

Joint Committee on the Draft Mental Health Bill

Oral evidence: Draft Mental Health Bill, HC 696

Tuesday 25 October 2022

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Written evidence from witnesses:

- [Professor Rose McCabe \(Professor of Clinical Communication and co-Director at Centre for Mental Health Research - City, University of London\) \(MHB0047\)](#)
- [Dr Shubulade Smith \(Clinical Senior Lecturer at IOPPN, King's College London\), Dr Lucy Stephenson \(Clinical Research Associate at IOPPN, King's College London\), and Dr Claire Henderson \(Clinical Reader in Public Mental Health at IOPPN, King's College London\) \(MHB0050\)](#)
- [VoiceAbility \(MHB0054\)](#)
- [Dr Nahed Arafat \(Interpreter and academic professional at Independent/University of Sheffield\), and Dr Jane Woodin \(Intercultural Communication Programme Lead at University of Sheffield\) \(MHB0066\)](#)

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Members present: Baroness Buscombe (The Chair); Baroness Barker; Baroness Berridge; Lord Bradley; Baroness Hollins; Baroness McIntosh of Hudnall; Dr Dan Poulter; Dr Ben Spencer; Sir Charles Walker.

Questions 55-65

Witnesses: **Dr Nahed Arafat**, Research Student at School of Languages and Culture, University of Sheffield; **Professor Rose McCabe**, Co-Director at Centre for Mental Health Research - City, University of London; **Jonathan Senker**, CEO at VoiceAbility; **Dr Lucy Stephenson**, Clinical Research Associate, King's College, London.

Q55 The Chair: Welcome everybody. This is the fourth session of the Joint Committee's inquiry into the Draft Mental Health Bill, which will explore how the initiatives designed to increase patient autonomy and choice will function in practice and how effective they will be. I would like to begin the session by asking the four witnesses to introduce themselves and then we will go to the first question. Let us start with Jonathan.

Jonathan Senker: I am the chief executive of VoiceAbility. We work to make sure that people have a voice when it matters most in their lives.

Professor Rose McCabe: I am professor of clinical communication in mental health and co-director of the Centre for Mental Health at City University. We are representing research, working with service users, people with caring responsibilities and clinicians in terms of video recordings of communication and intervention studies to improve experiences and outcomes of care.

Dr Lucy Stephenson: I am a psychiatrist and psychotherapist at South London and Maudsley and a researcher at the Institute of Psychiatry, Psychology and Neuroscience, Kings College London.

Dr Nahed Arafat: I am an academic researcher with a PhD from the School of Languages and Culture, Sheffield University. I am also a transcultural mental health worker and interpreter. I combine my experiences to find out more about patients' experience with mental health in order to have more of an impact and to improve that experience.

Q56 **The Chair:** Let me ask the first question. I ask you to give brief top-line answers, and then we will delve deeper into some of the issues as we go through the remaining seven questions. First of all, in a few sentences, what are your thoughts on the Draft Mental Health Bill as it stands? Professor McCabe, can I go to you first?

Professor Rose McCabe: I very much welcome the positive changes in the draft Bill. For the draft Bill to succeed in achieving the aims of increasing autonomy and choice, I believe it needs to go further in specifying how these guiding principles will be enacted in practice. Based on our research with people with lived experience, carers and clinicians, we have identified that clinicians need training to offer choice and autonomy in order for the positive aspects of the Bill to stick. We need to involve people with lived experience in designing, delivering and evaluating that training for these principles to be enacted in routine practice.

Dr Lucy Stephenson: My focus is on advance decision making in the Bill, and my views are informed by the views of service users, carers and professionals who took part in a pilot project of advance choice documents in south London. Broadly, I am pleased to see the provision for advanced decisions and more weight for patient wishes about treatment, but I am concerned about some of the rollback on the more detailed advance choice documents and the level of statutory support for implementation, particularly around an active offer of support for making documents.

Jonathan Senker: It is a really important step in the right direction, but it has got to go further, faster and deeper to achieve the changes that are desperately needed. There are some practical measures within the scope of the Committee to recommend which could help achieve that. They include further strengthening the entitlement to independent advocacy so that people are at the heart of decisions about their lives, stronger provisions in relation to people with learning disabilities and autistic people to address the continued blight on our society of the way that these people are treated in in-patient settings and enhancing the role of the mental health tribunal. There were some more powerful steps, some of them recommended by the independent review, which are not in the Bill, which would really help to reduce racial disparities.

Dr Nahed Arafat: I welcome the Bill as well, and I agree with what everybody has said about the changes. I am very concerned about how it will be implemented, as well as the length of time it is taking to be implemented. I am also concerned about information, how these

changes will affect people and how they will know about it. I am mainly concerned about language issues, how black and ethnic-minority patients will be able to understand these changes, particularly those who are either illiterate or have language barriers. My concerns are about the cultural as well as the language issues, mainly relating to the changes in the draft Bill. With changes giving people choice and decision, there are a lot of language and cultural issues involved.

The Chair: I would like to thank all of you who sent in written evidence. It is incredibly helpful in terms of our thinking and as a background to today's session. Would any of my colleagues like to ask a supplementary, or shall we move on to question 2? Baroness Hollins is with us remotely.

Q57 **Baroness Hollins:** I want to ask this question first to Professor McCabe. To what extent will making care and treatment plans statutory increase the meaningful involvement of patients when creating and negotiating care and treatment decisions? I am also very interested in how your work on co-production is relevant here.

Professor Rose McCabe: This would be a very positive change and would increase the transparency around decisions that are made for people's clinical care. There are three main points I would like to make. First, conversations are critical. Care and treatment plans will only be as good as the conversations of which they are a product. Secondly, we know that there are currently problems with these conversations in terms of meaningful involvement, and we really want to avoid this being a tick-box exercise; it must be meaningful involvement. Thirdly, we know we can improve these conversations. Conversations are critical. It is tempting to think of the care and treatment plan as a document, but we need to focus on communication and the process by which the document is produced. This relates to Dr Arafat's point. If I am at the centre of this plan, do I understand it, and am I involved in it? Do I believe in it? Only if that is the case, am I going to go along with that treatment plan.

The way questions are asked in these conversations strongly impacts on what people can or cannot say and that people often feel very disempowered. For example, if I ask you, "Is there anything else you want to tell me about your medication?", I am inviting you to say, "No", whereas if I say, "Do you have something else you want to tell me about your medication?", you are much more likely to say, "Yes" and that opens the door for further discussions. That is just one word different. We are talking about the details of how communication takes place. Decisions do not take place in a vacuum; they take place in the context of relationships. We know that a lot of the witnesses have mentioned issues of trust in relationships. The ongoing relationship with the clinician can be very important. According to service users, that is the most important factor in good-quality care. Even if they do not agree with the treatment proposal, if they trust the person, they are much more likely to go along with it.

Secondly, we know that people do not feel empowered to speak up. Clinicians vary widely in how much they involve people. It is an individual style issue that is not influenced by diagnosis or other patient factors. For example, in conversation, a decision about medication lasts around two minutes. This is very short for such an important decision, and clinicians themselves have identified a need for training.

How can we improve these conversations? We know we can, by showing clinicians how you optimise meaningful involvement through involving people with lived experience. In relation to co-production, sometimes clinicians feel they are involving people, but from the other person's perspective, they are not really feeling involved. Some of the involvement can be very rudimentary. There are structured steps to take in shared decision-making, and we need those to be implemented. We need to involve people with lived experience in delivering the training, because sometimes it is about a lack of understanding about where the person is coming from. Involving people in co-production, in delivering training, designing it, and evaluating it means that we will make a much stronger impact. It increases empathy and understanding between clinicians and people with lived experience in a valuable way. We can look at other things like the decision tools which structure conversations.

To summarise, we need to be looking at approved, mandatory training to get these conversations right, otherwise what is good about the Bill is not going to stick.

Baroness Hollins: I do not know whether what you are talking about applies to people with learning disabilities and autistic people as well. Do you have any additional comments about this particular group?

Professor Rose McCabe: My expertise is in analysing communication and micro-analysing communication, so we have not done a lot of research to date on that. I could follow up in writing, in terms of other groups of researchers who have done that, but we would need to be looking at it in terms of how to offer people preferences and choices that are not overwhelming, for example. Sometimes people say, "I do want to know about the choices, but I do not want it just to be on me. I want to share it." Sometimes people can feel left in the dark in terms of making decisions. We must get the balance right for those groups of people as well.

Baroness Hollins: I wonder whether Dr Arafat might like to comment here as well?

Dr Nahed Arafat: I agree with what is being said. When giving people choices, you have to consider that people come from different cultures. Some cultures look at clinicians as the ones at the top of the hierarchy, the ones who make decisions. In this situation it becomes very difficult to give people this kind of decision-making.

On another note, with communication, I agree that the way the questions are put impacts people. A lot of people from black and ethnic minorities are refugees in the asylum system and are actually quite worried. They have experienced a lot of things back in their home countries, and they are afraid of putting their opinions or their viewpoints on the table. Again, at the time of admission to mental health, people often lack understanding. They feel unable to take in a lot of information. Sometimes there are a lot of interpreters provided, but they lack the right training in how to put information to the patients. In my research, I was looking at patient experiences when they are accessing mental health. Quite a lot of people felt that, although they have a choice, they are not able to exercise it. We need training to enable patients to be able to talk about different things.

Q58 **Baroness Hollins:** To what extent do you think statutory care and treatment plans would reduce disparities in the way different ethnic and racial groups are treated under the Mental Health Act?

Dr Nahed Arafat: Having a say in your treatment plan is a way forward, if you are able to decide on what you want, specifically if you are from a religious or cultural background that looks at things differently. A lot of people were saying “Nobody's caring about our religious or cultural beliefs.” If they are able to express this, and if it is taken into consideration, that would be really good, but we are far away from this. Even in asking patients about these issues, up until now a lot of clinicians or health and social care professionals are unable to put the questions right to people. Therefore, people sometimes become offended if they are being asked about their cultural or religious beliefs, or sometimes they are a little withdrawn. They do not know how the other person is going to accept these things. They do not have that kind of trust in order to talk freely about it, particularly if they find the person in front of them is unable to understand.

Baroness Hollins: Would either of the other panel members like to make a comment about how care and treatment plans could be strengthened?

Jonathan Senker: I was thinking about how the proposal to make care plans statutory would map on to a recent experience that I had, and I concluded that it would be beneficial. If I tell you a little bit about it, it was in a single hospital over a period of one hour with two different psychiatrists. The first one was really empathetic. I could not have wanted for a better psychiatrist myself if I needed one in those circumstances. He listened, involved the person and was honest and open. He did not tell the person all the things he wanted, but they had a really good conversation. Making care plans statutory probably would not have changed the way that he interacted, because he was great, but it would have given a greater perception of the importance of the plan that they could develop together. It would have helped to model the way that he behaved broadly within that culture. The second psychiatrist was hectoring; she did not listen to the person; she wanted to win a battle against him. It probably would not have changed her behaviour either, but it would have meant it was perceived as even more maverick and unacceptable than it already was.

That segues into the other point, which is that making care plans statutory is really important in reinforcing the kind of conversations we want to have, that colleagues have spoken about, but also that we need to have a really good route of redress if the patient wants to challenge the plan or challenge the fact that the plan has not been implemented. That moves on to some of the conversations later on around the role of the tribunal. Having that easy access and a way to challenge the non-implementation of a care plan or the inappropriateness of a current treatment plan is essential. In terms of when we think about how it engages with disparities, the more objective, the more open and the more routes to challenge there are, the more we have the opportunity to undermine those racial disparities and non-objectivity in decision taking.

The Chair: Lord Bradley, would you like to come in here?

Lord Bradley: I apologise for my late arrival and if you have already covered this. In terms of communication, the draft Bill is almost silent on the role of the speech and language therapist. Do you think they play a crucial role in supporting the communication of the patient in the putting together of their care plan?

Professor Rose McCabe: They could play a supportive role, particularly for people with learning disabilities and autism, for example, depending on the level of functioning. They could be a good support for those people.

Q59 **Baroness Barker:** Dr Arafat has already answered a great deal of the questions in section three. To what extent do you think changes in legislation can change the underlying cultural influences on behaviour and communication that lead to the disparity between different minority groups and their incidence within the population of people who are receiving mental health services?

Dr Nahed Arafat: The legislation needs to be worded correctly so people will be able to understand it. For example, I was looking at the independent mental health advocacy, and it says that it introduces the concept of an “English qualifying compulsory patient” and an “English qualifying informal patient”. If I am a black ethnic patient who does not understand the language very well, with regards to the term “English qualifying compulsory patient” and the word “English”, I know it might mean from England, but I will think it means that I, as a minority, will not qualify for independent mental health advocacy. Even with the wording itself, we will have to be careful.

It also says in the draft that managers have a duty to inform patients orally and in writing about the complaint procedures and make sure that they understand them. I am pleased that the word orally is added because quite a lot of people are unable to read and write, so it is very important that you inform them about the complaint procedures. However, again, if these procedures are not worded in a way that people are able to understand their rights, in order to be able to carry them out, it is a little bit difficult.

When I was doing training last week, we were discussing a case study that I had made up, but it turns out to be true. We were talking about black and African people and their admission to wards and how they are sometimes treated unfairly. A lady witnessed that a patient was not treated very well, and she asked him why he did not complain. The simple answer he gave is, “I am a mental health patient with no power, so who will listen to me?” Even these little things about the legislation, people do not understand. It is very difficult, so I am really concerned about the wording of some of this legislation.

First of all, it needs to be changed and addressed in the right manner. We need to take language and cultural issues into consideration in order for people to understand their rights. You need to tell people what they are entitled to. Also, when they are detained, it is a mistake if you are telling people about their rights at the time of admission to hospital because they are in a very difficult mental state. Sometimes even if you explain things fully to the nearest relative, they will find difficulty in understanding. The most important thing of all is that we need to train interpreters to understand the legislation and to be able to put it into an easy layman language for patients to understand their rights.

The Chair: Do any other members of the panel wish to comment?

Professor Rose McCabe: There has been some promising work going on recently where, rather than informing about the availability of cultural advocacy, for example, a much more proactive approach is taken. Advocates actively come on to the ward and manage to engage people who would not have accessed it previously or in their own right. A proactive approach seems to be successful in engaging people who would not necessarily feel they have a right to

it. They do not understand it. It is really about spending time on the wards and also doing that in a staged way. The presence has to be staggered as well. As you said, Dr Arafat, it depends on the place that the person is in immediately after admission. It takes time. That seems to be quite a promising approach in getting over some of these difficulties.

The Chair: Can we move on to Lady Berridge because this segues quite well into the next question on advance choice documents.

Q60 **Baroness Berridge:** Dr Stephenson, first of all, what is your view on the way the draft Bill deals with advance decisions—if you could be quite practical in the outlook? What kind of situations in treatments and decisions are we talking about here?

Dr Lucy Stephenson: I feel very pleased that there is provision for advance decisions to refuse treatment, which brings things in line more with the Mental Capacity Act. I have two main areas of concern. The first is in Section 56A. There is an emphasis on taking into account patient wishes, but the focus seems to be mainly on medical treatment, which in a psychiatric setting means medication. What we know from our pilot project is that service users, carers and health professionals are likely to want to put more detail about their care, as well as treatment.

For example, people might want to give a hierarchy of medical treatments: their preferred medication, medication they would find acceptable and then medication they absolutely want to refuse. Alongside that, they might want to make care preferences around the ways they should be de-escalated if in distress, or trauma-informed approaches to restraint for them, or to tell nursing staff about particular injuries they have, which they need to know when considering restrictive practices. Allowing for treatment and care requests would bring things more in line with advance statements in the Mental Capacity Act and overall increase parity.

The second issue is that I have a concern about how much the draft Bill supports the implementation of advance decisions. It is really important that we learn from the experience of other jurisdictions. Across countries where there have been attempts to implement mental health advance decision-making, there is a gap between the aspiration to make documents and actualising them. We know that when you ask service users, the majority want to make advance decision-making documents but only a minority manage it. We see this in Scotland, where they have had advance statements in place for several years, but when they looked at the people who had been detained between 2017 and 2020, only 6.6% of those people had advance statements. People from backgrounds where they were facing socioeconomic disadvantages were far less likely to have those statements, and that is because there is less support for implementation.

Our pilot projects set out to really understand those barriers and to co-produce implementation strategies to help overcome them. We came to understand that there are three hurdles to overcome if you want successful advance decision-making: the first is getting the document made; the second is accessing the document in a crisis; and the third is applying it. My concern is the draft Bill only really tackles step three, applying the document, and it is the first two in practice that are the most challenging. We need to roll back and have a look at some of the recommendations in the review and the White Paper around ensuring that there is an obligation for everybody who has been detained or is at risk of being detained to be

actively offered support in getting the document made and more clarity around the obligation on clinicians to look for those documents and check for their existence, and read them and use them when they are formulating care and treatment plans.

Baroness Berridge: Just to follow up—and then I will ask the other panel members—the review wanted to include advance choice documents and that is not in the draft Bill at the moment. Can you describe what the different world would be if we had advance choice documents in as well as advance decisions, and what would be the advantages and disadvantages?

Dr Lucy Stephenson: This is what we were doing in our project: trying to anticipate what an advance choice document would be like to implement using the recommendations that were in the review. That advance choice document combines information about relapse indicators, crisis planning, treatment requests, treatment refusals, detail about a nominated person and information about a personalised capacity assessment. This is the person's own view on when they need support from others about making decisions.

To contrast with the draft Bill, there is reference to advance decisions, and needing to take note of the patient's past and present wishes, but there is no structure on where you would find those, or how you go about recording them. This really is a recipe for a lack of clarity for service users and clinicians seeking to make and use these documents. Advance choice documents would bring us more in line with the legislation in the Mental Capacity Act because there is more nuance; there is more room for detail about care rather than just treatment. There is also the likelihood that advance choice documents are more likely to deliver on the economic advantages of advance decision-making because the evidence we have is looking at crisis planning and thresholds for admission and decisions about admission. In the advance choice document, you can put detail about relapse indicators, and it is that which might decrease the rate of admissions, as well as tackle the quality of the experience when the person is an in-patient and the level of autonomy and empowerment they have around treatment decisions once submitted.

The Chair: That is very helpful.

Q61 **Dr Dan Poulter:** Dr Stephenson, you mentioned that in Scotland, for example, just over 6% of patients had made advance decisions. We are talking about mental health, but do you have any comparable data for people with chronic, long-term, physical health conditions?

Dr Lucy Stephenson: No, I do not, but I can find out.

Dr Dan Poulter: It would be quite helpful to understand whether there really is a disadvantage for people with mental illness compared to those who perhaps have relapsing-remitting conditions or chronic physical health conditions.

Dr Lucy Stephenson: We have made links with the palliative care world, which has been putting a lot of effort into helping people make advance care plans around place of death. They have made a big pan-London database called Coordinate My Care to support this effort and it is much more advanced, embedded in clinical practice, and an expected part of routine

clinical care. This is something that paramedics, urgent care teams and GPs can access, which is something that would be really important to see for mental health.

Dr Dan Poulter: Another area of healthcare where we often look at advance decision-making, probably more so than in palliative care, is maternity care. There is often a birth plan, but we also recognise that the clinical reality is that the birth plan may not be followed in circumstances that were not foreseen. How would you deal with advance directives if they become too prescriptive?

Dr Lucy Stephenson: The big fear for clinicians is that people will use advance decision-making to make radical refusals or to refuse all treatment. The evidence is that only a very small minority of service users actually do that. What people want to do is make requests and quite nuanced refusals. Getting good-quality, clinically helpful documents is all about the effort that you put into drafting.

The process that we developed in this project was that, first of all, the service user drafts the document by themselves to ensure it is their voice and their views going into the document, and they can meet with an independent supporter to do that. Then, they meet with their clinician and a family member to discuss the plan to make sure that the service user has all the information about what is actually clinically feasible within services that exist. We also really encourage them to put their values into the plan.

Using the birth plan analogy, it might be difficult to predict exactly which clinical action is taken, but it is going to really help the clinician to decide what the most important thing is for this woman. There is an organisation called ReSPECT that looks at resuscitation decisions and it has a sliding scale. On the one end of the sliding scale is reduction in pain and on the other end is staying alive at all costs. Once you know where the person's value lies along that spectrum, it is much easier to make the clinical decision. Again, as we were talking about earlier, it is the conversations around making those decisions that makes those decisions feasible and reduces the likelihood that you are going to have a clinically impossible document.

Q62 Dr Dan Poulter: We know the WHO would suggest that 70% to 80% of people with psychosis lack insight into their condition. How would you see this working for people with chronic psychosis with an ongoing lack of insight who may not recognise that they are unwell?

Dr Lucy Stephenson: That is a more complex question about the status of advance decisions where the person has capacity to make decisions about treatment and care versus the person who does not have capacity to make decisions about their treatment and care. I am aware of the danger of conflating insight and capacity. Even if a person does not have the capacity to make decisions about their treatment and care, at any point—maybe they do not recover that capacity between episodes—we can still go through a therapeutic process of finding out what their preferences and values are.

Coming back to the importance of knowing care preferences, they might not have the capacity to make decisions about treatment, but they might know how they want to be approached in a crisis, how they want to be de-escalated, how they want distress to be managed and who they want to be contacted. Those are all still very meaningful parts of their care that are going to support their recovery and are important to document.



Dr Dan Poulter: Take the example of someone who has a chronic psychotic illness. What would you say in the case of somebody who lacks insight and therefore, maybe because of that, is making potentially very bad decisions that may be very harmful to their health and their general social well-being?

Dr Lucy Stephenson: If I have got it right, you are thinking about somebody who lacks insight into their psychosis; they do not have the capacity to make treatment decisions when they are in the community, let alone when they are even more unwell as an in-patient. In that scenario, they would not be able to make an advance decision.

My understanding of the draft Bill as it stands is that they would not be able to make an advance decision with the same weight as somebody who does have insight into their condition and has the capacity to make an advance decision about their treatment. None the less, it is important that their wishes are documented in some form and referred to so we understand something about their preferences. Again, it is important to go wider than which antipsychotic does this person want or not want when admitted.

Dr Ben Spencer: Thanks for the evidence, Dr Stephenson. Could you explain why you feel this needs to be on the face of the Bill as opposed to something that is put in the code of practice?

Dr Lucy Stephenson: In the code of practice there is already reference to making note of and taking patients' advance wishes seriously, but we all know that does not actually happen in practice. Having spent several years engaging with clinicians around this topic, it is only the idea of statutory change that enables them to take this seriously, especially with all the other clinical pressures. Statutory change is going to be the thing that nudges into clinicians' consciousness and ensures it is taken seriously and resourced seriously as well.

Q63 **Baroness Berridge:** I understand there is evidence that using advance decisions and advance choice documents would particularly help black and ethnic-minority communities in terms of their experience of mental healthcare. Could you also touch on what the effect might be of these decisions being overruled as it is not a physical treatment decision?

Dr Lucy Stephenson: Participants in our project from black communities were very clear that advance decision-making is even more important for people from black communities because of their experience of trauma, increased disempowerment and increased discrimination. Importantly, they are even more difficult to make because of lower trust and the increased emotional load, and also potentially because of the stereotypes we have around people who might want to engage in advance decision-making. That is why it is really important to emphasise that we have this active offer of support to everybody who has been detained or is at risk of detention, not just the people who we think might like it.

Baroness Berridge: Potentially putting it in as a specific part of aftercare that then would be resourced?

Dr Lucy Stephenson: Yes.

Baroness Berridge: If I have understood the Bill correctly, these treatments can still be overruled. Have you any data as to how often?

Dr Lucy Stephenson: There is some data from Scotland and some data from the United States. In Scotland, about 39% of people detained between 2017 and 2020 had their advance decisions overridden. I do not have the exact figures from America at my fingertips, but I can get them for you. The risk of these advance decisions being overridden is dictated by the quality of the writing that goes into them. If you have no structure or support for people writing these decisions, then they are far more likely to be unrealistic. For example, when I was sitting down with people and writing these decisions, you first ask them what they really do not want and they say they do not want any antipsychotics, for example. Then, you ask them whether it is about all antipsychotics or whether there are particular antipsychotics they do not get on with. You get down into the detail and, importantly, you understand why and which side-effects they want to avoid, what experiences they have had in the past. Unless you have the support for encouraging that specificity, you end up with unrealistic decisions that are more likely to be overridden.

The Chair: Dr Stephenson, you referenced that those in palliative care have developed this database. I have heard about this too, and I think we might look at this Coordinate My Care and see how that might apply to this subject.

Q64 **Baroness McIntosh of Hudnall:** You have all already touched on advocacy, which is clearly a matter of considerable importance to all of you. I want to try and run together two or three different questions about advocacy to give you all a chance to respond to whichever of them you would like to respond to.

What is your view of the intention to extend advocacy rights to be provided on an opt-out basis and what effect do you think that might have on patient experience? As drafted, is the draft Bill currently adequate or would it benefit from further refinement and what can you tell us about evaluations of the effectiveness of different types of advocacy?

In relation to the issues about advocacy for different groups of people, what are the most appropriate ways, in your view, to improve access to culturally appropriate advocacy or specialist advocacy for people with learning disabilities or autism? I am particularly interested in what you think about the recruitment of a workforce—perhaps workforce is the wrong term—or a body of people who can provide these services because, quite clearly from what we have heard already in evidence and what you have said to us to some extent today, a great deal of reliance is being placed on advocates and on their ability to operate in a very skilful and targeted way with different kinds of patients. My untutored impression is that requires quite a lot of training and probably quite a lot of people. That is a question about deliverability, frankly. Whatever our aspirations are, do we look around us and think, “Yeah, we can do that”?

Finally, can any of you just explain what the difference is between an IMHA and a cultural advocate? Are there any general views to start with and then does anybody want to pick up any of the specifics?

Jonathan Senker: There are lots of really good questions there. Let me make a first response to them. Opt-out is absolutely essential. Advocacy is really vital in people's lives, but too often the people that need it most do not receive it. At the moment, the duties are on the

healthcare provider staff to inform people about the right to advocacy. It is a weak duty to inform. Does it mean a poster on the ward or a quick chat, "Oh, there is an advocate if you want one"?

Professor Arafat spoke earlier about the need for a proactive offer. One of my colleagues spoke about the importance of advocates being available on the ward, being seen and heard. That is really important, but it is not enough. It does not get to the person that Professor Arafat spoke about who said, "I am only a mental health patient with no power: no one will listen to me." That person does not ask for it and is not necessarily on the ward to be seen.

Opt-out means that everyone gets the choice. Everyone gets to meet an advocate to understand directly how it can benefit them. The CQC has found that many people just do not get informed about things at the moment despite the duties as they are. The ad hoc approaches we currently have are not working. It is absolutely essential that we move to opt-out rapidly and that we make sure it is available to voluntary patients, because the distinction between being a voluntary patient and being detained often is, "Well, look, if you are not here voluntarily, we will detain you." It is not a very big difference in practice for many people.

Baroness McIntosh of Hudnall: Before you move on, Mr Senker, could I just ask your colleagues whether, in broad terms, they all agree that the opt-out principle is critical and whether there is anything they want to add to what Mr Senker has already said on that specific subject?

Professor Rose McCabe: I agree.

Dr Lucy Stephenson: It could be a really important tool for getting support for people to draft advance choice documents and advocates could have an important role to play in that.

Jonathan Senker: I totally agree. In terms of strengthening the draft Bill, make it apply to advance choice documents, advance decisions outside of hospital, not just for people on CTO, provide an entitlement to people with learning disabilities and autistic people who are on dynamic support and dynamic risk registers. These people need that specialist advocacy because they are at risk of detention.

We need to resolve the out-of-area issue. Despite guidance, we have some hospitals where there could be five different advocacy providers within one ward. It is confusing for the person, and it is confusing for the staff and people do not get advocacy.

We need to address the issue of advocacy for people who are autistic and people with learning disabilities who are in-patients. We need a model of support that gets to know the person and understands how to work effectively with people with learning disabilities and autistic people and which works effectively with people's families when appropriate. Usually, it is appropriate and important to work with families. The model of support must have the skills, tenacity and robustness to ensure that people get the support they need and can make the transition to more appropriate provision. The only way we are going to move to that within the timescale people need—which is yesterday, but we are not going to do that, so as soon as possible—is through a national service which can then also follow people so that it is not disrupted as people hopefully move on to more appropriate provision.

Having the availability of really skilled people to provide the advocacy is essential. I would turn it around a little bit and say, on behalf not just of our organisation but of the advocacy sector generally, it comes down to resource. We can find the people if we are given the resource. As an organisation, of course we have to work hard to recruit people with the skills, attitude, and behaviours we need, but we can find them and it is not a reason not to proceed with vital changes to protect people's rights. It is achievable.

I can move on to some of the distinctions with cultural appropriate advocacy. I am aware that I have been talking for a while if other colleagues want to come in, or would you like me to continue?

Baroness McIntosh of Hudnall: I wonder whether Dr Arafat might want to address the cultural appropriateness, as she raised that before.

Dr Nahed Arafat: There is a big difference between independent mental health advocacy and cultural advocacy. I can see it is important that it is offered to everyone. Cultural advocacy is not just somebody giving you advocacy and advice. They are very skilful, very aware of the cultural and religious beliefs and the viewpoint and are able to provide all of this in a skilful manner.

We need culturally appropriate advocacy people in order to support the patient. To give a quick example, I was supporting one of my patients and, unfortunately, although we had explained to the husband what would happen when she was detained in the hospital, the husband went to visit his wife in the hospital and he found that women and men were seeing each other. One of the male patients was in his wife's room and he was really upset about this. He wanted his wife to be taken out of hospital and he approached me to do this. I managed to speak with the staff and the psychiatrist in order to see what we could do.

When there is a scarcity of resources or less funding, we always feel that, unfortunately, black and ethnic-minority support work—the workers and supporters—are the first to be targeted and the service ended. This is exactly what happened to our transcultural team after it had been in place for 10 years, supporting patients from the different black and ethnic minorities. We were providing not just appropriate care but culturally appropriate care for these patients. Once there was a scarcity of funding and resources, the first team to be dispersed was the transcultural team. We need to maintain these teams in order to be able to provide people with the support they need.

Professor Rose McCabe: The workforce issue is very important and we are placing a lot of emphasis on advocacy and what that is going to do. I do think we need to bring this back also to the entire workforce that has conversations with people because it is only going to work if this cuts across people's care journey; it is not going to be solved just by advocacy although advocacy plays a really important role.

Another interesting piece of work being led at City is peer support, which is another option. We need to be looking at diverse options because one solution is not going to fix everything. We need to be looking across the board. Interestingly, black people who had been admitted under the Mental Health Act and were provided with peer support were much less likely to be readmitted after 12 months. It is a very promising approach. Although they found it difficult to connect and form trusting relationships with staff, they could do it with their peer

supporters. That seems to be a protective factor against readmission for these groups. In terms of addressing your workforce issue, we need to be looking for a range of solutions.

Baroness McIntosh of Hudnall: When you have a variety of different ways of thinking about how you can support people in crisis, how does that get co-ordinated? There is an administrative cost, both financial and operational. How do you evaluate that? How do you assess where to place the resources you do have?

Professor Rose McCabe: You raise an excellent point around co-ordination because we do hear from people repeatedly, and you may have heard from people, around lack of continuity in their care. Other witnesses have mentioned things not being joined up and that is really problematic for people. A lot of these more novel approaches like proactive, cultural advocacy or peer support are in the research stages in terms of mainstream services, otherwise it tends to be a bit more ad hoc and a postcode lottery in terms of what people get. Obviously, we need stronger evaluations of the more effective ways of reducing detentions because that is the aim of the Bill. The jury is still out on some of those, but there are some promising approaches coming through.

In relation to cultural advocacy, we do need much more proactive support and not to wait for people to pick up referrals: “Oh, you have been referred to an advocate”; that has a minimal chance of succeeding. We need to have much more proactive approaches. I take your point about the resource issue and more is always better, but we can also do better across the workforce in terms of the conversations that are had with people.

The Chair: Does anybody want to come in because we have two more questions we really want to cover on nominated persons and tribunals? Should we move on?

Baroness Barker: Can I make a suggestion? We have eight minutes. Tribunals are really important. Would it be possible for the panel members to write us a note on nominated persons?

The Chair: In fact, we have already had some good written evidence from you, but unless anybody wants specific questions on nominated persons, we shall move on to tribunals.

Q65 **Dr Ben Spencer:** My question is on the proposed new powers of mental health tribunals, which came out of the Wessely review, with regard to giving more ability for patients to appeal decisions. That has been somewhat truncated in terms of what the Government propose in the draft Bill. What do you feel about that and what do you feel about some of the challenges and concerns that were raised around the tribunal having the ability to review treatment decisions, particularly with regard to workforce and the doctor-patient relationship? Although it is declared to the Committee, I should say I was on the Wessely review and on the tribunal panel as well. This is a declaration in terms of asking those specific questions about the tribunal.

Jonathan Senker: Clearly, in terms of people having the ability to challenge their care plan, it is really important that there is a route to do so. I would like to make a broader point about the importance of tribunals being able to direct community-based provision to community-based support, which was not included in the draft Bill.

The Committee Members will be very familiar, for example, with the case of Tony Hickmott who was in hospital for almost three decades which was many years beyond the point that he was said to be ready to discharge. He was in the process of being discharged because he could go to the Court of Protection which could make a judgment and a decision to direct community-based support. If somebody in his situation had capacity, that is not a remedy that is available through the mental health tribunal. That is a critical weakness, particularly if, as I hope, we move to a position where people are only detained in mental health provision under the Mental Health Act rather than under the Mental Capacity Act, as can happen at the moment. We need to make sure there are clear ways of people challenging that and making sure that the tribunal can be forward-looking. It should not just be taking an instant decision about whether somebody is ready for discharge and can be discharged because there is somewhere available, but actually lending some weight to make sure that people are not detained for longer than necessary. It is essential to do so.

I recognise the concern around resources. The human cost of not extending the powers of the tribunal is potentially much greater.

Professor Rose McCabe: I would also agree that, as a safeguard, it should be there as a recourse to review decisions—not to make treatment decisions but to review decisions—that have been agreed or discussed and negotiated in care and treatment plans and advance choice documents. Particularly with the lack of continuity, it would increase the pressure to join these up and make patients’ experiences better in that respect. People do not like their decisions being overruled and not understanding why is very disempowering. It would be very helpful to have a recourse to understand why something has been overruled.

Dr Ben Spencer: You say it should not have the ability to make decisions but should be able to review decisions. How can you review a decision, as a corollary of that, without then making a decision?

Professor Rose McCabe: The appropriateness of the decision would need to be reviewed and then a decision can be made on whether it would need to be referred back to the responsible clinician to determine whether further treatment was necessary.

Dr Ben Spencer: Do you mean the tribunal would decide it does not agree with the decision and ask them to go away, think again and come back with something else?

Professor Rose McCabe: If, for example, it rules in favour of the patient in terms of their decisions being overruled, then that would have to go back to the responsible clinician.

Dr Ben Spencer: How does that work? Does the tribunal then ask the responsible clinician to make a different decision or to just think again?

Professor Rose McCabe: It would ask the responsible clinician to think again, in negotiation with the patient.

Baroness Berridge: Rather like judicial review, “Look at your process again.”

Dr Lucy Stephenson: I see the tribunal as having a vital role as a level of accountability about the attention paid to advance choice documents—in other words, making sure people

have made reasonable efforts to establish that an advanced choice document exists and looking at how the document has been incorporated into a treatment and care plan.

The Chair: That is very helpful.

Dr Nahed Arafat: I agree with what everybody has said. The tribunal can challenge people and will also ensure people know why they have been given a particular treatment and how it is going to work, which are really important questions.

Dr Ben Spencer: Dr Stephenson, if your super-empowered advance choice document and the work you have done was implemented as you would like to see it, would that mean the enhanced tribunal powers proposed in the Wessely review would be necessary? Fundamentally, this is about trying to make sure people's wishes and feelings, beliefs or capacitous decisions, are given power.

The Chair: No, as we have heard, they will not.

Dr Lucy Stephenson: Do you mean that if everybody had perfectly made advance choice documents, the tribunal would have less of a role because there would be accountability in the document itself? The reality is that not everybody will have a perfectly made advance choice document and a layer of accountability is then needed.

Baroness McIntosh of Hudnall: With regard to the relationship between the advance choice document and the issue about tribunals, some advance choice documents—a lasting power of attorney for example—are incredibly complicated and difficult. They take days to complete, have to be signed off by everybody you can think of and their brother, and are also quite costly, but that is a separate issue. How do you imagine the practical provision of a template for an advance choice document would be achieved and from whom could it first be secured? Would it be a GP or a hospital practitioner, and how would it work in practice?

Dr Lucy Stephenson: Those are precisely the questions our project set out to ask. We did it all online during the pandemic—as online as possible—and we found that people first needed a one-to-one session to draft their document, which took on average about 50 minutes, and then they needed a meeting with their clinician and family member to discuss the document, and that took just over an hour.

Baroness McIntosh of Hudnall: Is the first meeting a completely open session where nobody has any documents to start with? Or do you start with a template, “These are the questions to which we need answers”, and, by implication, “These are the questions to which we do not need answers because they are not on the paper”? Is it that kind of very structured discussion?

Dr Lucy Stephenson: We have a publication available with the template we used. We sent the template to the service user in advance then, during the meeting, we put the template, with some set prompts, on the screen. The service user was simply asked the prompts and they wrote in their own words what they wanted to go on the document. The document was then taken to the meeting with the clinician where the issues that arose from the prompts could be discussed. The role of the clinician during that meeting is to help translate the service user's wishes into a bullet point plan that future clinicians will find easy to follow.

Service users see everything that is in the document and have the final sign-off. We found that discussion usually took one, or, in some cases, two meetings, and took just over an hour.

We would like to see pilots of advance choice document clinics in several major mental health trusts in order to create hubs where you would have psychiatrists, peer supporters and advocates who are able to facilitate making documents and also train clinical champions, so they can support others in clinical teams and develop education and training materials to allow wider rollout.

Baroness McIntosh of Hudnall: Gosh—nothing much then.

The Chair: Thank you very much indeed. I am sorry this session has gone so quickly. It has been incredibly helpful and informative. Thank you for being so incisive and bearing with us on the tight timeframe.