Mental Health Act White Paper engagement report

Service users with experience of using the Mental Health Act

Rethink Mental Illness
May 2021

1. Executive summary

Main findings

1. Our main findings were strong support for the ambition and vision presented in the White Paper, both in terms of the direction of travel and many of the specific proposals we discussed in detail.
2. This strong support is tempered with a lack of confidence from previously-detained people that the ambitious proposals will succeed in changing the ways that they expect to be treated when detained under the Act. This shows the significant cultural, practical, and legal barriers that the current Mental Health Act presents to the future of reform, and the challenge that integrating these proposals presents.
3. Other feedback on the White Paper proposals is discussed under each of the themes presented in this report.

Methodology

1. This commissioned research engaged people with previous experience of the Mental Health Act, alongside carers and families, in order to build a picture of their views on proposals outlined in the White Paper entitled Reforming the Mental Health Act.
2. This report is one of two, with the other focussed on the perspectives of people currently detained under the Mental Health Act.
3. In order to determine the manner of this engagement, Rethink Mental Illness built a panel of Experts-by-Experience who translated the technical White Paper questions into accessible themes and determined the questions which were placed beneath each theme. The themes do not cover all of the questions posed in the White Paper.
4. Using these themes, we then conducted 11 engagement sessions with 46 people with experience of detention under the Mental Health Act. Further subcontracted engagement was conducted with children and young people by YoungMinds, who conducted workshops and 1:1 calls with a total of 19 children and young people.

2. Introduction

In January 2021, the Department for Health and Social Care and the Ministry of Justice published a joint White Paper setting out the government's proposals for reform of the Mental Health Act 1983, and responding to the Independent Review of the Mental Health Act.

The White Paper contained 35 consultative questions aimed at gathering feedback on a wide variety of specific policy areas, in addition to proposals which were not consulted on. For example, the section on Advance Choice Documents (ACDs) contains a consultation question on what could be included in an ACD, but does not frame that question around whether ACDs should be implemented (because the government has already accepted that recommendation).

The Department for Health and Social Care advertised for commissioned engagement activity with multiple key cohorts of people with experience of the Mental Health Act, and awarded the contracts for two of these cohorts to Rethink Mental Illness. These cohorts were:

- People with previous experience of the Mental Health Act
- People currently detained under the Mental Health Act

This report details the engagement which was undertaken with people previously detained under the Act.

Rethink Mental Illness worked with a specifically recruited and paid panel of Lived Experience Advisors with experience of detention under the Act to turn the consultation questions posed in the Mental Health Act White Paper into more accessible themes and specific questions which could be usefully answered by people with experience of detention under the Act. Appendix 1 shows the themes that we and the LEAs identified, alongside the eventual questions posed in the engagement sessions.

3. Theme 1: Principles

3.1 White Paper questions

Consultation Question 1: We propose embedding the principles in the MHA and the MHA Code of Practice. Where else would you like to see the Principles applied to ensure that they have an impact and are embedded in everyday practice?

- We found strong evidence that previously-detained people would like to see the principles embedded across the Mental Health Act, and believe that they would be of benefit during both initial detention assessments and in community settings (even if this latter location is beyond the scope of the White Paper).
- We found high levels of concern about implementation of and adherence to these proposed principles within mental health inpatient settings, with calls for accountability by staff and clinicians, and for thorough training and monitoring.
- As with other areas of the White Paper, we found strong support for the necessity of support to help patients understand any new rights and to make use of them.

3.2 Detailed discussion

'You have to be treated as you and not as every other person…you are detained as you…'

Lived experience advisor

The White Paper on the reform of the Mental Health Act sets out four proposed guiding principles to govern the use of the Mental Health Act, with the ambition of informing everyday practice, setting out expectations on how service users are to be treated, and giving legislative weight to the aim of rebalancing power between service users and staff.

The principles are:

- '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 as quickly as possible
- The person as an individual – ensuring patients are viewed and treated as individuals'[1]

We engaged formerly detained service users on their views of the principles, including how and where the principles could or should be used within the Act, and who should be required to follow them.

All participants from all cohorts and backgrounds agreed that the proposed principles were worthwhile, positive, and would make a significant difference to their care and treatment if appropriately implemented and carefully managed. For those who had generally had positive experiences within the Mental Health Act (though these were a minority of participants) it was felt that their care had broadly been aligned with these principles as they stand, and their feedback focussed on how far their care had matched these already.

In a common theme across this research, even those with positive experience of good care recognised that it was important to extend that to those who'd had worse experiences. All participants expressed support for enshrining the proposed principles across the Mental Health Act, and frequently beyond it.

When asked where and how the principle could be used, participants highlighted the need to thread them throughout the inpatient experience. In order to do so, participants talked about the need to see these fully supported by management, clinical, and ward staff. Some participants placed additional emphasis on the need for short-term and agency staff to understand and administer the principles, given negative experiences they'd had. Most participants agreed that the principles should be incorporated through thorough training and hospital policy changes, and assessed by the Care Quality Commission.

Participants expressed concern that the principles could end up being in a similar situation to the current Mental Health Act principles within the Code of Practice – positive in theory, but implemented in a manner which is highly variable at best[2]. Some participants contrasted their experiences with blanket restrictions, traumatic experiences within inpatient units, and a lack of holistic or person-centred care, with the current good practice outlined in the MHA Code of Practice. Mirroring feedback across the rest of the questions, many participants expressed the view that accountability should be viewed as a vital additional principle, whether explicitly or through practical and cultural changes. They were used to staff and services ignoring good practice, including the Code of Practice, and felt that these new legal changes were unlikely to make a substantial difference without some means of encouraging compliance.

1 Department of Health & Social Care (2021), Reforming the Mental Health Act , page 20

2 Care Quality Commission (2019) Mental Health Act Code of Practice 2015: An evaluation of how the Code is being used

Many participants shared a view that the proposed principles should have influence beyond their time in hospital. A number had experienced trauma and highly negative situations during their initial detention process, and felt strongly that people involved in that stage – from Approved Mental Health Professionals (AMHPs) to police officers – should be required to apply the principles in their assessments and actions.

Some went further still, and spoke about the importance of extending these principles to community mental health services and secondary mental health settings in general. The implications of the principle of therapeutic benefit, with the assumption that this would mean the guaranteed availability of treatment, was discussed in this context. The participants who made this point tended to see their Mental Health Act experience as acceptable (or at least necessary at the time), but often had very negative experiences with the availability of community mental health services which they contrasted with their time in hospital.

Some participants identified concerns with the framing of the principle of therapeutic benefit, and particularly with the reference to "discharge as quickly as possible". Many spoke of people they knew who had been discharged too rapidly, or far too late, and in these sessions the groups agreed that there needed to be a greater emphasis on person-centred care, to ensure that people were discharged when it was right for them. Interestingly, this point emerged strongly from a session with families and carers, and from some of the few participants we engaged with who had co-morbid autism and mental illnesses. These were the participants more likely to encounter situations where people were kept in hospital for periods they considered too long.

Finally, almost all of the participants spoke to an extent about the importance of assisting service users to understand their rights under the Mental Health Act, which links in to other recommendations (on advocacy and the Nominated Person, for example, which we will go on to discuss in greater detail). They felt that support and clear communications were particularly important to permit them to exercise choice and autonomy, since there were inherent challenges in making choices if the person's understanding of the options was not good (such as if they had only recently been detained). They spoke movingly about the importance of ensuring that choice and autonomy is respected and enhanced even when they were in crisis, because the impact of not treating people with respect at this initial stage could have a huge impact later in their recovery journey.

That said, the participants acknowledged the challenge of involving people in their own care when there were other considerations for staff around them, such as physical safety, or when the patient may lack insight into their illness. For these patients, we can see the importance of the least restrictive principle – ensuring that restrictions are as minimal as possible, while still being sufficient to keep people safe.

4. Theme 2: Therapeutic benefit and detention criteria

4.1 White Paper questions

Consultation question 2: We want to change the detention criteria so that detention must provide a therapeutic benefit to the individual. Do you agree or disagree with this proposal?

- All participants agreed that ensuring detention has a therapeutic benefit is crucial and would make a significant difference to their care and treatment.

Consultation question 3: We also want to change the detention criteria so that an individual is only detained if there is a substantial likelihood of significant harm to the health, safety or welfare of the person, or the safety of any other person. Do you agree or disagree with this change?

- For some participants, their treatment and care in hospital was helpful because it provided a safe place for them while they were in crisis. Some of these participants expressed concern that raising the detention threshold could mean people were barred from help they might need.
- Some carers and families expressed concern that people would be discharged too early without the right support. They felt that community support would need to be in place to ensure that a person's health and recovery is supported outside of hospital.
- Young people felt that inpatient units are places where young people get better, but only up until a certain point due to the limited therapy and intervention for service users who are detained for a long time.

'All good saying "therapeutic benefit" but the most I've been offered is one OT between six wards…it's all very good saying that but I haven't had that benefit offered in any hospital…'
Lived Experience Advisor

4.2 Detailed discussion

The White Paper on the Mental Health Act proposes to amend the detention criteria in Section 3 of the Act, and elsewhere, to more clearly stipulate that in order for a person to be detained, it must be demonstrated that the purpose of treatment and care is to bring about therapeutic benefit.[3] The White Paper aims to reform the criteria so that the purpose of detention is always about helping patients to recover and supporting them towards discharge.[4]

We engaged with participants on this proposed change, this included what the term 'therapeutic benefit' meant to them, as well as what would they like to be told when being detained, in regard to their rights and what is happening to them.

Participants told us that ensuring there is therapeutic benefit to their detention is vital. For many participants, their experience of detention did not provide therapeutic benefit, and often worsened their mental distress, sometimes for the long-term. Despite the many negative experiences of detention which were shared with us, there were nevertheless some participants who believed that their treatment when detained had facilitated their recovery.

Participants provided many examples of what therapeutic benefit meant to them and the majority of these were non-medical interventions. Participants also stated that staff had the potential to play a major role in their recovery by showing empathy and kindness, being open and honest with them, and providing clear and accessible information about their rights and the reasons for them being detained.

For young people the importance of having access to regular therapy and a variety of interventions from mental health professionals came through even more strongly than it did for adult participants. Young people expressed a strong desire for a more holistic approach to their care, based on a mix of therapy and medication, rather than a reliance on medication alone.

In general, participants agreed that therapeutic benefit meant they should be treated individually and holistically, and they should have their experiences and wishes considered as part of their care – in line with other proposed principles.

3 Department of Health & Social Care (2021), Reforming the Mental Health Act, page 24
4 Department of Health & Social Care (2021), Reforming the Mental Health Act , page 24

4.3 Previous experiences of treatment and care during detention

'My last experience in hospital wasn't therapeutic in any way, in any way.'

Young female participant

Although all participants agreed that ensuring detention has a therapeutic benefit is vital, for many, their previous detention under the Act did not have a clear therapeutic benefit.

Several stated their experience in detention hindered their recovery rather than supported it and was sometimes a major contributing factor to the worsening of their mental illness. Some participants stated that their negative experience of detention has impacted their mental health long-term and others described their experience of an inpatient settings as 'traumatic' and 'frightening'.

Several reasons were given for this including:

- Staff attitudes: several participants highlighted a lack of empathy, kindness and respect from staff on their wards.
- Lack of communication and information: many participants were not given information about what was happening to them, resulting in confusion, anxiety and fear.
- The physical environment: some participants stated that the physical environment wards contributed to their worsening mental health, for example, if they were required to share a room with another patient.

'I think therapeutic benefit is so important as 9 times out of 10 there isn't any'

Lived Experience Advisor

Despite the many negative experiences of detention which were shared with us, there were some participants who believed that their treatment when detained had facilitated their recovery.

'Hospital was a bit of haven for me and allowed me to concentrate on me.'

Older female participant

For participants who did receive therapeutic benefit from their treatment and care in hospital it was often because it provided a safe place for them while they were in crisis. For those participants who had been detained more than once, several said while that some inpatient settings provided a more therapeutic environment, there were others that did not. This inconsistency in service provision was a common experience and noted by participants who had been detained in different facilities, including privately provided ones.

A participant who had been previously detained under a forensic section of the Act felt very strongly that the therapeutic benefit proposals should be extended to Part 3 of the Act, and that to do otherwise would be unjust and discriminatory.

Through their specific work with children and young people with experience of detention, YoungMinds found that young people felt that inpatient units are places where young people get better, but only up until a certain point due to limited therapy and intervention, as the quote below shows. Short term stays were considered helpful by some because they allow the young person to take some to rest but remaining an inpatient in the longer term can mean it becomes a part of the young person's identity and can leave them disengaged with life outside of the unit.

"They're focused on the quantity of your life (how long you live for) but not as much on the quality of your life."

Young person

Overall, most participants had experiences in hospital that were not conducive to recovery and in several cases worsened their condition. For those who did see their detention as vital it was often because hospital provided a safer place when they were in crisis.

4.4 What does therapeutic benefit mean to you?

Participants were asked to discuss what therapeutic benefit meant to them. For the majority, therapeutic benefit involves more than just medical intervention.

'I've recently found out about mindfulness, and it's changed my life.'

Male participant who has been detained 3 times over several decades

Participants, including both patients and carers, gave many examples of the types of treatment that would support their recovery while in hospital, these included:

- Meditation or mindfulness sessions
- Talking therapy with a psychologist or counsellor
- Occupational therapy
- Peer support
- Exercise activities

"The unit where we had group therapy twice a day with actual psychologists who were interested in helping you. In another unit, the activities coordinator (an Occupational Therapist) who made sure we had things to do and advocated for us getting off the ward for regular walks. The sensory room in one hospital was also really helpful, especially if there was a nice staff member on to sit with you and talk you through some relaxation techniques."

Young person

Feedback from young people showed that they felt that CAMHS units are better at providing a holistic mix of therapies and treatments than AMHS units. Young people said that staff at CAMHS focus more on their future than staff at AMHS, which felt more beneficial overall.

For many adult participants, recovery could be supported by having activities to participate in during their time in hospital.

"There were days and days where there was nothing to do but to sit on the floor in my room or pace the corridor."

Female participant previously detained

Many also felt that people needed to be respected as individuals with a life, identity and preferences beyond that of their diagnosis or mental health status, in line with the proposed principles of treating the person as an individual. Two participants from Black and Minority Ethnic (BAME) backgrounds stressed that their background and cultural preferences can impact their engagement with services and what treatments they are comfortable or uncomfortable with. They felt that failure to recognise them as individuals can compromise the potential therapeutic benefit of their engagement with services.

'There would have been people in my network that could have been contacted to support me. I have autism so it's important that I know the people. You are more likely to listen which will reduce the risk and restrictive practice in hospitals [upon admission]'

Female participant with autism and bipolar disorder

For carers and families, being involved with and informed about a person's care, as soon as possible, is vital to ensuring that their treatment is of therapeutic benefit. Some carers and families expressed concern that people would be discharged too early without the right support. Community support would need to be in place to ensure that a person's health and recovery is supported outside of hospital.

4.5 What would you want or expect staff to tell you when you are being detained?

"*When I've been detained in hospital, they used all the buzz words and I could not understand anything, it would have nice to have a bit of paper in 'our' language. My family also struggled to understand the process - we didn't understand what the implications were which made them anxious - there needs to be information in a simple form with no jargon"*

Female participant

Many participants said that when being admitted, staff often provided them with long documents and/or used medical jargon and legalese. All participants highlighted the need for information to be provided in an accessible way.

"jargon is always used on admission – you need to be clear"

Male participant

Many participants highlighted that when entering hospital, you are not always in the best position to understand the complexity of your rights under the Mental Health Act. They stated that though it was is important for people to be informed of their rights upon admission, they should also be given this information at other points during their time in hospital, and particularly when they are in a better position to understand.

There are ways in which people could be assisted to better understand their rights, even if not in the right state of mind. Individuals may be better able to understand if the information was presented in a different way (e.g. large font, pictures).

"A lot of people are given their rights but nothing is really properly explained to young people. I've spoken to a lot of people about this too. If you're in hospital and really poorly, you're not going to have the brain power to properly understand this information. Therefore people end up being really compliant when they don't really know what's going on. You're told your rights like someone is when they're arrested. It's not a calm and supportive chat."

Young person

Young Minds recommended as a result of their findings that when a young person is detained, staff should always take the time to have a supportive conversation with the young person to discuss their rights and recognise that each young person may need their rights explained to them in different ways and at different times, depending on how unwell they are. For example, staff may need to regularly revisit the discussion about rights with a young person during care and treatment reviews, particularly if the young person's rights change due to moving from informal patient to sectioned patient or after moving from CAMHS (children adolescent mental health services) to AMHS (adult mental health services). Providing information sheets would be helpful in addition to, not instead of, in-person conversations.

'Miscommunication between the staff and the family or service user is a big issue that needs to be resolved.'

Family member of son who has been detained multiple times in Wales

Many participants stated that staff should clearly explain to both patients and their carers/ families what section a person is being detained under. Confusion around this was a common experience for participants. It was highlighted that the difference between 'voluntary' and 'compulsory' admissions should be made clear. One participant shared that when they believed they were on a 'voluntary' admission and then asked to leave, this resulted in a *"24/7 clamp down with nothing explained."*

'[I'd like] *Not to be lied to.'*

Female participant with Autism and Bipolar

Participants felt that a clear purpose to their hospitalisation should be communicated. One participant who had autism told us that she was initially told she would be detained for a short time but then stayed in hospital for many months. Participants wanted to know why they were being detained and how it would help them.

Overall participants expected staff to provide clear and easy to understand information on their detention, and that this information should include, their rights, the reason for their detention, the available support services, and a clear purpose to their hospitalisation.

5. Theme 3: Care and treatment in hospital

5.1 White Paper questions

Consultation question 8: Do you have any other suggestions for what should be included in a person's advance choice document?

- A person's long-term aspirations.
- Preferences for locations to receive treatment.

Consultation question 9: Do you agree or disagree that the validity of an advance choice document should depend on whether the statements made in the document were made with capacity and apply to the treatment in question, as is the case under the Mental Capacity Act?

- Participants broadly agreed, but stressed that ACDs should be taken seriously and treated as valid unless proved otherwise
- Participants felt that significant efforts should be made to ensure that ACDs were integrated as thoroughly as possible, and rarely over-ridden.
- Participants stated that improving greater access to ACDs was essential.

Consultation question 10: Do you have any other suggestions for what should be included in a person's care and treatment plans?

- Participants called for family and carer involvement in the CTP process, and for the development of clear strategies to ensure that CTPs are shared between services appropriately and that they are of high quality.

5.2 Detailed discussion

Within this broad theme, the Lived Experience Advisors agreed to group several key consultation questions around the care and treatment of a person while they were detained in hospital. Given the emphasis within the White Paper on enhancing choice and involvement for people detained under the Act, these questions focus on the two key mechanisms for improving choice and involvement: Advanced Choice Documents and the statutory Care and Treatment Plan.

In order to build a picture of any potential additions to the ACD or the CTP, and through consultation with the Lived Experience Advisors, we posed a central question, with a number of accompanying prompts based on specific questions from the White Paper. Our central question was:

If you thought that you might be detained again in the future, what would you want people involved in your care to know?

Under this theme, participants tended to discuss specific aspects of their care which had gone poorly in the past, and which posed a risk of retraumatising them or jeopardising their recovery if they were to reoccur in the future. In general, participants across all cohorts were eager to stress that the opportunity to outline helpful and unhelpful interventions would make a significant different to their future care, and allow the clinical team to learn from the patient's previous experience.

For the previously-detained cohort specifically, contributions were focussed around the idea of their recovery. These participants saw their experience with the Mental Health Act as a part of their wider mental health journey, though for many it was a particularly challenging part. In this context, participants expressed their desire to let staff and clinicians know about their longer-term hopes, aspirations, and goals. They often felt that the inclusion of this information, even if it might risk being clinically irrelevant, would help to humanise them in the eyes of the clinical team.

As with the other themes across this piece of research, participants were concerned with the practical implementation of enhanced choice and involvement in both proposed statutory forms. Many were concerned, based on previous experience, that staff would find means to circumvent ACDs or to make CTPs insufficiently detailed to make a difference. Many also expressed concern about how the documents would be integrated and shared between services.

> *'I feel it is all well and good that service users have more of a say in their care, but if there isn't a unified system or robust integrated approach to share these documents between services, I feel it can impact on the quality of care you receive.'*
>
> **Female participant with experience of detention**

5.3 Care and treatment plans

> *'Service users in my session were very keen on care plans as they felt in limbo…there was no pathway or care and treatment plan…'*
>
> **Lived Experience Advisor**

Previously-detained participants shared their experiences with care plans as they currently stand, since they are used in secondary mental health settings across England (and are mandatory in secondary mental health settings in Wales). Many linked their experiences with current care planning to scepticism of the new proposals unless there was a robust means by which care plans could be quality assured, integrated, and shared between services.

One service user with experience of multiple detentions under the Mental Health Act and a diagnosis which included autism and co-morbid mental illnesses said they'd experienced Care and Treatment Plans which staff had obviously copied and pasted with very obvious errors (such as the wrong patient's name or age). Because the plans in this instance are written in the patient's voice, this makes them particularly shocking if you haven't been involved in developing it, and a clear indication of a lack of person-centred care.

While this example is particularly poor, it also speaks to broader concerns about integration and information-sharing between and within services. Engagement with families and carers highlighted these challenges across both CTPs and ACDs. Carers shared the issues they'd faced in having their views heard by clinicians, and which they'd faced in sharing information with clinical relevance, only to have this not passed on or not taken into account.

> *'I parented her for 25 years – no one knew her better than me.'*
>
> **Parent of a formerly detained service user who took their own life**

They called for enhancing family and carer involvement in the CTP process, in line with the proposals in the White Paper, and improving communication between and within mental health services.

5.4 Advanced Choice Documents

Under the Advanced Choice Documents sub-theme, participants shared their views on what they felt could usefully be included:

- Medication preferences and experiences with specific medications (including side effects)
- Preferred approaches for interventions, such as how much information clinical staff should give, and whether an intervention (like restraint, for example) might carry a risk of retraumatising a person
- Opportunities to list indications that a person is at risk of relapse or crisis
- A person's long-term aspirations
- Preferences for locations to receive treatment

The last of these points is not currently present in the list of proposed information for ACDs within the White Paper. It emerged strongly from multiple participants, and from the family and carer sessions. One example in particular stemmed from a service user who was also a mental health professional, and who asked for the inclusion of this element because they would not want to be treated in a location where they had worked previously. Others discussed positive or negative experiences they'd had in particular hospitals or wards, and felt they should be able to share these experiences and have them taken into account in their ACDs.

When the participants came to discuss other considerations relating to Advanced Choice Documents, including how binding they should be and how frequently they should be reviewed or updated, points which were similar to the CTP discussions emerged with regard to the fear that opportunities to override ACDs would be over-used by staff.

Overall, participants generally agreed that there should be frequent opportunities to review or update an ACD, and that service users should be supported to make amendments to the document if circumstances changed. Many participants spoke about the benefits that including information about their caring relations could bring, and this was heavily supported by the families and carers we spoke to. Several participants said that when they or their loved ones were in crisis, they were likely to try and exclude a carer or loved one, and would use an ACD to make sure staff knew not to exclude that person.

With regard to the use of ACDs when a person is in crisis, service users agreed that mental health crises were particularly challenging, and that an ACD could make a significant difference if using sensitively. One service user gave an interesting example of receiving ECT against their wishes and finding it to be helpful, though they would have refused it if they had been given the choice, either in advance or at the time. This was counterbalanced in the same session by a service user who felt they had been given ECT against their wishes as a voluntary inpatient, and found the communication around it very limited.

Overall, the previously detained engagement strand was much more likely to have given careful thought to their behaviour while in crisis, and what weight should be given to their decisions in advance of that fact. Most felt that valid and applicable ACDs should override their views while in crisis, and be as binding as possible, though crisis should still be carefully managed and communication should be as clear as possible.

> *'First of all I think the advanced choice document is a good development and well needed. It's almost like a birth plan, where you put down your wishes and wants, but sometimes it doesn't always go to plan, but adaptions and preferences are there to be enacted upon and considered.'*
>
> **Family member of someone who was detained multiple times in Wales**

There were suggestions from several participants that planning early for ACDs would have a significant impact on their time in hospital and their overall recovery. Many participants likened ACDs to a will or birth-plan and stressed the need to develop them when there were early signs that someone may be at risk of severe mental illness. Several participants recommended that ACDs be developed outside of the hospital setting is possible, for example done in development with their GP.

When prompted on how binding ACDs should be, most participants tended to make points similar to the assessment of Advance Decisions under the Mental Capacity Act. They said that if the ACD was relevant to a treatment at hand, and had been made with capacity then it should be as legally binding as possible. This view was further reinforced by the arguments made about ways in which staff and services could undermine ACDs unless their implementation was enforced through legal means.

5.5 Concerns regarding implementation of ACDs & CTPs

In addition to the points above which address the specific questions from the White Paper, although all participants were positive about the proposals for ACDs and CTPs, the theme of distrust and scepticism over implementation within services emerged strongly. This is unsurprising, given that it would represent such a major reorientation of mental health inpatient services in the eyes of service users.

It is possible that the integration, standardisation and legal weight given to ACDs and CTPs as part of the Mental Health Act reforms will address the well-founded service user scepticism we encountered, but it is worth noting that significant effort will need to be invested in order to permit these statutory documents to be as transformative as service users, families, and carers hope they can be.

6. Theme 4: People who support you in hospital

6.1 White Paper questions

Consultation question 13: Do you agree or disagree with the proposed additional powers of the Nominated Person?

- All participants, including both previously-detained people and families and carers, supported the additional powers for the Nominated Person. Many participants highlighted the need for support for NPs to be able to exercise these powers effectively, and to place them on a level playing field with clinicians and services.

Consultation question 14: Do you agree or disagree that someone under the age of 16 should be able to choose a Nominated Person (including someone who does not have parental responsibility for them), where they have the ability to understand the decision (known as "Gillick competence")?

- Neither Rethink Mental Illness nor YoungMinds compared the Mental Capacity Act approach with 'Gillick competence'. YoungMinds found strong support among formerly-detained children and young people for under-16s choosing their Nominated Person, provided that they could understand and freely make the decision in question.
- We found some concern from carers and family members about the implications of this proposal, namely the prospect of someone inappropriate being chosen. They recommended strong guidance and rules around such a decision.

Consultation question 15: Do you agree or disagree with the proposed additional powers of Independent Mental Health Advocates?

- Many participants had not received good support from an Independent Mental Health Advocate, and felt that the way that the service was currently delivered was insufficient.
- Participants supported the proposed additional powers for Independent Mental Health Advocates, and felt that they had the potential to permit IMHAs to make a significant difference to their care and treatment, in part, because they had the potential to increase access for service users to IMHA support.

Consultation question 16: Do you agree or disagree that advocacy services could be improved by: Enhanced standards; Regulation; Enhanced accreditation; None of the above, but by other means?

- For those participants who had accessed IMHA services, some had not received the support that they had expected. They felt that advocacy services should be improved through broadening access, and through enhancing the quality of service, training of advocates, and raising standards – all of which support the improvements suggested in this question.

6.2 Detailed discussion

Within the fourth theme, the Lived Experience Advisors grouped questions relating to people who support a detained person while they are in hospital. The White Paper contains several proposals to enhance the powers and involvement of specific individuals – namely the revised powers of the Nominated Person (who will replace the Nearest Relative) and Independent Mental Health Advocates (IMHAs).

Within this engagement, this theme was an opportunity to discuss how effectively people with a caring or professional advocacy relationship to the detained person have been able to become involved in their care, and what changes could be made to support that involvement in the future.

Overall, we found strong support for the changes to the Nearest Relative mechanism and the proposed additional powers. For IMHAs, we found considerable variability in the level of access people had received to advocates under the current system, but those who had used them had in general found their involvement very helpful. Participants supported widening the role and powers of IMHAs, but expressed concern that this would not prove practicable if current arrangements for providing advocacy to inpatients are not improved.

6.3 The Nominated Person

We initially framed the question around who was best to involve in the care of previously-detained people, and whether the most appropriate people had been able to be involved in their experience. Many respondents focussed on the inherent issues of the current Nearest Relative system, particularly where they had found their experience to be negative. Many who shared negative experiences referred specifically to their relationships with their parents, as the Nearest Relative system defaults to the oldest living parent in the absence of a spouse or civil partner.

> *'At some points when I'm most unwell all relatives and close ones are in the bad books – seems to happen every time. Having the opportunity to choose somebody else would be fantastic because I am in this negative process of pushing everyone away… having somebody neutral would be better.'*
>
> **Lived Experience Advisor**

Many of the participants had negative relationships with their Nearest Relatives and felt that someone else would be better-placed, either because of a relationship which had broken down, or simply because their designated NR did not have the ability or knowledge of the system to be involved. Some highlighted the fact that because age was a deciding factor in the NR process, this meant that the selected relative could be very old indeed, and therefore potentially less able to be involved. Several female participants shared examples of abusive current or former partners or parents being selected as the NR, and all of these participants shared their view that the displacement process was too long and complex.

Even for those participants who hadn't had particularly negative relationships with their Nearest Relative, there were many who felt that their Nearest Relative had not sufficiently understood the complex mental health system to advocate on their behalf, or being sufficiently able to be involved. Many participants expressed worries that they were a burden on their Nearest Relative, and that this wouldn't necessarily be addressed through the addition of new powers and responsibilities unless the support for the Nominated Person was also expanded. Some participants called for carers and family members to be provided with advocacy support, as is already the case for the Relevant Person's Representative under the Mental Capacity Act.

Perhaps unsurprisingly this suggestion was particularly supported in the family and carer engagement sessions, with these participants sharing the challenges they'd faced in being as involved as they would like to be, and the difficulties they'd faced as a result.

> '*Nearest Relative puts a lot of pressure on people to make a lot of decisions.'*
>
> **Carer for someone previously detained under the Act**

As mentioned earlier, the overall feedback demonstrated strong support for the proposals around the Nominated Person, particularly with regard the element of choice over who would fill the role, and enhancing the powers available to them. In the view of carers and family members, the expanded powers and responsibilities for the Nominated Person posed a significant opportunity to address the challenges they had identified in becoming involved in care, provided they were implemented in the correct way and supported by services.

Interestingly, some previous service users inquired whether they would be able to nominate staff members to fill the Nominated Person role. We feel this is likely to stem in part from our framing of the question 'who is the best person to involve in your care?' It could also reflect positive relationships with some staff (and indeed many participants described these) and the feeling that this role should be able to achieve change on behalf of the detained person.

Carers and family members expressed concern that staff members (including advocates) would be nominated by patients as their NPs, and felt that safeguards should be put in place to prevent this from occurring, given that services could then use the mechanism to circumvent the safeguard that they felt it should provide. Carers also felt strongly that the NP should have to agree to take on the role.

Both carers and service users felt that there needed to be robust assurance processes to ascertain whether a nominated was appropriate, and service users also stressed that their view of who should be NP could change over time. They felt that it was important to support changes to the NP as a result of the normal shift of relationships, but acknowledged that in crisis, service users did not always want to involve those who would be best to keep close.

In the subcontracted work conducted by YoungMinds with previously-detained young people, they identified strong support for permitting people under the age of sixteen to choose their Nominated Person, provided that they had the ability to understand the decision.

> *"Yes. When I was sectioned they asked my family member but they have a lot of stigma about mental health. My school would be good."*
>
> **Young person previously detained under the Act**

Families and carers felt that the risk of a young person under the age of sixteen choosing a Nominated Person who was inappropriate was higher than it was for adults. They felt that there should be clear guidelines and boundaries for this cohort, and that the carers or family should be able to challenge such a decision.

Given time constraints and the necessity of translating the White Paper questions into an accessible form, we did not aim to answer the White Paper question of whether the Mental Capacity Act or Gillick competence was more appropriate for establishing whether an under-16-year-old could choose their Nominated Person. Participants who supported the proposals, across both previously and currently-detained workstreams, tended to outline characteristics that under-16s would need were they to appropriately take this decision, including 'ability to understand' and 'able to retain information'. These characteristics would appear to support the Mental Capacity Act approach, but we did not gather firm feedback on the proposals compared to one another.

6.4 Independent Mental Health Advocates

> *'I've spent 31 years in and out of hospital, and I've never been supported by an advocate. I didn't know advocacy existed until this discussion.'*
>
> **Participant with experience of multiple previous detentions**

By contrast to some of the engagement sessions with currently detained service users (particularly within CAMHS and high secure services), awareness of statutory advocacy across previously-detained service users was low in general. For those who had received it, it tended to have been variable in both delivery and results – some examples of support were excellent, but these were counterbalanced by examples of poor practice, poor integration, or general failings by the services or advocates.

Several major themes emerged around advocacy, and we found strong support for the enhanced powers and responsibilities which the White Paper proposes. Mostly, this support was predicated on the idea that service users might be able to access advocates more readily than they currently can.

For some participants who had accessed advocacy support, they found that the service did not meet their expectations or that advocates were unable to help them. Some described a lack of knowledge or skills on the part of their advocate, particularly with regard to more complex cases. One participant gave an example of asking questions about the Mental Capacity Act to their Independent Mental Health Advocate, and the IMHA being unable to support them to find out more about the legal framework.

> *'The advocate I had didn't offer anything I couldn't do myself, and I didn't want them to be in conflict with my clinicians.'*
>
> **Female previously-detained participant**

The quote above also shows a further challenge which participants expressed – the fact that services did not always support the involvement of advocates. Several people described struggles accessing advocacy, including out-of-date phone numbers for contacting advocates, limited awareness-raising by staff, and the fear that making use of an advocate to raise issues would be interpreted as challenging the way that they were being treated, with negative consequences. A lack of availability of private space on the ward, the fact that often advocates are not available on the wards themselves or available outside of office hours, and the fact that the service is frequently accessed through telephone referrals all contributed to the overall lack of awareness and access. Some participants felt that even if the powers of IMHAs were to be expanded, it was possible that this wouldn't make a difference as the views of clinicians would still hold more weight in discussions about treatment.

Among those who had used advocates, some had found the experience to be very helpful. Several carers said that their loved one had found advocacy support to be helpful in appealing detention, or understanding complex information which the carer hadn't been able to support them with. These positive experiences were reflected in the wide support that the proposals for enhancing the powers and responsibilities for advocate received from participants.

However, the engagement sessions made clear that it is crucial that access to advocacy is improved at a service level, and that patients are made aware of their right to an advocate and given an explicit explanation of the powers and responsibilities of an IMHA. Some participants shared examples which are likely to constitute coercive treatment, and felt that an advocate could have helped them to understand their rights:

> *'I was in a general hospital and my mental health was in a bad place. I wanted to check out but they if I tried, I'd be sectioned. I wasn't aware of the advocacy routes then.'*

Overall, these perspectives make a strong case for expanding the powers and responsibilities of Independent Mental Health Advocates. Along with the participants in the engagement sessions, we hope that the expansion of the powers will help to enhance access to advocacy in hospital, and to allow IMHAs to make a substantive difference in helping people detained under the Act to exercise their rights on an equal footing with the views of clinicians. It was also clear from those who had accessed advocates that changes to the ways that IMHA services are delivered are needed – both to ensure equality of access (including for voluntary inpatients) and to ensure that the knowledge and skills of IMHAs are sufficient.

7. Theme 5: Tribunals

7.1 White Paper questions

Consultation question 5: We want to give the Mental Health Tribunal more power to grant leave, transfers and community services. We propose that health and local authorities should be given 5 weeks to deliver on directions made by the Mental Health Tribunal. Do you agree or disagree that this is an appropriate amount of time?

- Many participants highlighted the important role that Tribunals played during their stay in hospital and supported greater access to them.
- Many participants believed there were improvements that needed to be made to Tribunals to make them fair and accessible. These included:
    - More information on the process
    - Accessible and plain English documentation
    - Support with speaking to solicitors
    - More access to IMHAs
    - Support with understanding the judgement
    - An empathic understanding from all people involved that the tribunal process was an important stage in a patient's detention

7.2 Detailed discussion

The White Paper proposes expanding the role of the Mental Health Tribunal[5] through granting it new powers across many of the changes proposed within the White Paper. This is particularly the case for the statutory Care and Treatment Plan, the core principles, and the revised detention criteria, each of which will inform future tribunal decisions. The White Paper also proposes revised timelines under which people can apply or be automatically referred to the Tribunal that in most cases will increase access.

The Lived Experience Advisors advised that covering Tribunals as a theme in discussions for the previously detained workstream would ensure that participants could detail their individual experiences of Tribunals and provide suggestions for how they could be improved, in order to see whether those suggestions match or broaden the proposals within the White Paper. As a result, participants were asked to discuss their experience of tribunals and then asked what more tribunals should do.

Participants' experiences of tribunals were mixed. While some participants felt they were able to participate in the process, and others were pleased with an outcome they'd secured, others found tribunals confusing and overwhelming, particularly given the intensive preparation for them.

5 Department of Health & Social Care (2021), Reforming the Mental Health Act, page 12

Participants believed that involvement in the tribunal process must be fair, equitable, accessible and simplified for patients and their carers/families. Participants also said that it was vital that this involvement included support pre- and post-tribunal. For example, this could include support with speaking to solicitors, as well as support with understanding and coping with the impact of a judgement (which may cause significant distress).

7.3 Experiences of Tribunals

Many participants highlighted the essential role that independent scrutiny played during their stay in hospital and supported greater access to the tribunal as a result.

> *"You felt like you were in a different space where people are trying to understand what is going on for you and trying to get you home if that is an option."*
>
> **Young female participant**

Participants spoke about the importance of tribunals being independent from the hospital and some patients said that the knowledge they'd gained about the tribunal was reassuring and could encourage them to participate more fully in the future. However, many wanted deliberations and decisions to be more transparent so that they could understand how and why a judgement was made and could have avenues to contest it.

> *'There was a real need for transparency, for deliberations by the panel, for example, because otherwise there was no way to evaluate the fairness of a tribunal decision.'*
>
> **Male participant**

There was a feeling among some patients that tribunals are weighted towards the needs of clinicians, rather than patients. One participant observed from her experience in hospital that occasionally the focus appeared to be on someone spending a set amount of time in hospital, rather than whether the patient was well or not, or needed to be there.

> *'It is positive that you're being heard and your case is reviewed but they can be quite upsetting as well as I never won my tribunals. This can be quite damaging.'*
>
> **Female expert by experience co-facilitator**

Overall, participants agreed that more access to tribunal was vital, but highlighted that this was a major event in their hospital experience and could be traumatic, so should be a point at which they are heavily supported by staff, family/carers and Independent Mental Health Advocates.

7.4 How can Tribunals be improved?

One of the main issues flagged consistently by participants was the need for more support with the Tribunal process.

> *"It was a confusing process to go through, especially if you've not done it before and don't understand it, so it needs a thorough explanation of what it is, especially when you're in crisis."*
>
> **Male participant previously detained in Wales**

Many found participating in the Tribunal process confusing and overwhelming, particularly if they were in crisis. Participants wanted more support with the process, including involvement from Independent Mental Health Advocates (IMHAs), in line with the proposals in the White Paper.

'I didn't have much to say, or capacity.'

Female participant

Many participants identified a need for more support with speaking with solicitors. Participants spoke about experiences where they were required to speak to a solicitor while experiencing psychosis. This was another point at which participants said support from an IMHA would be vital. One participant said that *'unless you have this support, it's unlikely you'll be discharged'*.

'the experience was quite intimidating, and there was a focus on the bad bits rather than the good bits of the patient's behaviour. They'd found it confusing – there were lots of documents and information'

Carer

Several participants highlighted the importance of "demystifying" tribunals. The formal language of tribunals was also perceived as sounding overly legal and formal, in contrast with how they operate in practice, and that this can be off putting for patients. Many participants said that support should be provided after the Tribunal, particularly if they were not happy or did not understand the judgement. This was a point at which they often felt significantly distressed.

Overall participants stated that Tribunal could be improved through:

- More information on the process
- Accessible and plain English documentation
- Support with speaking to solicitors
- More access to IMHAs
- Support with understanding the judgement
- An empathic understanding from all people involved, that the tribunal process was an important stage in a patient's detention

8. Theme 6: Routes out of hospital

8.1 White Paper questions

Consultation question 7: Do you agree or disagree with the proposal to remove the role of the managers' panel in reviewing a patient's case for discharge from detention or a CTO?

- Given very low levels of awareness of hospital manager's hearings, coupled with their perceived ineffectiveness among those who were aware of them, participants supported removing these hearings.
- Participants felt that changes to the mental health tribunal would more effectively safeguard their rights, and would potentially mean more robust criteria for discharge as well as enhanced support for discharge overall.

8.2 Detailed discussion

In this section, the Lived Experience Advisors sought to examine the process of transitioning out of inpatient mental health settings. The questions were based on some technical questions from the Mental Health Act White Paper, particularly the proposals relating to hospital manager's hearings and community supervision. In the process of translating these questions, the Lived Experience Advisors decided to ask about the process of discharge and leaving hospital more generally, and the feedback we gained has broader implications than the White Paper itself.

8.3 Hospital manager's hearings

> *'I think it should be scrapped'*
>
> **Lived Experience Advisor**

One major finding from our engagement is that almost no one had experience of a hospital manager's hearing. This finding was true across both the currently detained and the previously-detained workstreams, and was somewhat surprising given the breadth of experience with different hospitals, different sections of the Act, and the length of time in which the experience of our participants had occurred. Nevertheless, as a result of feedback from early engagement sessions we began asking if anyone had experience of the manager's hearing at the start of this section, to build a more comprehensive picture. All previously-detained participants who we spoke to from this early point told us that they had never experienced a hospital manager's hearing.

Notably, awareness of the hearings was much higher among the carers and family members who we spoke to. This could perhaps indicate that, as relatively active carers who were aware of the powers of the Nearest Relative, they were familiar with the right to discharge someone and the fact it could be overruled by a manager's hearing. It could also imply that carers might have been told if someone had an upcoming hearing in circumstances where the service user was not made aware of that fact, though this seems unlikely.

One carer's relative had been discharged by a manager's hearing into their care, and they blamed this fact for the lack of support their loved one had received as a result. Support for removing the hearings was unanimous among the carers and relatives we spoke to, with the person who had seen their relative discharged by one particularly supportive:

> *'There was nothing in place for my daughter and she was set up to fail again and again.'*
>
> **Carer for someone formerly detained under the Mental Health Act**

These carers attributed the lack of support and resources after discharge in part to the context of the manager's hearing as a means of discharge – with the implication that discharge through the tribunal would have at least considered the provision of support to someone upon discharge.

The fact that almost no formerly-detained participants had experienced or heard of the manager's hearing has implications for the White Paper proposals to remove them as a mechanism which can discharge service users from hospital. Once participants were made aware of their duties and responsibilities, most supported their removal (in part because they hadn't made a material difference to their time in hospital). Some participants contrasted the panels to the tribunal, of which they were all aware, and around which the reform proposals had previously been discussed.

> *'They need to be scrapped… They think they're giving you more opportunities but you're not going to get out of there…'*
>
> **Lived Experience Advisor**

Participants who opposed the removal of hospital manager's hearings after they had been made aware of them did so on the principle that the removal of safeguards and potential routes towards discharge should be preserved, and that in theory the hearings could be valuable for advocates and Nearest Relatives under the current system. These participants acknowledged that reforms to the tribunals could address their concerns.

8.4 Experiences of discharge

In general, participants had negative experiences leaving inpatient detention settings. For the most part this was because the experience of discharge was experienced as extremely abrupt, either occurring before the participants felt ready to leave hospital or so long after they believed they'd be leaving that much of their time detained appeared inappropriate.

For most participants, a lack of support within the community, or stretching from hospital into the community, was the standout feature of their discharge experience. While some recalled staff in hospital attempting to prepare them to leave hospital, most shared experiences which demonstrated a lack of joined-up community mental health and social care services, struggles to access secondary care within the community, and pressure on inpatient beds which led to discharges more rapid than were appropriate.

For those who accessed more intensive care and support in the community, numerous challenges were experienced in the course of waiting for these social care services (such as supported housing), funding to access them, and the transition into them. We heard from multiple participants that people who were on Community Treatment Orders were fortunate, in that their placements were automatically funded. Section 117 aftercare was not raised organically, though we did not enquire into funding arrangements specifically.

Support from professionals in the community was raised in a number of sessions, and while these sessions were not asking specifically about the proposed role for Community Supervisors, some support was expressed for granting further power and resources to those professionals who managed transitions out of hospitals. One participant shared very positive experiences with their Care Coordinator, who helped them though the:

> *'fear and panic around leaving hospital, and was extremely knowledgeable about the support available in the community.'*
>
> **Previously detained female participant**

This participant felt that their positive experience was down to effective information sharing by their Care Coordinator, and acknowledged that this experience was not shared by other people with experience of detention.

Overall, participants felt that there was a clear need for improving support available both within hospital to support people approaching discharge, and in the community to ensure a smooth transition. While we did not enquire about the specific proposals in the White Paper to improve aspects of this experience (such as strengthening the Social Supervisor role, as this is primarily aimed at patients detained under Part 3; or the power of the tribunal to direct service delivery, which we covered under a separate set of questions), these findings are indicative of a wider issue with mental health services and mental health social care in the community.

Throughout all the sessions and across all cohorts, the issue of insufficient community mental health care and treatment emerged as a cohesive and detrimental factor in the lives of our participants, and as an element to which many pinned their hopes for future improvements to the system. We will conclude in part by looking at this vital issue, alongside the key findings from our engagement.

9. Children and Young People

This section outlines the key findings and themes from workshops and 1:1 calls facilitated by YoungMinds with 19 young people with lived experience of the Mental Health Act. This section is extracted from the Executive Summary (section 1.0) and the Main Findings and Analysis (section 1.4) sections of the final report produced by YoungMinds, which has been separately submitted.

The key theme that emerged throughout the research was that young people did not feel listened to or able to engage meaningfully in their care and treatment.

- Young people said that the care they received felt more like detention, and that instead of being person-centred and tailored to individual needs, staff tend to adopt a **one size fits all approach** to the care and support provided.

- Young people are **assumed to be difficult** and often **feel like a burden** when trying to engage in their treatment. The young people we spoke with shared experiences of how professionals defined young people's efforts to engage – for example, through asking questions, challenging decisions, expressing preferences or making notes - as challenging behaviours or symptoms of their diagnoses.

- Young people want to be meaningfully involved in decisions made about them and staff are often seen as the main barrier to this, with informal patients being threatened with being sectioned if they are seen to be 'challenging' their treatment and care.

- Young people want staff to take the time to talk to them, clearly explain their rights, listen to their thoughts and concerns, and offer **individualised treatment and intervention**, as well as medication, to provide a more well-rounded approach to their care and support.

Having supportive staff and access to an advocate throughout the process of being detained and during their time spent in hospital made a huge difference to young people's experience of the care and treatment they received. However, accessing advocacy is problematic. Many young people cited out of date information, a lack of staff knowledge about advocacy and the lack of availability of advocates outside of 'office hours' as reasons why they were unable to receive this support.

> *"The nurse took the advocate round to each patient then asked each person if they needed an advocate. This was really good and I think this is something which should happen more often."*

9.1 Main findings and analysis from subcontracted work by Young Minds with Children and Young People

Ultimately, the key theme running throughout the feedback we received is that professionals should truly listen to young people and work *with* them to plan and deliver their treatment and care. Young people are experts in what they need by way of their experiences and their thoughts, feelings, wants and needs. It is their right to have their voices carry real weight in their individual care and treatment plans.

In addition to the above, and to the key themes and experiences outlined in this report, we want to highlight the following:

- **Young people entering services as voluntary patients reported experiences of being threatened with a section for disagreeing with or challenging their treatment and care.** This uncertainty about their rights disempowers young people further when they can already feel unsafe and as though their wishes are not considered to have the same weight as those of the parents, carers and professionals involved in their care.
- **Young people said that sometimes detention can feel like the best thing at a point of crisis, despite stigma and previous negative experiences**. Although many highlighted significant areas for improvement, some young people shared concerns that always following the guideline of 'Least Restriction' could lead to young people missing out on the right support i.e. inpatient care. This aligns with their concerns about the standard and quality of community-based care, with many young people we spoke with saying that there needs to be considerable investment and improvement for it to be a genuine alternative to inpatient provision.
- **Young people highlighted that professionals need to have a better understanding of racism and of issues facing trans and non-binary young people.** We heard examples of young people having difficulties accessing choices of Halal food and the importance of professionals understanding the social and cultural issues that can contribute to young people's mental ill health e.g. cultural stigma about mental health and family members not believing in mental health difficulties. Consideration also needs to be given to the difficult and potential traumatic experiences that may be caused by placing trans and non-binary young people on single gender wards. These experiences further highlight the importance of the principle of 'Treating the person as an individual'.

10. Conclusions and recommendations

Throughout this commissioned research, we have been struck by two common factors which emerged across the vast majority of the engagement sessions, regardless of who we were speaking to. The first of these was how much support was expressed for the White Paper proposals across the vast majority of the people we engaged with experience of detention under the Mental Health Act. This is seen most clearly in areas such as the list of suggested aspects for including within Advance Decisions – when we asked participants what should be included, most of those proposals were already included within the White Paper itself. This is highly encouraging, and indicates that in many respects, the ambition of the White Paper is strongly supported by people who have been detained under the Act.

The second common factor is the low trust and lack of expectation that these proposals will be implemented, which was common among people with direct experience of detention. This was often directly expressed by participants feeding back on the proposals, who frequently said that the proposals sounded positive but they couldn't imagine them being implemented. For the most part, this was because the participants had experienced such negative treatment – ranging from traumatic experiences to the lack of person-centred or holistic care during mental health detention– that they couldn't imagine the delivery of the ambitious proposals outlined in the White Paper.

In many instances, this linked strongly to the experiences of people previously detained under the Act outside of detention. Given strong feedback on the importance of community mental health services in preventing detention in the first place (including from our Lived Experience Advisors), we began early on to introduce the White Paper proposals by first discussing the importance of the NHS Long Term Plan and the ambitions for reform to community services. This allowed participants to situate the White Paper proposals within the wider direction of reform.

As well as the fact that support for the specific White Paper proposals was strong, if anything it was even stronger for the broad ambition of the White Paper to improve involvement in care and treatment. While we have grouped specific points made during the sessions under the relevant White Paper questions, there are many which will have a broader influence.

When the time eventually comes to implement any new Mental Health Act, this engagement has showed us that a great deal of weight will need to be placed on the effective implementation of any new proposals, especially if they remain as potentially far-reaching as the current White Paper suggests. This will be true across both the legislative changes and for the many changes that rely on shifting professional or clinical practices, or changing the culture inside wards. The changes will rely on well-resourced implementation, clear guidance from the Code of Practice and other sources, and extensive training and funding to make the alterations that the ambitious proposals rely on. Crucially, the ultimate success of the White Paper reforms will also rely on the successful delivery of greatly improved community mental health services – a process that is making substantial strides through the Community Mental Health Framework, but which is a long way from being complete. It is also dependent on the often-unsung work of mental health social care services, which we heard play a key role in successful discharge from inpatient care and in preventing the need for detention under the act in the first place.

While the effective implementation of the White Paper's vision is a challenge, it's clear that people previously detained under the Mental Health Act felt very strongly that it was necessary and worthwhile. And while their own past experiences had made them sceptical about whether the ambitions can be fully achieved, there was clear support from participants for the White Paper proposals forming the basis of a well-implemented new Mental Health Act.

11. Methodology

Rethink Mental Illness has significant experience engaging with people detained or previously detained under the Mental Health Act, given our longstanding work on the topic and previous publications which made a case for reform.

Our central aim for this complex project was to ensure that co-production was used to drive the overall approach and to balance the research approach to the Mental Health Act. Co-production played a vital role in determining the specific questions posed during engagement sessions, and in ensuring the technical nature of the questions posed in the White Paper would not present a barrier to engaging with this aspect of the consultation, by building an environment alongside experts by experience to use their views and perspectives to shape the project.

As a result of the coronavirus pandemic, engagement activity was designed to be delivered remotely, to ensure the safety of all participants and facilitators and to avoid unnecessary travel. In order to appropriately balance research capacity and to maximise the possibility of contributions to the project from as many participants as possible, we conducted virtual engagement sessions during the period 31 March to 14 May 2021. We offered all participants a £50 fee for participating in the engagement sessions.

11.1 Lived Experience Advisors

We began the project with the recruitment of 7 people with experience of the Mental Health Act (including carers) as paid Lived Experience Advisors (LEAs). The LEAs played a significant role across the life of the project. They shaped the formal documents required for the project and the overall approach, attended the engagement sessions to provide a peer researcher perspective and presence, and saw their skills developed as a vital part of this project.

As the final report was being drafted, we reconvened the Lived Experience Advisors in order to get their feedback on the emerging final themes of the research, get their perspectives on the sessions they'd attended, and check our analysis against their experiences. In addition to that specific feedback, some LEAs shared comments about their involvement with the process overall:

> *"I felt like I was really listened to…."*
>
> *"Thank you for sharing and being a voice of what's going on."*
>
> **Lived Experience Advisors**

11.2 Engagement sessions

Participants were recruited to engagement sessions through an online survey, launched on 2 March 2021. This survey was reviewed by the Rethink Mental Illness Communications Advisory Panel, in order to ensure that the language and questions were accessible and open. The results of the survey were used to assign people to engagement sessions based on their characteristics, and to make reasonable adjustments in advance to the format of the sessions.

11.3 Participant characteristics

We conducted 11 engagement sessions with 46 people with experience of detention under the Mental Health Act. Young Minds conducted workshops and 1:1 conversations with a total of 19 children and young people.

Of the engagement sessions undertaken by Rethink Mental Illness[6]

- 71% of participants identified as female and 29% as male.
- The predominant age group was 30-50, followed by 50-70, 25-30 and 70 plus.
- 23% of participants identified as LBGTQ+[7].
- 13% of participant identified their ethnic background as Black, Black British, Caribbean or African or Asian, Asian British, with 87% identifying as White. [8]

For Young Minds sessions, the age of participants ranged from 16 to 25 years old.

We spoke with participants who had been detained under one or more of the following sections of the Act:

- Section 2
- Section 3
- Section 135 or 136
- Part 3 of the Act
- Voluntary inpatients

We spoke with participants who stated they were diagnosed with one or more of the following conditions:

- Anxiety, including Generalised Anxiety Disorder and Agoraphobia
- Bipolar Disorder
- Depression, including Clinical Depression, Depressive Disorder, Depression with psychotic symptoms
- Obsessive compulsive disorder (OCD)
- Personality Disorders, including Borderline Personality Disorder
- Post-natal psychosis
- Post-traumatic stress disorder (PTSD)
- Schizoaffective Disorder
- Schizophrenia

There were several participants who stated they had a dual diagnosis of a mental health condition and Autism Spectrum Disorder.

In addition to the participants, the engagement sessions were attended by a facilitator and a note-taker from Rethink Mental Illness (except where subcontracted). Representatives from the Department of Health and Social Care attended some sessions as observers.

6 A small amount of participants at the engagement sessions did not complete the survey so their data has not been included in this analysis.

7 Some participants selected ‘prefer not to say’ and this has not been included.

8 These statistics do not include the family members or carers, or Welsh participants who were not assigned to sessions through the survey.

11.4 Session records and analysis

Notes made during the sessions were recorded under each of the themes, and anonymised at the time. Immediately following the meeting, top-line summaries of the group discussions were produced, with key quotes and comments highlighted. Where participants had comments which exceeded the scope of the questions posed, they were encouraged to respond to the public consultation on the White Paper, and to share their feedback with RMI by email, to be taken into account during analysis.

The analysis process was conducted through each of the identified themes, comparing and contrasting the perspectives of different cohorts against one another, and using the qualitative data to broaden our understanding within and beyond the comments made by participants. The responses under each theme can be translated back into the specific questions posed by the White Paper (as we have done at the end of each section).

11.5 Delegated engagement sessions

In order to ensure that the engagement events were able to access as broad a range of participants as possible, including for cohorts where Rethink Mental Illness does not focus, we agreed subcontracting arrangements with organisations who work in Wales and with children and young people. The arrangements allowed subcontractors to deliver a bespoke approach in each instance. Hafal and Young Minds were appointed as subcontractors. Hafal was appointed to conduct engagement in Wales across both the currently and previously-detained workstreams, while Young Minds conducted engagement across the previously-detained workstream only.

Appendix 1 Previously Detained Question Grids 25th

Theme	DHSC consultation question	Question aims	Suggested questions	ExE input	Final questions for engagement sessions
Principles	Consultation question 1: "We propose embedding the principles in the MHA and the MHA code of practice. Where else would you like to see the principles applied to ensure that they have an impact and are embedded in everyday practice?"	To ensure that the 4 principles [are]… at the forefront of people's minds – both service users and staff	How could the guiding principles be used? Who should have to follow them?	'How and Where' -Code of Practice -How do we make sure*the right* (i.e. police/ paramedics) people follow them? Training? More emphasis on other services (s136 suite) Comms aspect - making sure it's on the front of every leaflet Training Appropriate adults Ignorance vs malice Define code of practice Same question for each principle	How and where could the guiding principles be used? Who should have to follow them?

Theme	DHSC consultation question	Question aims	Suggested questions	ExE input	Final questions for engagement sessions
Reasons for being detained	Consultation question 2: "We want to change the detention criteria so that detention must provide a therapeutic benefit to the individual. Do you agree or disagree with this proposal?" Consultation question 3: We also want to change the detention criteria so that an individual is only detained if there is a substantial likelihood of significant harm to the health, safety or welfare of the person, or the safety of any other person. Do you agree or disagree with this change?	To ensure that people are only being detained and going into hospital when it is really necessary for them to feel better, or when it is for their own or someone else's safety	When and why should someone be detained?	How do we measure TB – whose point of view? V abstract at the moment S3: 'for treatment' but what exact treatment? Needs to be communicated at the point of detention Sectioning when they're not actually unwell i.e. family crisis – clinical reasons (think socioeconomic) Consensus on TB w/ medical staff, advocates, clearly communicated – social isolation TB could be very subjective –i.e. Is it amount or absence of symptoms, or about functioning (only as good as the community care provision?) People could explain what it means to them – what they got from hospital etc Trauma-informed care – not a bolt on but part of the culture (often people have trauma?) Safety - how is it different? Thinking about only if they are clinically unwell – not for social care! (S3) currently being misused Think about OOA – pressure to have section even if there isn't the need (in order to access services) No mechanism to rescind It did help to be explained to – even if it isn't understood at the time?	What would therapeutic benefit mean to you? What would you like or expect staff to tell you when you are being sectioned?

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Tribunals	Consultation question 6: We want to give the Mental Health Tribunal more power to grant leave, transfers and community services. We propose that health and local authorities should be given 5 weeks to deliver on directions made by the Mental Health Tribunal. Do you agree or disagree that this is an appropriate amount of time?		What has your experience of the MH Tribunal been? What more could the Tribunal do?	5 weeks could be really long? How long does it usually take? 5 weeks seems long for smaller adjustments – not necessary Waiting for decisions is already agonising – leaves them stuck Separate them out? Grant leave – Transfers – Comm services – Standards for each aspect Timeframe within the timeframe! (i.e. a week) – gives certainty and stops the painful wait Think about auditing and meeting targets – accountability? (CQC) Clarity – define 'leave' Don't always act independently – 'must' not 'should'! No urgency usually – need a timeframe (OOA again) Commissioning linkup	What has your experience of the MH Tribunal been? What more could the Tribunal do?

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Routes out of hospital	Consultation question 7: Do you agree or disagree with the proposal to remove the role of the managers' panel in reviewing a patient's case for discharge from detention or a community treatment order?	To determine how appropriate the role of a managers panel is in discharge	How did you leave hospital? How could that have been improved? Prompt on hospital managers route.	Stats aren't great – some people have RC has a lot of control – hospital managers have lot of power and say Makes people get stuck in the system – not effective Clinical background? Or lay person/admin? Pool of a panel – 'the inner circle' – private providers financial motivations Has to be in the benefit of the person Some ways it could be positive? Closer to the situation? Acknowledgement of progress – opportunity for feedback Hospital do interviews for panel – not fair and proportionate No training, accountability, of membership of professional body No transparency or independence	Who was involved in the decision of you leaving hospital? • What were the positive experiences? • What were the negative? • Who should make these decisions?

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	Consultation question 8: Do you have any other suggestions for what should be included in a person's advance choice document?	To determine the content of an advance choice document	If you thought that you might be detained again in the future, what would you want people involved in your care to know?	Sceptical on how much they would be respected and upheld? Legal weight not legal power? Advanced Care Directives? Validated by MH Team? i.e. ECT, olanzapine? Polypharmacy? Alternative interventions? Involvement of others? Evidence-based treatments – treatments for the right reasons	If you thought that you might be detained again in the future, what would you want people involved in your care to know? What would you like included?

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Capacity and the	Consultation question 9: Do you agree or disagree that the validity of an advance choice document should depend on whether the statements made in the document were made with capacity and apply to the treatment in question, as is the case under the Mental Capacity Act? Consultation question 11: Do you agree or disagree that patients with capacity who are refusing treatment should have the right to have their wishes respected even if the treatment is considered immediately necessary to alleviate serious suffering? Consultation question 10: Do you have any other suggestions for what should be included in a person's care and treatment plans?		When making decisions about your care in advance, what should be taken into account when people act on those decisions? Should those decisions always be respected? What checks or tests should be applied to an advance decision to make sure that it's valid?	Needs to have some formal process – for reassurance on both parties? Needs to be justified if they are going against your wishes Something for the first time you're unwell? Capacity so time and space specific – fluctuations? Timelines? Lasting Power of Attorney? Extra piece of protection – self advocacy How extreme can you be in the wishes you express? i.e. self-harm	What if your advanced choices aren't the same as when you are in a crisis? Should they still be followed? How often should they be reviewed or updated? What are the 'lines'/limits to that?

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Support for and from car-ers	Consultation question 13: Do you agree or disagree with the proposed additional powers of the nominated person? Consultation question 14: Do you agree or disagree that someone under the age of 16 should be able to choose a nominated person (including someone who does not have parental responsibility for them), where they have the ability to understand the decision (known as 'Gillick competence')**?**	Break into carers/ non-carers To determine the role of the nominated person (also for those under 16)	Carers: What do you think of the proposed powers and ways to be involved? Prompt: Q14 Non-carers: Who is the best person to involve in your care? Have they been able to be involved? Are there any challenges around naming them as the best person to be involved in the future?	NP to consult with advocates? As agreed in ACD/Care plans?	Carers: What do you think of the proposed powers and ways to be involved? • Prompt: Q14 Non-carers: Who is the best person to involve in your care? Have they been able to be involved? Are there any challenges around naming them as the best person to be involved in the future?

Theme	DHSC consultation question	Question aims	Suggested questions	ExE input	Final questions for engagement sessions
Advocacy	Consultation question 15: Do you agree with the proposed additional powers of independent mental health advocates? Consultation question 16: Do you agree or disagree that advocacy services could be improved by: enhanced standards, regulation, enhanced training	To determine the role of IMHAs	What have your experiences of advocacy been? What could have improved them?	Training – improve independence, mental health competency, issue specific not looking at whole picture NR= useless safeguard – need advocates more involved Make it clear how to access these advocates – current barriers in place Make it automatic? (opt-in opt out) They come to you? What about when you're unable to communicate/ self-advocate? They're not trained – go to NR/NP? Options to communicate in different ways – attend ward rounds – not just about tribunal	What has your experience been with an advocate in hospital? What else could they have done?

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For further information
on Rethink Mental Illness
Phone 0121 522 7007
Email info@rethink.org

rethink.org

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