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Increasing understanding and uptake of Advance Decisions in Wales

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Contents

Summary	2
History and context	3
The law in England and Wales.....	4
Uptake and effectiveness of advance treatment refusals	5
Attitudes to Advance Decisions.....	7
Health and social care practitioners' views.....	10
Barriers to uptake.....	12
Strategies to increase understanding and uptake of ADRTs	16
References	29
Annex 1 Summary of General Medical Council (2010) Treatment and Care towards the End of Life: Good Practice in Decision Making.....	33
Annex 2 Examples of amendments recommended to existing forms.....	35
Annex 3 Decision making flowchart for practitioners	38



Summary

- An ‘Advance Decision’ is a legally binding record (given statutory force by the Mental Capacity Act 2005) of the treatments that someone wishes to refuse if they lose capacity to make such decisions for themselves in future. The Mental Capacity Act 2005 refers to them as ‘Advance Decisions’ (s. 24(1)); given widespread confusion about the terminology associated with end-of-life planning tools, we have often opted in this report to use the term ‘Advance Decisions to Refuse Treatment’ (ADRTs),
- Barriers to uptake of ADRTs include misunderstanding about what is involved; scepticism about whether they will be respected; and the mistaken belief that an ADRT is unnecessary if people have already informed family members or healthcare professionals of their wishes.
- There is widespread misunderstanding about the power of family members to give or withhold consent for adult relatives, and misinformation and confusion about the distinctive legal status of ADRTs (compared with other advance planning tools).
- This report examines the legal position and identifies ways of increasing awareness and uptake of ADRTs in Wales. It suggests that the Welsh Government has a key role to play, alongside partner organisations such as charities, in promoting better understanding of ADRTs and ensuring that people’s right to refuse treatment is respected through:
 - Public education, media engagement and cultural events to encourage people to plan for potential future loss of capacity;
 - De-bunking the myth that ‘next of kin’ have decision-making powers and correcting official forms that may mislead people about the legal status of their own or a relative’s expressed wishes;
 - Facilitating access to well designed ADRT forms/guidance and skilled support, both for the general population and for particular groups;
 - Normalising ADRTs (e.g. offering registration when patients sign up with a GP);
 - Training relevant practitioners to ensure that they understand what ADRTs are (and when they are valid and applicable), are able to provide appropriate guidance or referral, and can act in accordance with the law concerning them;
 - Creating an All-Wales national repository – flagging key emergency decisions and ensuring accessibility of full ADRT documentation.

History and context

Patient-centred care is responsive to individual patient preferences, needs and values. It puts the person at the centre of their health care and respects their (capacitous) decisions to accept or to refuse the medical treatment they are offered. An 'Advance Decision' (formerly known as a 'living will') is the correct term in England and Wales for a legally binding record of what treatments (including life-sustaining treatments) someone wishes to refuse if in the future they lose capacity to make such decisions for themselves.

The right to refuse medical treatments, including life-sustaining treatments, is long established for people with capacity (*Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam)). An Advance Decision extends that right into the future when a situation could arise where capacity to refuse treatment has been lost. A basic Advance Decision might state, for example, "I refuse a feeding tube and all other life-prolonging treatments if I am diagnosed by two appropriately qualified doctors as being in a prolonged vegetative state". This would be a valid and legally binding Advance Decision in England and Wales if it were signed, witnessed and included a statement to the effect that 'this decision is to apply even if life is at risk'¹.

The concept and practice of making treatment refusals in advance of losing the mental capacity to do so originated in the USA in the 1960s alongside the development of new life-prolonging medical technologies. Over the next couple of decades, media reports of court cases involving young women in permanent vegetative states (Karen Ann Quinlan and Nancy Cruzan) drew attention to the importance of end of life care planning for healthy adults as well as for older people and those with life-limiting conditions. Mechanisms for making advance decisions were developed as a way for people to retain control over their medical care by specifying their treatment values and choices and by naming someone to make medical decisions once they were no longer able to do so (Wilkinson et al., 2007).

Statutory support for making advance treatment refusals spread from the USA first to other English-speaking countries (Canada, Australia, New Zealand), then beyond (e.g. Japan, Singapore), with Europe joining the trend relatively late (Tamayo-Velázquez et al., 2010). European countries that have implemented legislation over the last decade to support people's right to refuse treatment in advance include (in addition to England and Wales), Belgium and the Netherlands (Halliday, 2005), Spain (Simón-Lorda et al., 2008), Germany (Evans et al., 2012) and Austria (Halliday, 2011).

¹ This report focuses on advance refusals of life-prolonging treatments. Note that legally binding advance refusals of other kinds of medical treatment can be made orally (ss. 24-26 Mental Capacity Act 2005)

The Council of Europe (2009, 2012) has promoted legislation about advance treatment refusals in member states and recommends associated “awareness-raising campaigns for the general public, as well as for the medical and legal professions” noting that:

“[O]nly a tiny minority of the Council of Europe’s 800 million citizens actually have advance directives, living wills and/or continuing powers of attorney, making it difficult, if not impossible, to take their previously expressed wishes into account, and thus effectively protect their human rights and dignity.” (Resolution 1859 (2012), para.4). (<http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=18064&lang=en>).

The law in England and Wales

The legal position relating to medical decision-making for patients both with and without capacity is summarised (from General Medical Council guidelines) in Annex 1. This covers decision-making for patients who lack capacity who have an Advance Decision, an Attorney, or who have neither.

In England and Wales, Advance Decisions have a long history in common law that predates the Mental Capacity Act. For example, the common law “living will” has been used for decades by Jehovah’s Witnesses to refuse blood products and their right so to do, even when death results from refusal, was supported by the Association of Anaesthetists in 1999 (<http://news.bbc.co.uk/1/hi/health/293424.stm>). Advance Decisions were given statutory support by the Mental Capacity Act (MCA) 2005 (ss 24-26) as one of a series of measures designed to instruct, guide or protect health and social care practitioners in making decisions about people without capacity. These decisions can range from deciding where people live to decisions about sterilisation or life-sustaining treatment. The Act gives statutory force to Advance Decisions as legally binding upon health care professionals (and other potential treatment providers) (s.26 MCA 2005) but there was no associated information or awareness-raising campaign to accompany this component of the Act.

In addition to treatment refusals (the legally binding part of an Advance Decision), the same document may include a section explaining the values, feelings and beliefs that guided the person’s decision-making. This is not a *required* part of an Advance Decision and it is not legally binding. It does however assist health care professionals in understanding and (if necessary) interpreting the person’s treatment refusals and can help confirm to professionals that in withdrawing or withholding treatment they are providing truly person-centred care. If an Advance Decision is found not to be valid, or is not applicable to the patient’s situation,

these advance statements become a very important component of ‘best interests’ decision making (as happened in the case of one dementia patient, deprived of her liberty against her contemporaneous wishes in a care home, *Westminster City Council v Manuella Sykes* [2014] EWCOP B9).

The document of which an Advance Decision is a part can also record preferences about what sort of treatments the person *wants* to receive. Requests to receive treatments are not legally binding as nobody (with or without capacity) can *demand* that they are provided with a particular medical treatment (*Burke, R (on the application of) v General Medical Council & Ors* [2005] EWCA Civ 1003). There is asymmetry between *treatment refusals* which – in England and Wales - are legally binding on health care practitioners (and anyone else) and *requests for treatment* (which are not legally binding). This is why Advance Decisions are sometimes referred to as ‘Advance Decision to Refuse Treatment’ – emphasising that they enable exercise of legal right of treatment refusal (only).

There is a wide array of terminology used in connection with end-of-life decision-making including ‘advance care planning’, ‘advance statement’, ‘living will’, ‘statement of wishes and care preferences’. People also commonly refer to ‘advance directive’ or, even when referring explicitly to the Mental Capacity Act 2005 sometimes use the (incorrect) term ‘advanced decision’ (with a ‘d’ at the end of ‘advance’). Confusion about terminology can lead to (and reflect) confusion about the status of different ways of making and recording decisions. In particular, lack of clarity about the appropriate terminology can encourage failings to differentiate Advance Decisions (as identified in the Mental Capacity Act 2005), which are legally-binding decision, from other documents which are purely advisory or for the guidance of carers. When referring to Advance Decisions as defined by the Mental Capacity Act 2005 in England and Wales we henceforth use “Advance Decision to Refuse Treatment” or the initialisation ADRT, while referring more generically to ‘advance treatment refusals’ elsewhere.

Uptake and effectiveness of advance treatment refusals

Law and policy concerning advance treatment refusals (and other mechanisms for planning in advance of losing capacity) is quite disparate across jurisdictions, making international comparison problematic (Andorno et al., 2009). Nevertheless it is worth noting that highest recorded uptake is in the USA where uptake is around 1 in 3 of the general public: estimates vary from 26% (Rao et al., 2014) to about 33% (Pollack et al., 2010) depending on the study.

Uptake is higher among older Americans, 70% of whom now complete 'Advance Directives' (the American nomenclature, which includes both 'living wills' and 'power of attorney') (Silveira et al., 2014). Most Western European countries (excluding the UK) report uptake of advance planning tools is in the range of 10-20% among the general population with much higher rates evident in more recently published surveys and among patients who are severely ill. For example, in Germany uptake is about 10% among the general population (Lang & Wagner, 2007), rising to 48% among palliative care patients (Van Oorschot et al., 2004).

Uptake of ADRTs in England and in Wales is estimated to be around 4% in England and just 2% in Wales (YouGov Poll, 2013). Even given caveats about interpretation of these statistics (due to cross-national difference in law and health care, diverse study designs, potential confusion among respondents etc.), it is striking that uptake in Wales is the lowest recorded in any European country – and one of our stakeholder respondents reports that 'From "show of hands" surveys at community talks with the Women's Institute, University of the Third Age etc., I would say 2% might be high!'. This is despite survey findings *Dying* (ComRes, 2015, Table 48) which show that 10% of people in Wales who were asked to rank-order a series of factors that might be important to them in their end of life care put the following item top of their list: "To be involved in decisions about my care or, if I am not able to, for my family or those close to me to be involved". This was ranked higher than place of death, being with family or friends or being pain-free. This suggests a strong interest among a significant minority of people in Wales in advance care planning, ADRTs and LPAs.

Evidence about the effectiveness of advance treatment refusals (i.e. whether health care professionals comply with them and withhold or withdraw unwanted treatment) is patchy and (as with uptake statistics) difficult to assess across different jurisdictions and health care systems, and across time and legislative changes.

Recent research includes a longitudinal nationally representative retrospective cohort study in the USA which finds that written advance refusals of treatment ('living wills') are significantly associated with lower odds of intensive procedures (intubation, mechanical ventilation, CPR etc.) being administered in the last six months of life (Tschirhart, 2014). A randomized trial in Switzerland found a highly significant association between 'advance directives' and treatment withdrawal and withholding (in response to vignettes) among both generalists and intensivists (Escher et al., 2014). In Britain, a YouGov poll of around 2,000 British adults who were asked about the most recent death they had experienced found that patients with end-of-life wishes on their medical records (some but not all of which were in the form of ADRTs) were more likely to be judged by loved ones to have 'died well'. Where

wishes were recorded patients were 41% more likely to be judged by loved ones to have ‘died well’, where such wishes were not recorded, loved ones were 53% more likely to feel that the patient received treatment they would not have wanted. Findings also suggest that recording end-of-life wishes could reduce avoidable hospital admissions (Compassion in Dying, 2015).

Evidence from those working on the ground in England and Wales shows that, although some people don’t have an ADRT because they do not want to refuse treatment in advance, other people do, or might, want an ADRT but face barriers to writing one. Barriers include simply not knowing that this is an available option. The House of Lords (2014 para. 55) points to the need to “urgently address the low level of awareness among the general public” and the UK Government response (2014 para. 33) supports the recommendation that “further work be done to raise awareness and understanding of Advance Decisions to Refuse Treatment”.

Attitudes to Advance Decisions

People’s general orientation towards refusing treatment in advance of losing the mental capacity to do so can be divided into three categories:

- Those who *don’t* want to do this;
- Those who *might* want to (given appropriate information and support); and
- Those who *do* want to record formal ADRT (but usually have not actually done so).

The first group consists of those who would *never* be interested in having an ADRT. For some people this is because they want all available treatments whatever the circumstances. For others it is because they disagree on principle with the notion of ‘anticipatory autonomy’ believing, for example, that as someone who currently has mental capacity, they have no right to make decisions for a potential future self who will have lost capacity and/or that they are unlikely to be able to make the correct decision for that future person. Some want the decision to rest with God, or ‘fate’ or see no point in planning ahead since ‘what will be will be’.

A significant proportion of people decide against an ADRT because they believe that members of their family are the best people to make decisions concerning them once they have lost capacity (in England and Wales this would require appointment of a family member

as a Lasting Power of Attorney for Health and Welfare) or because they put their trust in doctors to make the right decisions.

One European study (a random survey of households across 7 European countries, Daveson et al, 2013) found that when presented with a hypothetical scenario involving a terminal illness only 74% of people want to be involved in decisions about their own medical treatment *when they have capacity*. This dropped to 44% when people were asked if they wanted to be involved in decision-making after loss of mental capacity via a mechanism such as an ADRT. These findings suggest that - although Wales was not included in the European countries sampled - it is rather unlikely that a majority of the Welsh population would wish to make ADRTs - but rather likely that a significant minority would wish to do so (see also ComRes, 2015, Table 48 for an indication of the strength of feeling about this for some people).

Often people would like to influence (but not determine) treatment decisions. One way of doing this is to create an advance statement about what they would like – but not one that is legally binding (e.g. a “Statement of Wishes and Care Preferences”). Another way is to assign decision-making power to someone they know and trust (such as a relative/partner) to act ‘in their best interests’ at the time. To do this they need to appoint that person with Lasting Power of Attorney, but uptake of this is also very low and might usefully be considered in parallel to the issues discussed in this report.

There are other people who *might* want to refuse some treatments in advance of losing capacity but do not actually do so because they find it very hard to think or talk about loss of capacity and/or death – even when this is imminent. Talking about death is still taboo and this underlies broader problems across the UK: for example, only 36% of adults say they have written a will; only 29% say they have let someone know their funeral wishes and more than half of the public who have a partner say their partner is unaware of their end-of-life wishes (ComRes 2015). Even some people who know they have a degenerative condition find it hard to face up to the possibility that they may lose capacity in the future (see Box 1).

BOX 1: Fear of thinking about the future can prevent people considering recording advance decisions to refuse treatment.

Mrs N was a 68-year-old woman with multiple sclerosis, originally diagnosed when she was in her mid forties. Her family described how she had been entirely unable to engage with the fact of her illness or its likely consequences - her consistent response to the illness was anger and denial. Within ten years the disease had led to severe cognitive impairment, an inability to communicate, and loss of capacity to make decisions about her own medical treatment. A feeding tube was placed in January 2008. In early 2015 her daughter instigated an application to the Court of Protection for withdrawal of the feeding tube because she considered that her mother would refuse it if she were able to do so. Eleven months later, the application was approved. The judge summarised the family's evidence saying that, "It [the likely future of her disease] was too painful for Mrs. N even to contemplate. When the reality of her circumstances did bubble to the surface she railed in intemperate language to her son that she wanted to die." He believed that Mrs N would have found her situation "profoundly humiliating" and that she "would have wished to have discontinued her treatment some considerable time ago". Mrs N's husband told the judge that he had an Advance Decision to Refuse Treatment to make sure that nothing like this happens to him. [Court case: *Re N* [2015] EWCOP76]

The group most relevant when considering improving uptake of ADRTs is those who do actively want to make an ADRT. Many people have a general sense that there are conditions they would consider 'a fate worse than death' and would prefer not to have on-going treatment – but are not particularly highly motivated to act on this. Others are very highly motivated because they (a) place a strong value on autonomy, and/or because (b) they wish to avoid what they see as intolerable 'quality of life' (especially, for example, in light of a particular diagnosis), and/or (c) because they have experience of caring for others who have lost decision-making capacity and have seen the problems that can arise when decisions have to be made concerning their medical treatment (see www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/reflections-own-end-life-wishes, also Kitzinger and Kitzinger, 2013; Wilkinson, 2013).

People may wish to write ADRTs to try to make sure that their own wishes are respected and to avoid disagreements between family members, or between family members and health care professionals. Some individuals who want to write ADRTs are motivated by a

desire to avoid leaving other people with the burden (and associated guilt) of making difficult decisions (e.g. about giving or withholding cardiopulmonary resuscitation or inserting or withdrawing a feeding tube). They may also want to minimise their family's distress at their death. (Research shows that advance care planning reduces stress, anxiety and depression in surviving relatives, Detering, 2009).

Among the wide range of people who want ADRTs, there is no 'one size fits all'. For example, after the Cardiff 'Before I Die' festival in 2013 (which included art, cultural events, debate and information about ADRTs), the authors of this report were approached by a very diverse group of people wanting support in writing ADRTs. They included:

- Fit and healthy people with no specific health conditions and no experience of caring for people who had lost capacity;
- A carer who had looked after both his parents as they died with dementia and was worried about his own future;
- A man who had recently been informed that he had an inoperable brain tumour; and
- A woman whose partner (with a severe degenerative condition) had chosen an assisted death at Dignitas, the Swiss assisted suicide clinic and who – while rejecting Dignitas for herself – wanted to be sure her own life would not be medically extended beyond the point that would be right for her.

In thinking about how to promote understanding and uptake of ADRTs in Wales it is important not to compel or cajole those who do not wish to make ADRTs, or to create a 'one-size-fits all' system. Rather the aim should be to ensure that people are aware of their options and have the support they might need to avail themselves of the right to make an ADRT if they so wish, and the opportunity to reflect on, and record, their wish to refuse treatments in line with their own values and beliefs.

Health and social care practitioners' views

Research suggests that, in general, health care professionals have a positive attitude to planning in advance for loss of capacity and to advance treatment refusals where appropriate (Coleman, 2013). As part of the preparation for this report we spoke to a wide range of practitioners. The Clinical Nurse Specialists in Cwm Taf who spoke with us believe the ADRTs they supported patients to write have been very successful in "enabling the patient's voice to be heard", as well as reducing patient anxiety about receiving unwanted

treatment, and (in one case) supporting a patient's chosen place of death. Having worked with a wide variety of health and social care practitioners in Wales and in England, our impression is that most practitioners feel that ADRTs are a good idea in principle – and, indeed, they are often very keen to make ADRTs themselves. However, some have ethical objections e.g. disagreeing with the notion that 'the present self' should make decisions for the 'future self'. Some are also very uncomfortable with allowing their patients to make 'unwise decisions' (a right enshrined in the Mental Capacity Act 2005) – especially when such a decision might be recorded in an ADRT and the practitioner would not have the opportunity to seek to change their mind if they first encountered the patient *after* loss of capacity. It is important to uphold the right of 'conscientious objection' to any health or social care practitioner who does not want to be involved in helping people write ADRTs (or who does not want to be involved in their implementation) with the caveat that they should refer the person to someone else who is able to help them.

There is also a range of opinion about how ADRTs might work in practice. Concerns include: whether the level of information/support will be available to people to ensure their ADRTs reflect their wishes; worries about pressures on people (e.g. re 'being a burden'); concerns about regular revision to accord with people's shifting perspectives; and practical questions about whether such documents can be accessed/useful in particular situations.

There are also diverse views among practitioners on the implications of ADRTs for them as professionals about: whether increasing uptake of ADRTs might lead to an increase or decrease in workload; whether it would help or hinder discussions about end of life; whether it would have a positive or negative influence on their relationship with service-users; and legal implications for them as practitioners and its implications for resource allocation. Initiatives to promote understanding and uptake of ADRTs within particular contexts will need to engage with the concerns and practical constraints within which different groups of practitioners work.

In the course of our research and consultation we have identified some general patterns in how enthusiastic people are about ADRTs depending on their professional background and experience. We have not done systematic research to test this observation, however it seems to us that palliative care practitioners working in the cancer field are sometimes less convinced of the need for, or value, of ADRTs compared with, for example, practitioners working with other client groups (e.g. people with dementia, acquired brain injury or neuro-degenerative conditions associated with long periods of living without capacity). This is perhaps not surprising given the likely value of ADRTs for these different service-users and the nature of relationships with services (e.g. whether or not the practitioner first meets the

person they are supporting while they have capacity to discuss their wishes). Similarly people working in hospices sometimes seem to attach less value to ADRTs than those working in other settings (e.g. care homes). In the course of discussion, some of the clinicians we talked with became interested in the potential of ADRTs to protect patients from unwanted CPR (e.g. from health care practitioners who did not feel confident in allowing a person to die without attempting CPR). It tends to be practitioners in non-hospice settings who placed most value on ADRTs (as distinct from general 'advance care planning'). Paramedics have described situations to us where they felt under pressure from family members to perform CPR, against prior verbally expressed wishes of the patient. Similarly a care home manager we consulted for this report was particularly passionate about the need for ADRTs to protect residents' choices.

"We can have discussed at length with a resident what they want to refuse but then when things go wrong a distressed family member may then arrive - or a social worker who wants to protect themselves - and they insist we do what *they* want, not what the resident said they wanted, and residents get whipped into hospital. People panic. It can be written down in a care plan, but if there is no legally-binding Advance Decision document, then the care plan can be ignored. It's heart breaking. We struggle to protect residents' choice and dignity in such situations. It's the final decision the person makes; it should be *theirs*, no one else's. I'd be very grateful to have something more solid to ensure residents can make their own decisions, and those are respected when they can't speak for themselves."

Barriers to uptake

Many more people would – or might - like to have an ADRT than actually have one. Barriers to writing an ADRT include the following:

- Lack of knowledge that the option of writing an ADRT exists: Research (conducted in the USA, but the problem is likely to be even greater in Wales) regularly finds that lack of information is a key barrier (Elpern et al., 1993; High 1993). We know from our own outreach activities that some people in Wales don't realise they have the legal right to refuse treatments and many have little or no idea what an ADRT is;

- The belief that ADRTs are only for people who are sick or dying: Early research in the USA showed a widespread belief that advance health care planning was unnecessary for young, healthy people (Ott, 1999). There is a mistaken belief that an ADRT is only necessary once one has been diagnosed with an illness that threatens one's mental capacity and/or life. In fact, loss of capacity can come very suddenly as the consequence of an infection, stroke, assault, sporting accident or road traffic accident (see Box 2). In these circumstances loss of capacity is unanticipated and prior to the incident the person is not (usually) considered to be 'end-of-life', meaning that they are unlikely to be involved in any kind of 'advance care planning';

Box 2: The relevance of an ADRT is not restricted to people who know they have a life-limiting diagnosis or who can predict imminent loss of capacity

Diane David, of Groesfaen, Pontyclun, was severely brain injured in a car crash in April 2006 and was subsequently diagnosed as being in a persistent vegetative state. By 2007 an application was being prepared for court proceedings to allow for life-sustaining treatment to be withdrawn but, after long delays in these proceedings, Diane's husband, Tudor, killed her – and also himself (in December 2008). The coroner delivering a narrative verdict said that Tudor's actions "were solely motivated by his continued devotion to – and love of – his wife". According to their son: "They both said that if their health was such that they could no longer have independent control of their lives, they would not want to live."

(<http://www.walesonline.co.uk/news/local-news/husband-killed-wife-himself-end-1907801>)

An ADRT enables people to prepare for a situation like this and could allow death from treatment withdrawal within the first year of the accident without protracted legal proceedings.

- The myth of 'next of kin' decision-making powers: Many people believe, incorrectly, that they already have guaranteed their right to refuse life-prolonging treatments if they have told friends and family what they would want to refuse. One study found that 88% of relatives of intensive care patients (in Scotland) wrongly believed they could give or refuse consent on behalf of an incapacitated adult (Booth et al., 2004) and we commonly hear this myth reported in research interviews (see Box 3). Conversations with relatives about what one would want in the event of loss of capacity and/or at the end of life is of course very important – but when a family member knows what their relative would want, but is unable to implement that, it can be very painful.

BOX 3: Some people think they are protected because they have told family members what they want. However, family members cannot guarantee their relatives' wishes will be respected because they have no legal power to do so.

Mikaela's father had experienced a stroke from which he made a good recovery, but which left him very clear about what he would want in future were he to experience another incident leaving him with more profound injuries. After a subsequent incident he was indeed left with severe brain injuries from which he did not recover, and which left him unable to move or speak and with no, or very limited, awareness. Mikaela felt very guilty for having been unable to ensure his wishes were respected.

He was in and out of hospital for a year [after the first injury] and he was paralysed on his left side. ... But he got about and he was very independent ... And then he said, "...if anything happens to me again and I can't [be independent], then just sort of – yeah, let me go, kind of thing." ... And even afterwards his friends were coming up to me in town and saying, "You know what his wishes are. You know he said after the last time... Why are you doing it [keeping him alive]?" ... [But] you're not given that sort of choice. It's not up to you. ... – if I could, I would [let him die]. But I can't.'

(Interview with authors of this report, see film of interviewee at www.healthtalk.org/peoples-experiences/nerves-brain/family-experiences-vegetative-and-minimally-conscious-states/mikaela - film clip no. 7

Mikaela's father could have been advised about the option of writing an ADRT specifying (for example) "if I have another stroke or any other incident resulting in brain injuries that leave me without the capacity to make decisions for myself, I refuse all life-prolonging treatments". This could have avoided the situation in which Mikaela believed her father was being kept alive against his wishes.

- A belief that one is disqualified from writing an ADRT: Some people (e.g. with dementia diagnoses or mental illnesses) believe that the option of writing an ADRT is not available to them because they will be found to lack the mental capacity to make treatment refusal decisions. This is not necessarily the case. The Mental Capacity Act provides that any adult 'with capacity' to make treatment refusal decisions can write a valid ADRT. A person must be presumed to have capacity unless it is established that they do not (s. 1(1) MCA). The Mental

Capacity Act is clear that in order to establish that a person lacks capacity to make an ADRT it is necessary to show (a) that they have “an impairment of, or a disturbance in the functioning of, the mind or brain” (s. 2 (1) MCA) and (b) that this renders them unable to understand, remember, or weigh information relevant to making the relevant decisions, or unable to communicate their decision (s. 3(1) MCA). A person with learning disabilities, mental illness or dementia does not necessarily lack such capacity. Additionally, those with borderline or fluctuating capacity to make decisions are entitled to receive support and help to do so (s. 3(2)), yet such help is rarely available.

- Not knowing where to start, or how to write an ADRT: A common obstacle to writing an ADRT is that people don't know how to do it or face practical obstacles (for example, they may have difficulty writing or using a computer, or be isolated from access to relevant material). Many people believe the process to be very complicated and are worried about getting it wrong, or think (incorrectly) that they need a lawyer (Pollack et al., 2010; Kitinger and Wilkinson, 2015). They may also find it difficult to formulate which treatments they might want to refuse under which conditions and they may (legitimately) be concerned that statements like “don't keep me alive if I'm a vegetable” or “I refuse burdensome treatments if I'm dying” are likely to cause problems for healthcare practitioners concerned about (for example) whether a minimally conscious state is included in the lay understanding of “vegetable” or when exactly someone can be said to be “dying”. Without skilled support in talking through these issues people who would like an ADRT sometimes try and find it impossible to produce one.
- Scepticism about the likelihood of an ADRT being effective in practice: People sometimes feel there is little point in writing an ADRT because they don't think their treatment refusals will be respected (e.g. they are concerned that treating clinicians will be unable to access their ADRT, or will simply ignore what they have written (acting in their 'best interests' or with reference to 'sanctity of life') – especially in a medical 'emergency' (Wilkinson, 2013)). On the basis of discussions with health care professionals in Wales, we believe this concern may have some basis in fact, and is something that we believe needs urgently to be addressed via training (see Recommendation 8 below) and improved form design (see Recommendation 4).
- A false belief that one already has an ADRT: Some people believe, incorrectly, that they already have an ADRT because they have told their medical team what

they want (and/or written their wishes down as part of advance care planning). None of these is a substitute for a legally binding ADRT: these communications are advisory, and can be lawfully over-ridden. In addition, some people have attempted to write a legally binding ADRT, but what they have written may well not be in a form that qualifies as a valid ADRT under the Act in the circumstances to which they would wish it to apply. A House of Lords report found that the standard of ADRTs is often "poor and would be challenged if it was ever to be put into use" (House of Lords 2014 para. 194). Some cases which have reached court include one in which the purported ADRT lacked a witness signature (*Re D [2012] EWHC 885 (COP)*) and one on which the date had been incorrectly recorded (*XB & YB [2012] EWHC 1390 (Fam)*). Others have been challenged on the grounds that the person may have lacked capacity to make the relevant decisions at the time that they wrote the ADRT (e.g. *Re E (Medical treatment: Anorexia) [2012] EWHC 1639 (COP)*). Many of the existing purported ADRTs reviewed by the charity *Advance Decisions Assistance* at clinics in both England and Wales are not in fact legally binding documents (for example because they are not witnessed or do not include a statement specifying that their refusals of treatment are to stand even if their life is at risk). This means that some people believe their rights to be protected by law when in fact they are not. It also points to a lack of expertise among some of those seeking to help others with ADRTs which needs to be addressed via training (see Recommendation 8).

Strategies to increase understanding and uptake of ADRTs

Despite the excellent work being carried out in Wales to develop end-of-life planning more generally, relatively little attention has been paid to the specific issue of ADRT. For example, Cwm Taf University Health Board employs two Advance Care Planning Clinical Nurse specialists (the first in the UK). In addition to delivering training and outreach work, they jointly received 92 patient referrals in the 7 months between 1 September 2014 and 25 March 2015 (<http://www.cwmtafuhb.wales.nhs.uk/news/36756>) but they tell us that over the last year they have supported only about 10 people in writing ADRTs. The Paul Sartori Foundation, a hospice at home service covering Pembrokeshire, has a strong commitment to Advance Care Plans and (with financial support from 2 St James Place Foundation Grants) has created bilingual conversation prompt cards, teaching materials and training programmes for professionals and volunteers, and given short presentations to community groups. They have supported around 50+ people in writing Advance Care Plans, only a

proportion of which included ADRTs. It is clear, then, that the numbers of people these organisations are able to support in completing ADRTs remains very low, and also that the focus so far has been (largely) on providing support for Advance Care Plans (rather than ADRTs) in connection with palliative care (rather than across the broader population).

There is an urgent need to address the lack of understanding and uptake of ADRTs in Wales. The Welsh Government has a track record for innovation in health policy and has an opportunity to work with the UHBs, the Trusts, charities and patient groups to address the low uptake of ADRTs in Wales and introduce effective mechanisms to support this tool for increasing patient-centred care.

We have identified the following strategies that could increase understanding of ADRTs (for everyone) and increase uptake of ADRTs for people and help to ensure that ADRTs are valid, applicable and effective in the way intended by the Mental Capacity Act 2005.

Recommendation 1 - Promote public health education, mass representations and cultural reflections on loss of capacity

Provide individual and cultural support to reflect upon, not only the *certainty of mortality*, but also to focus on the *risk of losing capacity* to make one's own decisions about treatment and how this can happen 'out of the blue' as well as being associated with old age or degenerative conditions. The key here is that the focus is not only – or even primarily - on 'death' but also on *surviving with lack of capacity*. An ADRT offers the opportunity to reflect on what medical treatment decisions you might then want if you were to lack the capacity to make decisions for yourself and how you would want decisions to be made. A public awareness strategy could include:

- Prioritising efforts to integrate discussions of how decisions are made for people without capacity (potentially all of us) into activities by bodies such as Byw Nawr including contributing to cultural events such as the Eisteddfod;
- Prompting discussion by providing key information in public spaces (e.g. 'Your next of kin can't decide for you' messages on the side of buses) and creating on-line and mass media explorations of the issues (e.g. see BBC Radio Wales programme on people's experiences in relation to ADRTs - e.g. www.bbc.co.uk/programmes/b0380n5c);
- Inputting into school curricula – to allow young people to be informed about the law, and reflect on the related ethical, political and personal issues as part of their education;
- Developing a media strategy to help inform journalists about the issues and improve informed coverage, as well as to avoid misunderstandings (e.g. the conflation of treatment refusal or withdrawal and 'assisted suicide' or euthanasia).

Recommendation 2 - Provide information about the option of writing an ADRT and alternative/complementary means of decision-making after loss of capacity.

Offer clear and timely information to the public (outside the health system), and to staff and ‘patients’ and clients/residents (within health and social care). This should include the provision of information to:

- Challenge the widespread myth that ‘next of kin’ can consent to, or refuse, treatments on another adult’s behalf; and
- Provide information about writing an ADRT, and discussion of pros and cons, so people can make an informed choice about whether or not they want to pursue this option.
- Provide guidance to clarify the types of interventions the person might want to consider. This might include addressing the distinction between different uses of antibiotics or the assumption that recording a refusal of CPR is enough to ensure no attempt is made at any life-sustaining interventions.

Discussion of the pros and cons of an ADRT could include:

- Discussion of the risks, benefits and associated dilemmas (e.g. that a person who had, in advance, considered an outcome to be intolerable, might, after losing capacity, be content in that situation);
- Exploration of attitudes to risk in the context of uncertainty (e.g. would the person rather risk being kept alive when they would rather have been dead, or risk dying when they would have preferred to be given treatment to keep them alive); and
- Clarification of definitions (e.g. distinction between euthanasia, assisted dying, and an ADRT, and presenting diverse ethical, political and religious positions on ADRTs).

It is also important to clarify the options available to plan in advance for lack of capacity – either as alternatives to, or *in addition to*, an ADRT. These include a Lasting Power of Attorney for Health and Welfare (i.e. appointing a named person with authority to make best interests decisions) and (where available, e.g. in Betsi Cadwaladr) Treatment Escalation Plans. It can also include best interests decisions made by a clinical team with input from advance statements (e.g. Statement of Wishes and Care Preferences) made as part of advance care planning (verbally or in writing) to health care professionals, and/or in conversations with relatives.

Any strategy to promote ADRTs should usefully include offering to review existing purported ADRTs which are likely to include 'Living Wills' (written prior to the MCA 2005 and non-compliant with its requirements for validity), Enduring Power of Attorney (pre-2005, dealing only with financial matters), and other (failed) attempts at legally binding documents in which people have inappropriately placed their trust.

Recommendation 3 - Normalise Advance Decisions to Refuse Treatment

One of the difficulties for health care professionals in raising ADRTs is that, for many patients, it signals an expectation of impending impairment. We recommend normalising consideration of ADRTs for adults of any age and any health status. We would like to see information about ADRTs made routinely available. They might, for example, be raised in the same way as flu jabs, with leaflets and electronic display messages in GP surgeries. We would also like to see questions about whether or not one has an ADRT integrated into routine practices (e.g. on registering for a driving licence or with a GP). Normalisation of ADRTs in these sorts of routine contexts would make it easier to ask about ADRTs (and their alternatives) when a person is hospitalised for elective surgery, moves into a care home or is diagnosed with a particular condition. Currently, given how rarely ADRTs are raised, in some of these latter contexts health care professionals may be reluctant to initiate the topic because they are keen not to provoke anxiety and want to be sensitive to the right time for such a conversation and not to impose discussion on people who don't want to think about treatment refusal at that point. It may also be easier for people to update and revise an existing ADRT in the light of a new diagnosis or change of circumstances than to engage with the topic of treatment refusal from scratch.

Government support for good institutional practice in relation to advance care planning in general, and ADRTs in particular, could be useful. One clinical services manager told us:

One of our GP practices is asking all people newly admitted to care homes to make a statement of wishes and care preferences. This is the kind of good practice that could be encouraged by Healthcare Inspectorate Wales as GP inspectors, Care and Social Services Inspectorate Wales as care home inspectors and Health Boards and social services departments as commissioners of care.

Offering the option of assistance in writing an ADRT in this sort of situation – and supporting it in the same way via formal channels – would help to normalise the practice.

Recommendation 4 - Amend official forms that may mislead people about the status of their own or their relative's expressed wishes.

All official forms should be written so as to avoid misleading people about the status of consent, refusal of consent, or the legal standing of their own (or the patient's) wishes and relationship between different documents. There is currently some potential for misleading people on a variety of health and social care forms we have seen in use in Wales including consent and best interest forms, advance care planning documentation, DNACPR and Treatment Escalation Plan (TEP) forms, and the Lasting Power of Attorney (LPA) documentation produced by the Office of the Public Guardian. In particular:

- Forms recording treatment refusal discussions with capacitous patients (e.g. as part of Advance Care Planning [ACP] or Treatment Escalation Plans and DNACPR) should offer patients the option of making their treatment refusals legally binding;
- Forms recording treatment decisions concerning non-capacitous patients should show how the expressed (present and/or prior) wishes of the non-capacitous patient have been taken into account and should accurately reflect the legally binding nature of a valid and applicable ADRT (which cannot be subsumed into best interests); and
- Forms to register Lasting Power of Attorney need more guidance on the interface between an ADRT and an LPA since we have clear evidence (from work with clients through the charity *Advance Decisions Assistance*) that this is causing concern and confusion. We have already advised The Office of the Public Guardian of this issue, but it might also be helpful for the Welsh Government to request revisions to the application form. (Further details of all these issues about form design are detailed in the Annex 2).

Recommendation 5 – Provide support for writing ADRTs for those who decide they want one

We recommend the provision of diverse forms of support (including multi-media resources, telephone and face-to-face advice as appropriate). This will help to reach different people in different ways and put support in place with the intention of ensuring that each ADRT accurately reflects the person's wishes, and is valid and applicable in the circumstances to which they wish it to apply.

An ADRT is a legally binding refusal of treatment if it is (a) valid and (b) applicable. The creation of a 'valid' ADRT is fairly straightforward: it requires only that a capacitous patient

signs a document that is witnessed and includes a statement to the effect that treatment refusal is maintained even if life is at risk (see s. 25 Mental Capacity Act 2005 for details). The applicability of treatment refusal can also be straightforward: for example, when CPR is refused under *all* circumstances. But applicability can also be more complicated and depend on diagnosis or prognosis – depending on what the person has said about the situation under which their treatment refusal should become applicable, e.g. “I refuse CPR *only* if I am in a permanent vegetative state”.

Some basic information and support could be provided online. This could collate, and translate into Welsh, existing good materials (e.g. outputs created by charities such as *Advance Decisions Assistance and Compassion in Dying*). In January 2016 the latter organisation launched an on-line tool (mydecisions.org.uk) to help people complete ADRTs. We also recommend the creation of a short video about ADRTs designed specifically for Wales (see the Scottish video on LPAs at <https://www.youtube.com/watch?v=3sz9UOxnois>).

Provision of information online is likely to be particularly useful for health care professionals and to those carrying out outreach activities in the community. It should be remembered, however that more than a quarter of households in Wales do not have access to the internet and only 22% of people over 75 in Wales have used the internet.

(<https://libalyson.wordpress.com/2013/06/27/internet-access-in-wales-detailed-survey-results/>) and a fifth of people aged 18 and over in Wales say that they have never used the internet.

One possible approach is to make it quick, easy and simple to complete a basic ‘starter’ ADRT (see idea explored below). Another (complementary) approach is to provide more in-depth support as appropriate. Research evidence shows that the best way to support people in writing ADRTs is to provide oral information over multiple sessions (Bravo et al., 2008). Dialogue and face-to-face support could come from health care professionals or others (e.g. advisors from charities)². In accordance with the spirit of the Mental Capacity Act 2005, there should be no charge to individual members of the public for help with writing ADRTs, they should be free and not subject to commercial forces.

Education about ADRTs needs to be *interactive* not *didactic* (Jezewski et al., 2007). This could be integrated relatively easily into at least some Advance Care Planning consultations (if health care professionals have the appropriate training and confidence with ADRTs).

Research suggests that the most successful interventions incorporate direct patient-

² Note: we do *not* recommend solicitors, unless they have had special training as there is evidence that some solicitors’ clients have signed a documents that does not refuse all the treatment that they in fact wished to refuse or does not refuse treatment under the circumstances under which they had intended to do so (Kitzinger, 2014).

healthcare professional interactions over multiple visits (Ramsaroop et al. 2007). This is borne out by the experience of Clinical Nurse Specialists in Cwm Taf who tell us that supporting a patient to write an ADRT (geared to the specific needs of the patient, rather than the 'starter' AD described above) usually involves 2-3 visits. Ideally the provision of support in writing an ADRT involves an in-depth, facilitated and holistic one-to-one discussion of a person's values, wishes, feelings and beliefs.

The support provided for ADRTs should explore the person's reflections about what (for them) constitutes a quality of life that they consider worthwhile and this should normally be incorporated into the same document as the ADRT. Examples we have seen include:

- "By 'a quality of life that I would consider worthwhile' I mean a return to independent living";
- "What I would want is being able to recognize my family and friends and to take pleasure from their company"; and
- "As long as I seem happy or content (and not in pain) that's a quality of life I consider worth living."

Support should be given to enable people to reflect on their values, explore their fears about how a disease might progress, and understand the kinds of treatments, care and support available to them in future.

Recommendation 6 - Adopt broadcast and narrow-cast targeting

We recommend a general 'broadcast' approach to raising awareness about ADRTs, including publicising the existing charity telephone helplines providing information and assistance, combined with targeted offers of face-to-face support in writing ADRTs where possible.

One strategy would be to target face-to-face support to people already highly motivated to write ADRTs (e.g. those with experience of caring for others who have lost of capacity or those concerned about their future because of a specific diagnosis). This approach has some benefits but might disproportionately serve the needs of the more educated/assertive/literate population. Special support would be needed to maximise inclusiveness for other people who might want an ADRT (e.g. support for people living in care homes, or people with reduced or fluctuating capacity such as people with learning difficulties who are also at higher risk of developing dementia).

Specific strategies could include:

- Providing free advice sessions for particular target groups e.g. older people caring for a partner with dementia or staff in specialist centres for severely brain injured residents.
- Partnerships could be developed with charities, such as dementia support organisations and employers, e.g. UHB, with 'surgery sessions' provided in partnership with employers in work time to support ADRT completion. (This would have the added benefit of raising awareness of ADRTs among health professionals.)
- Promotion of information and support during a *designated time* period (e.g. during 'Dying Awareness' week in May each year).
- Trialling the offer of support in *designated areas*. This could include choosing a particular postcode area in a city for intensive support or providing travelling facilities, such as 'an advice bus' located in a particular area for a few days at a time, especially in rural areas across Wales, with a Welsh speaking advisor. (A pool of volunteers already exist who would be willing to operationalise this)

In supporting people to write ADRTs, it is important to use the language of preference with people (the one in which they 'think' and communicate within the family) - this is key to engaging with vulnerable and frail people about the issue of medical treatments. Thomas and Conlon (2015), who have piloted innovative promotion of advance care planning in Wales, also note that: "Although there are very few monoglot Welsh speakers, it is a first language for many elderly people in the North of the country. Some people with dementia will retain their ability to communicate in Welsh long after their fluency in English diminishes. This is likely to coincide with a time when ACP is particularly needed." (Welsh language initiatives could include working with the Office of the Public Guardian to increase people's awareness of the OPG's webpages in Welsh about LPAs).

Recommendation 7 – Create well-designed documents and pro-forma that are compliant with the law on consent and treatment refusal, and ensure quality control

Any forms or documents put out by Health Boards that refer to consent to or refusal of treatment must be reviewed by staff employed by the Health Boards to oversee consent and capacity issues (e.g. Mental Capacity Act Managers or the NHS legal service). Without this there is a serious risk of non-compliance with relevant legislation (as we have seen in several of the documents we've reviewed).

We recommend creating partnerships to develop an identifiably Welsh-Government-approved version of a basic ADRT form, along with kite-marking of high-quality materials for public and professional use (including existing kite-marks such as ‘Information Standard’).

Easily accessible pro-forma are available (e.g. mydecisions.org.uk). We also recommend that such a form include the suggestion of a photograph of the person on the front page – making it clear that this is not a legal requirement but an enormous benefit to health care professionals who may need to identify very quickly that they have the correct person, and essential for paramedics who may have only information about the address but not the identity of the person with the ADRT. Clear permission on the form that the information can be shared with health care staff (and family members if wished) will also avoid potential problems with interpretation of ‘patient confidentiality’ (Note: We have also sent these recommendations to Compassion in Dying for mydecisions.org.uk and would want to incorporate these into a Welsh version of the resource.) Development and branding should draw not only on Local Health Board and Government sources but also on trusted sources such as charities and hospices – to ensure proper incorporation of expertise so that initiatives can not be misread as ‘money saving’ or top-down.

A vital first step, in our view, would be the development of a basic ‘starter’ ADRT for currently healthy people with no particular reason to suspect upcoming loss of capacity. This ‘starter’ ADRT would be designed to record the wishes of people who would not be kept alive if they suffered a prolonged period of unconsciousness likely to lead to the permanent vegetative or minimally conscious states: these are the two conditions which can come out of the blue for otherwise healthy people and which surveys show that around 80% of people would wish to avoid by refusing long-term treatment (Demertzi 2011).

Recommendation 8 - Train relevant practitioners to ensure that they understand and provide appropriate guidance or referral, and can assess ADRTs and respect those which are valid and applicable

The House of Lords (2014, para 195) has expressed concern about the levels of awareness among professionals of the role and status of ADRTs, citing evidence that health care professionals’ knowledge is “still very patchy”. It is essential to develop training provision for charities, social care and health care organisations and professionals. Some of this could be e-learning (e.g. see Williams and Rigby, 2015) and some via existing fora such as GP practice clusters developing services for the local population. Training provision will help relevant practitioners to have the information and confidence to inform people about ADRTs, and provide appropriate guidance to people who wish to write ADRTs – or refer them on to

people who can. The suggestion was made by one palliative care consultant that “perhaps there should be a proper training and accreditation program agreed with an academic body”. Other suggestions include the creation of an external “checking” facility to which people can send ADRTs before signatures are added for checking of validity, clarity and likely ease of use in practice and for a “network of professional medical volunteers to act as an expert resource and adviser when needed”. We think all these options are worth considering. This will require core standards, skills and competencies to be put in place, and could include support groups where emerging professional experience can be explored. For example, sometimes discussion of what people fear about end-of-life, and the offer of support to write an AD, can be an appropriate response to a dying person who expresses a wish for assisted dying or declares they want to ‘go to Switzerland’.

Specialist training - combined with nominated ‘ADRT champions’ within each relevant organisation - may help to create/confirm good practice. Training/championing could include providing reassurance about the law to those working in this field. This would be particularly relevant to raise awareness that, as stated in the Mental Capacity Act, ‘A person does not incur liability for carrying out or continuing the treatment unless, at the time, he is satisfied that an advance decision exists which is valid and applicable to the treatment (s.26(2)) and that ‘A person does not incur liability for the consequences of withholding or withdrawing a treatment from P if, at the time, he reasonably believes that an advance decision exists which is valid and applicable to the treatment (s. 26(3)).

It is important that practitioners are appropriately supported - by colleagues, ethics committees, legal advisors, and by the design of the forms they are expected to use - to respect valid and applicable ADs. Key information needed by health care practitioners includes:

- Knowing when an ADRT is not valid and applicable (e.g. an ADRT is not valid if P has withdrawn their decision (s. 25 (2a)) and this is not required to be in writing (s. 24(5));
- Recognising that capacity at the time the ADRT was made should be presumed unless there are grounds to believe otherwise;
- Recognising that an ADRT to refuse one treatment (e.g. CPR) does not mean assumptions should be made (either way) about other treatments (e.g. IV antibiotics).
- Providing information for health care professionals about what/how to respond if the family want to try to overrule an ADRT; and
- How to handle health care practitioners’ conscientious objection to following a patient’s wishes.

Dr Clifford Jones (who, among other roles, chairs the RCGP Wales End of Life Care Network) wrote:

"My experience is that GPs (and health care professionals in general) lack knowledge and confidence regarding ADRTs. And their understanding is based on anecdote and often incorrect. Education provision (via the most practical and appropriate means) may help improve GP confidence and competence in discussing and interpreting ADRTs".

Additionally, Andrew Jenkins (Deputy Director for Medical and Clinical Services of the Welsh Ambulance Service NHS Trust) has requested that CPD training about ADRTs be made available for paramedics and Nick Wilson (Deputy Manager of the Welsh Renal Networks) asked for training to be made available to chronic kidney disease and pre-dialysis nurses and nephrologists. Many psychologists are also interested in training (Kitzinger & Wilkinson 2015(b)).

In addition to existing training already available (on a small scale) in Wales (e.g. from the Paul Sartori Hospice and the Cwm Taf Clinical Nurse Specialists) several charities, including *Advance Decisions Assistance* and *Compassion in Dying* provide training of this type.

Compassion in Dying is a charity which supports people to write Advance Decisions with an online decision-making tool for members of the public (<https://mydecisions.org.uk>) - currently available only in English. It has also produced a 'tool kit' for health professionals with easy to follow guidelines (see Annex 3).

Recommendation 9 - Ensure accessibility of ADRTs

A major disincentive to writing an ADRT - and a commonly-voiced concern of those who have, or would like to have, one - is whether it will be accessed when needed and used to determine treatment. The House of Lords (2014, para. 197) found that there was no "systematic process for the recording, storage and retrieval of this information at the time when the person who made the [advance decision] lost capacity". The computerised data management systems used to record medical decisions must be fit for purpose.

In our consultations we picked up concerns about both the compatibility of systems used across different health boards and with the clinical patient management system Adastra used for out of hours services in Wales³. One GP working in Wales commented:

"The lack of standardisation in this field and the fact that we've combined primary and secondary care providers, ... but we haven't combined IT systems

³ www.advancedcomputersoftware.com/ahc/products/adastra-patient-management-system.php

makes this unworkable... The hospital in one health board doesn't even use the same data management system as the hospital in the neighbouring health board.”

Several GPs in Wales have reported concerns with how Adastral operates in relation to the way in which treatment refusals – especially but not only DNACPR - are recorded. This is something that we believe merits further consultation.

Charities routinely advise people about how to maximize the chance that ADRTs will be accessible to health care professionals when they are needed, e.g. requesting a GP to scan the AD into medical records (and Summary Care Records), using Medicalert jewelry and the Lions ‘message in a bottle’ scheme. The extent of the concern about this is evidenced by the fact that some people, anxious that nobody will know their wishes, go so far as to get tattoos refusing life-prolonging treatment. (Tattoos are *not* legally binding ADRTs). The Clinical Nurse Specialists in Cwm Taf report that the present system makes it very time-consuming to ensure that patient advance refusals of treatment are communicated separately to all relevant care providers (i.e. the care home, the hospital, the ambulance service etc.): having a central repository for ADRTs is a good idea because it would “improve communication about end of life care and reduce the time investment in making sure that communication happens” (Caroline Allen, Clinical Nurse Specialist, Cwm Taf LHB – Palliative Care).

There is not yet a national repository for ADRTs in Wales and we have had some preliminary discussions to explore whether the Welsh Care Record System might be usable for this purpose – with ADRTs uploaded by clinicians on patients’ behalfs but also with people able to upload their own via a patient portal. One possibility we have raised is that the Welsh Care Records System [WCRS] could include a ‘flag’ on the front page to indicate that the patient has lodged an ADRT and allow a clinician to access the documentation in order to then assess its validity and its applicability to the situation. In addition, we suggest that a simple advance validation process be put in place where a patient requests a DNACPR order, and this validated advance decision to refuse CPR could have a ‘flag’ of its own. Basing a DNACPR flag on a patient’s validated ADRT in relation to CPR would make the DNACPR notice legally binding. This would avoid some of the problems that currently occur when a DNACPR has simply been agreed between patient and clinician – but is not necessarily understood by, or binding upon, others who attend the patient e.g. a paramedic called to a care home or a locum doctor attending out of hours.

BOX 5: Some people are so concerned about potential lack of access to their advance decisions that they have tattoos to alert health care professionals.



Taken from a video in which one man explains why he feels so strongly about refusing treatment. The 3 min video can be viewed on the *Advance Decisions Assistance* website: <http://adassistance.org.uk/hints-and-tips/>

Since it is a good idea to review ADRTs to keep them up to date, it would also be useful to find a way of generating automated reminders on an annual basis – and ensuring the proper recording of succession documents. Discussion with the software developers and form-designers and with the Welsh Ambulance Service is necessary to make sure that the interface between DNACPR and other treatment refusals is clear and effective.

Recommendation 10 - Audit and research interventions

If and when initiatives are pursued to improve the situation in Wales, it would be invaluable to have a robust audit and follow up. We would also recommend that any government strategy to increase the uptake of ADRTs should, in addition to uptake-statistics, document the incidence and justification for informed rejection of ADRTs. It would also be useful to record uptake of any alternative or complementary mechanisms (e.g. LPAs). Such research on the implications of strategies to increase uptake in Wales would help to inform future strategy in and beyond Wales and would have international value in terms of providing information for other countries that might wish to follow the Welsh example.

References

- Andorno R., Biller-Andorno N., Brauer S. (2009). **Advance health care directives: towards a coordinated European policy?** *Eur J Health Law*, 16(3), 207-27.
- Booth, M.G., Doherty, P., Fairgrieve, R. and Kinsella, J. (2004). **Relatives' knowledge of decision making in intensive care.** *Journal of Medical Ethics*, 30: 459-462.
- Bravo, G., Dubois, M.F. & Wagneur, B. (2008). **Assessing the effectiveness of interventions to promote ADs among older adults: a systematic review and multi-level analysis.** *Social Science & Medicine*, 67(7): 1122-32.
- Compassion in Dying (2015) **Plan Well, Die Well.** Compassion in Dying.
- ComRes (2015) Dying Matters Survey. http://www.comres.co.uk/wp-content/themes/comres/poll/NCPC_Dying_Matters_Data_tables.pdf
- Council of Europe (2009) Recommendation CM/Rec (2009). **11 of the Committee of Ministers**, <https://wcd.coe.int/ViewDoc.jsp?id=1529977&Site=CM;>
- Council of Europe (2012) Resolution 1859 (2012). **Protecting human rights and dignity by taking into account previously expressed wishes of patients** <http://assembly.coe.int/nw/xml/XRef/Xref-XML2HTML-EN.asp?fileid=18064&lang=en>
- Daveson, B., Bausewein, C., Murtagh, F, E.M., Calanzani, N., et al (2013). **To be involved or not to be involved: A survey of public preferences for self-involvement in decision-making involving mental capacity (competency) within Europe.** *Palliative Medicine*, 27(5), 418-427.
- Demertzi, A., Ledoux, D., Bruno, M-A., Vanhauzenhuysse, A., Gosseries, O., Soddu, A., Schnakers, C., Moonen, G. and Laureys, S. (2011). **Attitudes towards end-of-life issues in disorders of consciousness: a European Survey.** *Journal of Neurology*, 258, 1058–65.
- Detering, K. (2010). **The impact of advance care planning on end of life care in elderly patients: Randomised control trial.** *British Medical Journal*, 340, c1345.
- Elpern, E. H., Yellen, S. B., & Burton, L. A. (1993). **A preliminary investigation of opinions and behaviors regarding advance directives for medical care.** *American Journal of Critical Care*, 2(2), 161–167.
- Escher, M., Perneger, T.V., Rudaz, S. et al (2014). **Impact of Advance Directives and a Health Care Proxy on Doctors' Decisions: A Randomized Trial.** *Journal of Pain and Symptom Management* 47(1): 1-11.

Evans N., Bausewein C., Meñaca A., Andrew E.V., Higginson I.J., Harding R., Pool R., Gysels M. (2012) **A critical review of advance directives in Germany: attitudes, use and healthcare professionals' compliance.** *Patient Educ Couns*, 87(3), 277-88.

General Medical Council (2010). **Treatment and Care towards the End of Life: Good Practice in Decision-Making.** http://www.gmc-uk.org/End_of_life.pdf_32486688.pdf

Halliday, S. (2003). **Decision - Making At The End Of Life and The Incompetent Patient: A Comparative Approach.** *Medicine & Law*, 22.3 (2003), 533-542

Halliday, S. (2011) **Legislating to give effect to precedent autonomy: comparative reflections on legislative incompetence.** *Medical Law International*, 11.2, 127-171

Halliday, S., Kitzinger, C. & Kitzinger, J. (2014) **Law in everyday life and death: A socio-legal study of chronic disorders of consciousness.** *Legal Studies*, 35(1), 55-74.

High, D. M. (1993). **Why are elderly people not using advance directives?** *Journal of Aging and Health*, 5(4), 497–515.

HM Government (2014). **Valuing every voice, respecting every right: Making the case for the Mental Capacity Act : The Government's response to the House of Lords Select Committee Report on the Mental Capacity Act 2005**

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/318730/cm8884-valuing-every-voice.pdf

House of Lords (2014) **House of Lords Select Committee Post-Legislative Review on the Mental Capacity Act 2005 (2014).**

<http://www.publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm>

Jezewski M.A., Meeker M.A., Sessanna, L., Finnell, D.S. (2007). **The effectiveness of interventions to increase AD completion rates.** *J Aging Health*, 19(3):519-36.

Kitzinger, C. (2014). **Advance decisions: do they work in practice?** *Elder Law Journal*, 4(2): 198-204.

Kitzinger, C. & Wilkinson, S. (2015a). **Evidence to The Law Commission 2015 Consultation on the Law on Mental Capacity and Deprivation of Liberty**

Kitzinger, C. and Wilkinson, S. (2015b). **Advance decisions – a role for psychologists.** *The Psychologist*, 28(12): 972-975.

Kitzinger, J. (2015). **Evidence to The Law Commission 2015 Consultation on the Law on Mental Capacity and Deprivation of Liberty**

Kitzinger, J. and Kitzinger, C. (2013). **The “window of opportunity” for death after severe brain injury: Family experiences.** *Sociology of Health & Illness*, 35(7): 1095-1112

Kuhnlein P., Kubler A., Raubold S., Worrell M., Kurt A., Gdynia H.J., et al. (2008). **Palliative care and circumstances of dying in German ALS patients using non-invasive ventilation.** *Amyotroph Lateral Scler*, 9: 91–8.

Lang F.R., Wagner G.G. (2007). **Living will incidence in non-clinical population samples: conditions and reasons for refusal.** *Dtsch Med Wochenschr*, 132: 2558–62

NICE (2011) **Quality standard for end of life care for adults** National Institute for Health and Care Excellence.

Ott, B. B. (1999). **Advance directives: The emerging body of research.** *American Journal of Critical Care*, 8(1), 514–519.

Pollack, K.M., Morhaim, D., Williams, M. (2010). **The public's perspectives on advance directives in Maryland: implications for state legislative and regulatory policy.** *Health Policy*, 96(1): 57–63. <http://www.ncbi.nlm.nih.gov/pubmed/20106542>

Ramsaroop, S.D., Reid, M.C., Adelman, R.D. (2007). **Completing an AD in the primary care setting: what do we need for success?** *J Am Geriatr Soc*, 55(2): 277-83.

Rao, J.K., et al. (2014). **Completion of advance directives among US consumers.** *American Journal of Preventative Medicine*, 46(1): 65-70.

Resuscitation Council (UK) (2014). **Decisions Relating to Cardiopulmonary Resuscitation.** 3rd edn. <http://compassionindying.org.uk/library/dnar-forms-and-cpr-decisions/>

Silveira M.J., Wiitala W., Piette J. (2014). **Advance directive completion by elderly Americans: a decade of change.** *Journal of the American Geriatrics Society*, 62(4): 706.

Simón-Lorda, P., Tamayo-Velázquez M.I., Barrio-Cantalejo I.M. (2008) **Advance directives in Spain. Perspectives from a medical bioethicist approach.** *Bioethics*, 22(6), 346-54.

Tschirhart, E.C., Du, Q., Kelley, A. S. (2014) **Factors Influencing the Use of Intensive Procedures at the End of Life.** *Journal of the American Geriatrics Society*. 62(11): 2088-2094.

Thomas, S. and Conlon, L. (2015). **Think about it, talk about it, write it down’.** Volunteer-facilitated ACP (Conference poster from Paul Sartori Hospice Care and Community Choice and Inclusion, Pembrokeshire, Wales. Presented at ACPEL 2015 in Munich)

Van Oorschot, B., Hausmann, C., Kohler, N., Leppert, K., Schweitzer, S., Steinbach, K., et al. Patients as partners. (2004). **Tumor patients and their participation in medical decisions.** Bundesgesundheitsblatt Gesundheitsforschung Gesundheitsschutz 47, 992.

Veshi, D. & Neitzke, G. (2015). **Living wills in Italy: Ethical and comparative law approaches.** European Journal of Health Law, 22(1), 38-60

Wiesing, U., Jox, R., Heßler, H., Borasio, G. (2010). **A new law on advance directives in Germany.** Journal of Medical Ethics, 36, 779.

Wilkinson, A., Wenger, N. & Shugarman, L. (2007). **Literature review on advance directives. US Department of Health and Human Services.** <http://aspe.hhs.gov/basic-report/literature-review-advance-directives#note20>

Wilkinson, S. (2013). **An analysis of calls to the Compassion in Dying information line.** Available at: <http://compassionindying.org.uk/library/analysis-calls-compassion-dying-end-life-rights-information-line/>

Wilkinson, S. (2016, in press). **Barriers to making an Advance Decision to refuse treatment: An analysis of calls to an end-of-life rights helpline,**

YouGov Poll 2013

Williams, L. and Rigby, J. (2015). **Advance decisions in psychiatry: England and Wales'**

CPD online course Royal College of Psychiatrists (accessed 9 December 2015)

www.psychiatrycpd.co.uk/learningmodules/advancedecisionsinpsychiatr.aspx

Annex 1 Summary of General Medical Council (2010) Treatment and Care towards the End of Life: Good Practice in Decision Making

A. ADULT WITH CAPACITY TO REFUSE TREATMENT

The doctor uses specialist knowledge and experience and clinical judgement, and the patient's views and understanding of their condition, to identify which investigations or treatments are clinically appropriate and likely to result in overall benefit for the patient. The doctor explains the options to the patient, setting out the potential benefits, burdens and risks of each option. The doctor may recommend a particular option which they believe to be best for the patient, but they must not put pressure on the patient to accept their advice. The patient weighs up the potential benefits, burdens and risks of the various options as well as any non-clinical issues that are relevant to them. The patient decides whether to accept any of the options and, if so, which. They also have the right to accept or refuse an option for a reason that may seem irrational to the doctor or for no reason at all.

B. ADULT WITHOUT CAPACITY TO REFUSE TREATMENT - WITH ADRT

If the patient has made an advance decision ... refusing a particular treatment, the doctor must make a judgement about its validity and its applicability to the current circumstances. If the doctor concludes that the decision ... is legally binding, it must be followed in relation to that treatment. Otherwise it should be taken into account as information about the patient's previous wishes.

C. ADULT WITHOUT CAPACITY TO REFUSE TREATMENT - WITH ATTORNEY FOR HEALTH AND WELFARE (REGISTERED WITH THE OFFICE OF THE PUBLIC GUARDIAN) WITH AUTHORITY TO MAKE THE DECISION IN QUESTION⁴

The doctor explains the options to the Attorney (or other legal proxy) as they would do for a patient with capacity), setting out the benefits, burdens and risks of each option. The doctor

4. ⁴You should bear in mind that the powers held by an Attorney may not cover all healthcare decisions, so you should check the scope of their decision-making authority. If the attorney does not have the power to make a particular decision, the doctor must take account of the proxy's views (as someone close to the patient) in the process of reaching a decision.

may recommend a particular option which they believe would provide overall benefit for the patient. The legal proxy weighs up these considerations and any non-clinical issues that are relevant to the patient's treatment and care, and, considering which option would be least restrictive of the patient's future choices, makes the decision about which option will be of overall benefit. The doctor should offer support to the legal proxy in making the decision, but must not pressurise them to accept a particular recommendation. As well as advising the legal proxy, the doctor must involve members of the healthcare team and those close to the patient as far as it is practical and appropriate to do so, as they may be able to contribute information about the patient that helps the proxy to reach a decision.

D. ADULT WITHOUT CAPACITY TO REFUSE TREATMENT AND WITH NO ADRT OR ATTORNEY WITH THE RELEVANT DECISION-MAKING POWER.

The doctor is responsible for making the decision. The doctor must consult with members of the healthcare team and also with those close to the patient (as far as it is practical and appropriate to do so) about the patient's values, feelings wishes and beliefs and what they would have wanted and/or do want in this situation. The doctor must make a decision in the patient's best interests.

Annex 2 Examples of amendments recommended to existing forms

1) Forms recording treatment refusal discussions with patients with capacity to make their own decisions (e.g. as part of Advance Care Planning, Treatment Escalation Plans or DNACPR assessments) should offer them the option of making their treatment refusals legally binding.

It is rarely the case that ACP or DNACPR discussions result in documentation meeting the criteria of an ‘Advance Decision’ to refuse treatment as defined by the Mental Capacity Act 2005. These discussions may, however, leave the patient believing that they have assured that their treatment refusals will be honoured, thereby misleading them about the legal status of their stated wishes. We recommend that such documentation should explicitly state that the recorded wishes are not legally binding on health care practitioners and should offer the option of making them legally binding where this is possible and the person wishes it. For example, ACP forms could include the statement: ‘Please note: this record of your preferences is not legally binding on your treatment team, and, if you lose capacity, your choices recorded here can be over-riden if considered to be in your best interests to do so. If you do NOT wish anyone to be able override some/any of these treatment refusals then you need to write these out in Section X, sign and have your signature witnessed”. (Section X would be so written as to ensure that these decisions met the criteria for a legally binding AD, e.g. by including the phrase ‘I maintain this refusal even if my life is at risk’). It might also be advisable, if capacity might be in doubt, to include the safeguard of some testimony to the individual’s capacity at the time.

The All-Wales DNACPR form should avoid misleading the patient that an “Advance Decision” (the title of Section 3) has been made by a patient who states in discussion with a health care professional that CPR is not in accord with their expressed wishes. Since an oral declaration to refuse a life-prolonging treatment is advisory only (s. 25(6) Mental Capacity Act 2015) – and nothing about recording that decision on a DNACPR form changes that – a patient who makes such a declaration should be offered the opportunity to write an ADRT refuse DNACPR in a legally binding form so that it constitutes an ADRT (i.e. including a signature, witness and statement to the effect that they maintain this refusal even if their life is at risk). There should be a system of flagging this advance decision to refuse CPR on all documentation relation to the patient to avoid problems in emergency situations. In addition we recommend that the patient is invited to give explicit consent to the sharing of

this information with anyone legitimately concerned with their care (to avoid ‘patient confidentiality’ creating subsequent difficulties as we know happened in at least one case).

2) Forms recording treatment withholding or withdrawal from non-capacitous patients should show how the expressed (present and/or prior) wishes of the non-capacitous patient have been taken into account by routinely including three alternatives for each treatment decision.

The three key alternatives which should be included are:

(a) This decision has *already been made* by the person in advance via a valid and applicable Advance Decision to Refuse Treatment. (In this case the patient’s refusal is legally binding and the views of ‘next of kin’, those who care for the patient and have an interest in the patient’s welfare and health care professionals are NOT relevant to the decision to withdraw or withhold treatment, unless the ADRT explicitly requests that these should be taken into account.)

(b) (*if a does not apply*) This decision has been made in the patient’s best interests by:

(i) an attorney appointed by the patient via a Lasting Power of Attorney for Health and Welfare who has the appropriate authority to act; or

(ii) a Welfare Deputy appointed by the Court who has the appropriate authority to act. (Note that neither ‘next of kin’ (*per se*) nor IMCAs have any decision-making power, although they should be consulted as to what the patient wants/would have wanted.)

(c) (*if neither a or b apply*) This decision has been made by X [e.g. treating clinician] in the patient’s best interests.

The form may also need to include guidance regarding the process of reaching ‘best interests’ decisions (i.e. both (b) and (c), but *not* (a), which is not a best interests decision). The process of best interests decision making a record of the process of consultation, including consideration of the patient’s own current views (if accessible) and the views of ‘next of kin’ (and/or an IMCA) *about what the person wants/would have wanted*, and consideration of other evidence of the person’s views including any written documents and the ‘habits and behaviours’ that might indicate a person’s values, wishes, feelings and beliefs (Mental Capacity Act Code of Practice).

In addition to the above, we recommend revision of the All-Wales DNACPR form to avoid conflating ‘next of kin’ (who have no decision-making authority) with ‘proxies’ such as attorneys who may have full decision-making authority to refuse CPR on the patient’s behalf.

3) Forms to register Lasting Power of Attorney need to include more guidance on the interface between an ADRT and an LPA

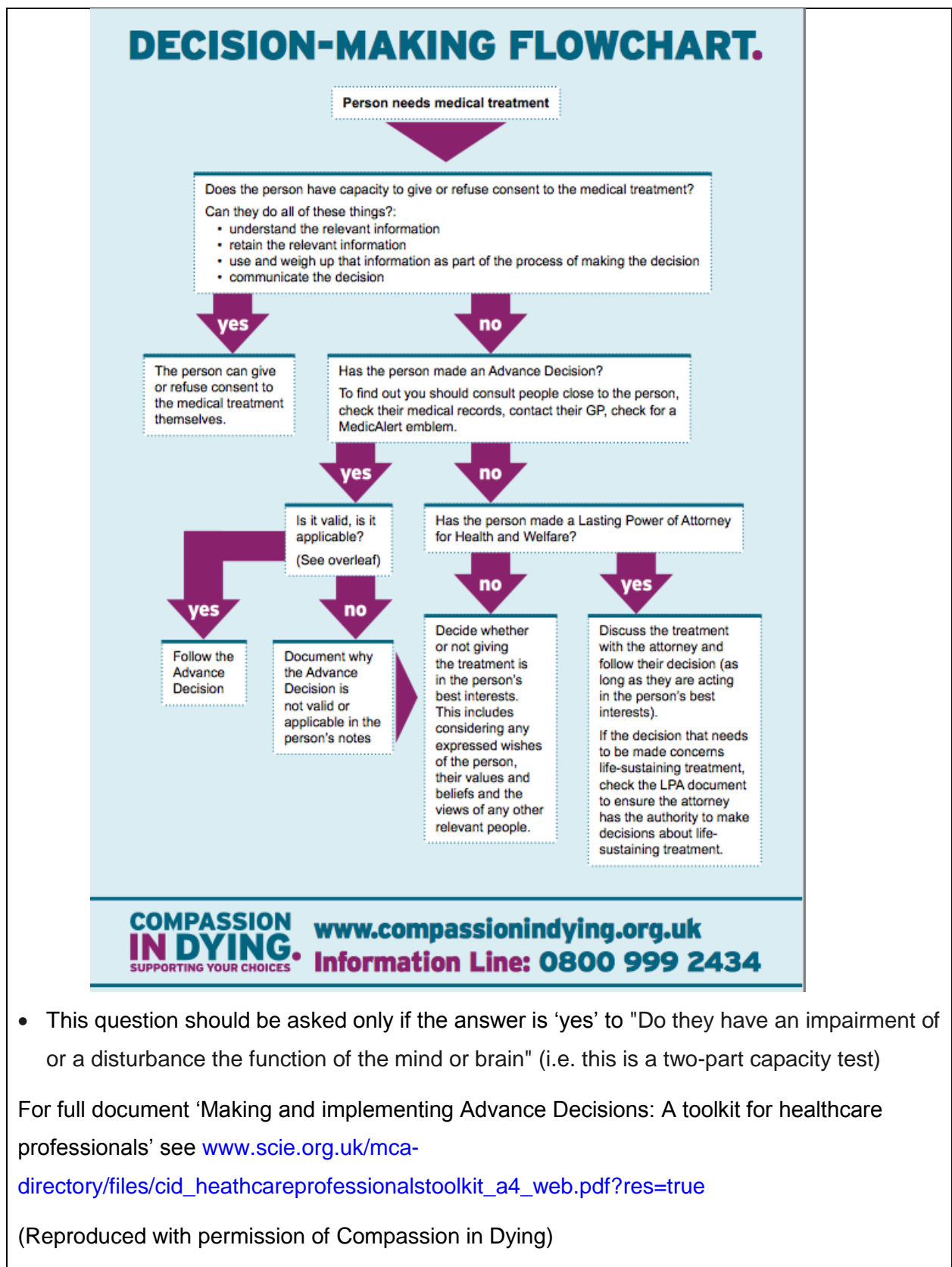
Application forms for the creation of a Lasting Power of Attorney for Health and Welfare (LPA(H&W)) are available from the Office of the Public Guardian (<https://www.gov.uk/power-of-attorney/make-lasting-power>). Although the guidance accompanying this form does provide some information about the relationship between an ADRT and an LPA(H&W) (including, “If you give your attorneys the power to decide about life-sustaining treatment and have made an advance decision, your LPA might override your advance decision”, p. 26 Section A5) there is insufficient information about this, and the form is also badly designed with respect to people who have *both* an AD and an LPA(H&W). In our work with the charity *Advance Decisions Assistance* we have uncovered widespread confusion and misinformation about this. The Office of the Public Guardian has no immediate plans to revise the application form. It would be helpful for the Welsh Government to request it to do so.

4) Data management systems need to be designed to accurately record paper forms and to be compliant with the Mental Capacity Act 2005.

The digital records of these forms held on data management systems across different health boards, with Adastral and with the Welsh Care Record System (if relevant) should be compliant with the provisions of the Mental Capacity Act 2005. For example, they must be able to record legally-binding treatment refusals (e.g. of CPR) from people without any life-limiting conditions who are not on an end-of-life care pathway. The conversion of completed ADRTs (and similar documents) into electronic format needs careful consideration and cross-checking. Professionals we consulted very commonly expressed dissatisfaction with either the paper forms, or their electronic versions or the interface between them. One noted:

“Really helpful that you’ve mentioned the problems/misunderstandings in official forms/documents – e.g. ACP forms and DNACPR. The problem with terms being wrongly used/stated is that they quickly become received wisdom and then it’s a hard job getting people to understand what the Mental Capacity Act actually says!”

Annex 3 Decision making flowchart for practitioners*



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Acknowledgements

As preparation for this report we held a consultation event with invited stakeholders in Cardiff in November 2015 and we talked to diverse individuals and representatives including social workers, ICU and palliative care practitioners, care home staff and GPs, 'service-users' (with capacity but with life-limiting conditions), Mental Capacity Advocates, Advance Care Planning and Mental Capacity Act support workers, and representatives from charities (e.g. AgeCymru). We would like to thank everyone who gave their time to share their insights with us. For a list of attendees at our November event see <http://cdoc.org.uk/news-2015/>

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