridden by the Mental Health Act.</p>
Nearest Relative:	<p>Under the Mental Health Act, the Nearest Relative mechanism uses a hierarchical list of assumed relationships that determine a person that is involved in a service user's care.</p> <ul style="list-style-type: none"> • The Nearest Relative has specific rights when someone is detained under the Mental Health Act. This can include a right to get information about the way that their relative is being treated. • Nearest Relatives can ask for an assessment to decide if their relative should be detained under the Mental Health Act. They can also request that their relative is discharged from hospital.

Term	Definition
Nearest Relative continued:	<ul style="list-style-type: none"> • An application can be made by a service user, their advocate, or their clinicians to the County Court to have a Nearest Relative removed or changed if they do not feel that they are the right person for the role. • The Nearest Relative does not have the right to be told everything about the patient. This will depend on whether the patient is happy for information to be shared. <p>Under the Nearest Relative system, on occasion inappropriate people can be allowed to influence service users' treatment (e.g. estranged family members).</p>
Multi-Disciplinary Team (MDT)	<p>In the context of a person detained under the Mental Health Act, a group of health care and other professionals who are members of different disciplines or professions (e.g. psychiatrists, social workers, nurses), each providing specific services to the service user. The team members independently treat the needs a service user may have, focusing on the areas they specialise in. The activities of the team are often brought together using a care plan.</p>
Tribunals and appeals	<p>The Mental Health Act allows service users to appeal their detention to a tribunal at different intervals, depending on which section of the Act they are detained under.</p> <p>The Mental Health Tribunal is made up of three members: a judge, a lay member, and a medical member. They have the power to order the discharge of a person from detention under the Act, and can set conditions on their discharge. Service users are automatically referred to the tribunal after a set period of time if they have not requested one – this varies, depending on which section they are detained under.</p> <ul style="list-style-type: none"> • Service users can also appeal their detention or aspects of their treatment informally, and these will be addressed depending on the hospital's policy. They can also make complaints via other means (such as the NHS complaints system, the ombudsman, or the regulator).



Appendix

Background

The Mental Health Act 1983 sets out the legal framework for compulsory powers in England and Wales. It has a huge impact on the lives of individuals needing mental health treatment and their families and loved ones.

The Mental Health Alliance is a coalition of more than 65 organisations with common concerns around reform of the Mental Health Act.

In 2017, Rethink Mental Illness conducted a survey on the principles behind the Mental Health Act on behalf of the Mental Health Alliance. This research surveyed over 8,000 individuals, including those with lived experience, families, carers, and professionals. It resulted in the publication of the Mental Health Alliance report entitled 'A Mental Health Act Fit for Tomorrow' in June 2017¹.

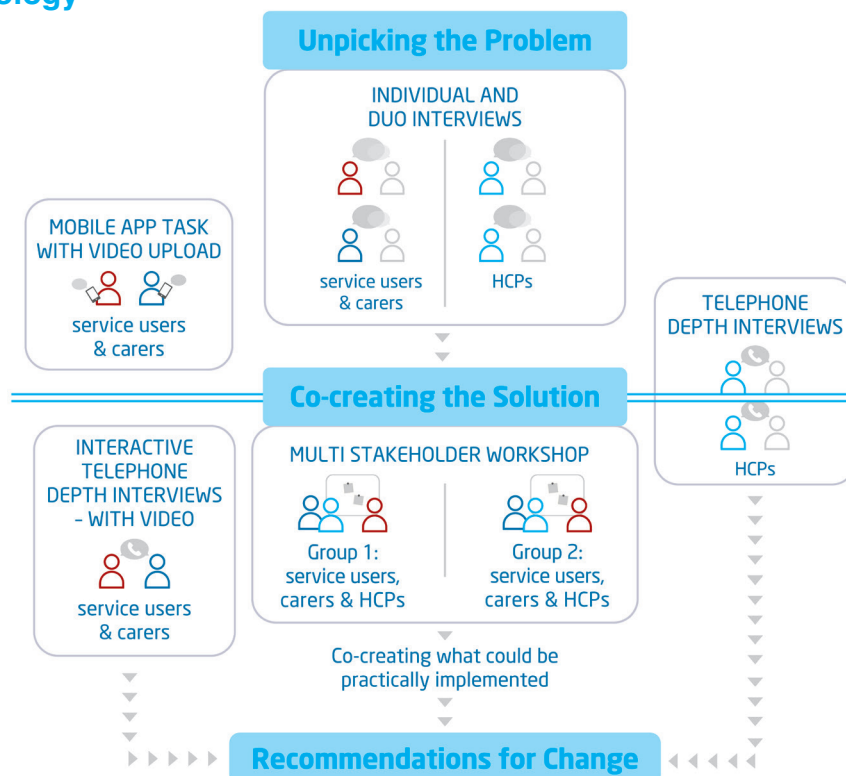
Following the publication of the Alliance report, and as part of a partnership between Rethink Mental Illness, Adelphi, and Janssen, research was conducted on the extent to which patients and their loved ones are involved in their care and treatment under the Mental Health Act. Rethink Mental Illness independently commissioned this report, based on the findings of the Alliance research. Janssen provided financial support for this research but had no involvement in the development of this report.

The main objective of the research was to explore the extent to which people who have been detained under the Mental Health Act, and their families and friends, are involved decisions concerning their care and treatment. The research also explored the type and consistency of information provided and the culture and environment for care. Views of service users, carers, clinicians and other healthcare professionals were sought to firstly understand the current environment, and then together identify practical improvements and potential legislative changes that could improve care going forward.

Methodology Details

We employed a three-stage, qualitative research approach combining face-to-face, telephone and mobile 'app' interviewing as shown in **Figure 1**.

Figure 1: Methodology

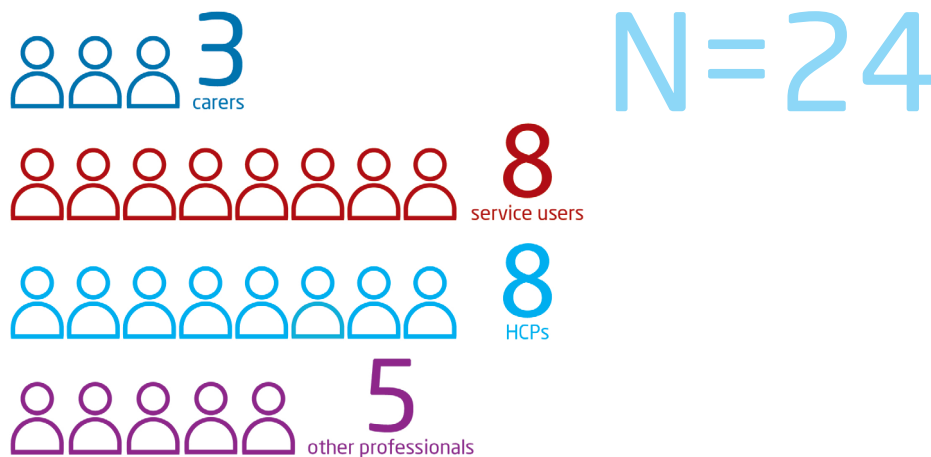


¹ Mental Health Alliance (2017) "A Mental Health Act fit for tomorrow"

We interviewed a total of 24 people who had been detained, or had cared for someone who had been detained under the Mental Health Act in the last 10 years. The sample as shown in Figure 2 included service users (n=8), carers (n=3), HCPs (n=13).

The HCP sample comprised mental health nurses (3), community psychiatric nurses (3), and psychiatrists (2). The 'other professionals' included mental health worker/social workers (3) and IMHAs (2).

Figure 2: Sample



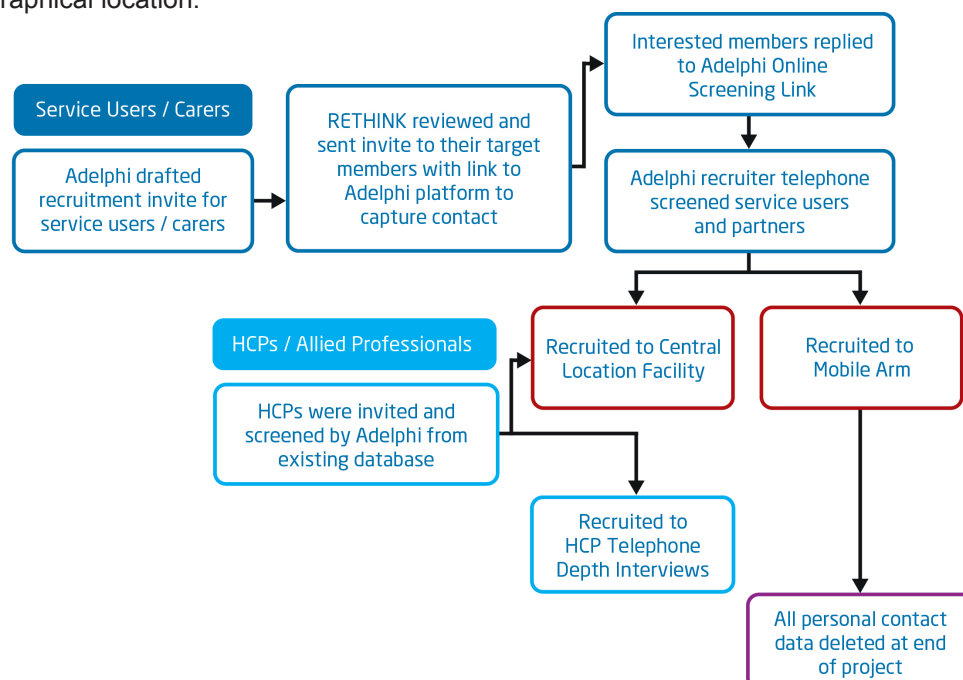
Recruitment

Service users, carers and IMHAs were recruited via the Rethink Mental Illness network. A recruitment screening questionnaire was applied to service users and a range of mental health diagnoses were recorded. To be included, all had to have been detained under the Mental Health Act at least once in the last 10 years, or have cared for someone who has.

Clinicians, mental health nurses and social workers were recruited by Adelphi Research UK. All were screened to ensure they had been actively involved in care of patients who had been detained under the Mental Health Act.

The goal of this research was to obtain depth of views and specific examples of how care is delivered and received, firstly to understand or 'unpick' the problem and then to encourage co-creation of potential solutions. As such, a qualitative sample of respondents was recruited.

All service users, carers and IMHAs were invited to participate by Rethink Mental Illness and then directed to Adelphi Research UK for screening. Information on the specific section under which the service user was detained and their mental health diagnosis was recorded at screening. In recruiting we aimed for a spread of age, ethnicity, gender identity and geographical location.



All HCPs were recruited by Adelphi Research UK from a panel of respondents who had previously consented to being contacted for market research purposes. All had to have been involved in treating service users detained under the Mental Health Act in the last 5 years.

In terms of recruitment, we employed a comprehensive approach to maximise response, to ensure transparency at all times, and to respect the sensitivity of the subject matter including the duty of care for service user respondents and the Data Protection legislative requirements.

In the screening interview, all respondents were asked questions to assess their eligibility to participate and asked to provide consent for use of the research findings in written reports, use of video clips in internal reports, for Rethink Mental Illness public awareness campaigns and for discussion with Parliamentarians.

A question was also put to all respondents to ensure that their safety and wellbeing would be protected if they were to attend an interview.

Methodology Rationale

We used in-depth, face-to-face interviews led by highly experienced interviewers to allow the tailoring of questions to different stakeholder types and to provide the necessary sensitivity to illicit information from people who had previously been detained on a subject that would be potentially difficult to talk about.

The use of duos and triads, where availability allowed, added a dynamic to the discussion where alternative perspectives and experiences could be contrasted. At the end of Stage 1, service users and HCPs who had been interviewed separately were brought together to work in a group setting to co-create solutions. This approach was designed to leverage the collective brainpower of the group and create a real sense of shared ownership of ideas that could be implemented in practice.

The mobile app arm of the research collected additional insights from other service users and carers spread across the UK. It provided an opportunity to answer questions in a candid way without a moderator and gave respondents an opportunity to record experiences via video upload providing a more 'in the moment' approach and having the benefit of enabling body language to be seen to illuminate 'what' was being said with 'how' it was being said.

A follow up telephone depth-interview was arranged following completion of the mobile tasks, which enabled further depth exploration of responses and videos shared.

To supplement interviews conducted face-to-face and in the workshop groups, an additional cohort of HCPs from a wider geographical area recruited from Adelphi's database were interviewed to ensure a more diverse perspective was captured.

To ensure fully informed consent and compliance with data protection legislation, respondents were provided with detailed information on what was to be discussed. In addition, explicit consent to share personal data and video clips was obtained and recorded ahead of their interviews.

About Us

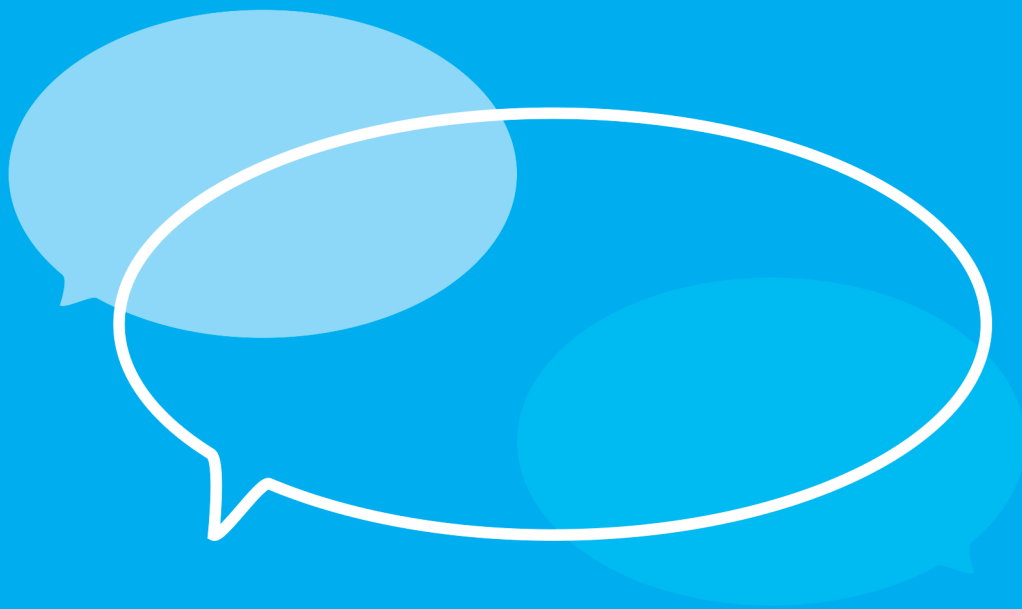
Rethink

We help millions of people affected by mental illness by challenging attitudes, changing lives. We believe a better life is possible for millions of people affected by mental illness. Over 40 years ago, one man bravely spoke about his family's experiences of mental illness in a letter to the Times and in the process brought together hundreds to talk about their experiences of mental illness and support each other. Today we directly support almost 60,000 people every year across England to get through crises, to live independently and to realise they are not alone. And we change attitudes and policy for millions. For further information please visit <https://www.rethink.org/>

Adelphi Research UK

Adelphi Research UK is a healthcare market research agency based in Bollington, Cheshire. We are part of the Adelphi Group of companies who specialise in local and global market research, health outcomes research, real world evidence and healthcare communications. We are commissioned by pharmaceutical companies, patient advocacy groups, charities and NHS organisations to help navigate challenges and support key decisions across a range of health related topics. For further information please visit: www.adelphiresearchuk.co.uk





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