

Written evidence submitted by Professor Rose McCabe, Professor of Clinical Communication and co-Director at Centre for Mental Health Research, City, University of London (MHB0047)

Summary of evidence

I am [co-Director of the Centre for Mental Health Research at City, University of London](#). This submission briefly summarises research studies we and others have conducted on increasing choice and autonomy in mental health care. The evidence for this submission comes from video-recordings of clinician-patient communication when making treatment decisions in mental health care, along with interviews with clinicians, patients, friends and families.

In this submission, I make particular reference to clauses 9 (making treatment decisions) and 18 (care and treatment plans) of the Draft Bill, focusing on two main areas:

- Choice and autonomy
- The person as an individual

Supporting choice and autonomy, as well as basing clinical decisions around the patient's wishes, preferences and individual needs become increasingly complex when people are unwell and detained under the Mental Health Act. Most do not agree they are unwell and are typically in a state of high distress and agitation.

Most research on choice and autonomy in mental health care is based on what people *say* about treatment decision making. We can see much more clearly whether choice is offered by analysing video recordings of what people *actually do*. Looking at this evidence, **meaningful involvement based on the principles of choice and autonomy often does not happen**. Many patients who have been subject to coercive treatment feel that their experiences about how they were treated are not believed or taken seriously.

Clinical decisions and treatment plans do not exist in a vacuum. They often take place in the context of a pre-existing relationship with a clinician. **The quality of the patient-clinician therapeutic relationship is the basis for treating the person as an individual and knowing about their concerns, preferences and wishes**. When the patient has not met the clinician before, the ability to develop a rapport quickly becomes even more important. Developing a rapport with patients, validating their experiences and negotiating a shared understanding of the problem all increase patient acceptance of treatment.

Currently, most mental health and other **clinicians are not trained in how to communicate effectively to involve patients in decisions and improve the therapeutic relationship**. Clinicians report that they are trained to ask questions but not how to negotiate with patients. We have developed effective training programmes to improve choice and autonomy. **People with lived experience of being detained under the Mental Health Act should be involved in training clinicians** because this increases choice and involvement in decision making.

Even when decisional capacity is reduced, patients can be supported to have more choice and autonomy and participate in decisions about their care. Patients should be **involved in decisions within the first few days of an inpatient admission, and this should involve the whole clinical team**. Everyone who has been detained under the Mental Health Act should be **supported to make an advance decision**.

Finally, careful consideration should be given to whether a new duty should be added to the Bill, especially with regard to Clauses 9 and 18, regarding the need for the approved clinician to have received adequate and recent training in how to offer patients choice and autonomy in practice, at different stages of the treatment process.

Summary of recommendations:

- 1. Additional resources are needed for training mental health and other professionals in involving patients in decision making.**
- 2. People with lived experience of being detained under the Mental Health Act should be involved in training professionals because this increases choice and involvement in decision making.**
- 3. On inpatient wards when people are detained under the Mental Health Act, shared decision making should be started within a few days and involve the whole clinical team.**
- 4. Research is needed to evaluate whether the process through which advance decisions are arrived at *meaningfully* involves patients and truly supports choice and autonomy rather than being a tick box exercise.**
- 5. Careful consideration should be given to whether a new duty should be added to the Bill, especially with regard to clauses 9 and 18, regarding the need for the approved clinician to have received adequate and recent training in how to offer patients choice and autonomy in practice, at different stages of the treatment process.**

What changes and additional support do you think will be needed to help professionals and the third sector implement the proposals effectively? Will additional staffing and resources be required?

Supporting **choice and autonomy** and **basing clinical decisions around the patient's wishes, preferences and individual needs** become increasingly complex when people become unwell and are detained under the Mental Health Act. Involving people in decisions in this context is challenging as many people do not agree they are unwell and do not agree they need to be admitted to hospital.

Currently, most **mental health and other professionals are not trained in how to offer choice and involve patients in decisions**, so they are ill equipped to deal with this complex challenge. Most clinicians believe that they try to involve people in decisions but, looking closely at actual communication in video-recordings of mental health consultations, meaningful involvement often does not take place. There is also wide variation in how much different clinicians offer patients choice.ⁱ Patients report that they do not feel respected or

listened to and that their concerns are not taken seriously. Often in decision making, patients are presented with limited options rather than a range of options upfront so that they can weigh up all the pros and cons. As one clinician stated: *“Yeah, I mean. I think any sort of training in communication and helping with choices and that sort of thing is probably helpful. ‘Cause as much as you do in psychiatry, in psychiatry you learn how to ask questions, I don't know if you really learn how to negotiate that much ...”*.ⁱⁱ

We have developed effective training programmes to improve choice and autonomy, specifically in the context of psychosis where patients and clinicians often do not see eye to eye on treatment.ⁱⁱⁱ Involving people with lived experience in this and similar training is very well received and impactful in increasing involvement in decisions. Clinician experiences were very positive as the training was based on actual practice using video-recordings of communication with people with psychosis. We also used a novel simulation of hearing voices, developed by a person with a diagnosis of schizophrenia, while performing everyday tasks and attempting to ignore aggressive voices so clinicians could better understand patients’ experiences. Clinicians were given hidden earpieces containing a hearing voices simulation and asked to perform basic tasks such as buying coffee, holding a conversation or doing a work task. As two clinicians reported:

“The hearing voices simulation is probably one of the most important and relevant training exercises I have done in my career. It was eye-opening to discover the extent to which the constant hearing of sounds and voices disorients you and slows you down. It definitely helped improve my communication skills with people with psychosis”.

“I have found the training very useful. It has allowed me to strike a balance between my own priorities as a clinician and patient priorities. It has improved my listening skills...Overall, I have learnt to use less jargon and be a better communicator.”

When decisional capacity is reduced when people are detained under the Mental Health Act, patients can be supported by preparing for the consultation with their psychiatrist to increase their ability to participate in decision making. On inpatient wards, patient involvement works better if initiated early after admission, if the whole clinical team is on board and supported by carers who provide additional information and comfort for the patient.ⁱⁱ

In the words of one patient *“In the first two days it [shared decision-making] can produce a positive effect [...] a lot of the time what happens is you are admitted on a Friday and it's not likely you would see a psychiatrist on the Monday. It could be up until the Wednesday before you are allocated a psychiatrist and by that time, if there is any negativity it's already set in and it's firmly set in”*.ⁱⁱ

Clinical decisions and treatment plans do not exist in a vacuum. Often, they are made in the context of an ongoing relationship with a clinician. Even if decisions are taken when the patient has never met the clinician, **developing rapport is essential to elicit the patient's concerns, preferences and wishes**. Validation of patients’, often very difficult and traumatising previous coercive, experiences, is strikingly absent but, as one person said, *“You need to say “You’re really distressed. You’re in a lot of pain.” I think that kind of*

acknowledgement alone can be really, really, powerful for someone who feels like they're completely alone, isolated, and they don't feel like they even have control over their own mind."

Many patients who have been subject to coercive treatment feel that their experiences about how they were treated are not believed or taken seriously by others. Validating these experiences and taking them seriously is very important. In addition, what is happening should be explained to people, as they are often very distressed and confused. As one patient said: *"I would have stayed in hospital... I went there voluntary and ended up getting sectioned... I did agree to go to hospital... I probably did need the medication... I'm not too sure why I got sectioned...I don't think anyone really gave me a proper answer... I think it was the right thing for me to go to hospital... I just think it's a bit unfair being sectioned..."*.^{iv}

Along with listening to patients' concerns and preferences, trying to reach a shared understanding with the person lays the foundation for treatment decisions. If there is not a shared understanding of the problem, patients are unlikely to buy into clinical decisions. When clinicians focus on developing a shared understanding about the concerns and the treatment options^v, patients are more likely to accept treatment, even if they are not keen on the treatment itself.^{vi, vii}

In shared decision making, the devil is in the detail.^{viii} How clinicians communicate and ask questions matters. For example, asking a patient if he/she has questions about a decision or care plan by asking "Any questions?" is designed not to elicit further information, whereas asking "Do you have some questions?" is more likely to elicit further discussion. Asking about medication with questions such as "No problems with the medication?" invites the patient to confirm that there are no problems, making it very difficult for the patient to discuss concerns he/she may have and influence subsequent treatment. Clinicians are not trained in these important aspects and are unaware of the effect they have on offering patient choices and more autonomy.

Recommendations:

1. Additional resources are needed for training mental health and other professionals in involving patients in decision making.
2. People with lived experience of being detained under the Mental Health Act should be involved in training professionals because this increases choice and involvement in decision making.
3. On inpatient wards when people are detained under the Mental Health Act, shared decision making should be started within a few days and involve the whole clinical team.

To what extent is the Government right in the way it has approached people taking advance decisions about their care?

Advance decisions which help people to state in advance what treatment they would prefer to have, or not have, if they are unwell in the future **should be integrated into routine**

practice. All patients should be supported to make an advance decision. Clinicians should be trained in communicating to optimise choice and autonomy in these discussions. Research is needed to evaluate whether the **process through which advance decisions are arrived at** is not just a tick box exercise and meaningfully involves patients and truly supports choice and autonomy.

Recommendation:

4. Research is needed to evaluate whether the process through which advance decisions are arrived at *meaningfully* involves patients and truly supports choice and autonomy rather than being a tick box exercise.

Are there any additions you would like to see to the draft Bill?

To really increase choice and autonomy for people detained under the Mental Act, we need to see *how* this will happen. How will people be offered choice and how will autonomy be optimised in practice? Choice and autonomy are guiding principles, but **clinicians need training in exactly how to do this in practice at different stages in the process from advance decisions to Mental Health Act assessments to decisions in inpatient wards and beyond.** Mental health creates many challenges for communication. This is particularly heightened when people are unwell and feeling that others are out to harm them, leaving them mistrustful and often very agitated. Currently, clinicians do not receive training to overcome these challenges and involve patients and carers in important decisions. This is a requirement if the Bill is to achieve its aims of supporting choice and autonomy, and basing clinical decisions around the patient's wishes, preferences and individual needs.

Recommendation:

5. Careful consideration should be given to whether a new duty should be added to the Bill, especially with regard to clauses 9 and 18, regarding the need for the approved clinician to have received adequate and recent training in how to offer patients choice and autonomy in practice, at different stages of the treatment process.

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References

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