



*Towards a Humane, Practical and Evidence-Based
Approach to Advance Care Planning*

Public Consultation on Advance Healthcare Directives

March 2014

Contents

Executive Summary	3
1. Introduction	6
2. Advance Care Planning	6
2.1. Current professional and ethical standards	6
2.2. Principles underpinning advance care planning	7
2.3. Key points from the research	8
2.4. Advantages of advance care planning	8
2.5. Future developments in advance care planning	9
3. Advance Healthcare Directives	10
3.1. The case for legally-binding advance healthcare directives	10
3.2. General concerns about legally binding advance healthcare directives	11
3.3. Conclusion	13
4. Specific Comments on the Draft Scheme	13
4.1. The exclusion of 'Best Interests' as a consideration for those who are incapacitated.	14
4.2. When doubts about validity or applicability of AHCD arise.	17
4.3. Definition of basic care	18
4.4. Code of Practice	18
5. Response to Consultation Questions	19
6. Conclusions	26
References	29

(See also amendments, issued in April 2014 at end of document)

Executive Summary

Advance care planning refers to a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient's condition with loss of capacity to make decisions and communicate these to others. This concept is a feature of good clinical care in Ireland, and is promoted by RCPI through its educational programmes. The advance plans of a person already carry significant ethical and moral force and respect for those plans is currently a professional and ethical requirement.

While accepting that legally-binding advance healthcare directives may be helpful in some specific cases, The Royal College of Physicians of Ireland has significant reservations about the *Draft General Scheme for Advance Healthcare Directives* as it is at present.

RCPI has concerns regarding legally binding advance healthcare directives refusing treatment as a general response to planning for end-of-life care.

Research indicates that this is an area of extreme complexity and that interpretation of advance healthcare directives is not straightforward. In particular, it will never be possible to legislate for - or to legislate away - the enormous complexity of individual decision-making as the end of life approaches, and there is a real risk that legally-binding directives may serve as an obstacle rather than a support to good end-of-life planning.

There are however some, generally limited situations where a legally binding health care directive may be helpful to people and to their doctors. An example of this where a person has a strong, specific preference or special reason to proscribe certain life-saving treatments or interventions even though those interventions would be medically-indicated and usually successful in the patient's situation. Safeguards, including time limits and automatic review, may be helpful in such situations.

The ethical and professional respect afforded to advance care plans as currently practiced, should continue, and an advance care plan that does not satisfy legal requirements but that does satisfy the ethical and professional requirements of the Medical Council and the HSE guidance should be respected.

Response to specific consultation questions on the Draft General Scheme for Advance Healthcare Directives in addition to general comments on the draft scheme are detailed in the main body of this document. In summary:

- The absence of reference to the principle of best interests, which has always been the ethical, professional and legal basis for making decisions for those who lack capacity, seems extremely unwise, unrealistic and is likely to lead to considerable practical problems and potentially worse care for those who lack capacity
- The development of an advance healthcare directive (AHCD) should require consultation with a healthcare professional with knowledge of the relevant medical condition of the person, and the legal and ethical issues that may arise. We accept the exception that AHCDs based on well-known religious principles are more likely to have involved appropriate consideration of the implications.
- Hard and fast rules for review of AHCDs may be difficult, but review of AHCDs may be appropriate under certain circumstances.
- It is difficult to say whether a standard format for an advance healthcare directive is appropriate. The directive should however contain certain minimum information.
- A healthcare professional is not legally obliged to provide a treatment not clinically indicated, and an advance healthcare directive should not be allowed to mandate provision of a specific intervention that is not clinically indicated.
- Taking on the role of a patient designated healthcare representative is a grave responsibility, and support is needed for the individual to assume that role. The *Do Not Attempt Resuscitation* (DNAR) section of the HSE National Consent Policy provides useful guidance.
- Legislation should provide safeguards for both health care professionals as well as for patients. For patients, safeguards include:
 - Voluntariness, i.e. that the presence of an AHCD does not become a pre-condition for access to services or for admission to certain health care settings.

- Limits to treatment that can be refused by patient designated healthcare representatives unless explicitly stated in the advance healthcare directive.
- Maximising decision-making abilities of those with possible incapacity.
- For health professionals, they should be protected from liability if they:
 - Stop or do not initiate treatment that they reasonably believe has been refused by a valid and applicable advance decision;
 - Provide treatment if they have taken reasonable steps to find out if an advance decision exists but are unable to satisfy themselves that there is a valid and applicable advance decision.

RCPI welcomes the development of a code of practice as stipulated, and is willing to be part of the development of such a code.

Additional analysis of the legislative provisions of the draft scheme as they affect the care of women in pregnancy is presented in a separate submission from the Institute for Obstetricians and Gynaecologists.

1. Introduction

In this submission, **advance care planning** is distinguished from legally binding **advance healthcare directives** refusing treatment.

The Royal College of Physicians of Ireland strongly supports the principle of **advance care planning**. This is a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient's condition with loss of capacity to make decisions and communicate these to others. RCPI notes that such planning is already a feature of good clinical care and integral to the ethical guidelines of the Irish Medical Council and the policy of the Health service Executive.

In contrast, while accepting that legally-binding advance healthcare directives may be helpful in some specific cases, The Royal College of Physicians of Ireland has significant reservations about the *Draft General Scheme for Advance Healthcare Directives* as it is at present.

2. Advance Care Planning

2.1. Current professional and ethical standards

The advance plans of a person already carry significant ethical and moral force and respect for those plans is currently a professional and ethical requirement. Both the Medical Council and the HSE explicitly endorse advance care planning in official documents. Thus whether or not there is legislation governing such plans is of little account in most cases.

For example, the Medical Council *Guide to Professional Conduct and Ethics for Registered Medical Practitioners* (2009)¹ states (41.2):

“An advance treatment plan has the same ethical status as a decision by a patient at the actual time of an illness and should be respected on condition that:

- *The decision was an informed choice, according to the principles of informed consent.*
- *The decision covers the situation that has arisen, and*
- *The patient has not changed their mind."*

Similarly, the HSE *National Consent Policy*² (Section 7.8) states:

"Sometimes service users may wish to plan for their medical treatment in the event of future incapacity, including advance refusal of medical treatment..... such an advance plan should be respected on condition that:

- *The decision was an informed choice, according to the principles discussed in sections 2-5;*
- *The decision specifically covers the situation that has arisen, and*
- *There is no evidence that the service user has changed their mind since the advance plan was made"*

The Royal College of Physicians of Ireland supports the principle of advance care planning: a process of discussion and reflection about goals, values and preferences for future treatment in the context of an anticipated deterioration in the patient's condition with loss of capacity to make decisions and communicate these to others. RCPI notes that such planning is already a feature of good clinical care and integral to the ethical guidelines of the Irish Medical Council. RCPI promotes this important component of healthcare through educational programmes, including a dedicated online course. Such advance care planning often occurs in the context of current care planning, given the fact that a significant proportion of people will be unable to speak for themselves during their dying process.

2.2. Principles underpinning advance care planning

The following principles meet the complex challenge of matching the general desire among both professionals and public for advance care planning as well as the complexity and reality of illness, due prognostic humility and flexibility in the face of altering attitudes and increased insight into the personal narrative of illness, and the evolving sciences of dementia and disability care.

- Advance care planning should be initiated at a point where the person has some experience and knowledge of the likely conditions.
- The plan should be developed with a healthcare professional who has in-depth knowledge of the relevant condition(s) as well as the necessary communication skills.
- The person's health condition should be maximised as far as possible, with particular attention to mood and cognitive problems, before discussion.
- There is respect for the preferences of the patient if they wish others to be involved in advance planning or to speak on their behalf when they can no longer speak for themselves.

2.3. Key points from the research

This approach is consistent with the following key points, which have emerged from the extensive body of research on the area:

- The experience of illness causes personal growth³ and brings about changes in attitudes. It is well established that people themselves, as well as their doctors and carers, are prone to underestimate the quality of life of their older, more disabled or cognitively impaired selves.
- Older people themselves accept the complexity and unpredictability of later life and often defer advance care planning to a time when the reality of illness and disability are salient⁴.
- Patients and healthcare professionals do not wish for a stark dichotomy between life-sustaining treatment and palliative care⁵.
- In general patients trust their doctors to do the right thing⁶.

2.4. Advantages of advance care planning

Advance care planning occurs in the context of a reasonably foreseeable decline in the person's condition, due usually to an illness which the person has experienced, and it involves open communication between clinicians and their patients. This approach has a number of advantages:

- The fact that the person has knowledge of and experience of the illness that has led to the discussion provides greater confidence that their choice will be an adequately informed choice.
- The fact that the plan is developed in discussion with a healthcare professional with knowledge of the person and of their condition(s) reduces the risk of poorly structured plans.
- It provides greater flexibility:
 - Many people do not necessarily want to couch their wishes in terms of refusing treatment but may wish to make a positive commitment to ensuring high quality care with a predominantly palliative approach is provided, when active medical treatment is unlikely to be effective.
 - Some people, acknowledging the uncertainties of making decisions for the future, prefer to describe their overall values or goals of treatment or to designate someone close to them to speak on their behalf when they can't speak for themselves.
- Advance care planning remains applicable in those situations where the issue of refusing treatment does not arise because no effective treatment is possible.
- Advance care planning also encompasses situations where the individual hasn't clearly expressed their own preferences but where health care professionals, following appropriate consultation with those close to the patient, formulate a plan for the future care of the patient in the event of a foreseeable further decline in their condition.

2.5. Future developments in advance care planning

Although there is much current good practice and advance care planning in Ireland about end-of-life care decisions^{7,8} the Royal College of Physicians of Ireland accepts and supports the need for further improvement. The HSE National Consent Policy, in particular the section on 'Do-Not-Attempt-Resuscitation', has recently provided greater clarity around the whole area of end of life decisions and discussions.

Continuing improvement of end-of-life planning will primarily occur through continued education of the public and of health care professionals as well as the welcome efforts of several groups actively engaged in research and development of initiatives in this area, rather than through changes to the law.

3. Advance Healthcare Directives

3.1. The case for legally-binding advance healthcare directives

A legally binding advance healthcare directive refusing treatment will be helpful to people and to their doctors in certain, generally limited, situations, namely; where a person has a strong, specific preferences or special reasons to proscribe certain life-saving treatments or interventions even though those interventions would be medically indicated and usually successful in the patient's situation.

In clinical practice, the classic example of such a situation is when a Jehovah's Witness wishes to make clear their advance refusal to accept blood and/or blood products even if such treatment were necessary for their life and health. It is indeed important that a legal mechanism should exist to ensure that, even if incapacitated, the wishes of some Jehovah's Witnesses for advance refusal of blood and/or blood products is respected. However, given that that choice may lead to an entirely preventable death, such as in women with treatable post-partum haemorrhage, it is also necessary that adequate safeguards exist to ensure that such a refusal is indeed a voluntary and informed choice. (This need is highlighted by different attitudes of some individual members, including pregnant women, to certain blood products and procedures^{9,10}).

3.2. General concerns about legally binding advance healthcare directives

The RCPI has concerns regarding legally binding advance healthcare directives refusing treatment as a general response to planning for end-of-life care. In particular, it will never be possible to legislate for - or to legislate away - the enormous complexity of individual decision-making as the end of life approaches, and there is a real risk that legally-binding directives may serve as an obstacle rather than a support to good end-of-life planning.

Legally-binding directives may serve as an obstacle rather than a support to good end-of-life planning.

- Many people are understandably nervous of anything involving the law or legal processes, and people (including health care professionals) may shy away from taking part in what may be seen as a dauntingly formal process involving a legal directive made in writing which under head 4, "*must be witnessed by two persons who have reached the age of 18 - one of whom must not be a member of the person's family and must not be entitled to any part of the person's estate.*"
- If legally-binding directives are interpreted as the only legitimate way in which valid advance planning can occur, there is a risk
 - that advance care planning which, as it discussed earlier, is a broader and more widely applicable approach than advance healthcare directives, will not be done; and
 - that the absence of a legally-binding directives may be misinterpreted as mandating treatment even when it is no longer clinically indicated or in the best interests of a person who lacks capacity.
- There is a risk that safeguards appropriate to advance directives may be misapplied to advance care planning. People can and do change their mind¹¹ and it is essential that there are safeguards, including time limits and automatic review, when people make advance healthcare directives for illnesses or conditions that they have not as yet experienced and may not experience for many years. Similar safeguards are unnecessary and might

be burdensome or impede appropriate decision making where proper advance care planning in the context of an existing illness is occurring, and the will and preferences of the person are unlikely to change within the more limited timeframe of the illness that they are experiencing.

Complexity of decision-making requires planning, not directives in most cases

The cases that generate the most public and legal discussion such as those of people in persistent vegetative states or Jehovah's Witnesses and blood transfusions are very dissimilar from those that occur in usual clinical practice. In the former, the decisions to be made are often simple, if stark (unless there is transfusion/ventilation/feeding, death will inevitably occur); in the latter, such as people with end-stage organ failure or dementia, the decisions are more complex and there is often uncertainty about whether interventions will be successful or even harmful.

This complexity requires careful discussion and consideration. It is often appropriate, and almost always acceptable to patients, to leave some latitude depending on the circumstances that may pertain at the time of a crisis. An example is that of attempting cardiopulmonary resuscitation. Success rates are always higher for witnessed cardiac arrests where a speedy response leads to the finding of a treatable rhythm disturbance and lower for unwitnessed arrests with absence of any cardiac trace. Some people will opt to accept attempted resuscitation when the chances of survival are relatively high but prefer to forego attempted resuscitation (and to be regarded as having died peacefully in their sleep) if found during the night by nurses after an unwitnessed arrest morning during the night.

The experience with advance directives shows their limitations

The experience with advance directives or 'living wills' especially in the United States shows several limitations for this approach¹²,

- Despite legal, medical and institutional support for the concept, only 18% of the population have advance directives.

- People often find it hard to articulate what they want and because clinicians and those close to the person often find directives hard to read and interpret, it is debatable how often they influence care in practice.
- There is a substantial literature which views current formulations of legally binding advance directives as problematic including frequent descriptions in the literature of problems which arise when poorly structured advance directives are patently in conflict with what previous standards of decision-making would regard as the patient's best interests.
- In large US studies most patients preferred to leave final resuscitation decisions to their family and physician instead of having their own preferences expressly followed (70.8% in HELP and 78.0% in SUPPORT) Thus, even in the US, most people do not seek a rigid legal straitjacket for those caring for them in uncertain situations: uncertainty is the norm not the exception, and some degree of flexibility is essential.

3.3. Conclusion

A provision for legally-binding directives should not explicitly or by implication limit or interfere with advance care planning as it is currently practiced. In other words, an advance care plan that does not satisfy legal requirements but that does satisfy the ethical and professional requirements of the Medical Council and the HSE guidance should remain worthy of ethical and professional respect.

4. Specific Comments on the Draft Scheme

A legally binding advance healthcare directive (AHCD), as described under the Draft General Scheme, is but one component of the advance care planning process. A discussion that focuses exclusively on the legal aspect of advance healthcare directives without recognition of the full complexity of advance care planning may influence the individual into making an unwise or ill-informed decision on their future care.

4.1. The exclusion of 'Best Interests' as a consideration for those who are incapacitated.

The Royal College of Physicians of Ireland notes with concern the lack of any mention of 'best interests' as a factor when considering treatment options for those who lack capacity. The RCPI acknowledges: (1) the importance of respecting and putting into effect the 'will and preferences' expressed in any advance directive or plan, (2) the primacy of a patient's preference to refuse treatment even if that seems medically unwise and is likely to lead to their death and (3) that 'best interests' has in the past been used as a formula or mechanism to disregard people's contemporaneous preferences regarding their own care. It is also accepted that 'best interests' must always be taken in a broad context: it is not just 'medical best interests' or 'preserve life at all costs'.

However, the complete exclusion of what has always been the ethical, professional and legal basis for making decisions for those who lack capacity seems extremely unwise, unrealistic and is likely to lead to considerable practical problems and potentially worse care for those who lack capacity.

'Best interests' is the basis for decisions regarding appropriateness of treatment

While the proposed legislation deals with advance refusal of treatment, it is important to note that, irrespective of any such legislation, treatment will only be an option (that is, available to be accepted or refused) if it (1) has some chance of achieving its clinical purpose; and (2) is judged to be in the overall best interests of the person, taking into account their preferences and values among other factors. Thus, 'best interests', defined broadly, remains an important consideration, even when primacy is given to 'will and preferences' as the standard for decision-making.

'Best interests' cannot be excluded from decision-making in those who lack capacity.

Some advance directives, especially those drawn up without discussion from healthcare professionals, will inevitably be poorly drafted or fail to encompass all eventual scenarios. It would be entirely wrong that such a directive, even if meeting legal criteria for validity, should lead - inadvertently - to harm and distress for the person who lacks capacity.

The following example may be helpful to illustrate the potential problems that may arise.

Example 1

Some people may decide that in the event of suffering from advanced dementia they would prefer not to be hospitalised or have any surgical procedure. However, one of the commonest reasons to consider surgery in those with advanced dementia is because they have a fractured hip and the fracture is unstable. Without surgery, that person will often be in great pain and it may be impossible without exacerbating that pain to even move or sit the person out of bed. In the vast majority of such clinical situations, the risk: benefit ratio is found to be in favour of having the fracture fixed, even though this may involve some operative risk since these individuals are invariably also very frail.

Is it right that the earlier self of that person, who may never have foreseen or known about or been advised of that particular and common scenario - and who almost certainly will never have known the suffering that an unstable fracture can cause - should be able to veto in advance the provision of appropriate treatment to ensure comfort?

Example 2

Cardiopulmonary resuscitation is a common subject of advance directives (and plans). This is entirely appropriate: in those with severe physical, functional or cognitive impairment, the results are usually very poor and the risk of causing a prolonged or distressed dying process very high. However, one cause of respiratory arrest is obstruction of the airway by a foreign body such as a food bolus, and checking the airway is a basic step in someone who is unexpectedly found not to be breathing. Notwithstanding any 'do-not-attempt-resuscitation' decision, made under current advance care planning, healthcare professionals are expected to use common sense and common humanity in such cases and to relieve a blocked airway.

Again, can it possibly be right that a legally binding directive, drafted without consideration of this issue, should prevent - or cause any delay in - doing what is unequivocally in the 'best interest' of that person?

Much of the debate surrounding advance directives focuses on the risk that healthcare professionals and, indeed those close to the person, might try to circumvent directives they don't agree with by questioning their validity. There is also a risk that healthcare professionals and those close to the person will, through respect for or perhaps fear of challenging a directive, fail to appropriately challenge the validity of any directive and instead act in a manner that is harmful to someone who lacks capacity.

'Best interests', interpreted broadly, should be the basis for decisions by alternative decision makers, including personal representatives, regarding appropriateness of treatment for those who lack capacity when the expression of 'will and preferences' does not specifically deal with the issue at hand or is unclear.

RCPI accepts the basic principle that people may make contemporaneous or advanced decisions based on their 'will and preference' to limit or refuse medically-advisable care and that such decisions should be respected even if they lead to death. However, such an advance decision made by the person him- or herself is one thing; a decision to forego such treatment based on a secondary interpretation or judgement, even by those close to the person and designated by them as their personal representative, of what they might have decided does not carry the same moral weight and, can is argued, should not carry the same legal weight.

One example may be that of a Jehovah's Witness who doesn't make an advance directive refusing blood transfusion but does appoint a family member who is also a Jehovah's Witness as a healthcare representative to make decisions on their behalf. If the person subsequently requires a life-saving transfusion and is unable to speak for themselves, should the latter have the legal power to refuse the transfusion? It might be difficult for that representative to separate their own sincere views from what the actual will and preference of the person might have been. It could be argued that if the preference of person themselves had been strong enough; they would have specified those preferences. Furthermore, the literature suggests that neither health care providers nor proxies are good at knowing or predicting patients' preferences about medical care.^{13,14,15} In fact, patient designated and next-of-kin proxies have been shown to fail to predict patients' end-of-life treatment preferences accurately in one third of all cases.¹⁶

4.2. When doubts about validity or applicability of AHCD arise.

Situations will inevitably arise where a healthcare professional has doubts about the validity or applicability of an AHCD. In such situations, the existing text suggests (Head 5, Subhead a)

“Where any doubt arises about the validity or applicability of an advance healthcare directive -

(a) the healthcare professional concerned must consult with the person’s patient-designated healthcare representative or with the person’s family and friends (if there is no nominated patient-designated representative) and seek the opinion of a second healthcare professional in an effort to clarify any ambiguity.

(b) If following this process of consultation, with the parties in (a), the validity or applicability of the advance healthcare directive remains ambiguous, any such doubt shall be resolved in favour of the preservation of life.”

There are several problems with this and it might give rise to great difficulties and inappropriate care in practice.

The absence or invalidity of an advance care plan or directive should not interfere with providing appropriate care, including not providing interventions that are unlikely to succeed or might prolong a patient’s dying process. This might occur, for example, if a doubt is raised by someone close to the patient about the validity of an AHCD refusing treatment, and that person wants the treatment given.

Clinicians in that circumstance should certainly take into account the views of those close to the patient; in particular the person the patient appointed as a representative or asked to be consulted. They would also want to consider whether the patient’s lack of capacity is temporary or permanent and to seek any other indications of the patient’s wishes and preferences. However, the most important consideration would be the likelihood of whether treatment would be effective and would provide overall benefit or harm for the patient.

A healthcare professional is not obliged to provide a treatment that is not clinically indicated. It is essential that the wording of the legislation does not imply that the absence or invalidity of an AHCD refusing a particular treatment mandates provision of that intervention even if it is not clinically indicated.

Another issue is the requirement to '*seek the opinion of a second healthcare professional*'. This ignores the fact that many such problems arise in an acute or urgent situation and that second opinions from appropriately qualified and experienced professionals will not be easy to access.

4.3. Definition of basic care

The draft legislation defines "basic care" as including, but not limited to, warmth, shelter, oral nutrition and oral hydration and hygiene measures.

It would be appropriate to amend the wording of this to the 'warmth, shelter, hygiene, pain relief and offering of oral nutrition and oral hydration'.

This is because near the end of life, patients seldom want, or indeed benefit from, oral nutrition or hydration. In such situations it is inappropriate to 'force feed' individuals and instead basic care measures such as moistening a patient's mouth for comfort should be instituted.

While they are competent, individuals may prefer to tolerate some pain or discomfort but in situations where an individual has lost capacity, in the RCPI's view, it would be unacceptable for health professionals to leave a person in pain.

4.4. Code of Practice

A code of practice is mentioned throughout the document, without reference to who will be involved in the process of developing this code practice, or how it will be carried out. RCPI would welcome having a representation in a committee to develop this code of practice.

5. Response to Consultation Questions

1. *What are your views on requiring an individual to obtain professional advice (e.g. clinical and/or legal) before preparing an advance healthcare directive?*

In general, RCPI would recommend that patients engage with advance care planning as outlined in this document rather than legally-binding advance directives.

It a general principle of advance care planning that it should be conducted with a person by a health care professional with the necessary knowledge of the medical condition(s), of the person themselves and of the legal and ethical issues that may arise and with the necessary experience and communication skills.

While we accept that health care professionals should not have a veto over people expressing in advance how they would wish to be treated, it is our view that an Advanced Health Care Directive should at least require consultation with - even if not necessarily the agreement of - such a healthcare professional.

There are a number of reasons for this recommendation:

1. It will reduce the risk of poorly thought out/ poorly structured AHCDs.
2. The legislation places significant responsibilities on clinicians for interpreting and managing the implementation of AHCDs and should support this role by specifically requiring their input in the development of the AHCD.
3. Under Head 4 (a), the bill states that the name of a GP/health professional should appear on the AHCD; it doesn't seem reasonable or sensible that their name should appear - with the possible implication of their imprimatur - on a legal document without their knowledge.
4. The validity of AHCDs drawn up without clinician input may be uncertain. This is particularly true of directives drawn up long in advance of any potential illness or crisis. The ethical requirement for information provision and patient understanding in advance care planning is same as that in contemporaneous decision-making. The same is logically true of AHCDs. As Fagerlin and Schneider have noted:

'Even patients making contemporary decisions about contemporary illnesses are regularly daunted by the decisions' difficulty. How much harder, then, is it to conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments?'

In general, it is difficult to see how clinicians can have confidence that a person drawing up an AHCD had sufficient information or knowledge without being involved in some way. We accept the exception that ACHDs based on well-known religious principles are more likely to have involved appropriate consideration of the implications.

2. Is it necessary for the provisions to designate a specific, mandatory time period within which an advance healthcare directive must be reviewed (e.g. every 2 years, every 5 years, every 10 years)?

In general, RCPI would recommend that patients engage with advance care planning as outlined in this document rather than legally-binding advance directives.

It is difficult to make hard and fast rules since it will depend on the clinical context and the person's own preferences, and there is evidence that people often change their mind. Indeed, the RCP in England (2009) notes that up to one third of patients will change their statement over months to years due to changes in health status but also mood, functional status and social circumstance.

In the context of advance care planning as defined earlier, that is when planning for a reasonably foreseeable decline in the person's condition has involved consultation between clinician and patient, it would be burdensome and unreasonable for patients to be asked to review their decision every time they were admitted or their condition declined.

A reasonable compromise might be to seek a review: (1) if the person has requested it in an AHCD or asks for it, (2) if the person has acted inconsistently with their AHCD since this may indicate a change of mind or (3) after a fixed time period if an AHCD has been drawn up without professional advice.

3. Should a standard format be developed for advance healthcare directives?

A standard format for advance care planning and AHCDs would have advantages in ensuring that directives and plans were familiar and easily interpretable by staff. While every effort should be made to read, interpret and comply with advance care plans or AHCDs, it is acknowledged that decisions often have to be made in an emergency situation: the greater the familiarity of staff with a particular format or approach and the clearer the 'bottom line' in such documents, the more likely that the patient's wishes will be complied with.

However, it is also the case that:

- It remains unclear what particular approach to advance care planning is best suited to people in different settings. This is the subject of ongoing research and debate, and a rigid requirement or insistence that documentation should be in a particular format or on a particular form would be inappropriate.
- Even if there were an agreed optimal format, staff would still be required to interpret and to try and adhere to the spirit of directives and plans such as those drawn up in other jurisdictions if they complied with the general principles. Rejecting such plans or AHCDs solely because they were not on a particular form or in a particular wording would, for example, be contrary to the spirit of supporting advance planning.

4. If a standard format for advance healthcare directives was developed what information should it contain?

In advance care planning, it is necessary to know what has been decided; however, this may not be a treatment refusal but a statement of values or a designation of someone to speak for the person if they can't speak for themselves. It is also necessary to know why - whether it is in the context of a particular illness or diagnosis - and who was involved in the discussions.

Therefore, the following information should be contained in advance healthcare directives:

- The name, date of birth and address of the person making the advance healthcare directive
- Specification - in medical or lay terms - of the treatment refused
- Additional information on the circumstances in which the refusal is to apply may be included if relevant
- The name and address of any nominated patient-designated healthcare representative and/or any attorney appointed through an enduring power of attorney (if appointed)
- The degree of authority that the individual wishes to grant the patient-designated healthcare representative over decision-making (if appointed)

5. Where should advance healthcare directives be kept to ensure that their existence is known about and they can be readily accessed when required?

We would note that when advance care planning occurs in consultation between clinician and patient and in the context of a known illness, it may be relatively easy to ensure that health care staff can access information in an emergency, for example by ensuring that the plan for someone with a severe chronic illness with frequent hospitalisations in residential care is known to the GP, to the staff in the residential unit, if they agree to those close to them, to their Consultant and is recorded in the notes of their local hospital. This will not be the case if someone has an AHCD planning for the distant future for an unspecified illness. In such cases, the primary responsibility for alerting health care staff would seem primarily that of the person themselves.

6. What additional measures could be included in the provisions to ensure that healthcare professionals are made aware that an individual has prepared an advance healthcare directive?

Although a system like the donor card, where an individual carries a card as an alert to healthcare workers that the he or she has prepared an AHCD might be considered, this would not of itself necessarily suffice to assure staff of the nature and validity of an AHCD without access to the actual document.

7. The provisions enable an individual to make a legally-binding refusal of treatment in an advance healthcare directive, however, requests for treatment in such directives will not be legally-binding. What should be done to ensure that such treatment requests, while not legally-binding, are adequately considered during the decision-making process?

A person's requests for treatment should always be considered, and this is particularly important if the best course of action is unclear. Ultimately, however, this depends on what specific treatment is requested. It should be possible - if usually unnecessary - for an individual to request appropriate care as the end-of-life approaches including for example early involvement of palliative or specialist dementia care. However, a healthcare professional is not obliged to provide a treatment that is not clinically indicated. It is essential that an AHCD requesting a specific intervention is not, in practice, allowed to mandate provision of that intervention even if it is not clinically indicated. An advantage of advance care planning is that this can be explained sensitively to the individual.

8. Given that advance healthcare directives relating to mental healthcare and treatment are intended to be used on a recurring basis, as opposed to advance healthcare directives for general healthcare which are predominantly used once, should a different format be used for both types of directive?

No specific comment

9. What do you think the role of the patient-designated healthcare representative should be? Should the representative's role be limited to that of interpreting the individual's advance healthcare directive? Should the representative have a broader role to advise as to what the individual's will and preferences regarding treatment are likely to be?

The Do Not Attempt Resuscitation (DNAR) section of the HSE National Consent Policy provides useful guidance. Section 4.3.3 reads:

"If the individual wishes to have the support or involvement of others, such as family or friends, in decision making, this should be respected. If a person has decision-making capacity then his/her family or friends should only be involved in discussions regarding his/her treatment and care with that individual's consent. If the individual is unable to participate in discussions due to his/her physical or cognitive condition, those with a

close, on-going, personal relationship with the individual may have insight into his/her previously expressed preferences, wishes and beliefs. They may also have their own views as to the appropriateness or otherwise of interventions, based on their knowledge of the individual's circumstances. In general, the closer the relationship to the individual, the greater weight should attach to such views. However, the role of those close to the individual is not to make the final decision regarding CPR, but rather to help the senior healthcare professional to make the most appropriate decision. Where CPR is judged inappropriate, it is good practice to inform those close to the patient, but there is no need to seek their 'permission' not to perform CPR in these circumstance."

Being a patient-designated healthcare representative is a potentially difficult and stressful role,¹⁷ especially if there is disagreement with other people close to the person whose views may also need to be at least considered. It is important that health care professionals work closely with and support the role of such representatives.

The literature suggests that neither health care providers nor proxies are good at knowing or predicting patients' preferences about medical care.^{18,19,20} In fact, patient designated and next-of-kin proxies have been shown to fail to predict patients' end-of-life treatment preferences accurately in one third of all cases.²¹ Hence we are wary of any extension of the role of the representative beyond interpreting the advance directive or providing insight into the will and preferences of the incapacitated individual. Also, decisions that benefit someone other than the patient are not decisions that an individual should be allowed to make under the authority of a patient-designated healthcare representative.

The Act should contain safeguards to investigate complaints regarding the potential abuse of individuals by a patient-designated healthcare representative and, if upheld, to apply for a court order to remove or reduce powers, or seek directions. Patient-designated healthcare representatives should also be able to seek directions if there are difficulties which cannot be resolved in any other way.

10. What additional safeguards may be required in relation to the provisions for the patient-designated healthcare representative to protect the individual who made the advance healthcare directive and to ensure that the representative carries out his/her wishes?

There are a number of safeguards needed for the sake of patients

1. Voluntariness

Some patients do not and will not wish to engage with advance care planning or AHCDs. This should be respected and it is important that people are not pressurised or made to feel it their duty (for example, to those close to them or to their clinicians) to participate. It is also important (1) that arbitrary decisions to engage people in advance care discussions at a particular time, such as just following admission to residential care, are not promoted; and (2) that the presence of an AHCD does not become a pre-condition for access to services or for admission to certain health care settings.

2. Limits to treatment that can be refused

Medically necessary and appropriate measures to relieve pain and suffering and improve the quality of life in those who are incapacitated must always be provided irrespective of any AHCD or judgement of a patient-designated healthcare representative. The legal transfer of health decision-making authority to a patient-designated healthcare representative should be specific and should not extend to refusing life-sustaining treatment unless this is *explicitly* stated. In the absence of such a clear instruction from the person themselves, the actions and recommendations of a healthcare representative should be to benefit the person, taking into account the nature of the situation, the person's known prior and current wishes and the likelihood of success of an intervention.

3. Maximising decision-making abilities of those with possible incapacity.

It is acknowledged that a welcome thrust of the Assisted Decision-Making bill is to support residual decision-making abilities in those with potential difficulties making decisions including, for example those with cognitive impairment including due to dementia. Good care recognizes and enables preserved abilities and understands that communication can be through a range of expression, including physical gestures such as removal of tubes and iv lines, and changes in behaviour²². For example, people with dementia who can communicate their current preferences, even if lacking in capacity, should not inevitably be bound by the

decisions of their former non-demented selves. Incapacitated individuals should similarly not be inevitably bound by the decisions of a patient-designated healthcare representative if there is clear evidence of a patient objecting to the decision of his/ her patient-designated healthcare representative. Mechanisms that facilitate directions being sought if there are difficulties that cannot be resolved in any other way must be put in place.

11. Are there any other issues relating to advance healthcare directives that should be included in the legislative provisions?

Safeguards are required for health care professionals as well as for patient.

The responsibility for sometimes difficult decisions regarding applicability and validity of AHCDs on health care professionals is a very onerous one. (Obviously, the difficulty will be less in advance care planning especially if that professional either is the one or can consult with the one who was involved with discussions with the person). Health care professions have an existing ethical and professional responsibility to do the best they can in these circumstances. It would be unfair if they were to face potential legal penalties or action in situations where there are genuine uncertainties about the meaning, applicability and validity of AHCDs.

Healthcare professionals should be protected from liability if they:

- Stop or do not initiate treatment that they reasonably believe has been refused by a valid and applicable advance decision;
- Provide treatment if they have taken reasonable steps to find out if an advance decision exists but are unable to satisfy themselves that there is a valid and applicable advance decision.

6. Conclusions

Late life is a time marked by complexity, increased inter-individual variability and unpredictability. Advance care planning is a process that engages the individual patient in a process of discussion about goals, values and preferences for future treatment usually in the context of a late life decline in the patient's condition, with loss of capacity.

Advance care planning is a complex and challenging area, and is already a feature of good clinical care in this country. RCPI recognises that there is room for continuing improvement in end-of-life planning.

The advance plans of a person already carry significant ethical and moral force and respect for those plans is currently a professional and ethical requirement. Therefore, a provision for legally-binding directives should not explicitly or by implication interfere with advance care planning as it is currently practiced. In other words, an advance care plan that does not satisfy legal requirements but that does satisfy the ethical and professional requirements of the Medical Council and the HSE guidance should remain worthy of ethical and professional respect.

It is important to distinguish advance care planning from legally binding advance healthcare directives refusing treatment.

A legally binding advance healthcare directive refusing treatment will be helpful to people and to their doctors in certain, potentially limited, situations. For example, it is important that a legal mechanism should exist to ensure that even if incapacitated, the wishes of some Jehovah's Witnesses for advance refusal of blood and/or blood products is respected.

RCPI has concerns regarding legally binding advance healthcare directives refusing treatment as a general response to planning for end-of-life care. In particular, it will never be possible to legislate for - or to legislate away - the enormous complexity of individual decision-making as the end of life approaches, and there is a real risk that legally-binding directives may serve as an obstacle rather than a support to good end-of-life planning.

Rather than binding healthcare providers into a out-dated view of a fast-changing medical landscape, RCPI recommends the promotion of advance care plans phrased in terms of advanced care preferences with a strong moral force rather than a legally binding directive.

Safeguards for both patients and healthcare professionals are necessary.

RCPI welcomes the development of a code of practice as stipulated, and is willing to be part of the development of such a code.

This document was prepared by:

Prof Desmond O'Neill

Dr Karen Ryan

Dr Shaun O'Keeffe

Ms Mairead Heffron

References

- ¹<https://www.medicalcouncil.ie/News-and-Publications/Publications/Information-for-Doctors/Guide-to-Professional-Conduct-and-Ethics-for-Registered-Medical-Practitioners.pdf> Accessed 03/03/14
- ² http://www.hse.ie/eng/services/list/3/nas/news/National_Consent_Policy.pdf Accessed 03/03/14
- ³ Pollard C, Kennedy P. A longitudinal analysis of emotional impact, coping strategies and post-traumatic psychological growth following spinal cord injury: a 10-year review. *British journal of health psychology*. 2007 Sep;12(Pt 3):347-62. PubMed PMID: 17640451.
- ⁴ Garavan R, McGee HM, Winder R, O'Neill D. When and how older people discuss preferences for long-term care options. *Journal of the American Geriatrics Society*. 2009 Apr;57(4):750-1. PubMed PMID: 19392974.
- ⁵ Casarett D, Van Ness PH, O'Leary JR, Fried TR. Are patient preferences for life-sustaining treatment really a barrier to hospice enrollment for older adults with serious illness? *Journal of the American Geriatrics Society*. 2006 Mar;54(3):472-8. PubMed PMID: 16551315.
- ⁶ Fournier V, Berthiau D, Kempf E, d'Haussy J. [Are advance directives useful for doctors and what for?]. *Presse medicale*. 2013 Jun;42(6 Pt 1):e159-69. PubMed PMID: 23433956. Quelle utilite des directives anticipees pour les medecins ?
- ⁷ Robinson D, O'Neill D. Communication and documentation of Do-Not-Associate orders in an Irish teaching hospital. *Medico-Legal Journal of Ireland*. 2005;11(2):60
- ⁸ O'Keeffe ST. Development and implementation of resuscitation guidelines: a personal experience. *Age Ageing*. 2001 Jan 1;30(1):19-25.
- ⁹ Elder L. Why some Jehovah's Witnesses accept blood and conscientiously reject official Watchtower Society blood policy. *J Med Ethics*. 2000 Oct;26(5):375-80.
- ¹⁰ Gyamfi C, Berkowitz RL. Responses by pregnant Jehovah's Witnesses on health care proxies. *Obstet Gynecol*. 2004 Sep;104(3):541-4.
- ¹¹ Fried TR, O'Leary J, Van Ness P, Fraenkel L. Inconsistency over time in the preferences of older persons with advanced illness for life-sustaining treatment. *Journal of the American Geriatrics Society*. 2007 Jul;55(7):1007-14. PubMed PMID: 17608872. Pubmed Central PMCID: 1948955
- ¹² Fagerlin A, Schneider CE. Enough. The failure of the living will. *Hastings Cent Rep*. 2004 Apr;34(2):30-42.
- ¹³ Seckler AB, Meier DE, Mulvihill M, Paris BEC. Substituted judgment: how accurate are proxy predictions? *Ann Intern Med* 1991;115:92-98.

¹⁴ Covinsky KE, Fuller JD, Yaffe K, et al. Communication and decision -making in seriously ill patients: Findings of the SUPPORT project, J Am Geriatr Soc 2000; 48:S187-S193.

¹⁵ Layde PM, Beam CA, Connors AF, et al. Surrogates' predictions of seriously ill patients' resuscitation preferences, Arch Fam Med 1995;4:518-523.

¹⁶ Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166:493-7.

¹⁷ Wendler D, Rid A. Systematic review: the effect on surrogates of making treatment decisions for others. Ann Intern Med. 2011 Mar;154(5):336-46.

¹⁸ Seckler AB, Meier DE, Mulvihill M, Paris BEC. Substituted judgment: how accurate are proxy predictions? Ann Intern Med 1991;115:92-98.

¹⁹ Covinsky KE, Fuller JD, Yaffe K, et al. Communication and decision -making in seriously ill patients: Findings of the SUPPORT project, J Am Geriatr Soc 2000; 48:S187-S193.

²⁰ Layde PM, Beam CA, Connors AF, et al. Surrogates' predictions of seriously ill patients' resuscitation preferences, Arch Fam Med 1995;4:518-523.

²¹ Shalowitz DI, Garrett-Mayer E, Wendler D. The accuracy of surrogate decision makers: a systematic review. Arch Intern Med. 2006;166:493-7.

²² Kitwood TM. Dementia reconsidered : the person comes first. Buckingham England ; Philadelphia: Open University Press; 1997. viii, 160 p. p.

Advance Healthcare Directives

This document outlines a number of amendments to the RCPI submission to the Public Consultation on Advance Healthcare Directives (*Towards a Humane, Practical and Evidence-Based Approach to Advance Care Planning*), made in March 2014. The points below are intended to clarify some statements within the submission.

Amendments

P 6, Section 2.1. Current Professional and Ethical Standards

Both the Medical Council's *Guide to Professional Conduct and Ethics (2009)* and the HSE *National Consent Policy* are understood to be based on the general legal principles that a person has the right to consent and to refuse medical treatment.

P 8, Section 2.2. Principles Underpinning Advance Care Planning

Reference to maximising the person's health condition, before discussion, is intended to clarify that the goal of maximising health in this context is to maximise the ability to elicit the person's preferences before they discuss their advance care plans.

P 11, Section 3.2. General Concerns about Legally Binding Advance Healthcare Directives

The expressed concern regarding legally binding advance healthcare directives as a general response to planning for end of life care is intended to emphasise that planning for end of life care should not be limited to discussion of advance healthcare directives. We acknowledge that the proposed legislation under head 4 clarifies that a treatment refusal within an advance healthcare directive will be specific, both in respect of the treatment to be refused and the circumstances in which the refusal is to apply.

The statement that "*the absence of a legally binding directive may be misinterpreted as mandating treatment even when it is no longer clinically indicated or in the 'best interests' of a person who lacks capacity*" acknowledges that this is not the intent of the legislation. However, it suggests that if advance

healthcare directives are overemphasised and seen as the only response to end of life planning, then the absence of a directive may be misinterpreted. Clear codes of practice and communication of the provisions of the legislation to both the public and to clinicians should help to resolve this. RCPI, as previously indicated is willing to participate in the formulation of these codes of practice.

P13.

Reference is made to US studies showing that “patients preferred to leave final resuscitation decisions to their family and physician instead of having their own preferences expressly followed”. We acknowledge that individuals may wish to leave their decision to others, and this should be fully respected.

P14, Section 4.1. The exclusion of best interests as a consideration for those who are incapacitated.

We acknowledge that the principle of best interests has in the past been interpreted subjectively and been used to disregard people preferences regarding their own care. We also acknowledge that the stated will and preference of an individual must take primacy, even where the stated will and preference is seen as medically unwise. However, best interests, defined broadly, remains an important consideration in clinical treatment, especially when will and preference is not known.

This broad interpretation of best interests (to include consideration of will and preferences) should also be the basis for decisions made by alternative decision makers including patient designated healthcare representatives. Again codes of practice should provide guidance on the consideration of best interests by a surrogate decision maker. For example, the role of the patient designated healthcare representative and the situation in which they are to make decisions should be clearly indicated.

P20. Response to Consultation Questions (Q1)

Where it is stated that *“it is difficult to see how clinicians can have confidence that a person drawing up an AHCD had sufficient information or knowledge without being involved in some way”*, this is intended to suggest that advance healthcare directives would ideally be discussed in the context of a current illness with the treating clinician. We recognise though, that this may not always be the case, and this statement does not imply that doctors will refuse to comply with legally valid advance healthcare directives where there does not appear to have

been due and appropriate information available to the patient at the time of making the directive. However, this fact should be considered in addition to any emergent concern that the directive may have been made under undue influence or duress, in determining whether or not they should seek legal advice on the most appropriate course of action to be followed.