

Annex D

Advance planning documents discussion paper

By

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Introduction

1. This paper addresses the questions of when advance planning documents are created, the points when circumstances which they are intended to address arise, and what consequences should flow when such a situation does arise. It addresses these points primarily from the perspective of what the law could/should be at a conceptual level. This is deliberate, for two reasons:
 - a. Procedurally, the author is not Scottish-qualified so is not well-equipped to interrogate the minutiae of current provisions within Scottish law.
 - b. Substantively, within the context of both the remit of the Working Group and the wider work being done by the Scott Review, it seems appropriate to focus on normative rather than descriptive questions.
2. The primary focus of this document is upon unilateral instruments – i.e. those documents prepared by the person in question and seeking in some way to provide the framework for what should happen to them at a point when (for whatever reason) they are unable to participate in the decision-making¹ process at that point. The document could include categorical statements (e.g. refusals of specific interventions, or requests for the involvement of specific individuals in decision-making) or statements of wishes or values (i.e. focused less on specific decisions but the way in which the individual would like decisions to be taken). It could also include statements about how the person would wish their legal position to be characterised. For instance, a person could purport to give advance consent to admission to a facility where care and treatment is to be provided such that, as at the point of admission, they are to be treated as consenting to it even if they are not presently able to do so – such might well then track through to whether they are to be regarded as deprived of their liberty. It may well be that the same considerations apply also to documents whereby the person seeks to give authority to another to stand in their shoes, but this is not the primary focus of this paper.
3. The paper looks at three key stages:
 - a. Creation of the document;
 - b. The period between the creation of the document and the point at which the intended circumstances arise;
 - c. The point at which the intended circumstances arise.
4. The paper does not purport to provide solutions at each stage, but rather to frame the dilemmas to aid discussion. In similar vein, it draws upon case studies from England & Wales, not to purport to dictate similarities of approach, but to flesh out dilemmas that have arisen to stimulate consideration.

¹ For clarity: the use of the term 'decision-making' here is intended to encapsulate decision-making on behalf of the person, if that is relevant, as well as decision-making by whoever it is (whether that be professional, informal carer, or family member) who has to act.

5. Finally, by way of preliminary, it should be emphasised that the views set out here are personal (save where they are quoting views expressed by bodies or organisation). They are not intended to be reflective of the views of any other members of the Working Group, but rather to inform consideration by the Working Group of the issues under discussion.

Creation

6. At the creation stage, it seems to me that there is a fundamental tension between formality and accessibility. The more formal the document,² the more likely it is that it will not be subject to challenge at a later date – above at all at the point when the creator will have wanted the document to take effect.
7. Conversely, the more formal the document, the less accessible advance planning documents risk becoming. There are (at least) two aspects to this: (1) cost; and (2) access (if relevant) to a person able to certify relevant matters such as the capacity of the person to create the document. These risks can be mitigated (as in the case of advance statements under the MHA 2003) advance plans are, in effect, integrated into care planning undertaken by statutory authorities. However, this is not a panacea because: (1) it does not mean that the exercise is cost-free – the cost is simply shifted from the individual to the organisation and (2) it is not obvious that every person who might want to make an advance plan about aspects of their care and treatment will be in contact with statutory authorities.
8. For present purposes, I would also highlight a particular issue in relation to ‘authentication’ in relation to the capacity of the person to make the plan. This question will arise no matter (1) whether ‘capacity’ is a relevant criterion for the plan to enter into force; and (2) what the components of that capacity are considered to be.
9. Depending upon one’s perspective, authentication is either a sensible insurance policy, or an unnecessary – and potentially discriminatory – departure from the presumption of capacity. This issue has caused considerable dissension in the context of the proposed introduction of ‘advance choice documents’ (‘ACDs’) into the Mental Health Act 1983 in England & Wales, which further crystallises another issue: the significance of the weight to be placed upon formality is directly linked to the consequences which flow from the making of such a document. See in this regard this extract from the White Paper consulting upon the proposals advanced by the Mental Health Act Review:³

Under the reformed Act, decisions made by people when they have the relevant capacity to make them will have a real power and influence over decisions and appeals regarding care and treatment. Any statements of preference in an advance choice document will, in most cases, be considered as equivalent to those made in real time by a patient with the relevant capacity.

To remove the potential for doubt later as to whether the person had capacity to make the choices contained in an advance choice document, the review recommended that service users should seek to have their documents authenticated by a health professional. As part of this, the health professional would ensure that the patient understands the foreseeable consequences of

² An advance plan can, of course, be made other than in a document – by way of example, the Mental Capacity Act 2005 provides that an advance decision to refuse treatment (other than life-sustaining treatment) can be made orally. In my experience, the problems of identifying whether, when and how one was made are so significant that decision-making in the context of an asserted oral decision collapses almost inevitably into a ‘presentist’ analysis of the correct course of action.

³ https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/1002885/reforming-mental-health-act-consultation-response-print-ready.pdf at page 38.

an advance choice document, including the potential risks of refusing treatment; the circumstances in which treatment refusals can be overridden; and in what circumstance wishes and preferences may not be followed, for example if preferred treatments are not available or clinically appropriate.

While we agree an authentication process would be beneficial in ensuring that the patient is fully informed of the decisions they are making and in giving the responsible clinician confidence in the document's contents, we do not think that formal authentication should be necessary for the advance choice document to be valid. Instead, we think that for an advance choice document to be valid and have legal effect, it must have been made by someone who had the relevant capacity and apply to the treatment in question. This is the same approach as under the MCA. Authentication would be one way that an individual could seek to ensure that there is no doubt later about whether the statements were made with capacity. Otherwise, it would be for those concerned with the patient's care and treatment to consider whether the statements were made with capacity, at the point when decisions need to be made.

10. The Westminster Government consulted upon the proposal simply to align ACDs under the MHA 1983 with those under the Mental Capacity Act 2005 (where there is no authentication required). There were 1,278 responses to the question in the consultation: overall, 69% of responses agreed/strongly agreed with the proposal; while 10% disagreed/strongly disagreed and 21% were not sure.⁴ Of relevance for present purposes are perhaps the contrasting positions of the Equality and Human Rights Commission and the National Survivors User Network:
 - a. The EHRC “recommend[ed] a requirement for advance choice documents to be authenticated by a health or social care professional to help ensure the patient understands their choices and the implications, and to prevent any disputes about whether the patient had the relevant capacity and information at the time they made the decision.”
 - b. NSUN, by contrast “are concerned that the proposals in the White Paper may lead to a two-tier system, where those judged to have capacity and who have benefited from extended support and care will enjoy a significantly different level of autonomy to those who have not had such prior support.”
11. The practical consequences of the absence of a requirement to include any ‘authentication’ in relation to advance decisions to refuse treatment in the Mental Capacity Act 2005 in England & Wales can be seen in the *E* case.⁵ That case merits reading to test one’s reactions: did the judge’s overriding of the advance decision on the basis that he could not be satisfied that it had been made with capacity serve or harm *E*’s interests?
12. It also perhaps worth highlighting for completeness that the same issues as regards ‘authenticating’ in respect of capacity will arise in respect of authenticating or otherwise confirming that the document is the product of the person’s own free will.
13. The Working Group may feel that different issues arise in respect of advance planning documents made those in the mental health ‘zone’ to those in the physical health ‘zone’ – but an immediate challenge in this regard is as to the basis upon which any differential approach can be justified, so as not to amount to discrimination.

⁴ [Reforming the Mental Health Act: government response \(print ready\) \(publishing.service.gov.uk\)](#) at pages 35 and 36.

⁵ *Re E (Medical treatment: Anorexia)* [2012] EWCOP 1639.

The period between creation and the intended circumstances arising

14. It seems to me that two key issues arise at this stage: (1) recording of the fact of creation; and (2) the potential for time to elapse before the document is created and the intended circumstances arising.
15. A critical and immediate practical problem in relation to the creation of an advance document is whether (and if so, how) they should be stored in relevant records – whether medical, care or otherwise. The problems in this regard in relation to advance decisions to refuse treatment in Wales are vividly described in a 2016 report.⁶ Again, however, the greater the requirement for recording, the higher the potential burdens to accessibility. It is also always necessary to have a backstop in relation to any legal provision to cater for the situation where a person has made an advance planning document but it is not (for whatever reason) made its way into the relevant records.
16. As to the second issue, the concept of advance decision-making has (in different forms) been around for many years, and it is now possible to start to see the potential problems caused in relation to ‘old’ documents. A case study is *Re PW*⁷ concerning a 20 year old advance decision to refuse treatment, apparently not revisited in the intervening years (and also not brought to the attention of the attorneys appointed by the woman in question to make decisions about her health and welfare). Under the relevant provisions of the MCA 2005, the age of the document did not, per se, affect its validity or applicability, but clearly weighed heavily in the mind of the judge: was he right to be concerned?
17. It should be noted that (1) the more successful policies of supporting advance planning are; and (2) the more that the law relating to decision-making at the point where the person is unable to participate is predicated upon taking those documents into account, the more likely that, over time, there will be documents in existence which may have been around for some considerable period before they are relevant.
18. A similar, although perhaps less acute, dilemma arises in relation to the gap between the document being created and the intended circumstances arising to that which arises in relation to that at creation. The greater the degree of formality imposed (for instance, formal time-limits to validity or formal requirements for review) the more inaccessible they become. Conversely, the greater the degree of informality, the greater the risk that those charged with deciding/acting at the relevant point will be troubled as to whether they should do so. And, arguably, the greater the argument that they should be so troubled because the more there is a prospect that the document no longer reflects the person’s actual wishes.

The consequence when the intended circumstances arise

19. It seems to me that two key questions arise at this point:
 - a. Whether the intended circumstances can or should be entirely ‘self-directed’?
 - b. Whether and under what circumstances it is legitimate not to follow a choice intended by the person to be a categorical one.
20. In respect of the first question, the traditional approach to advance planning has been contingent upon such documents taking effect at the point where the person does not have the capacity (however defined) to participate in decision-making. That determination is

⁶ ppiwi.org.uk/files/2016/02/PPIW-Report-Increasing-the-awareness-and-uptake-of-Advance-Decisions.pdf

⁷ *Re PW (Jehovah’s Witness: Validity of Advance Decision)* [2021] EWCOP 52.

not made by the person themselves, but by those who need to take action.⁸ The CRPD (or, more precisely, the Committee on the Rights of Persons with Disabilities) have thrown this into doubt, General Comment 1 to Article 12 providing that:

*The point at which an advance directive enters into force (and ceases to have effect) should be decided by the person and included in the text of the directive; it should not be based on an assessment that the person lacks mental capacity.*⁹

21. The Working Group will no doubt wish to consider this, but for present purposes, suffice it to say that such an approach to advance planning – taken to its logical extremes – is fundamentally incompatible with the governing legal frameworks for health and social care within the United Kingdom. These are based upon a binary distinction between a person whose current actions or decisions are taken as having legal effect, and a person whose current actions or decisions are not taken as having such effect.
22. The question of whether the Working Group **must** follow this interpretation of Article 12 CRPD is beyond the scope of the discussion paper and is, frankly, unlikely to be productive. More interesting and important is the question of whether the Working Group **should** follow the interpretation – which is also linked to (1) a rejection of the validity of the conception of mental capacity as it applies in the United Kingdom; and (2) an approach predicated upon all interventions being based upon informed consent. In its favour might be thought to be the following:
 - a. It enables, in essence, unlimited self-direction as to the circumstances under which the advance planning document is intended to be effective. It could, therefore, include provisions for it to take effect at a point **prior** to the point that others might identify the person as having lost decision-making capacity. This could be particularly important for a person with a cyclic condition such as bipolar disorder, who may recognise the signs of an impending crisis in advance of those who do not know them, and have very clear views as to what the most appropriate course of action to take at that point might be. These views could include nudging, persuading, or even compelling them to do something that, at that point in time, they are rejecting;¹⁰
 - b. The three elements of the Committee’s approach set out above appear to provide a clear answer to the dilemma of what to do where the person’s past wishes (as recorded in an advance planning document) clash with the current manifestation of those wishes and feelings. Unless it is clear (according to whatever evidential standard is adopted) that the person’s will as recorded in their advance planning document is that any current preferences contradictory to that will are to be ignored,¹¹ all those concerned should proceed on the basis of the person’s current desires.

⁸ Albeit it can be informed by statements made by the person in advance to help guide the process of assessment: see in this regard the “PACT” advance planning documentation prepared as part of the Mental Health and Justice Project, which includes a section where the service user can set out signs that they may have lost capacity to make decisions about mental health treatment: see the template in the appendix to Stephenson, L. A., Gergel, T., Ruck Keene, A, Rifkin, L., & Owen, G. (2020). The PACT advance decision-making template: preparing for Mental Health Act reforms with co-production, focus groups and consultation. *International journal of law and psychiatry*, 71, 101563.

⁹ General Comment 1, paragraph 17.

¹⁰ For an argument in favour of this approach, see Gergel, T., & Owen, G. S. (2015). Fluctuating capacity and advance decision-making in bipolar affective disorder—self-binding directives and self-determination. *International Journal of Law and Psychiatry*, 40, 92-101.

¹¹ I.e. the situation provided for in the sub-paragraph above.

23. Against this interpretation might be thought to be the following (over and above the incompatibility with current legal frameworks if these are to play for):

- a. Making 'entry' and 'exit' solely contingent on the person's own decision raises the prospect of the person being held to a document which does not, in fact, represent their will at that the time that action is required. This could have consequences which – at the limits – are fatal for the person concerned. It would also have consequences which are likely to give rise, at a minimum, to moral distress on the part of those who might be required to act upon the basis of that advance planning document;
- b. If the sub-paragraph above sets about suggests an extreme which may appear unpalatable, it is also important to note that, more broadly, the Committee's approach otherwise pushes to an extreme which feels equally unpalatable. With the exception of the scope for self-binding set out above, the heavy skewing of the Committee's approach towards the present position makes it much more difficult for those with degenerative conditions who hold to the importance of precedent autonomy to secure the essential interests which form the basis of that approach. Unless in every case they make expressly clear whether and under what circumstances their wishes and feelings were not to be determinative something which, decision-making would **always** proceed on the basis of those current wishes and feelings. Whilst it may be (relatively) easy for a person with a cyclical condition to have a sense of how they present when they self-identify as 'not being themselves,' it is very much less easy for someone with a degenerative condition to project forwards to be able to predict precisely what they may do or say when their condition advances to the point that they might wish their advance planning document to take effect. Adopting the Committee's approach without further consideration of the potential impact upon such individuals would not easily sit with the 'nothing about without us' approach central to the Convention;
- c. At a purely practical level, and without being unduly pessimistic, it is not unlikely that having entirely self-directed documents will generate uncertainty on the part of those who might need to take action (often rapid action) to secure what they consider to be the interests of the person as to the weight that they are to place upon the document. Further complications also potentially arise in respect of self-directed documents which move beyond statements of what the person would **not** want to statements of what the person **would** want. To take the example of an attempt to 'self-bind' to bring about admission to a facility in advance of a severe mental health crisis: assuming the reality that the places in such a facility are not unlimited, how are those charged with decision-making in relation to admission to weigh the demand of that person as against the position of the person who is **currently** in crisis?

24. The discussion above feeds into consideration of the second question – i.e. when what circumstances it is legitimate not to follow a choice intended by the person to be a categorical one. The Committee appears to give a clear answer to this question: i.e. only under circumstances when the person themselves has made clear that there is a 'let-out.' If this – very strong – approach does not appeal, then consideration will be needed as to the correct 'objective' test to apply. As noted above, the setting of this test will then have upstream effects in relation – above all – to the importance of formalities at the entrance point. In other words, the more limited the scope for those **currently** considering the person's position to proceed on a different basis to that set out in the advance planning document, the more important it is that that document can provide a secure basis – both legal and ethical – for them to do so. The concept of advance consent to confinement provides an example of the dilemma given that such will feed into the characterisation of

whether the person is **at that point** to be considered to be deprived of their liberty, and thereby attracting the procedural safeguards required by Article 5 ECHR.¹² Concerns as to the prospect of such individuals – in effect – opting out of those protections and remaining opted out of those protections on the basis of documents generated in advance of admission led the Independent Review of the Mental Health Act 1983 in England & Wales to a (rare) point where consensus could not be reached.¹³

25. In relation to medical treatment, it may be of interest to the working group to know that the 'let out' identified by the Court of Protection in *PW's* case (in which the judge was statutorily permitted¹⁴ to take into account views expressed by *PW* after the point she was said to have lost capacity to make medical treatment decisions) will not be possible in the Republic of Ireland when its Assisted Decision-Making (Capacity) Act 2015 comes into force. That Act enshrines a much harder-edged approach to precedent autonomy than does the MCA 2005 in England & Wales, expressly providing that the equivalent to the relevant statutory provision only applies to "clearly inconsistent" actions done at a point when the person had capacity to do so.¹⁵
26. It may be thought that this issue is – ultimately – one where attempts by the law to prescribe outcomes are both practically doomed and ethically unattractive. If so, then the true focus should be upon:
- a. the processes by which decisions/actions in any given situation are approached;
 - b. the circumstances under which it is considered appropriate for dilemmas are to be resolved informally; and
 - c. the circumstances under which formal resolution is required – including by whom.

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¹² A separate issue would arise in relation to Article 14 CRPD, which is arguably even starker if the Committee's approach to the Article is adopted. The Committee's approach suggests that consent forms the only basis upon which a disabled person could be admitted to circumstances of confinement. On the Committee's logic, it would therefore be possible to give binding consent to admission in circumstances of confinement and irrevocably commit oneself to the characterisation of that position as falling outside the definition of deprivation of liberty.

¹³ See

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/778897/Modernising_the_Mental_Health_Act_-_increasing_choice_reducing_compulsion.pdf at pages 81-83.

¹⁴ By s.25(2)(c), providing that an advance decision if the person has done anything else clearly inconsistent with the advance decision remaining his fixed decision ("else" being read in conjunction with s.25(2)(a), which talks of withdrawing the advance decision when the person has capacity; and (b), which talks of granting authority to an attorney to make the decision covered by the advance decision))

¹⁵ Section 85 (1)(b).