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Re: Advanced Choice Documents

We are broadly supportive of the draft Bill, and have answered several of the questions posed by the Committee below. We would like to begin by making some crucial overarching points on resourcing:

Firstly, we believe it is crucial that resources are provided to support the commitments made in the Bill. This includes more *staffing and infrastructure* so that those needing support and treatment can access it. Without these resources, the risk is that the measures in the Bill are not properly implemented, resulting in poorer outcomes for patients.

Secondly, there is an urgent *economic* case for resourcing the proposals in the bill adequately. In our research we have shown that the rise in involuntary admissions under the Mental Health Act cost almost £600 million **extra** between 2008/2009 and 2015/2016 (Smith et al. 2020). We concluded that key drivers of these increased admissions have been legislative changes and the impact of austerity measures on health and social care services.

Thirdly, our research has also found that if promises are made to service users that are not delivered, then not only do people not get the services they need, but [there is a significant risk that](#) their trust in services is broken, resulting in poorer outcomes (Stephenson et al. 2022).

Does the draft Bill strike the right balance between increasing patient autonomy and ensuring the safety of patients and others? How is that balance likely to be applied in practice?

We believe the draft Bill goes a long way in increasing patient autonomy. However, we are concerned about how this is likely to be achieved in practice. Increased autonomy will only come about if sufficient resources are provided to support patients. Crucially, providing those resources would potentially mean enormous cost savings. Advance Choice Documents (“ACDs”) are a essential to increase patient autonomy. . ACDs have also been shown to reduce detentions (de Jong et al. 2016; Molyneaux et al. 2019) ;detentions under the Mental Health Act on average cost £18k, and if ACDs reduce 10% of detentions (a conservative estimate), that would be 5,000 people a year, at a cost saving of around £90 million.

To what extent will the draft Bill reduce inequalities in people’s experiences of the Mental Health Act, especially those experienced by ethnic minority communities and in particular of black African and Caribbean heritage? What more could it do?

People of black African and Caribbean heritage are disproportionately detained under the Mental Health Act, so support for these groups is vital. Our research (and that of others) shows that it is even more important for people from ethnic minority communities to be given the opportunity to make ACDs, but they are likely to face even more barriers to doing this (Stephenson et al. 2022). Outreach and better ways to access and approach these communities are needed. Multiple service users, family/friends and professional participants in our research identified this group as more likely to experience discrimination, micro-aggressions and trauma during mental health treatment. They felt that this made it even more important for service users from this group to make ACDs, yet they faced additional barriers in the form of the increased emotional load required to make the document as well as lower trust in services. Participants again emphasised the importance of active offers of culturally sensitive support with ACDs to all groups, and suggested community engagement e.g. liaising with religious groups and third sector organisations to raise awareness and increase acceptability. This will require resources, but again, there is good evidence that there is a compelling economic argument for providing these resources. Our research found economic benefit for services of having Joint Crisis Plans (a form of ACD), especially in black and ethnic minority groups (Barrett et al. 2013).

The NHS is committed to advancing mental health equality (<https://www.england.nhs.uk/mental-health/advancing-mental-health-equalities/>), and we believe that ACDs are one effective way to do that. If ACDs are properly implemented they will support people to have a better relationship with services, and better access, experience and outcomes. Moreover, we understand that many of the things which contribute to mental health inequalities cannot be addressed in this Bill (eg improving workforce disparity, reducing school exclusion, other systemic issues), but there is action which can be taken, not only ACDs but other measures: initiatives such as Recovery Colleges (eg at South London and Maudsley NHS Foundation Trust <https://www.slamrecoverycollege.co.uk/>) support people to learn about their mental health and how to navigate mental illness, linking clinical advice with peer support, advocates and the voluntary sector.

What more could the draft Bill do to reduce the impact of financial inequalities in people's experiences of the Mental Health Act?

Although the use of digital technologies may improve efficiencies and service delivery for some, there are many who live in digital poverty. For this reason, if digital methods are being used to support ACDs, there will need to be a flexible approach for those who do not have access to digital support.

Service users who experience socioeconomic disadvantages may be less likely to have family members/friends who are available to advocate for the use of their document in crises. The draft bill could address this by placing more obligation on clinicians to check for the existence of ACD documents even if they present alone and out of hours.

What do you think the impact of the proposals will be on the workforce within community mental health services and multidisciplinary working practices both in inpatient and community services?

Hopes

Health professionals who took part in an ACD pilot reported they are likely to increase clinical efficiency, communication and improve decision making under crisis (Stephenson et al. 2022; Henderson et al. 2009). They can also help teams communicate, from A&E to ward to community. The evidence also shows that costly, coercive treatments can be reduced by using ACDs (de Jong et al. 2016).

Concerns

However, we make the point again about staffing and resources. A consistent message from a South London & Maudsley NHS Foundation Trust (SLAM) pilot project and the international literature on mental health advance decision making is that additional support is required to help service users draft, discuss and disseminate their documents (Stephenson et al. 2022; de Jong et al. 2016). This additional support should ideally be someone who is independent of the service users' treating team and therefore in a position to address power imbalances inherent within psychiatric care. These supporters could be trained advocates, peer supporters or clinicians (Stephenson et al. 2022; Ruchlewska et al. 2014; Ruchlewska et al. 2012; Lenagh-Glue et al. 2020).

There is a risk if care co-ordinators will be expected to work on ACDs on top of everything else, with no extra resources, the result will be poorly completed documents and demoralised care workers. Multi-centre pilot studies are urgently needed to establish implementation strategies tailored for local contexts. Given this, it is important to acknowledge that there may be a balance to achieve – if an external person joins a team to manage ACDs, they need to be accepted by the team, particularly given that ACDs may contain perceived judgements about treatment that team has been providing

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?

Our research suggests staff need **education and training** to support people to write ACDs (Stephenson et al. 2022). We recommend **clinical champions** who can provide on the spot coaching, as well as independent support outside of the clinical team (for example a health professional not involved in the service user's care, or a peer supporter) to address power differentials and increase the trust of the service user. **quality of collaborative advance decision making** around these controversial topics, in particular: capacity assessment and medication refusal (e.g. <https://psymatik.com>). This may include provision of **structured templates** and guidance.

Multi agency Training is needed not only for mental health staff, but for others who will also interact with the ACD – this might include police, hospital ED staff, service users and carers. Therefore, it is crucial that ACDs are stored in a place where people can find them, and that those who need to see the ACD have an obligation to look for an ACD when a person presents in crisis lacking capacity. Health and social care IT systems need to be prepared for this change and make **digital space** to record and store advance decision documents. It may be necessary to codify a basic standard of looking, e.g check records/GP/ask patient/ask nominated person.

Trusts should be given guidance and support to **embed ACDs into clinical pathways**. This should include the timing of an active offer of support to make an ACD, alerts around accessing the document in crisis and support to appropriately document reference and use of the document when formulating care and treatment plans.

Third sector organisations have an important role to play in increasing awareness of service user rights to create ACDs, reaching communities that have low trust in services and supporting the drafting process. These organisations should be engaged and provided with resource to train individuals to become ACD document supporters and liaise with clinical champions in local mental health trusts.

We suggest a vital first step is to **pilot ACD clinics** in several trusts. These clinics could comprise psychiatrists, psychologists, nurses, peer supporters and advocates who form a hub of expertise in facilitating the creation of ACDs and developing education and training.

How far will the draft Bill allow patients to have a greater say in their care

ACDs are the chief mechanism by which patients will be able to have a greater say in their care, and there is lots of research to support their effectiveness (Henderson et al. 2004; Barrett et al. 2013). But to give people a greater say in their care, we must also give greater support to make ACDs, and this means more resources.

ACDs should be developed when a person is well, and has capacity, and should include a personalised capacity assessment (where the clinician assisting with the ACD confirms that the person making it had capacity at the time of making). By the time someone is in crisis, it may be too late to participate fully in developing an ACD. Currently, levels of support and advocacy for making ACDs are piecemeal across the UK.

A key principle of ACDs is that if the treatment request of the person making the ACD is reasonable and appropriate, then it should be followed, and patients must have the ability to challenge when an ACD is not followed. We believe this is best done under the existing tribunal system, by having treatment discussion as a standard and priority part of an existing tribunal system, rather than having separate treatment tribunals which would double up the number of tribunals.

Research says that ACDs are the only intervention which makes a difference to detention rates (de Jong et al. 2016). However, they also make people feel more positive about services, which in turn increases trust and improves outcomes (Stephenson et al. 2022).

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