

Reforming the Mental Health Act

The potential role of advocacy in supporting the use of Advance Choice Documents (ACDs) in mental health hospitals

February 2024



About this research

This research has been undertaken for the UK government's Department of Health and Social Care (DHSC) as part of the Complex Needs Consortium's work programme for the VCSE Health and Wellbeing Alliance¹. The purpose of the research was to explore the potential role of advocacy services in supporting the use of Advance Choice Documents (ACDs) by people admitted, or at risk of admission, to mental health hospitals in England.

The UK government is undertaking reforms of the outdated Mental Health Act (MHA) so that people admitted to mental health hospitals are supported to make more choices for themselves and to reduce coercive and restrictive practices². An important element of the reforms is to give people's preferences greater legal weight in decisions about their care and treatment, including through the use of ACDs.

The government's Reforming the Mental Health Act white paper states that: "Advance Choice Documents give individuals the opportunity to record a range of choices and statements about their care and treatment in preparation for a future situation in which they are too unwell to express these decisions themselves"³.

However, whilst "research shows that patients welcome ACDs and value them in practice, uptake can be low; although this may be due to lack of support to complete them"⁴. According to Stephenson et al (2022), "as the intervention has already been established the key outstanding questions for service users, their family members, clinicians and mental health organisations are around which implementation strategies could help utilise ACDs"⁵.

The government has highlighted a potential role for Independent Mental Health Advocates (IMHAs) in supporting the implementation of ACDs⁶. However, in practice little is known about their potential effectiveness in this role. Research in the UK has largely focused on advance decision-making by people living in the community following hospital discharge. By contrast, the IMHA role is focused on supporting people currently detained in a mental health hospital as only they have a legal right to support from an IMHA (except for those on a Community Treatment Order (CTO)).

This research explores the views of advocates on the usefulness of ACDs in promoting people's voice whilst in hospital and whether people currently in mental health hospitals would likely be interested in completing an ACD. It also considers the potential role of advocates in implementation strategies to support the use and uptake of ACDs.

What we did

We asked questions about ACDs in seven focus groups held with IMHAs across England (as part of wider research on reforming the Mental Health Act and advocacy). IMHAs generally had some awareness of the proposals to make greater use of ACDs. However, they had very little practical experience of supporting advance decision-making and where this did exist, it was usually in a different context (e.g. Mental Capacity Act).

The research findings on this topic are therefore inevitably limited but do provide some insights into the potential role of advocates in implementation strategies to support the use and uptake of ACDs.

The research findings are presented in three sections as follows:

- 1) The usefulness of ACDs
- 2) When to complete an ACD
- 3) Role of advocacy in supporting people to complete an ACD

Each section opens with a headline finding and closes with a headline conclusion.

Key messages

- **Advocates felt ACDs would be a useful tool in promoting people's preferences. However, their effectiveness would be dependent on 'big cultural change' in mental health hospitals.**
- **Advocates felt ACDs would help them to perform their advocacy role of supporting the person's voice whilst in hospital. They were interested to know how they could be made aware of, and access, an ACD as part of the advocacy referral process.**
- **Advocates felt that some people may be interested in completing an ACD whilst still in hospital. However, for many people it was more likely to be after discharge when they are back in the community and further on in their recovery journey.**
- **The potential role for advocates to support people to complete ACDs is uncertain and inevitably limited as only people currently in hospital have a legal right to support from an IMHA (except for those on Community Treatment Orders).**

1. The usefulness of Advance Choice Documents (ACDs)

Advocates were positive about the greater use of ACDs in mental health hospitals and felt they would be an 'important document'.

Advocates reported that care plans for people in mental health hospitals were often 'very tokenistic' and not often developed in collaboration with the person. Although it is currently possible for treatment preferences to be expressed, it was 'very variable what Responsible Clinicians do with it' and that 'firming up is a good thing'.

One advocate cited an example of a client who had been a victim of sexual abuse before admission to hospital. They had requested to only be attended by female staff in a crisis. However, in a recent crisis event they had been attended by a mix of female and male staff, all of whom had been unaware of her history and preferences.

Due to the issues highlighted above and elsewhere around the barriers to hearing the patient voice in mental health hospitals⁷, advocates felt there 'will need to be big cultural change' for ACDs to be consistently acted upon by healthcare staff.

However, advocates were more positive that ACDs would help them to perform their advocacy role of supporting the person's voice whilst in hospital. They felt it 'would be useful for advocacy work and helpful in engaging with clinical team with/on behalf of the patient' and 'also useful to bring together all that information in one place'.

Advocates had questions on where ACDs would be held and stored and if advocates would be aware and have access to it. One advocate suggested it would be helpful if advocacy services were notified if a person had an ACD as part of the referral process so they could seek to gain access to it if the person consented.

There was mixed feedback from advocates on the template ACD being developed. They were positive about the range of information being collected but also felt it could be condensed or made more user-friendly.

Despite the barriers, advocates felt ACDs would help them to perform their advocacy role of supporting the person to have their voice heard in decision-making about their care and treatment.

2. When to complete an ACD

Advocates had mixed views on whether people would be interested in completing an ACDs whilst still in hospital.

The UK academic research on advance decision-making have largely focused on people living in the community⁸. The pilot studies focused on people engaged with community mental health services who received specialised support to negotiate advance decisions with clinical staff to prevent future crisis and risk of hospital re-admission.

Considerable uncertainty therefore exists with regard to the potential for advance decision-making by people currently in mental health hospitals and therefore what role IMHAs could play in implementation strategies for increasing the uptake and use of ACDs in England.

Advocates felt that some people in mental health hospitals would be interested in completing, or at least starting, an ACD. It was felt it would be more likely close to the point of hospital discharge. One advocate commented that there 'are times on the ward where people might be interested - when crisis has passed and getting ready for discharge'. Another commented they 'can think of people who might use it - some patients want to make sure they don't come back!'

However, advocates had some concerns around capturing future wishes whilst the person might still be quite unwell and whether these might change significantly when better. One advocate cited an example of a person they had supported who had changed their mind over time concerning Electroconvulsive Therapy (ECT).

One advocate commented that a person's stay in hospital is 'just long enough to adjust medication and for people to start to get better' and they are 'still fairly unwell when they leave hospital and a long road to go through time in the community'. They suggested that for most people 1-2 months after discharge from hospital might be a better time and it 'needs to be when the person is in a good place'. Another advocate commented that if someone meets the MHA detention criteria then they were 'not well enough to be completing an ACD'. There were also concerns about the practicality of completing an ACD in hospital when other care and treatment processes were ongoing and potentially complex.

Advocates felt that some people may be interested in completing an ACD whilst still in hospital. However, for many people it was more likely to be after discharge when they are back in the community and further on in their recovery journey.

3. Role of advocacy in supporting people to complete an ACD

Advocates were generally supportive of advocacy having a role in supporting people to complete ACDs but also highlighted a number of constraints.

Many advocates felt they were 'well placed' to support people to complete ACDs because they were gathering wishes and preferences all of the time and were independent from healthcare services. Advocates could 'help them understand the purpose of it' and there was 'scope for advocacy to support in some way or another'. Others highlighted concerns about resources and whether advocates would 'have time to do it' and that 'advocates will need specific training'.

One advocate explained how they had been involved in supporting someone to develop a 'safety plan' which was a form of ACD with guidance on what to do and who to contact in the event of a crisis.

However, this work was undertaken as part of community advocacy when the person was not in hospital and was undertaken in collaboration with the care co-ordinator and Community Psychiatric Nurse (CPN).

This example highlights the primary barrier that people only have a legal right to support from an Independent Mental Health Advocate (IMHA) when they are in hospital. Unless they are on a Community Treatment Order (CTO) or can access to another form of advocacy, an advocate would not be able to support them to complete an ACD whilst they were in the community. As noted earlier, completing an ACD once discharged from hospital and further on in their recovery journey is likely to be better for many people.

One advocate also warned that whilst advocacy could have a role in signposting and supporting the person to engage in completing an ACD, if they wanted to, they should be careful not to stray into functions that should be performed by others.

The potential role for advocates to support people to complete ACDs is uncertain and inevitably limited as only people currently in hospital have a legal right to support from an IMHA (except for those on Community Treatment Orders).

Acknowledgements

We are grateful to all the advocates who shared their insights as part of this research.

Particular thanks to the advocates in the following services:

Advocacy Focus

Empowerment Charity

Rethink Advocacy

South West Advocacy Network (SWAN)

VoiceAbility

This project has been undertaken as part of the 2023/24 work programme of the Complex Needs Consortium for the VCSE Health and Wellbeing Alliance.

To discuss any of the issues raised in this report, or to find out more about VoiceAbility's work, please contact publicaffairs@voiceability.org.

¹ <https://www.england.nhs.uk/hwalliance>

² <https://www.gov.uk/health-and-social-care/mental-health-service-reform>

³ <https://assets.publishing.service.gov.uk/media/5ffc7d65d3bf7f65d55056a6/mental-health-act-white-paper-web-accessible.pdf>

⁴ <https://researchbriefings.files.parliament.uk/documents/POST-PN-0695/POST-PN-0695.pdf>

⁵ <https://wellcomeopenresearch.org/articles/7-182>

⁶ <https://assets.publishing.service.gov.uk/media/5ffc7d65d3bf7f65d55056a6/mental-health-act-white-paper-web-accessible.pdf>

⁷ <https://www.gov.uk/government/publications/rapid-review-into-data-on-mental-health-inpatient-settings-final-report-and-recommendations>

⁸ <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6544565/>