Response ID ANON-KENE-NFSV-Z

Submitted to Scottish Mental Health Law Review - Additional Proposals
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Advance Statements

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?

Please give us your views on the proposed system:

This response is from the Scottish Partnership for Palliative Care www.palliativecarescotland.org.uk . Unfortunately we only became aware of the consultation belatedly, and time constraints have impacted what we have been able to do in terms of engagement with our members and the depth of our response. We would be very keen to continue to engage with any subsequent processes to develop a new framework. This response focusses on issues relating primarily to end of life care.

SUMMARY OF KEY POINTS

We welcome a move to reform the law so that it contains legislative provision for advance directives in Scotland, and this should not be left to common law as is currently the case. The revision should also include clarification of what constitutes a legally binding advance directive.

We would like to see greater clarity and more detail about how the proposed SWAP model would build on existing mechanisms and approaches for planning ahead and advance decisions towards the end of life. There are currently multiple Anticipatory Care Planning models and the ReSPECT process which creates personalised recommendations for a person's clinical care and treatment in a future emergency in which they are unable to make or express choices. There is potential for creating greater complexity and confusion (professional and public) which is already a major barrier to better outcomes.

We have some concerns about proposed legal underpinning for preferences for treatment sitting alongside decisions to refuse treatments. Having one model which conflates implied legal weight for requests/preferences for treatment with the legal right to refuse treatments will create pressure on clinicians to provide treatment which is not clinically appropriate. There is an existing problem with public belief there is a legal right to CPR even in circumstances where there is no clinical benefit. The proposed reform risks widening this problem to other treatments.

Consideration should be given to the adoption of common terminology across the UK to refer to such directions (currently termed Advance Decisions to Refuse Treatment under the Mental Capacity Act 2005 in England). The uptake and awareness of advance planning is greatly reduced by a multiplicity of methods and template and a lack of robust access and communication. This proposal is an opportunity to address this issue and secure a legislative underpinning for advance refusal of treatment within Scotland.

Thought should be given to how the proposal might operate in the eventuality that assisted suicide is legalised in Scotland. It should not become possible for a SWAP to be used refuse intervention in advance for a future suicide attempt - wording around excluding life-sustaining treatments in such circumstances should be strengthened.

There is a need to ensure that the law relating to incapacity is fit for purpose when people have delirium towards the end of life.

1a 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?

Please give us your views:

We agree that any such statement should apply across all of these health and care domains. We support your statements in the introduction to the consultation that any change in the law will not deliver the desired outcomes unless education, training and awareness work to support implementation is adequately resourced.

1b What do you think of the general approach to a 'statement of will and preference' (SWAP)?

Please give us your views:

We the principal that 'there should be consistency between advance decision making in relation to treatment for mental disorder and other medical decisions'. However, we have some concerns about the introduction of yet another new model. Another acronym will not solve the misunderstanding and the lack of accessibility of information and will, if anything, worsen the problem. The SWAP model proposed is, in effect, an anticipatory care plan and as such that model is very well established and yet poorly used in Scotland's health and social care system. ACP should and already does include the ability to document wishes and preferences around care and treatment for those with a mental health disorder. We would like to see proposals which building on and strengthen what is already established and calling for national consistency of approach in ACP process rather than calling for an entirely new model.

1c What do you think of the possibility that a SWAP could give advance consent for something the person might refuse when they are unwell?

Please give us your views:

We have some concerns about proposed legal underpinning for preferences for treatment sitting alongside decisions to refuse treatments. Having one model which conflates implied legal weight for requests/preferences for treatment with the legal right to refuse treatments will create pressure on clinicians to provide treatment which is not clinically appropriate. There is an existing problem with public belief there is a legal right to CPR even in circumstances where there is no clinical benefit. The proposed reform risks widening this problem to other treatments.

1d What are your thoughts on the process for making a SWAP and the requirements for its validity?

Please share your views:

This is very similar to the process for establishing an advance directive in Scotland and we would question the need for a separate process for those with a mental health disorder. The current proposal does not add clarity to the legal power of advance decision-making. It is essential that decisions which must be respected in law are clearly defined and this proposal does not request this. Consent to treatment and refusal of consent to treatment are the legal rights which are removed from the adults who lack capacity. What is missing in Scotland is the ability of adults to clearly state in advance what treatment they would wish to refuse and what treatments they would not wish to refuse if offered and to know that these decisions will be robustly communicated and respected when it matters for them. The proposed process need to make clear what is the legal request and what adds weight to clinical and social care decision-making but is not legally binding.
This proposal also mentions using the SWAP to communicate advance decisions regarding emergency care but does not mention the existing systems in Scotland for doing that. Currently the Key Information Summary communicates such information where it exists across all emergency Health care services. Very soon the digital realisation of the ReSPECT process (Recommended Summary Plan for Emergency Care and Treatment) will provide the ability for this information to be communicated across all health and social care settings and with patient access and role based read and write access via the National Digital Platform. It is essential that any proposals for advance decision-making for emergency care relating to individuals with mental health disorders align with the existing national work which is progressing. The ReSPECT digital process could give robust and immediate access to any digitally held ACP or SWAP data set in an emergency situation

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

Please share your thoughts on the proposals as to who can decide if a SWAP should not be followed?:

These are reasonable and in line with current capacity legislation and thinking around person-centred care and shared decision-making. We would emphasise the importance of awareness and education for those health and care staff who may come across this process infrequently. Current awareness of the AWIS process is very poor. Any new model would need significant profile and clarity of process guidance for staff outwith mental health care.

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?:

This should continue to be separately addressed but the guidance needs to be strengthened. Advance decisions to refuse treatment which have to be respected in law need to be clearly defined and underpinned by relevant legislation.
Any proposal needs careful consideration of the likelihood of legislation for assisted suicide to be embedded within healthcare and therefore to become a new duty of care for healthcare professionals. Current proposals to restrict this to those with terminal illness may well evolve (as has happened in in Canada for example) and opened up to those with Mental Health disorders. It is therefore crucial that any new proposal and request to review legislation around advance decisions to refuse or state preferences for treatment and care is cognisant of the future implications of wording and terminology as the implications for clinical practice are enormous.

3 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.

Please share your views on the overruling process proposed and if there are any others you think might be authorised to review certain decisions.:

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

Please share your thoughts about the proposals for dealing with conflict:

5. Do you have additional proposals for change?

Please let us know of any other changes you think are needed.:

There is a need to ensure that the law relating to incapacity is fit for purpose when people have delirium towards the end of life.

The Scottish Palliative Care Guidelines define delirium as:

"disturbed consciousness and inattention with cognitive impairment; acute onset and fluctuating course as a physiological consequence of disease or treatment."

Other terms used to describe delirium include acute confusional state, agitation, and terminal restlessness, but the terms terminal restlessness and terminal agitation should be used only once reversibility has been excluded.

Around 57,000 people die each year in Scotland, of these around 46,000 will do so following a period of poor and deteriorating health. Delirium presents in around 30% of palliative care inpatient admissions and as the very end of life approaches this increases to around 80-90%. Very large numbers of

people will therefore experience delirium and consequent incapacity in the context of end of life.

Delirium is often reversible and people with delirium in palliative care can rapidly move from normal cognition to incapacity and back to normal cognition within hours, days and weeks. Delirium can therefore create potential for uncertainty for families and carers. Delirium also creates challenges and uncertainty for healthcare professionals - the Adults with Incapacity Act is currently insufficiently clear as to how clinicians are required to manage loss of capacity in the context of fluctuating delirium and in respect of loss of capacity and delirium at the very end of life.

Currently, practice in palliative care is inconsistent across Scotland in relation to implementation of the Adults with Incapacity (Scotland) Act 2000 for patients with delirium. In some areas of Scotland, clinicians are in receipt of legal advice which recommends the use of a Certificate of Incapacity under Section 47 of the Act (section 47 forms) for everyone who loses capacity in the last days of life. The advice states that without this in place, healthcare practitioners are not legally allowed to treat the patient under the Act. However, in other areas in Scotland this is not standard practice and loss of capacity is seen as a normal part of the dying process.

We believe that the law should be reformed so that the requirements and responsibilities of clinicians are clear when they are managing situations involving incapacity due to delirium, whether that is fluctuating delirium or delirium experienced at the end of life.

We believe that any reform to the law, whilst continuing to protect the human rights of individuals, should not require processes which may cause distress for families or detract in any way from care processes at the end of life. There is a risk of a proper clinical assessment being delayed if medication can't be given to manage severe agitation associated with delirium. Timely symptom control in context of dying is essential. The risk of having to wait before treating distressing symptoms in context of providing end of life care needs to be balanced within safe-guarding capacity and autonomy.

If a time consuming process was required then may be a need to think about having to routinely seek pre-emptive permission from patients as a standard practice.

About you

What is your name?

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Are you responding as an individual or an organisation?

Organisation

What is your organisation?

Organisation:
Scottish Partnerhip for Palliative Care

The Scottish Mental Health Law Review would like your permission to publish your consultation response. Please indicate your publishing preference:

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Your response will only be viewed by members of the Scottish Mental Health Law Review. They may wish to contact you again in the future, but we require your permission to do so. Are you content for the Scottish Mental Health Law Review to contact you again in relation to this consultation exercise?

Yes

I confirm that I have read the privacy policy and consent to the data I provide being used as set out in the policy.

I consent