# Scottish Mental Health Law Review consultation (the Scott Review) – Questions for additional proposals

## Chapter 2: Advance statements

**General views**

1. **What are your views on the proposed system, any significant omissions and on other steps that might be taken to strengthen advance planning as part of the supported decision making framework in our wider proposals?**

- **Need to consider reasons for poor take-up of current Advance Statements** – Advance Statements (AS) have been possible under the Mental Health (Care and Treatment) (Scotland) Act 2003 since that Act came into force. As acknowledged in the consultation document, Advance Statements have been comparatively little used. Any reform or extension of Advance Statements must identify and address the issue of why this has been, lest any reformed system remains as poorly used by those it is supposed to benefit. There are a number of barriers to uptake of AS, all of which require different potential solutions. Some patients do not want to consider they may in future need compulsory care leading to reluctance to engage in care planning. Others may perceive the process as valueless, fearing that either their preferred interventions will not be available or that their wishes would be overruled in any case. Still others will be dissuaded by any difficulties and complexities in the process.

- **Fusion vs separate pieces of legislation –** At the time of writing it remains uncertain as to whether the Review will favour a 'fusion approach' or the retention of two main pieces of legislation. If fusion is favoured, then the fused law will need to provide for Advance Statements for both mental health conditions and physical health conditions. If this is the case then we would emphasise that mental health conditions can affect a person's judgment and actions in ways which are different from physical illnesses. This will need to be accounted for in the Advance Statements approach in any fused law. We believe that equality under the law requires laws which recognise and support the differing requirements of people to ensure the best possible health, respect, and human rights outcomes. In the case of separate legislation, consideration should also be given to adapting similar principles to the drawing up of an Advance Statement to allow for potential effects of a mental health condition on the choices made and the likely interventions specified. This would demonstrate real parity of esteem between physical and mental health care.

- **Effect on medical treatments provided to patients** – The implications of any Advance Statement on the medical treatment to be provided to the patient must be clearly thought through, particularly if the AS specifically requests or denies certain treatments. Our members, as clinicians, have obligations to deliver the right to health and to life through their interventions, and to prevent suffering. The proposed model must ensure clarity around any system which allows refusal of life-saving care.
- **Changing will and preferences** – Will and preferences can change over comparatively short periods, and a person may think differently about a real situation versus discussing it in the abstract. Any AS/SWAP taken at a time before a person presents in crisis, may well not reflect their will and preferences in that crisis. With this in mind the proposed system must have space for people to change their minds and to include additions or amendments to choices made previously.
- **Responsibility for fulfilment** – The AS or SWAP will potentially express aspirations about the type of care the person wishes. This raises the issue of who is responsible for providing all elements of that care and who is responsible if these wishes are not / cannot be fulfilled. This is especially important to consider where the care aspirations cover areas that will require multiple settings and bodies to be fulfilled. It will be important to be clear about what is deliverable in reality to ensure that there is not a gap between expectations and reality in AS/SWAPs. While there is a genuine aspiration towards better care for all persons accessing mental healthcare it would be inequitable to provide differentiation between the care provide to two patients based on whether an AS/SWAP had requested a particular provision or not.
- **Consent** – It is also felt there is a clear need to distinguish between a statement of will and preferences which would guide healthcare decisions once a person lacked the ability to consent and valid *current* consent. Members were generally uncomfortable with any notion of 'advanced consent', believing there were clinical, legal, and practical advantages to being clear as to whether treatment was with or without current consent, and maintaining clear legal and supervisory frameworks for the latter case.
- **Need for clarity on scope of SWAP requests for specific treatment –** We believe it would be helpful to clarify the scope of a SWAP with respect to requests for specific treatments. It should be explicit that a person could not articulate something in an advance statement that a capacitous person would not be able to demand.

**2. What do you think of the general approach to a 'statement of will and preference' (SWAP)?**

- **Will, rights and preferences –** We would urge the Review, as we did in our response to the wider consultation, to consider a statement of will, *rights* and preferences. This would ensure that the consideration of a patient's rights, including their fundamental right to health and to life, are incorporated into the considerations prompted by the SWAP. This would fit in with the human rights enablement framework for agencies providing care but should also be available to individuals. A *'What matters to you?'* approach to help inform decisions about balance of rights should be extended to all participants in the process.
- **Explicit consideration regarding balance of rights** – Further to the preceding point, we believe that it would be desirable for the statement of will, rights and preferences to consider the person's choices around balancing and prioritising rights as sometimes these can come into conflict in acute situations - for example, right to autonomy versus right to life.
- **Content of statements** – Consideration should be given to the form of 'standard' SWAP and to the advice given to those tasked with aiding individuals who are drawing them up. A generic and non-specific AS, particularly one which only specifies negative statements (e.g. 'I do not want any form of drug treatment') are more difficult to apply and utilise in real life scenarios.
- **Rights to appeal** – Where there are appeals in relation to the care specified under a statement of will and preferences not being delivered, it is essential that the body held accountable is that responsible for the provision of care, not an individual clinician or clinical team.

3. **What are your views on the application of the 'statement of will and preference' (SWAP) to treatment under Mental Health Law, other medical treatment and other welfare issues?**

- **Question of fusion** – As above, we struggled to respond to this question without a clarity in current proposals about fusion.
- **Provision** – Service provision needs to be in place to actually deliver on the range of will and preferences which may be expressed through a SWAP. This might include statutory duties on health or social care providers to deliver this and/or an acknowledgement of the limitations of provision. There may be instances where a treatment requested in a SWAP is not appropriate for the person's condition. A process to evaluate this would be necessary. It is also necessary to consider how SWAP may impact on resources which are limited. For example whether a person with a SWAP requesting a particular treatment

would be placed higher on a waiting list than a person with equal or greater needs who did not have it specified in a SWAP.

- **Need to consider views of families and carers** – A situation which might arise in actual clinical practice is one where the carer or family of the patient advocate, during an episode of illness, for an intervention refused by a patient in their AS/SWAP. Families and carers will advocate for optimal outcomes in those they provide care for as the best way of promoting their rights and preferences, and they will often acknowledge that those rights are best protected by a period of compulsory care. Families and carers might be opposed to not intervening if someone lacked decision making capacity when it could secure their health and potentially their recovery, even if in line with a previously made AS/SWAP.
- **Changing will and preferences** – A person's expressed will and preferences will change with time and experience and there is often a difference between someone 'predicting' what they want in care versus when they are in the actual situation. The model used must be able to flexibly take account of changing will and preferences.
- **Least restrictive practice** – We could foresee a challenging situation if a patient's AS/SWAP declined a particular intervention which then led to individuals still deemed a risk to themselves and/or others being detained against their will, when providing medical intervention could avoid such a measure. This could potentially lead to a situation against medical ethics and the principle of least restrictive practice.

4. **What do you think of the possibility that a SWAP could give advance consent for something the person might refuse when they are unwell?**

- **Significant concerns** – This proposal was universally felt to be problematic and raise significant concerns. As stated above, members were generally uncomfortable with any notion of 'advanced consent', believing there were clinical, legal, and practical advantages to being clear as to whether treatment was *with* or *without* current valid consent, and maintaining clear legal and supervisory frameworks for the latter case. Members felt that any form of 'advance consent' was not workable – there were a number of further specific concerns, but these should be read in the context of overall lack of support of the idea in principle.
- **Not responding to individual situations** – the idea of seeking consent in advance to a hypothetical situation, mechanically delivering their will and preferences, and ignoring the clinical presentations or changing will and preferences would be unacceptable for our members

- **Need to preserve clarity around non-consensual interventions** – In providing care for someone with impaired decision making or incapacity, mental health care and treatment is fundamentally non-consensual, regardless of whether the person 'consented' prior to that situation. Rights and safeguards still need to be in place. If a statement of will and preferences was considered advance consent then the person's rights may not receive appropriate scrutiny.

**SWAP process**

5. **What are your thoughts on the process for making a SWAP and the requirements for its validity?**

- **Initial engagement** – Most people considering an AS/SWAP will have been engaged in some way previously by mental health services, but those in contact for the first time need explicit consideration in how these statements are explained and the potential benefits of having them. Efforts to establish will and preferences at initial presentation should be built in.
- **Preferences versus fundamentals** – The need to distinguish between preferences of care rather than fundamentals which would inhibit potentially life-saving treatment is key. For example, asking that medication not be taken orally is different to someone asking that they be given no medication. It also needs to be clear that the person understood the implications of their choices when making the advance statement, for example excluding a particular medication may mean that their condition would be prolonged or not improve.
- **Meeting a person's needs** – There is a need to ensure that the timing of when a SWAP is developed and renewed is tailored to a person's needs. With that in mind, it is questionable whether an arbitrary timescale for updating these would be helpful. It should be applicable to the person, their condition and the individual circumstances. This could be rarely, if at all, for some, and very frequently for other.
- **Relationship to other methods of decision-making for persons who cannot consent** – Consideration should be given to the relationship between a SWAP and the views of, for example, a POA holder who can contribute to decision-making in real time and in the current context. Any previous choice of POA is a powerful statement of will and preference.
- **Need to ensure processes do not delay urgent care** – There are situations when people who cannot consent experience a deterioration in their health and capacity and need emergency and potentially lifesaving interventions.

Attempting a SWAP process should not inhibit or delay access to that care. Beyond this, there are a group of patients so acutely unwell who cannot consent, such as those in whom ECT is potentially life-saving, need to be borne in mind in the delivery of a SWAP. Emergency care should not be inhibited by any arbitrary processes.

- **Bureaucracy and safeguards** – Reducing bureaucracy in the process while maintaining safeguards is the critical balance. Getting this balance right is critical to enabling uptake of a process and production of a document that is meaningful to a person's care. This balance also needs to be considered in relation to any appeals process to ensure it is streamlined and efficient.
- **Change of will and preferences based on circumstance** – We would reiterate our urging of the Review to be mindful that a person who has capacity and gives consent in real time can change their mind. An AS/SWAP cannot be changed once a person has lost capacity which might lead to situations where it was increasingly inappropriate to current needs. There should in guidance be clear prompts for review, indications on recommended frequency and the appropriateness of when to engage a review.

**6. When can a SWAP not be followed and when can it be overruled?**

**7. What do you think of the proposals as to who can decide if a SWAP should not be followed?**

- **Application and process clarity required** – The development and refinement of ideas in this area requires further clarity around the detail of the proposed process. For example – when a SWAP may be activated – through commencement of compulsory measures? – or failing autonomous decision making test?
- **Checks and balances** – In delivering an overruling process, we need fundamental checks and balances that are not bureaucratic or unduly complex at the point of delivering care to the benefit of the patient. These checks must be clearly justified on the provision of person-centred care.
- **Authority to act** – The ongoing availability of an authority to not follow an advance statement is vital. This is critical in being able to deliver rights-based care in situations where there is a balance of conflicting rights, for example the right to life, or where there is a lack of clarity, or circumstances have changed in a way that would not have been anticipated at the time of the advance statement being made.

- **Who can decide on overruling** – We recommend that the decision to override in an emergency situation should be taken by the practitioner overseeing the proposed treatment or intervention. Clarity is also needed on range of staff who can override, as it is not only doctors out of hours who may need to do this but social workers regarding social care.

8. **S243 of the Mental Health (Scotland) Act 2003 allows for treatment to be given to prevent serious deterioration in a patient's condition. We have not included this as it may prove too broad a justification for many psychiatric treatments which a patient might reasonably refuse. What are your views on this?**

- **Value and wisdom of current protections** – S243 currently provides guidance for the range of situations in which emergency treatment might be legitimately given, balancing protections against non-consensual intervention with rights to receive intervention to prevent suffering, serious harm, and deterioration. We believe the current S243 strikes the right balance and would support the inclusion of all its justifications for intervention in the new AS/SWAP proposals. The notion that preventable and (crucially) *predictable* harm could occur while waiting for a 'serious deterioration' would go against clinical duties to prevent such suffering, and would move us towards a system of care that potentially allows harm to occur. This also goes against a system of care that is anticipatory and enables the best chance of recovery.
- **Potential lack of parity and inequality** – A person without capacity should by default receive the same treatment that would afford the best possible chance of a good outcome to someone who had capacity and consented. If the provisions for prevention of serious deterioration were removed then patients who were not able to discuss their treatment would be disadvantaged. Additionally, in physical healthcare, emergency treatment is given to prevent serious deterioration either under common law or AWIA depending on the urgency of the situation. To change such provision for the treatment of mental health care represents a potential lack of parity.

**We would like to know your views on the overruling process proposed and if there are any others you think might be authorised to review certain decisions.**

- **Purpose of providing essential care** – Essential and effective care needs to be delivered timeously. Decisions about care in situations where there are high risks frequently need to be taken on an urgent basis. The proposals for the overruling process may result in an unwieldy bureaucratic system which impedes the patient receiving justifiable emergency care and treatment

designed to save lives or minimise suffering. The overruling process needs to be sufficiently responsive to manage urgent situations whilst maintaining safeguards.

- **Workforce implications** – In order to ensure effective implementation and oversight, the workforce requirements for the delivery of these proposals - including monitoring by the Mental Welfare Commission - need to be evaluated and sufficiently resourced.

**What do you think about the proposals for dealing with conflict?**

- **Meeting rights** – In meeting a person's needs, we need to continue to enable the right specialist clinical interventions as part of a complete package of measures to meet a person's rights, will and preferences. It is important in considering the resolution of conflicts to consider intent and to recognise that there may be a balance of rights.