



Mental Health Act White Paper engagement report

Service users currently detained under the
Mental Health Act

1. Executive Summary

Main findings

1. We found that feedback was overwhelmingly positive, both with regards to the overall direction of travel outlined in the White Paper and for the majority of specific proposals. The particular proximity of these reforms to the everyday lives of currently detained patients and families and carers of those currently detained meant that the need for reform was strongly felt. Participants were able to relate the proposals to their experiences of care, and had clear ideas regarding how these should be implemented in practice.
2. The upcoming Mental Health Bill was recognised as a landmark first step towards positive change. However, we found also that participants also raised reservations and questions regarding the proposals and expressed a degree of scepticism regarding the ability of legislation to impact on their day-to-day experience of detention.
3. Their concerns highlighted the need for implementation to be well-resourced, informed by clear guidance and supported by training emphasising culture change within services and across the system. Experiences shared in sessions also emphasised the importance of shifts beyond the scope of this legislation, such as better availability of suitable accommodation for individuals leaving hospital settings.

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 previously 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 12 engagement sessions with 59 service users. We held 5 sessions in low and medium secure services with a good geographical spread across England and Wales and sessions in two high secure services. We also held a session specifically for Part II service users, two for families and carers of people currently detained under the Mental Health Act and two with young people currently detained in CAMHS services.
5. Other feedback on the White Paper proposals is discussed under each of the themes presented in this report.

2. Introduction

‘The MHA has been very badly put together for those suffering mental illness. It needs radical change.’

A service user currently detained in England

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

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

Rethink Mental Illness worked with a paid panel of Lived Experience Advisors 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 Consultation Questions

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?

- Participants liked the four proposed principles, especially the principle of least restriction, and agreed with the proposal for them to be embedded in the Mental Health Act and the Mental Health Act code of practice
- Participants wanted the principles to be applied as far and wide as possible in everyday practice, with all staff involved in an individual’s journey from detention to discharge having to follow them
- There were real concerns around implementation and accountability. Existing issues within services may mean that the principles are unable to be as embedded as they could be. The government should ensure that these principles are as broadly applied as possible across strategies, staff and services, right down to ward and individual levels to ensure they are as meaningful as possible.

3.2 Detailed discussion

“Principles need to be used to create collaborative discussions so there’s fairness and people are treated as individuals.”

A service user currently detained in England

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 expectations on how service users are to be treated, and giving legislative weight to the aim of rebalancing power between service users and staff.

We engaged currently 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. The people currently detained in adult and CAMHS services, who we spoke to were very supportive of the principles, the “least restrictive” one in particular, but had some concerns around their implementation and who would be held accountable for this.

The principles are:

1. Choice and autonomy – ensuring service users’ views and choices are respected

“Choice and autonomy is crucial but is not happening at the moment...my son is very clear what he wants and needs but staff aren’t able to facilitate.”

A carer of a forensic service user currently detained under section 3

Service users and families and carers were supportive of this principle and links were made to the proposed role for advanced choice documents in improving choice and autonomy of care.

The importance of information and empowerment to make decisions regarding your own care was evoked strongly by participants currently detained in secure services, particularly those under forensic sections.

“People in high secure under Section 3 are not allowed to have choice or autonomy...Their rights are taken away so they learn to live with no rights or voice.”

A carer for a service user currently detained in a high secure service.

Medication was also frequently discussed here, with participants stressing the need for more choice over drug treatments.

One young service user suggested that a focus in community mental health services on the choice and autonomy principle before and during the detention process could prevent a detention from being necessary.

2. Least restriction – ensuring the Act’s powers are used in the least restrictive way

This principle was supported for the most part by both service users and families and carers. Service users in Wales explicitly agreed that the principle of least restriction should apply not only in relation to hospital settings and the type of care and treatment received in hospital, but also to the length of time spent in hospital.

“Less restriction for how long people can be detained for is a good thing. 28 days is a long time and six months is a very very long time...”

A service user currently detained in Wales

People living in high secure services and their families and carers welcomed this principle and explored how restrictive a high secure environment can be.

“Patients in hospitals can feel like they’re in prison...handcuffs are used, how can that be least restrictive?”

A carer for someone currently detained in a high secure service

It was discussed how blanket policies cover every patient in high secure, even if the policy is based on a historical event and would only apply to a small group of service users.

‘Security says you can’t do things because something happened five years ago but I wasn’t there 5 years ago...’

A high secure service user

Young service users said that blanket restrictions and restrictive practices also meant that rules could be unfairly applied and not tailored to individuals. An example of this was a blanket ban on certain phone applications that would limit contact with friends and family. The young service users hoped that the least restrictive principle would address these issues.

In some sessions concerns were shared that this principle was unlikely to be followed in practice if interpreted in conflict with duty of care. A participant in a high secure service said that this principle would need to be ‘black and white’ to have any impact.

‘It should say...this is what least restriction is and if you don’t follow the principle you are breaking the law. The principle of least restriction is too subjective and open to interpretation...’

A male high secure service user

Other high secure service users wondered what would hold the most power over a decision, the Mental Health Act and its principles or a service’s security framework.

3. The person as an individual – ensuring patients are viewed and treated as individuals

“Often staff seems to be under the misconception that a one-to-one meeting constitutes their duty to the individual.”

A female service user currently detained under a CTO

Service users and families and carers agreed that care should be person centred and individualised as far as possible.

“People need to change the way they treat people, if you don’t change the way they treat people, nothing will change”

A male currently detained Lived Experience Advisor

‘My concern is that some practitioners are not treating people holistically, they are treating someone’s mental health but not the person...’

A carer of a high secure service user

It was felt that the system can be dehumanising, and that it can feel as though an identity beyond that of being an inpatient with a mental health diagnosis is forgotten and not considered with respect to their care and treatment. It was suggested that more attention be paid to an individual’s situation outside of being detained and other problems they are facing such as physical illness or housing.

High turnover of staff, particularly where agency services are used, was cited as a factor in why care is not currently delivered in a person-centred way. It was seen as valuable for staff to have the chance to build relationships with service users and get to know them as people.

It was suggested by the young people currently detained that the least restrictive principle and principle of treating a person as an individual be used together to address slow risk assessments so they could have access to specific items or phone applications faster.

Where this principle was already in use in services, it seems to have had a positive effect on service users:

“The staff are lovely and respectful and treat me as an individual...”

A female service user currently detained under section 3

4. Therapeutic benefit – ensuring patients are supported to get better, so they can be discharged as quickly as possible

“Starting off with ‘therapeutic benefit’ and ‘least restriction’ is a kind, useful approach....”

A service user currently detained in Wales

Currently detained service users and their families and carers were supportive of the proposed principle. It was felt that this principle should be at the forefront of all decisions made around a person’s care. The hope articulated in the White Paper is that this principle will help people leave hospital faster, and participants were supportive of this idea.

The currently detained young people who we spoke stressed that this principle would be especially important as they came to the end of their time in CAMHS and transitioned into adult services.

‘Your notes seem to carry on a theme to justify your continued detention...’

A service user currently detained in Wales

The comment above shows why it is important that ‘therapeutic benefit’ and ‘least restriction’ are used in tandem, to avoid the risk that care plans justify detention beyond what is necessary or beneficial, as happens to some people at the moment.

A staff member supervising one of the sessions reflected that many people remain in hospital despite this no longer providing them with any therapeutic benefit. While the current reality of living under the Mental Health Act for these service users is in conflict with the proposed principle, we can interpret this comment and the feedback we received more broadly from participants as supportive of the proposed principle’s aim to support people to leave hospital when this is no longer offering therapeutic benefit.

We will expand more on the role of therapeutic benefit under **‘Theme 2- Reasons for being detained’** below.

3.3 The guiding principles in practice

“In order to be least restrictive and have the most therapeutic benefit you need to treat the whole person...”

A carer of a high secure service user

It was clear that the principles were all interlinked. They should not be used in siloes and need to be used in collaboration to have the greatest impact on care.

“The principles need to be properly, simply communicated.”

A service user currently detained in England

“I like the ideas of the principles yes, but I don’t think it’s happening at the grassroots day to day level...”

A male service user currently detained in Wales

“Can change the law but also need to change the culture and the attitudes...”

A carer from the Lived Experience Advisory Group

Overall, while broadly supportive of the principles, service users felt that there was a risk the principles could be rendered meaningless in practice if not properly communicated both with them and with staff and services involved in their care and treatment. The importance of communicating the principles in a straightforward and accessible way was also highlighted by participants.

There was agreement that the four principles outlined should be followed as early as possible after or even before detention, for example in A&E departments. The need for the principles to be embedded into transitions between services for example during step downs between high secure and medium secure services was also mentioned.

The most common answer to the question of who should have to follow the principles was 'everyone involved in someone's care'. Ward staff, from nurses to support workers, who spend the most time with service users were singled out in some instances. The need for agency staff to follow the principles was also stressed since their turnover can be frequent and impact on person-centred care. Some participants said that the police force needed to embed the principle of least restriction in the way they treat people in mental health crisis. Robust inductions, education and training were all cited as places where staff could learn these principles.

In some sessions, it was suggested that other service users, family members and carers should also have to follow and subscribe to the principles. It was also stressed that service users under all types of section should benefit from the principles and have it embedded in their care:

"We tend to stay in longer than people on other sections...these principles need to reach everyone."

A service user currently detained under Section 3

It was also suggested that once someone is detained, the principles should be followed at all points, both when things are not going well, and when they are, with successes celebrated. Care Review meetings were one example suggested as a setting where principles could be placed at the fore.

Accountability was discussed across the sessions in relation to the principles, especially by long term service users and their families and carers. Participants asked how staff members would be held to account if they did not follow the principles, and to ensure that the principles are not just words but are embedded and implanted to have long term change and challenge 'typical' practice.

"I don't know how enforceable these are going to be...."

A male high secure service user

"Regardless of legislation, so much relies on the extent to which it is put into the practice and the competence and resource un services to be able to implement it properly. The Mental Health Act is only one part of the equation."

A female Lived Experience Advisor

More broadly, we found that those who had been detained in services for a longer period of time expressed more scepticism that the principles would make a significant change in practice. Our group of Lived Experience Advisors were not surprised by this and reflected that when you have been in services for a long time, you hear about lots of ideas like the principles coming in but then see no long-term change or impact from them.

"When people become revolving door patients, service users and their families and carers become weary of it..."

A male service user currently detained in Wales

4. Theme 2: Therapeutic benefit and detention criteria

4.1 White Paper Consultation 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?

- Participants agreed with this proposal and welcomed the prospect of person-centred recovery being at the forefront of care. It was hoped this would make a huge difference to the standard of care received and the length of stay in hospital.
- Participants explored the range and quality of therapies currently offered in their services and it was clear that this varied between and within services. Therapeutic Benefit is being undermined by service delivery in hospitals and in order to fulfil the criteria of the White Paper, they felt there should be a greater focus and consistency on delivering therapeutic interventions.

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?

- Participants agreed with this change and stressed the need for people to be detained only if it has therapeutic benefit, to avoid detentions being longer than they needed to be. It was clear that therapeutic benefit would need to be carefully balanced with risk assessments, especially for Part III patients, but participants implored staff to use the principle of least restriction in these cases,
- This is also explored more in **Theme 3: Care & Treatment Plans**, **Theme 6: Criminal Justice System** and **Theme 7: Routes out of Hospital**

4.2 Detailed discussion

The Mental Health Act White Paper proposes changing the criteria for detention under the Act to more clearly stipulate that the purpose of treatment and care is to bring about therapeutic benefit. In practice, this is likely to mean that people should only be detained if there is a clear plan for how detention will provide a benefit for their health or recovery, and in the least restrictive manner possible. People should be receiving the right support to be discharged as early as possible.

In this theme, the Lived Experience Advisors sought to gain feedback on the application of the proposed therapeutic benefit principle to the detention criteria, as well as what information could be given during the initial detention process. This was in order to build a picture of what difference changes to the detention criteria could make.

4.3 Therapeutic Benefit

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 regards to their rights and what is happening to them.

Many, including the young people currently detained in CAMHS, took this opportunity to talk about therapeutic interventions, such as individual or group talking therapies such as DBT, education and employment training or peer support, stressing that they felt services were currently falling short in their offers of care and treatment. It was also stressed across many engagement sessions that a range of talking therapies should be offered to complement

pharmaceutical treatment, as medication alone does not provide holistic or personalised support.

“I might want to engage in a therapeutic activity, but find there’s no one in the site with the relevant expertise. It’s my second time being sectioned, but thinking about my future, I’m thinking about what I might do for money. Personally, I’d like to be a barber, but there’s no one here who’s trained to do afro hair. So not only can I not meet my cultural needs, but it doesn’t fit my hopes for education and training. Black hairdressers don’t want to come here.”

A male high secure service user

“You can’t force yourself to enjoy activities on the ward such as reading... and this leads to boredom. When you’re bored, that’s when you do stupid things...”

Lived Experience Advisor

Participants emphasised the lack of consistency within and between services in the quality and range of therapies offered, meaning that the available therapeutic offer seems to vary within and between services. The lack of financial resources was discussed in many of the sessions as the reason for this as well as a lack of encouragement from staff to take part.

“Therapies offered is all down to funding isn’t it? In my seven years at a service, a lot of departments closed down... It was very beneficial to me engaging with all the therapies that were on offer there. There needs to be money to cater for them.”

Lived Experience Advisor

This means that Therapeutic Benefit is being undermined by service delivery in hospitals and in order to fulfil the criteria of the White Paper, there should be a great focus and consistency on delivering therapeutic interventions.

There were also discussions in sessions around the importance of balancing therapeutic benefit with risk assessments especially for Part III patients. It was suggested that the therapeutic benefit detention criteria apply to Part III as well as Part II service users, as this was not currently proposed in the White Paper. They said that this could be unfair discrimination against Part III patients; they are the one most likely to be detained for the longest periods of time and under the greatest degree of restriction. Therefore, it is especially important that these patients are only detained if there is clear therapeutic benefit, and that risk assessments to determine whether they pose a substantial risk is detailed, reasoned and evidence-based.

“Need to make sure that people are only detained if there will be benefit to them and if there is evidence that they are a risk...”

Lived Experience Advisor

We think therapeutic benefit is important for all detained patients and it is important that risk assessments take this into account and are as reasoned and detailed as possible. Strong feedback from a limited number of engagement sessions also recommended that the therapeutic benefit criteria is also applied to Part III patients, in order to avoid the emergence of a two-tier system as a result of split detention criteria, though it is possible that this would mean more people spending time in prison instead of mental health hospitals. As a result, while we note that this feedback emerged, we do not necessarily endorse it.

Currently detained service users and their families and carers across all the engagement sessions agreed that person-centred recovery needs to be at the forefront of their care, which reinforced therapeutic benefit as a key principle. It is clear that having therapeutic benefit at the heart of the Mental Health Act would make a big difference to the care that detained people would receive, and lead to shorter and more meaningful detentions.

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

Participants in our sessions for those currently detained within CAMHS suggested that the two doctors required to make a decision on whether a service user should be detained under the Act should be required to assess the person separately. It was felt that this would allow for two professionals to establish their own separate view as opposed to a joint one, which service users felt reduced the efficacy of this safeguard, though this is contrary to the current provisions in the Code of Practice.

Some service users stressed that in the first few months of being detained, they would have liked to have co-produced the pathway they would need to follow and the goals they would need to work towards to be discharged, in line with the current proposals around Care and Treatment Plans.

'I don't know what I need to do to get out...'

A service user currently detained in England

Some service users stressed that there needs to be a clear and ideally binding timetable for step down and discharge, so you are not detained longer than you need to be. A high secure service user told us that the goal posts were being moved constantly, giving them uncertainty. This affects their hope and condition.

'The therapeutic benefit of hope is so understated.'

A male high secure service user

Another service user told us they had been working towards being discharged into the community by summer 2021 but was told they could be recommended for schema therapy, that they had wanted to start for some time. However, this would mean that they would have to stay in hospital for another two years. They questioned the therapeutic benefit of this decision:

"We are all humans and we all have rights. The Act needs to change for everyone. We should be treated with respect. It needs to be specific and simple."

A service user currently detained in England

Feedback on long stays in hospital emerged much more strongly in the currently detained workstream than it did in the previously-detained one, perhaps as a reflection of the number of service users we spoke in higher levels of security. This feedback supports the need for Care and Treatment plans to be co-produced and delivered within 14 days of a service user being detained. It is clear to us that the principle of therapeutic benefit is best enacted and implemented through clear and well communicated Care and Treatment Plans.

5. Theme 3: Care and Treatment in Hospital

5.1 White Paper Consultation questions

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

- Participants said they would benefit from clear and consistent care pathways with an emphasis on recovery. These must be used properly, stuck to, and have positive progress along them recorded and recognised.
- The content of Care and Treatment Plans should consider the individual, their personality, preferences and goals in a broader sense.
- With regards to specific therapeutic interventions and activities, participants especially valued those geared towards recovery, such as community activities, opportunities to learn relevant skills and peer support from those already discharged into the community.
- The popular CHIME recovery model¹ was cited as a useful framework for a Care and Treatment Plan to be built around, as well as the idea of using SMART (specific, measurable, attainable, relevant and time-based) goals as milestones in recovery)
- Participants also felt that they would benefit from a wider range of therapy options and other informal therapeutic support.

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

- Preferences for and past experiences of particular medications emerged strongly as the most important detail to include in Advance Choice Documents
- Information regarding a patient's physical health profile, and how particular treatments may support or worsen physical health conditions was also mentioned.
- The Advance Choice Document should provide an opportunity for people to understand the individual outside of the context of mental health crisis, including how they prefer to be communicated with and their strengths and weaknesses as an individual and how these relate to recovery.
- It was argued that the content of Advance Choice Documents should be flexible and not prescribed, in order to reflect the variability of individuals.

5.2 Detailed discussion

"I had no idea what was in my care and treatment plan for the first five years of my detention..."

A male service user currently detained in Wales

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.

1 Mental Health Foundation (2018) [Recovery](#).

5.3 Care and Treatment Plans

The White Paper proposes that people's preferences are taken into consideration in a Care and Treatment Plan.

Participants felt strongly that Care and Treatment Plans must be clear, utilised properly, stuck to and with positive progress along them recorded and recognised. Multiple participants described experiences in which they felt there was no clear pathway for them towards recovery, or situations in which the pathway was more defined, but that the achievement of milestones had no practical impact on likelihood of discharge. Frequent turnover of staff was mentioned as a contributory factor towards this lack of stability.

Currently detained service users wanted clear and consistent care pathways that are co-produced with and adhered to by service users, mental health service staff and other stakeholders. Participants in our families and carers sessions thought that they too should be involved, whilst participants currently detained in CAMHS felt as though staff involved in the person's care and treatment in the community should also be involved to ensure continuity of care.

Participants felt that CTPs should be reviewed regularly to reflect changing circumstances and shared with and regularly discussed with service users to help them "know where they stand with the system." Participants in our sessions for people currently detained in CAMHS said that they have had to request to be involved in the compilation of their care plan, highlighting the importance of staff being proactive in their involvement of service users.

Participants in our sessions for families and carers agreed with individualised care, but additionally offered reminders of the difficulty of involving people who are very ill, and they stressed the need to think about best interests. They also expressed scepticism that their views or that of the person they care for will be considered in the compilation of Care and Treatment Plans, based on previous experience.

Linking back to the proposed guiding principles, participants felt the focus of the Care and Treatment Plans should consider the individual, their personality, preferences and goals in a broader sense, and not simply as a mental health patient. This meant that Care and Treatment Plans should be rooted in supporting patients to get better and moving them towards a place where they feel ready to leave hospital, in line with the current proposals.

Various participants cited examples of ways in which particular activities can be geared towards recovery, such as peer support from people who have already left hospital and are staying well. Group psychology and community activities were also cited as supporting people to prepare for life in the community. The popular CHIME recovery model² was seen as a useful framework for a Care and Treatment Plan to be built around, as well as the idea of using SMART (specific, measurable, attainable, relevant and time-based) goals as milestones in recovery. The My Shared Pathway³ model is another example shared by service users in one participating service.

It was felt that service users would benefit more broadly from wards which were designed as more therapeutic environments, and that this could be fostered through the provision of a broader range of support options. A number of suggestions emerged strongly during discussions, including:

- A range of therapy options, including commissioning of external therapies and services where needed (more insights regarding provision of therapeutic activities is detailed under **Theme 2: Reasons for being detained**)
- Informal support, including community activities such as book clubs, self-help, mental health journals and peer support

2 Mental Health Foundation (2018) [Recovery](#).

3 NHS England (2021) [My shared pathway – involving service users of secure mental health services](#).

5.4 Advance Choice Documents

The White Paper proposes that it become a legal requirement for Advance Choice Documents to be considered when patient's care and treatment plans are developed. Advance Choice Documents are an opportunity for individuals to set out in advance what care and treatment they would prefer, as well as any treatments they would like to refuse in the event that they are detained under the Mental Health Act and lack relevant capacity to express their views at the time.

Reception to the idea of Advance Choice Documents was generally positive, and it was thought that everyone should have one. One participant said that they already utilised an advanced statement, and supported the idea of this being formalised.

As with certain other proposals within the White Paper, participants felt that their introduction would have limited impact and purpose if service users are not actively encouraged to make an Advance Choice Document or if the documents are not used in practice. Families and carers questioned whether the Advance Choice Document was practically applicable for those becoming ill for the first time, since this often cannot be anticipated, and urged that it be more than a tick-box exercise.

“Will our voices be heard? Because there is only one voice to be heard and that's the consultant.”

A carer for a currently detained medium secure service user

They also felt strongly that culture change was necessary for the document to work in practice, as preconceived notions of hierarchy among senior medical professionals can stand in the way of co-operative approaches to care. Families and carers felt the Advance Choice Document should be compiled by the person with people who know them, including their carer and a trusted member of staff.

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

Preferences around treatment emerged as a strong theme here, with participants stating that the document should reflect things you don't want done to you or given to you as part of your treatment, such as specific types of medication. It was felt that the document should also provide opportunity to share experiences of medications and treatments that have been tried in the past. Relatedly, participants said that the Advance Choice Document could include information about any physical health issues they have, and how certain treatments for mental health issues can impact their physical health issues, either positively or negatively.

‘Lack of hope is the biggest cause of relapse in these places. Some patients, you see them functioning well but giving up hope. They give up hope, lose their self respect, give up exercising, and they let themselves go. They end up in hospital longer than they need to be, if they get out [at all].’

A male high secure service user

Other suggestions focused on information that would allow staff to get to know them as an individual, rather than as a patient, and to paint a picture of them as a person outside of the context of mental health crisis. Examples include how they prefer to be communicated with, as well as their individual strengths and weaknesses and how these interact with their mental health and recovery. Families and carers suggested that a person's triggers and things that make them feel unsafe should be included, while young people felt that Advance Choice Documents could also be a chance to look at the non-clinical elements of care.

Although a number of options for specific content emerged (many of which are already covered in the White Paper), it was also proposed that the content of Advance Choice Documents be flexible, or at least not prescriptive, in order to include whatever the individual feels it important to include, to reflect the variability of their lives.

The importance of person-centred approaches emerged in discussions when participants were asked how frequently they felt the Advance Choice Document should be updated. Participants stated that they felt the document should be updated to reflect changes in individual circumstances, while families and carers thought that they should be living documents. Young people emphasised the importance of there being no limit on the number of times a person could request a review or update of their Advance Choice Document.

In relation to the question regarding deviations between a person's preferences within the Advance Choice Document and their views when they are in crisis, we found that this did not frequently appear as a theme of discussion within sessions with currently detained patients, as opposed to those with people who have been previously detained. This might be a result of those who have been detained previously having had more of an opportunity to reflect on their experiences of crisis than those who are presently in the hospital environment.

6.1 White Paper Consultation questions

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

- Most participants felt positive about the introduction of the Nominated Person and their proposed additional powers.
- Based on the current experiences of those serving as Nearest Relative, it was felt that the introduction of the Nominated Person should be accompanied by positive changes in practice regarding the involvement of carers, family members and friends.
- Nominated Persons should receive independent and inclusive support and information to help them to understand and perform this role.
- It is important that guidance is set out alongside the introduction of the Nominated Person to provide clarity around who can and cannot serve as a Nominated Person, factors to consider when selecting a Nominated Person and other details regarding the role and process.

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

- Participants were broadly supportive of the enhanced powers for IMHAs, but felt that these would have to be properly resourced and managed carefully to ensure the best possible experience and outcomes for service users.

Consultation question 16: Do you agree or disagree that advocacy services could be improved by: enhanced standards, regulation, enhanced training

- Participants agreed that training could improve advocacy services, but did not express views regarding enhanced standards and regulation.
- Other factors cited as improving service users' experience of using advocates included provision of the same advocate on a consistent basis (and robust handover processes if/when that advocate moves on), following best practice around recruitment (e.g. service users on interview panels), and increased opportunities to speak with advocates in all settings.
- Strong sentiments regarding limited provision of information regarding advocates and resulting poor awareness among service users indicates support for the provision of advocacy on an opt-in rather than an opt-out basis.

6.2 Detailed discussion

Under the fourth theme, the Lived Experience Advisors grouped the set of questions relating to people who support a detained person during their time 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).

6.3 Nominated Person

‘As carers we have our own personal mental health to take care of...its drains the life out of you...’

A carer of a high secure service user

The White Paper proposes a change regarding who in a person’s life is formally involved in their care. Under the new proposals, the detained person would be allowed to choose a Nominated Person who would hold a statutory role. Under these proposals, the Nominated Person would also have more powers than are currently held by the Nearest Relative, including the right to be consulted on statutory Care and Treatment Plans, the power to object to the use of the Community Treatment Order if it is in the best interests of the patient, and the right to be consulted, rather than just notified, in relation to transfers between hospitals and renewals or extensions to a patient’s detention of Community Treatment Order.

“These are good changes and they need to happen.”

A currently detained service user

Most felt positive about the proposed change from the current system of Nearest Relative to selection of a Nominated Person.

6.4 Who is the best person to involve in your care?

“My sister has used her powers to her own advantage if we have an argument. Nominated person would be a good idea...”

A service user currently detained in Wales

Participants recognised that for various reasons, family members are not always the most suitable people to fulfil this role, because they are estranged, hold very different views to their family member, the family member is a contributory factor towards the person’s poor mental health, or because their family member doesn’t sufficiently understand their mental health condition. Multiple currently detained participants stated that for them, a trusted friend would be a more suitable person to help with decisions about their care than family members for various reasons, including age, capacity, and knowledge of the system. In our sessions for families and carers, older parents who currently serve as the nearest relative for an adult son or daughter were reassured that their loved one would be able to choose someone else as their Nominated Person as they got older or were no longer around.

On the question of whether those aged under 16 should be able to choose a Nominated Person, participants in our sessions for those currently detained in CAMHS had mixed views regarding the proposal. Some were in full support, some felt the age should remain at sixteen, and others expressed the view that capacity or competence should be a determining factor in whether they make that decision. This mixed feedback is in contrast to the previously-detained strand, which saw full support for young people under the age of 16 being permitted to choose their NP, provided there were methods of assurance that prevented them from choosing someone inappropriate.

6.5 Have they been able to be involved?

With reference to the experience of family members currently acting as nearest relative, it was suggested that the introduction of the Nominated Person should be accompanied by positive changes in practice regarding involving carers and family members. Some participants felt that the knowledge and support of their nearest relative was currently under-utilised, and that nearest relatives are not currently communicated with in a reliable way.

“I’m new to everything so going along with everything. Haven’t seen him for 6 months since he’s been taken in. The hospital are writing to the police to try and get me access.”

A carer for a medium secure service user

It was also recognised that performing the role of Nominated Person - particularly understanding and navigating the mental health system - could be challenging and complex. Participants felt that Nominated Persons should themselves be supported to support the person who has nominated them, such as through transparent information regarding care options and independent support to make decisions.

It was suggested that Nominated Persons could have access to advocacy in their own right, as is currently the case for friends or family members who become the Relevant Person’s Representative under the Mental Capacity Act. The importance of information being inclusive was also highlighted, as Nominated Persons may prefer to communicate or receive information in a language other than English, or have other communication needs.

6.6 Reservations

While response to the proposals for the Nominated Person was generally positive, participants also raised a number of questions and practical concerns regarding its introduction. It was felt that selecting someone as your Nominated Person could be a difficult task for a number of reasons, particularly if you yourself are lacking knowledge of the system and therefore may not know who the best person might be to formally involve in the process. Some participants said that there is more than one person in their life who should be meaningfully involved in their care and selecting just one person would be challenging, and stated that they would prefer the option to pick more than one person.

It was suggested that certain checks and balances may need to be in place to ensure the person does not select someone who would be inappropriate for the role as their Nominated Person, e.g. someone who significantly impacts the person’s mental health in a negative way. Some participants stated that they would like to select their advocate or another trusted professional in their life (e.g. social workers) with a good knowledge of their care and history to act as their Nominated Person, which is worth noting but unlikely to be possible due to the potential conflict of interest.

Participants noted that their opinion regarding who they would want to act as their Nominated Person could change over time, or that the person’s suitability could change as a result of circumstance. Questions were raised as to whether it was possible to change the Nominated Person once they had been selected, how easy that process would be and how frequently that could happen. Those currently detained in CAMHS felt strongly that protocols should be in place to ensure that if the Nominated Person is changed, the person now fulfilling this role is provided with all necessary information. It was noted also that some people may have no-one in their life who is suitable to fulfil this role.

Consent with regard to sharing of information was a notable theme of discussion particularly in our sessions for those currently detained in CAMHS and for families and carers. CAMHS service users felt a clear distinction should exist between information-sharing and formal involvement in care. With younger people, it is perhaps particularly pertinent that parents and guardians remain informed even if not performing the role of Nominated Person.

On information-sharing, young people additionally emphasised the importance of privacy and consent for particular types of information to be shared. Practical suggestions for how this could be implemented included an opt-in/opt-out list that young people are supported to complete. It was felt that this discussion could reveal important information regarding family or carer dynamics and the consequences this has for a person's mental health, care and treatment. However, participants in our sessions for families and carers of those currently detained felt strongly that they should be involved rather than just informed, referring to NHS England's Carer support and involvement in secure mental health services toolkit⁴, published in 2018. They shared challenges that they had faced when their loved ones had refused consent for information to be shared with them, and thought that staff must consider who is most likely to act in the best interests of the service user. Families and carers also indicated that they would find it extremely difficult if their loved one selected someone else to replace them as the Nominated Person.

All of the above highlights the need for clear guidance to be set out alongside the introduction of the Nominated Person. This guidance should, at a minimum, include an explanation of how the system of Nominated Person works in practice, who can and cannot serve as the Nominated Person and what factors should be considered when selecting a Nominated Person. It is clear that best practice resources will need updating in relation to the involvement of families and carers in secure services to reflect changes to the Mental Health Act.

6.7 Advocacy

The White Paper proposes to enhance the critical role played by Independent Mental Health Advocates (IMHAs). While IMHAs are currently responsible for supporting patients to understand their legal rights under the Mental Health Act, the White Paper proposes additional safeguards. These include the responsibility to support patients to take part in care planning, supporting people to prepare Advance Choice Documents, power to challenge a particular treatment where they have reason to believe it is not in the patient's best interests, and power to appeal to the Tribunal on the patient's behalf. Subject to funding, the White Paper also proposed the expansion of the role to support voluntary inpatients, and the provision of advocacy on an opt-out basis.

When asked whether they agree with the proposed additional powers for Independent Mental Health Advocates, participants broadly agreed that giving advocates more of a role would be positive.

6.8 What has your experience been with an advocate in hospital?

Many shared positive experiences of advocates and the specific benefits that advocates were able to provide, including:

- Staff being more receptive to ideas when advocates are involved
- Providing information to patients
- Compiling communications for solicitors and doctors
- Challenging restrictive practices on wards
- Encouraging patients to participate in their care
- Helping staff to understand information that a patient is trying to convey, which was considered by those currently detained in CAMHS to be of particular benefit to them

One participant shared that he advocates for himself in his Care Review meetings and chairs these himself. He found it helpful to speak to advocates ahead of these meetings to prepare, and suggested that advocates could play a role in helping patients to learn skills that would help them to self-advocate.

4 NHS England (2018) [Carer support and involvement in secure mental health services.](#)

No adult participants in sessions for currently detained service users shared experiences of being a voluntary inpatient, and it was therefore not possible to glean views as to whether they felt they would have benefited from the support of an IMHA. However, based on views shared by those previously detained on a voluntarily basis under our other workstream and the positive regard for advocates from currently detained people across all settings, it is likely that patients currently being treated as inpatients on a voluntary basis would support the expansion of advocacy provision to include voluntary patients.

6.9 What else could they have done?

Participants shared their views on how experiences with advocates could be improved. They stressed the importance of training in ensuring patients receive the best support possible from advocates. We also heard examples of best practice around recruitment of IMHAs, for example, the involvement of patients on interview panels for advocacy providers.

“Advocacy isn’t as independent as is suggested. They are often familiar with ward staff and not listening to service users or carers. If they’re not listening, then what do you do?”

A carer of a high secure service user

As the quote above highlights, participants in our sessions for families and carers of those currently detained stressed the need for the true independence of advocates, particularly with regard to the importance they attach to the views of carers.

Another factor which could improve the experience of working with IMHAs was the personalisation of services. It was recognised that this was aided by engaging with the same advocate as much as is possible. Participants described experiences of being allocated a different advocate for every meeting, which meant that they were unable to build a relationship with their advocate. While staff turnover was recognised as a reason for this lack of consistency, it was felt that robust handover processes could prevent patients having to retell their story, which can be retraumatising.

“I was not made aware of advocacy. This is the first time I have heard of it.”

A carer of a medium secure service user recently detained under section 3

Surprisingly, given that this workstream was focussed on currently-detained service users, our participants’ awareness of the availability of IMHAs was varied, and it was felt that some hospitals could do more to make patients aware of their rights and of the availability of advocates and encourage use of their support. This is a central element of the argument for providing advocacy on an opt-out rather than an opt-in basis and our findings suggest that service users are in favour of this.

A participant in our sessions for families and carers of those currently detained highlighted that experiences of advocates can vary based on the security level of a service, having experienced challenges being listened to by advocates while the person they care for was in a high secure service. Another participant currently detained in a high secure service additionally highlighted issues related to access, stating that advocates had to be contacted via ward telephones which requires the facilitation of staff. This can create barriers to advocacy if staff are unavailable or the issue you wish to discuss relates to the staff themselves. Young people participating in our sessions for those currently detained in CAMHS also said that they found it difficult to telephone advocates and were much more likely to speak to them if physically present on wards. This cohort also said that advocates were sometimes unable to provide support for issues at the speed necessary.

Some participants were sceptical as to the likelihood that advocates would be able to challenge the decisions of clinicians without the necessary medical or clinical knowledge. It was also suggested that the necessary impartiality of IMHAs can place limits on what they are able to do, but that other roles such as OTs and social workers could potentially work alongside advocates to address gaps.

In summary, participants were broadly supportive of the enhanced powers for IMHAs, but felt that these would have to be properly resourced and managed carefully to ensure the best possible experience and outcomes for service users.

7. Theme 5: Tribunals

7.1 White Paper Consultation questions

Consultation question 4: Do you agree or disagree with the proposed timetable for automatic referrals to the Mental Health Tribunal?

- Participants were in favour of improved access to tribunals, through changes to statutory timings for automatic tribunals and more opportunities for patients to decide to bring a tribunal
- Some of the changes proposed by the White Paper, particularly the aim to increase the number of times a person detained under section 3 can make an appeal in a 12-month period and closer links to statutory Care and Treatment Plans, are likely to be positive steps towards this.
- However, current experiences of service users suggest that a lack of community support, particularly a lack of suitable accommodation (e.g. supported housing), is likely to continue to create barriers to discharge if not address simultaneously.
- Service users would additionally benefit from improved information about Tribunals, to allow for more informed engagement with the process, and for a more significant focus on discharge within Care and Treatment Plans (more information on this under **Theme 3: Care and Treatment in Hospital.**)

7.2 Detailed discussion

The White Paper proposes expanding the role of the Mental Health Tribunal⁵ 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 grouped several questions relating to the Mental Health Tribunal together for this theme, while aiming to ensure that the questions were as accessible as possible and that the outputs were able to reflect the wealth of experiences of the tribunal within this cohort.

7.3 How long should people wait for access to a Mental Health Tribunal?

Service users said they had found that various positive factors had to align in order for someone to be approved for discharge, including the person's mental health progress, and other practical considerations, such as the availability of suitable accommodation. Because of this, some felt that positive outcomes often felt like a matter of chance.

“All of the moving parts are not done in tandem... you just have to hope it all dovetails together.”

A male secure service user

Participants described experiences where they had refrained from making an appeal for reasons related to the factors outlined above, and then an automatic tribunal had kicked in

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

when these circumstances were still yet to be resolved, and thus the tribunal did not end in a positive outcome. They then felt that they were then potentially not able to apply again when in the right position to do so.

“I would welcome three tribunals in a year”

A service user currently detained in Wales

While it was recognised in some instances that the increased frequency of automatic tribunals could improve this situation, the strongest sentiment that emerged regarding the timing of tribunals was that they should be provided on a tailored case-by-case basis, in relation to individuals and their progress and/or at the request of the service user. This evidence suggests that service users are likely to support the proposal to increase the number of opportunities for patients detained under section 3 to appeal to the Tribunal.

One participant urged a note of caution if automatic Tribunals are to increase in their frequency, stating that the experience of going through a tribunal could be difficult and demanding on patients to go through multiple times in quick succession. Participants in our sessions for those currently detained in CAMHS said that they found Tribunals particularly difficult, and that the unpredictable timing of automatic referrals was a source of stress and worry. However, this was attributed at least in part to lack of understanding of the process.

7.4 What has your experience of the tribunal been?

“The emphasis is on what the experts have to say... doctors, etc. I don’t think a lot of attention is given to what patients have to say. Seems more like a formality to ask us... in order to tick a box.”

“A tribunal in my experience has never approved a patient’s request, they put all the trust on the care team and the hospitals”

A male high secure service user

It was felt that decisions are currently geared towards the priorities of hospitals, and participants supported the White Paper’s ambitions for Tribunals to be informed instead by meaningful insight into an individual’s progress and relate more closely to their Care and Treatment Plan.

We heard, particularly from patients in high secure services, that discharge feels very much like a distant possibility. However, it was suggested that discussion of discharge as a realistic prospect, even with those with longer journeys towards that point, has a number of benefits for patients, including better preparedness for community life and the independence, autonomy and therapeutic benefit gained from hope of a future outside of hospital.

“The therapeutic benefit of hope is so understated”

Barriers to discharge was also a significant theme in our conversations. It was felt that gaps elsewhere in the system could present difficulties for the system in trying to adhere to a better system for tribunals.

“People are waiting weeks, months, and sometimes years for accommodation.”

A male secure service user

“My solicitor told me I shouldn’t apply for a Tribunal if I don’t have accommodation – but it has been four to six months now and I’m still waiting.”

A male secure service user

Lack of suitable accommodation in the community was cited alongside a lack of social care support as a frequent reason as to why patients are not discharged or are discouraged from applying for discharge. It was felt that better funding for housing, particularly supported housing, would enable more people to leave hospital when it is no longer of therapeutic benefit, and to avoid disparities in outcomes for patients living in better and more poorly resourced local authority areas.

7.5 What more do you think they could do?

“In the tribunal, the judge can discharge you, and they have the power to do that, but it’s very different from high secure than it would be in low secure, for example.”

A high secure service user

Participants stressed the wide variety of people, conditions and experiences of people detained under the Mental Health Act, and that with that in mind, it is difficult to suggest a one-size-fits-all approach to Tribunal.

“Insight is a big thing for service users. Lots of the tribunal language is exclusionary, and they could be done in a way that gave insight into what’s actually happening for the person.”

A male high secure service user

It was recognised that patients could benefit from better information about Tribunals and how they work, and the choice to have representation from an IMHA, or support from an IMHA to self-advocate. This would help to demystify Tribunals, and help patients to feel less intimidated and more informed when entering the process. Service users currently detained in CAMHS said that MDT meetings could do more to communicate this information, and that things like leaflets with accessibly communicated information could help also. Information and feedback should also be provided following the outcome of a Tribunal.

8. Theme 6: Criminal Justice System

8.1 White Paper Consultation questions

Consultation question 21: We want to establish a new designated role for a person to manage the process of transferring people from prison or an immigration removal centre (IRC) to hospital when they require inpatient treatment for their mental health. Which of the following options do you think is the most effective approach to achieving this?

- Whatever the chosen approach, our participants stressed the need for it to be as transparent as possible, and for communications between IRCs, prisons and hospitals to be more effective to ensure that people who require support for their mental health are able to receive it as soon as possible
- Transitions between prison and hospital environments were flagged as being difficult and having an impact on participant’s mental health and their sense of identity, so ensuring these is as easy as possible would be important

Question 22: Conditionally discharged patients are generally supervised in the community by a psychiatrist and a social supervisor. How do you think that the role of social supervisor could be strengthened?

- As participants seemed unsure what a social supervisor was or if they had worked with one before, we would suggest that they are made more visible in their role and their powers strengthened as far as possible

Question 23: For restricted patients who are no longer therapeutically benefiting from detention in hospital, but whose risk could only be managed safely in the community with continuous supervision, we think it should be possible to discharge these patients into the community with conditions that amount to a deprivation of liberty. Do you agree or disagree that this is the best way of enabling these patients to move from hospital into the community?

- In line with the principle of Therapeutic Benefit, some of our participants supported the idea of a supervised discharge into the community, provided that they were able to access mental health services suitable to meet their needs and prevent them from being detained again
- Other participants were more wary, believing that this would not work in practice. There seemed to be distrust of the recall process.

Question 24: We propose that a ‘supervised discharge’ order for this group of patients would be subject to annual tribunal review. Do you agree or disagree with the proposed safeguard? Beyond this, what further safeguards do you think are required?

- Transparency and honesty around the conditions that would be placed on a patient in the community and support to access suitable services in the community emerged most strongly as themes with our participants.

8.2 Detailed Discussion

“...the proposals relating to changes to the criminal justice system are some of the most important.”

A service user in a high secure service

The Mental Health Act White Paper contains a number of proposals relating to Part III of the Mental Health Act – the criminal justice sections. The Paper makes recommendations to speed up people’s transfer from prison or Immigration Removal Centres (IRCs) into secure care services, and discharge from hospital for people under section 41, known as a supervised discharge. It also recommends strengthening the role of ‘social supervisors’, who supervise conditionally discharged patients in the community.

Following the recommendations of our Lived Experience Advisors, we asked participants to tell us about their experiences of these transfers, as well as the timings and conditions around them. We also asked what supervision of service users looks like in the community, and whether patients would prefer discharge into the community with restrictions or remaining in hospital (prompted by question 23 in the White Paper, which discusses a small group of restricted patients who may be discharged into the community with restrictions amounting to a deprivation of liberty).

The Criminal Justice theme did not apply to all the participants we spoke to, but for those participants it was relevant to it prompted some of the most impassioned discussions in the sessions.

8.3 If you were going to be discharged, would you prefer it to be in the community with restrictions or in hospital?

‘I’ve seen people suffering in prison, who are very, very unwell.’

A high secure service user

“Prisoners should transfer to hospital sooner...”

Lived Experience Advisor

Participants who had experience of both prison and hospital environments asked for prisoners with mental illness to be transferred or discharged to hospitals faster, and for better communication between hospitals and prisons to exist throughout this process. It was stressed that prison was not a therapeutic environment for people with severe and enduring mental illness.

“...wardens and prison officers are not equipped to deal with severe mental health problems.”

A high secure service user

However, others had concerns that discharges or transfers from prisons to hospitals were not always appropriate:

‘It can be abused...people finish their prison sentence and then spend years and years in hospital...’

A high secure service user

One participant told us that it was confusing once in hospital to still be classed as a prisoner by law but as a patient by the hospital, especially in terms of rights and identity. In addition, it was mentioned that some service users will be discharged back to prison after a stay in hospital which can lead to a revolving door of detentions:

“It is a bad idea when you get someone better then put them back in a space [prison] that triggers their mental illness...”

A Lived Experience Advisor

Therefore, some participants preferred the proposal that some service users be discharged into the community with restrictions rather than hospital.

“CTOs should be used a lot more...that is least restrictive practice...should be used when being in hospital does not have therapeutic benefit...”

A male service user currently detained in Wales

However, it was also recognised that conditional discharge can be difficult to navigate in practice. We were told that rules are applied in a very ‘black and white’ way, which means people can be recalled to hospital very quickly and easily for breaking them, despite ward staff feeling you are too well to be there. One participant said it would be preferable if this were a more collaborative process and that room for error was made explicit to provide more clarity.

Other participants suggested that no further powers be given to recall teams as they believe reasons for being recalled are often exaggerated.

“We want a multi-pronged and transparent approach when it comes to decision making, when assessing whether someone fits the criteria for detention/recall under the Act.”

Two service users currently detained in a secure service

It was also emphasised that if people were to be discharged into the community, that improving access to mental health services in the community was even more important, to stop people getting back into crisis.

“If access to services were less scary and less restrictive in the community then I feel this would prevent a lot of crime and a later deterioration of mental health...”

A high secure service user

“...a lot of the problem, especially in the black community, is that if you’re unwell, black people don’t know who to call. They don’t want to call the police, and it ends up being too late and the person’s in crisis. Not many people in the community know who to call, and the police can make things worse.”

A high secure service user

The issue of MAPPAs (Multi-Agency Public Protection Arrangements)⁶ which are in place to ensure management of violent and sexual offenders by police, probation trusts and the prison service, was also brought up in some sessions by forensic service users. Some participants called for more transparency between the Ministry of Justice and health care providers around MAPPA, especially around what is discussed in MAPPA meetings about their case.

8.4 Social supervision

Participants seemed unsure as to what a social supervisor was or the role they could play during a conditional discharge. Given that some of our participants may rely on the support of a social supervisor when discharged, they felt strengthening their role and their visibility in services would be a good idea, especially as social workers were often mentioned by participants as a staff member who could be trusted and who provided support.

Overall, our engagement with forensic service users saw substantial and helpful points raised on the wide variety of technical and specific questions posed by the White Paper. We recommend that the Ministry of Justice and the Department of Health conduct further direct engagement with service users on these changes, in order to further inform the implementation of the proposals.

9. Theme 7: Routes out of hospital

9.1 White Paper Consultation 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 community treatment order?

- We found that the vast majority of participants in our sessions had limited or no experience of managers’ panels. One staff member who sat in on a session shared that this was an option “not readily discussed” in their hospital, so there is a possibility that a shift away from their use has already happened at service level.
- Only one participant across all sessions explicitly objected to the removal of managers’ hearings, stating that these can provide most of the things a Tribunal can provide and also provide more opportunity, in their experience, for patient voice. However, this participant also felt that this may be less important if Tribunals are improved and delivered more frequently.

⁶ Ministry of Justice (2014) [MAPPA guidance](#)

9.2 Detailed discussion

“We want our relatives to become better...everything takes so long. The longer they are incarcerated, the longer they are away from home and the more institutionalised they become, then they feel unsafe leaving. Sometimes in hospital you become more ill, and then harder to treat...”

A carer of a long term high secure service user

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 proposal relating to hospital manager’s hearings. In the process of translating these questions, the Lived Experience Advisors decided to ask about the process of discharge and leaving hospital more generally.

9.3 Who was involved in the decision of you leaving hospital? What were the positive experiences, what were the negative, and who should make these decisions?

All participants in our sessions with currently detained children and young people felt that the decision for them to leave hospital should be a collective decision.

In sessions for currently detained adults, participants discussed what was required to feel prepared for discharge. Reflecting on a previous experience, a service user now currently detained in a high secure facility reflected that they were extremely unprepared for their release, saying that a lack of therapy during their time in hospital meant that they hadn’t developed coping mechanisms of their own, and that they felt alienated from professionals, including their social worker and CPN, whilst living in the community. Families and carers reflected on the anxiety and stress that can be caused by the prospect of being stepped down or leaving hospital, and that if handled poorly service users can relapse prior to or immediately following this change.

It was felt that more should be done to prepare patients for life in service with a lower level of security, or in the community. It was felt that patients moving between services should be introduced to and shown around their new service in order to familiarise themselves with the setting before formal transition takes place. For those leaving hospital, it was felt that supervision in the community would also help.

9.4 Managers’ Panel

The Independent Review of the Mental Health Act recommended removing the role of managers’ panel in discharging patients, based on concerns around the effectiveness of this safeguard and the lack of formality surrounding panel hearings.

With regard to the consultation question “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?”, we found that the vast majority of participants in our sessions had limited or no experience of managers’ panels. One staff member who sat in on a session shared that this was an option “not readily discussed” in their hospital, so there is a possibility that a shift away from their use has already happened at service level.

The few participants who did have experience of manager’s hearings discussed them in largely negative terms. Only one participant explicitly objected to their removal, stating that they can provide most of the things a Tribunal can provide and also provide more opportunity, in their experience, for patient voice. However, this participant also felt that this may be less important if Tribunals are improved and delivered more frequently.

9.5 Broader themes

We found that our sessions for those currently detained under the Mental Health Act contained fewer reflections on routes out of hospital than in our sessions for those who have been previously detained, as some participants had never been through the process of leaving hospital. Therefore, the majority of reflections on this theme mirrored those shared on recovery under Theme 2: Reasons for being detained, **Theme 3: Care and treatment in hospital**, **Theme 5: tribunals**, and **Theme 6: Criminal Justice System**.

These themes included:

- The application of Therapeutic Benefit criteria to service users sectioned under Part III, as well as those under Part II, in order to ensure shorter and more meaningful detentions for those detained under both types of section.
- The need for service users to be able to access or continue to access relevant therapies in the community in order to allow discharge when being detained is no longer providing therapeutic benefit more broadly, as well as increased use of Community Treatment Orders.
- The feeling for many that they have no clear pathway towards recovery, or where a pathway is defined, that the achievement of milestones had no practical impact on the likelihood of discharge. It was felt that clear and consistent care pathways, that are co-produced with and adhered to by service users, mental health staff and other stakeholders would improve this situation.

“There need to be clear and straightforward criteria to be discharged and for section. There should be a limit on the time spent on sections. This gives you something to look forward to and hope for the future.”

A currently detained service user in England

- The inclusion of activities designed to prepare people for a life outside of hospital within Care and Treatment Plans.
- The involvement of staff involved in a person’s care in the community being involved in preparing Care and Treatment Plans to ensure continuity of care.
- The need for discharge to feel like a realistic prospect for all service users to inspire hope, and facilitate support to better prepare service users for community life and independence outside of hospital.

“Even in this place we have hopes and aspirations, and no one knows what the future holds. It’s those possibilities that keep you getting out of bed in the morning.”

A high secure service user

- Barriers to discharge from hospital due to lack of available suitable housing, such as supported housing and support from social care as well as community mental health services.

10. Conclusions

It is difficult to overstate the extent to which currently detained service users welcomed the opportunity to engage with other service users and feed into this consultation process through our sessions. Although these currently detained service users are the cohort for whom these reforms are of the utmost importance and interest, they are less likely to have the opportunity to inform the planned legislation through traditional routes. It was apparent throughout our engagement that people who are currently detained and their families and carers had particularly strong feelings about the need for reform, and that their participation was driven by a hope that their detention and the care and support they receive can be improved upon.

Similarly strong was the support expressed for the vast majority of the White Paper's proposals and its wider ambition to improve choice and involvement in care. Participants not only understood the impetus for these reforms and were able to relate proposed changes to their own experiences in services, but also had clear ideas about how these should be implemented in practice, which have been detailed throughout this report. It is very positive that a number of the suggestions we heard, for example, a greater relationship between tribunals and statutory Care and Treatment Plans, reflect the direction of travel already outlined within the White Paper.

However, within this feedback it is also important to appreciate the scepticism that many participants felt. Many currently detained service users and families and carers had low expectations that new legislation will impact positively on their day-to-day experience of detention. This was not necessarily unexpected – many feel badly let down by the system as it currently stands – but it is clear that for many the success of Mental Health Act reform will hinge on the translation of policy into practice.

The upcoming Mental Health Bill will serve as a landmark first step towards making mental health services fit for the future, which all currently detained and families and carers agreed was both long-awaited and much-needed. Concerns around effective implementation highlight the need for this to be well-resourced, informed by clear guidance, and supported by training that emphasises culture change within services and across the system. Continued proactive involvement would help to ensure reforms are co-produced with service users and embedded on the ground.

It is also clear that wider reform may be required for a new Mental Health Act to realise its full potential. Prior to each engagement session, we were keen to highlight complimentary reforms to community mental health services to participants and their relationship to proposed changes to the Mental Health Act. Rethink Mental Illness welcomed the commitments of the Long Term Plan, and hopes that the current rollout of the Community Mental Health Framework will help to reduce need for detention and will support discharge into the community. Beyond this, our engagement highlighted the need to look at the role of factors outside of inpatient services, such as the availability of supported housing and other suitable accommodation, as well as social care services, in improving people's experience of detention.

While recognising these challenges, the overwhelmingly positive response we received from those currently detained, their families and carers for the proposals of the White Paper are a strong basis from which to create a new Mental Health Act. These reforms are clearly seen as a significant opportunity by currently detained service users and families and carers and we believe that this consultation has given valuable insights into the details of the legislative reforms needed and the wider changes needed to deliver fully on the White Paper's ambitions.

11. Methodology

The central aim of this complex project was to ensure that co-production was used to drive the overall approach and to rebalance 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.

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 30th March to 20th May 2021.

11.1 Lived Experience Advisors

We began the project with the recruitment of 10 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.

The Lived Experience Advisors also reflected on the findings of the engagement sessions after they had taken place and provide feedback on the themes that emerged.

11.2 Engagement sessions

Currently detained participants were recruited to engagement sessions through our Recovery and Outcomes Network⁷. The Recovery and Outcomes network of involvement groups is commissioned by NHS England and run by Rethink Mental Illness to bring together people living in, working in, and commissioning adult low and medium secure mental health services to ensure that people are as involved as possible in influencing local and national practice and the way services are commissioned and provided.

We sent out a newsletter to our network, made up of service users, staff and commissioners, asking people to express interest in hosting an engagement session at their service. We held 5 sessions in low and medium secure services with a good geographical spread across England and Wales and sessions in two high secure services. We also held a session specifically for Part II service users, two for families and carers of people currently detained under the Mental Health Act and two with young people currently detained in CAMHS services.

Unlike the previously detained workstream, the nature of the secure environment meant that project staff were reliant on service staff to recruit service users to take part in an engagement session. This meant the number of participants was not consistent across the engagement sessions. In addition, due to being currently detained, some service users felt unable to attend on the day due to feeling unwell or decided to leave during a session as they did not feel comfortable.

In addition to the participants, the engagement sessions were attended by a facilitator and a note-taker from Rethink Mental Illness and where possible, a Lived Experience Advisor also attended as a peer facilitator. Representatives from the Department of Health and Social Care attended some sessions as observers.

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11.3 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.

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
Principles	<p>Consultation question 1:</p> <p>“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?”</p>	<p>To ensure that the 4 principles of ... are at the forefront of people’s minds – both service users and staff</p>	<p>How could the guiding principles be used?</p> <p>Who should have to follow them?</p>	<p>Least restrictive practises</p> <p>Shouldn’t make people worse</p> <p>Accountability</p> <p>Who should have to follow the principles? All professionals and the CQC!- not just a risk of losing job but enforced by law</p> <p>Choice around treatment (autonomy)- chance to try things</p> <p>Embedded in care plans- but not tick box exercises</p> <p>Embedded in diverse communities</p> <p>Honour your views and wishes when you have capacity</p> <p>Focus on the everyday</p>	<p>Who do you think should follow the proposed principles embedded in the Mental Health Act and Code of Practice?</p>

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
Tribunals	<p>Consultation question 4:</p> <p>Do you agree or disagree with the proposed timetable for automatic referrals to the Mental Health Tribunal (see table 1 for details)?</p>	To gauge appropriate timeframes for referrals to a MH Tribunal	How long should people wait for a referral to a MH Tribunal?	<p>Only dates for automatic referrals, not everyone realises you can refer yourself/or an advocate can- will link to IMHAs having more power, Nominated Person too</p> <p>Automatic- not chosen by SU, sometimes they are too early, support from an IMHA</p> <p>Some people on Section 3 might want the tribunals to come quicker!</p> <p>Everyone should have access to a tribunal as quickly as possible, whether they want to take it up or not, you don't have to go for it, a protective method</p> <p>Applications for hearings</p> <p>About communicating how tribunals work to service users and staff</p> <p>Effect of Covid on reports and tribunals, haven't had 1:1s</p> <p>Parole boards- in the WP it says this would be combined with tribunals</p>	<p>How long should people wait for access to a MH Tribunal?</p> <ul style="list-style-type: none"> • Distinguish between application and automatic referral

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
	<p>Consultation question 5:</p> <p>We want to remove the automatic referral to a tribunal received by service users when their community treatment order is revoked. Do you agree or disagree with this proposal?</p>	<p>To determine how acceptable a new proposal is</p>	<p>Should the referral be automatic when you are on a CTO?</p>	<p>Use tables to show referral times</p>	

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
	<p>Consultation question 6:</p> <p>We want to give the Mental Health Tribunal more power to grant leave, transfers and community services.</p> <p>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?</p>	<p>To explore how the MH Tribunal has been working and changes may be necessary</p> <p>To determine how acceptable a new proposal (5 weeks) is.</p>	<p>What has your experience of the MH Tribunal been? What more could the Tribunal do?</p> <p>Would 5 weeks/How long would be an appropriate time for the MHT to action their decisions?</p>	<p>5 weeks would be good for something to happen, especially around leave, discharge is more complicated- wording needs to be clear here, you can't discharge anyone properly in 5 weeks, but a plan for the discharge would be good in this time frame</p> <p>Discharge plans are supposed to be put together on admissions</p> <p>Would the time limits be met in practise, would systems conform to them</p> <p>The word should</p> <p>5-6 weeks would be good</p> <p>Mayne the time could depend on the type of section</p> <p>Only meet you once, and base it on a report-tribunals should be tailored, judged on there and then</p> <p>Tribunal from community vs going down sections</p> <p>Reports if you have just moved, people who don't even know you- independent report maybe?</p> <p>Making sure we have definitions for all the words e.g. tribunals being courts</p>	<p>What has your experience of the MH Tribunal been, and what more do you think they could do?</p> <ul style="list-style-type: none"> • How long would be an appropriate time for health authorities to deliver on decisions made by the Tribunal? • How long would be an appropriate time for local authorities to deliver on decisions made by the Tribunal?

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
Routes out of hospital	<p>Consultation question 7:</p> <p>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?</p>	To determine how appropriate the role of a managers panel is in discharge	<p>How did you leave hospital? How could that have been improved?</p> <p>Prompt on hospital managers route.</p>		<p>Who was involved in the decision of you leaving hospital?</p> <ul style="list-style-type: none"> • What were the positive experiences? • What were the negative? <p>Who should make these decisions?</p>
Involvement in care and choices	<p>Consultation question 8:</p> <p>Do you have any other suggestions for what should be included in a person's advance choice document?</p>	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?		<p>If you thought that you might be detained again in the future, what would you want people involved in your care to know?</p> <p>What would you like included?</p>

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
Capacity and the	<p>Consultation question 11:</p> <p>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?</p>	<p>To determine if someone has the right to refuse treatment when they still have capacity</p>	<p>Provided that someone has capacity, should they be able to refuse certain treatments?</p> <p>What checks or tests should be applied to an advance decision to make sure that it's valid?</p>		<p>Provided that someone has capacity, should they be able to refuse certain treatments?</p> <p>What checks or tests should be applied to an advance decision to make sure that it's valid?</p>
Care and treatment plans	<p>Consultation question 10:</p> <p>Do you have any other suggestions for what should be included in a person's care and treatment plans?</p>	<p>To determine the content of care and treatment plans</p>	<p>What has worked well for you in your care and treatment plan? What do you think should be included in this?</p>		<p>What has worked well for you in your care and treatment plan? What do you think should be included in this?</p>

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
Support for and from carers	<p>Consultation question 13:</p> <p>Do you agree or disagree with the proposed additional powers of the nominated person?</p>	<p>(Break into carers/non-carers)</p> <p>To determine the role of the nominated person</p>	<p>What powers/role do you think is appropriate for the nominated person? (prompt with proposals)</p>		<p>Who is the best person to involve in your care?</p> <p>Have they been able to be involved?</p>
Advocacy	<p>Consultation question 15:</p> <p>Do you agree with the proposed additional powers of independent mental health advocates?</p> <p>Consultation question 16:</p> <p>Do you agree or disagree that advocacy services could be improved by: enhanced standards, regulation, enhanced training</p>	<p>To determine the role of IMHAs</p>	<p>What do you think the role of advocates should be?</p> <p>How could that role be improved?</p> <p>(prompt with proposals)</p>		<p>What has your experience been with an advocate in hospital?</p> <p>What else could they have done?</p>

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
Criminal Justice System	<p>Consultation question 20:</p> <p>To speed up the transfer from prison or immigration removal centres (IRCs) to mental health inpatient settings, we want to introduce a 28-day time limit.</p> <p>Do any further safeguards need to be in place before we can implement a statutory time limit for secure transfers?</p>	To determine appropriate safeguards and time limits around IRC transfers	What do you think could make the transfer process from IRCs to hospital as appropriate/safe as possible?	<p>V niche and specific questions</p> <p>IPP, 47/49 and the role of MAPPA</p> <p>Effect on different communities</p>	What do you think could make the transfer process from prison and IRCs to hospital as appropriate and safe as possible?
	<p>Consultation question 21:</p> <p>We want to establish a new designated role for a person to manage the process of transferring people from prison or an immigration removal centre (IRC) to hospital when they require inpatient treatment for their mental health.</p> <p>Which of the following options do you think is the most effective approach to achieving this?</p> <ul style="list-style-type: none"> • expanding the existing approved mental health professional (AMHP) role in the community so that they are also responsible for managing prison or IRC transfers • creating a new role within NHS England and Improvement (NHSEI) or across NHSEI and Her Majesty's Prison and Probation Service to manage the prison or IRC transfer process • an alternative approach (please specify) 	To determine who should be responsible for transfers between IRC and hospital	Who should oversee these transfers?	Who should be responsible for and oversee these transfers?	

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
	<p>Consultation question 22:</p> <p>Conditionally discharged patients are generally supervised in the community by a psychiatrist and a social supervisor. How do you think that the role of social supervisor could be strengthened?</p>	<p>To determine supervision in the community</p>	<p>Have you ever been supervised during a conditional discharge? Who did this – was it the right person?</p> <p>What was the role of the social supervisor – how could this improve?</p>	<p>Social supervisor and CPN</p> <p>You cant pick the SS or choose them, what if you don't get on with them?</p> <p>someone to look after someone's care from start to finish, would be an app person</p> <p>Make it clear what they are!</p>	<p>Have you ever been supervised during a conditional discharge? Who did this – was it the right person?</p>

Theme	DHSC consultation question	Question aims	Suggested questions	ExE Input	Final questions for engagement sessions
	<p>Consultation question 23:</p> <p>For restricted patients who are no longer therapeutically benefiting from detention in hospital, but whose risk could only be managed safely in the community with continuous supervision, we think it should be possible to discharge these patients into the community with conditions that amount to a deprivation of liberty.</p> <p>Do you agree or disagree that this is the best way of enabling these patients to move from hospital into the community?</p>			<p>You can be on a 37 across all of the levels of security and prisons</p> <p>Certain things assumed if you have travelled through certain levels/or at the prison- treated as individuals- sections run out</p> <p>Agree - because at least you can go into the community</p> <p>Not concerned with your abilities, don't treat you as an individual, not receiving an therapeutic benefits by jumping through these hoops, should include the groups you have been part of etc, section 41 and living independent!</p>	<p>If someone is no longer benefiting from being in hospital but needs to be continuously monitored do you think they should be released with restrictions so severe they effectively restrict their liberty?</p>
	<p>Consultation question 24:</p> <p>We propose that a 'supervised discharge' order for this group of patients would be subject to annual tribunal review. Do you agree or disagree with the proposed safeguard?</p>	<p>To determine the suitability of a supervised discharge order</p>		<p>worries me greatly- you can apply for your tribunal on a yearly basis</p> <p>Reports should be reflective of the ind, MAPA, home office restrictions</p> <p>Opinions not facts, politics and not medicine</p> <p>Role of media?</p> <p>And then if a patient becomes upset, can be used as a reason</p> <p>Timelines- one or two years for a decision</p> <p>Bias in proceedings, MHA is too weak- standard of proof needed- so evidence based reasoning needed for part 3 patients</p> <p>'Are the proposed changes for part 2 and part 3?'</p>	



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