

## Geriatricians' views of advance decisions and their use in clinical care in England: qualitative study

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**Geriatricians' views of advance decisions and their use in clinical care in England:  
Qualitative study**

Catherine Jane Bond<sup>1</sup> and Karen Lowton<sup>2</sup>

<sup>1</sup>Geriatric Medicine, University College London Hospital, London, UK

<sup>2</sup>King's College London, Institute of Gerontology, London, UK

Address for correspondence:

C. J. Bond. Tel: +44 (0)20 7380 9910.

Email: [catjedwards@hotmail.com](mailto:catjedwards@hotmail.com)

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**Background:** an anticipatory decision document records a person's wishes regarding medical treatment at a time when they have capacity to make choices, to be enacted when this capacity is lost. In England and Wales an advance decision to refuse treatment (ADRT, or advance decision), a legally binding document, is currently rarely used. A disparity is suggested to exist between physicians' support for anticipatory decisions in principle and their lack of impact on decision-making in practice.

**Objective:** to elicit geriatricians' views on advance decisions and their use in decision-making in England.

**Design:** a qualitative approach was taken. Semi-structured interviews were conducted with 10 geriatricians. An inductive approach was used for data analysis.

**Results:** geriatricians held positive views on anticipatory decisions in principle. In practice, they reported being highly likely to follow a decision which was in line with their clinical view. They would also favour an ADRT which was prescriptive in terms of the situation and treatment to which it applied. However, geriatricians expressed concerns in relation to patient understanding of the role and limits of these documents. Participants expressed discomfort in following an ADRT which, in their professional opinion, did not represent the patient's best interests, despite it being a legally binding document. A conflict between doctors' beneficence and patients'

autonomy was apparent, with geriatricians differing in their views on how ADRTs should fit into medical decision-making; particularly how far anticipatory decisions can represent ongoing patient autonomy.

**Conclusion:** despite their status in law, an ADRT which conflicts with a geriatrician's clinical opinion may not be implemented, in breach of the Mental Capacity Act. To avoid this, they must be seated within wider advance care planning.

## **Introduction**

Although life expectancy and medical interventions for older people continue to advance [1, 2] most experience multiple chronic conditions in later life, making prognostication difficult [3]. In response to acute illness, the most appropriate treatment, from symptom palliation to intensive therapy, must be chosen. If the patient is unable to express a treatment preference the physician must decide what is in the patient's best interests; a complex situation arises when the outcome of treatment is uncertain and the patient's wishes cannot be ascertained.

Recent policies including the National End-of-Life Care Strategy [4] and the Royal College of Physician's best practice guideline [5] have echoed patient advocacy groups such as the Dying Matters coalition [6] in promoting advance care planning, a process through which an individual can record preferences for their future treatment and care should they become unable to make such decisions. In England and Wales, decisions can be conveyed through a formal written document known as an advance decision to refuse treatment (ADRT, or advance decision).

The legal status of ADRTs was clarified by the Mental Capacity Act 2005 [7]. This states that to be valid an ADRT must be written witnessed and signed at a time when an individual has capacity to make healthcare choices. It is applicable when relevant clinical circumstances arise and decision-making capacity has been lost. An ADRT can be used to state refusal of future medical interventions but cannot legally request that treatment be given. A request to withhold treatment even in the event this will shorten life must be explicitly stated. Although legally binding in England and Wales, such refusals in Scotland and Northern Ireland are only potentially binding. The Act also clarifies the process of making a 'best interests' decision in an

adult without capacity. To reach this, many factors must be considered including: the views of any party interested in the individual's welfare; values or beliefs held by the individual and the individual's present and past views (these can be documented in an advanced statement which is not legally binding but must be adequately considered).

Written anticipatory decisions remain uncommon in Britain, with only around 8% of the population having any form of advance care planning document [8]. Most research on these documents has focused on North America, in the United States they have been used since the 1980s and have become more common following the Patient Self Determination Act 1994 [9].

Surveys of doctors and patients have shown consistently positive attitudes to all forms of anticipatory decisions in principle [10–12]. However, they have been found to have little impact on physician decision-making in practice. In a North American study, despite specialist nurses' liaising with doctors to encourage their implementation, anticipatory decisions had little influence on their decision-making at end-of-life [13]. British doctors have limited experience of using these documents in decision-making; studies using hypothetical vignettes have examined how they might be used in practice. In one study 80% of medical trainees chose a different level of treatment from that requested by the patient [14], suggesting doctors may not always follow documented patient preferences. Qualitative work in Scotland demonstrated that the interpretation and use of an anticipatory decision can differ between individuals [15]. Canadian nurses, doctors and patients shared similarly positive attitudes to the use of these documents, however when using them in decision-making doctors differed from nurses and patients by placing more weight on benevolence and less on patient autonomy [16]. This suggests a doctor's

dilemma: how to best respect the patient's right to make autonomous choices for future care while prescribing the treatment they deem to be in their 'best interests'.

Geriatricians constitute the largest medical speciality in the United Kingdom [17]. As there is a high prevalence of dementia in older people and a high incidence of delirium in unwell older adults they care for a significant number of patients who lack capacity to make healthcare decisions [17]. Geriatricians will be central in determining how anticipatory decisions are used in clinical practice, yet little is known about their attitudes towards them. This is the first qualitative study in England to examine geriatricians' views of using ADRTs in their decision-making.

## **Methods**

London area geriatricians were recruited using purposive sampling to construct a sample varied in age and clinical experience. Semi-structured interviews were conducted using a topic guide developed using concepts from existing literature. Each interview covered the participant's understanding and experience of using anticipatory decision documents and their potential advantages and disadvantages. Hypothetical scenarios were used concerning the treatment of an older person who lacked capacity to make treatment choices and who had an ADRT declining intervention in three situations: (i) the patient would die regardless of intervention; (ii) the outcome of treatment was unclear; (iii) the patient was likely to survive if given a particular treatment. (See topic guide in Supplementary data available in Age and Ageing online for these scenarios). Each participant was asked to consider how far their responses were influenced by the type of treatment declined and which factors other than medical treatment were important in their decision-making. Interviews typically lasted 40 min were audio recorded and transcribed

verbatim. A grounded theory approach was used for the analysis, with codes being created from the transcripts on an emergent basis [18]. Codes were examined both in meaning and dimension; through this the three main themes were constructed. Box I shows quotes illustrating themes.

## **Results**

The sample comprised ten geriatricians: six consultants and four trainees (Specialist Registrars in Geriatrics) working across six different clinical settings. The trainees were younger (mean age 33 versus 54 years for consultants) and less experienced in geriatric medicine (mean 5 versus 24 years). All participants reported at least one situation where they had used an advance care planning document in their decision-making. At the beginning of each interview the participant's understanding of an ADRT as a legally binding document was confirmed. However, as the interviews progressed it was evident that participants' understanding of the legal status of ADRTs was not the main consideration in the discussion of the use of written anticipatory decisions in clinical decision making.

All participants expressed support for ADRTs in principle (Box 1, quotes 1 and 2). However, the majority voiced concerns about their use in practice. Three factors appeared to influence this: (i) advance decisions as written documents; (ii) the situational context in which they could be used and (iii) geriatricians' professional attitudes.

INSERT BOX ONE ABOUT HERE

### **Advance decisions as written documents**



In considering the content of an ADRT, most geriatricians expressed a preference for a document that was very specific, both in terms of treatment(s) declined and clinical situations in which it should apply. It was felt that a request to withhold 'life-prolonging treatment' would only be useful if a statement detailed precisely to which treatments this referred. In particular, clarification was deemed necessary of what was considered 'invasive' treatment; for example, whether this referred only to treatments which geriatricians considered 'invasive', such as intubation or admission to intensive care, or to treatments that geriatricians might consider 'low level', such as intravenous antibiotics and fluid replacement.

### **The situational context**

The second influence was the clinical situation. In the first scenario, where the patient was very likely to die regardless of medical intervention, all participants reported being willing to withhold treatment in line with the patient's decision. In the second scenario, where the outcome of treatment was uncertain, several participants believed that an ADRT would be very useful in guiding their clinical decision-making. Some suggested that they would use the document as the principle factor in their decision to give or withhold treatment, whereas others felt it would be only one of a number of factors they would consider in deciding what they thought would be in the patient's best interest (Box 1 quotes 3 and 4).

In the third scenario, where the patient was likely to survive if given a particular treatment, most participants expressed discomfort in following a written request to withhold this (Box 1 quote 5). Some stated that they would respect the patient's decision, particularly if this was documented explicitly and unambiguously, however others felt they would not be able to do this. This

difference appeared to relate to personally held values and professional practice rather than age, gender or clinical experience.

### **Professional attitudes**

All participants saw end-of-life decision-making as part of their professional role (Box 1 quote 6), relating this to their medical knowledge which enabled them to predict the likelihood of patient survival. Having made many previous end-of-life decisions was felt to be an important component of their decision-making, helping them to know the 'right' decision to make. In this context the use of an ADRT was viewed as potentially altering the geriatrician's professional role by changing the balance of responsibilities between the doctor and patient in decision-making (Box 1 quote 7).

Some participants believed patients would be unable to grasp the complexity of medical decisions documented in their ADRT (Box 1 quote 8). Many suggested that if patients had the same level of knowledge and understanding as their doctor, they would concur with their doctor's decision in any given event. However, there was broad acknowledgment that geriatricians' judgements of patients' quality of life (QoL) might also influence their clinical decisions. Some felt that to judge a patient's acceptable level of QoL was an appropriate consideration for geriatricians when deciding whether withholding a treatment was in the patient's best interests. However, others believed that this judgement was inherently personal to each patient, thus it would be inappropriate for a doctor to base their treatment decision on this (see Box 1 quote 9). Again, this difference did not appear to relate to age, gender or experience but rather to be associated with how each geriatrician viewed their role and that of the patient in shared decision-

making.

It is likely that older people would perceive an ADRT as a set of instructions for doctors making medical decisions at a future point when mental capacity has been lost. However, our data suggest that the only situation in which an ADRT would definitely be followed by geriatricians is when it: (i) fits the clinical scenario tightly and (ii) supports the doctor's own view of the best management plan. Therefore, while general support for anticipatory decisions exists in theory and in law, whether an ADRT is followed in clinical practice in England is complex, being dependant on multiple factors (Figure 1).

INSERT FIGURE ONE ABOUT HERE

From these influences the most important factors in determining a treatment course will differ in each situation, relating to the ADRT's written content, the clinical situation and the professional attitudes of the doctor. Figure 2 models the pathway of how an ADRT is likely to be used in geriatricians' decision-making. We suggest that if the ADRT does not fit, or fits only partly with the doctor's view, the treatment plan devised becomes dependent on the geriatrician's belief of what the patient's role should be in clinical decision-making.

INSERT FIGURE TWO ABOUT HERE

## **Discussion**

This study demonstrates the complexity of how an ADRT might be used in English geriatric

practice, being dependant on how it is written, the particular treatment(s) and clinical situation to which it pertains and the extent to which the attending doctor supports patient involvement in clinical decision-making.

This is a small qualitative study of London geriatricians. Although it identifies key factors in the use of ADRTs in decision-making, these may not be generalisable to doctors in other locations or specialities. Doctors' views are likely to become modified following more clinical exposure to anticipatory decisions; however, we have set out a number of important broad issues that need consideration before they are used effectively.

The doctors in our sample all supported in theory the use of anticipatory decisions to increase patient autonomy. However, when talking through their decision-making in hypothetical scenarios, most identified significant problems in maintaining this in practice. The decisions detailed in an ADRT usually refer to a potential end-of-life situation and the withholding of possibly life-prolonging treatment. These decisions are both technically and emotionally complex, requiring consideration of more than medical 'fact'. This study demonstrates a fundamental conflict when using an ADRT in practice—that it may direct geriatricians to follow a course of action which they believe is not in the 'best interests' of the patient. In this context, the four principles of medical ethics [19] have traditionally been advocated to guide doctors in making a decision that is balanced in terms of malevolence, beneficence, justice and equality. For geriatricians here, the principles of autonomy and beneficence cannot both be upheld; some would give priority to patient autonomy and follow the ADRT despite feeling uncomfortable in doing so, others would override the decision and give the treatment they felt was most

appropriate, although this would mean they would be in breach of the Mental Capacity Act.

In attempting to remedy this conflict, geriatricians expressed preference for a prescriptive ADRT in terms of treatments to be withheld and the circumstances in which it would apply. However, an older person would find this type of document extremely difficult to draft as comorbidities would lead to an inordinate number of scenarios and treatments needing to be considered.

Both the Mental Capacity Act [7] and GMC guidelines [20] direct doctors to view a patient's best interests in the broadest possible sense, giving prominence to the individual's prior wishes.

Despite these mandates the participants did not necessarily give prominence to ADRTs in their hypothetical decision-making. Geriatricians viewed as synonymous acting beneficently and in the patient's best interests as they largely considered the 'best interests' of the patient in terms of whether a treatment would achieve medical success e.g. prolonging life. The narrow medical focus of difficult decisions may have allowed participants to avoid ethical dilemmas [21] by concentrating on the correct diagnosis and treatment plan, or it may have been our study's focus that encouraged them to answer in this way. However, consideration of the patient's desired outcome is likely to be lost when medical decisions are seen in such narrow terms. To achieve the patient's documented preferences and compliance with the Mental Capacity Act, it is likely that geriatricians' view of beneficence must be widened to encompass consideration of their patient's acceptable level of QoL, supporting the suggestion that North American patients would rather produce a document stating broad principles of care than one that is prescriptive [22].

Modern medical practice and decision-making has been conceptualised as having a 'distributed'

nature, taking place with a number of people over a number of settings and encounters [23]. This conceptualisation moves the doctor's role away from a paternalistic decision-maker towards participator in shared decision-making; it is hoped that anticipatory decision-making will, in time, become a key part of this 'distributed' nature of healthcare decision-making. Older people appear to have difficulty influencing decisions relating to their care when they have discussions with doctors [24]. It may be that despite having documented an anticipatory decision they also have difficulty doing so when capacity is lost unless we begin to overcome the practical problems.

## **Conclusion**

Advance care planning that includes doctors' and patients' discussion of future treatment choices and acceptable level of QoL is key to achieving good care for older people. To be effective, anticipatory decisions must be incorporated into this wider discussion. However, patients must be aware of the complexities of clinical decision-making and the uncertainty of many prognoses. Doctors must acknowledge that many medical decisions must be based on judgments that take into account broader patient factors rather than being founded on medical 'fact' alone.

## **Key Points**

- Geriatricians hold positive views on anticipatory decisions in principle.
- Geriatricians appear most likely to use an anticipatory decision which is prescriptive in terms of the precise situation and treatment to which it applied.
- Anticipatory decisions which conflict with geriatricians' clinical opinions may have limited influence on decision making.

- To be useful, anticipatory decisions must be seated within wider advance care planning including open discussion of prognosis with patients.

### **Acknowledgement**

We thank the geriatricians of London who gave their time to be interviewed.

### **Conflicts of interest**

There are no conflicts of interest

### **Ethical approval**

Ethical approval was granted by University College London Hospital ethics committee. All participants gave written informed consent. (REC reference 08/H0715/40).

### **Supplementary data**

We wish to make available the topic guide containing the hypothetical clinical scenarios at Age & Ageing online.

## Box 1. Illustrative quotes from geriatricians

### The AD as a written document

- Female trainee  
5 yr experience      *1: I think they're a very good idea. I suppose it's difficult because I have views as a clinician and views as a person with a family. So I think as a doctor I would assume that it would make decision-making a lot easier if somebody had set out quite clearly what they wished before they became mentally incapacitated. Although I think there are obviously lots of difficulties from a doctor's point of view.*
- Male consultant  
14 yr experience      *2: To deal with clinical idiots like me, it's best to be as clear as possible in envisaging the situations in, where the advanced statement should be enacted. Some of them are very vague ... so the more detailed somebody can be the better - it helps decision-making. If it's vague it's open to interpretation and people might not get what they want.*

### The situational context

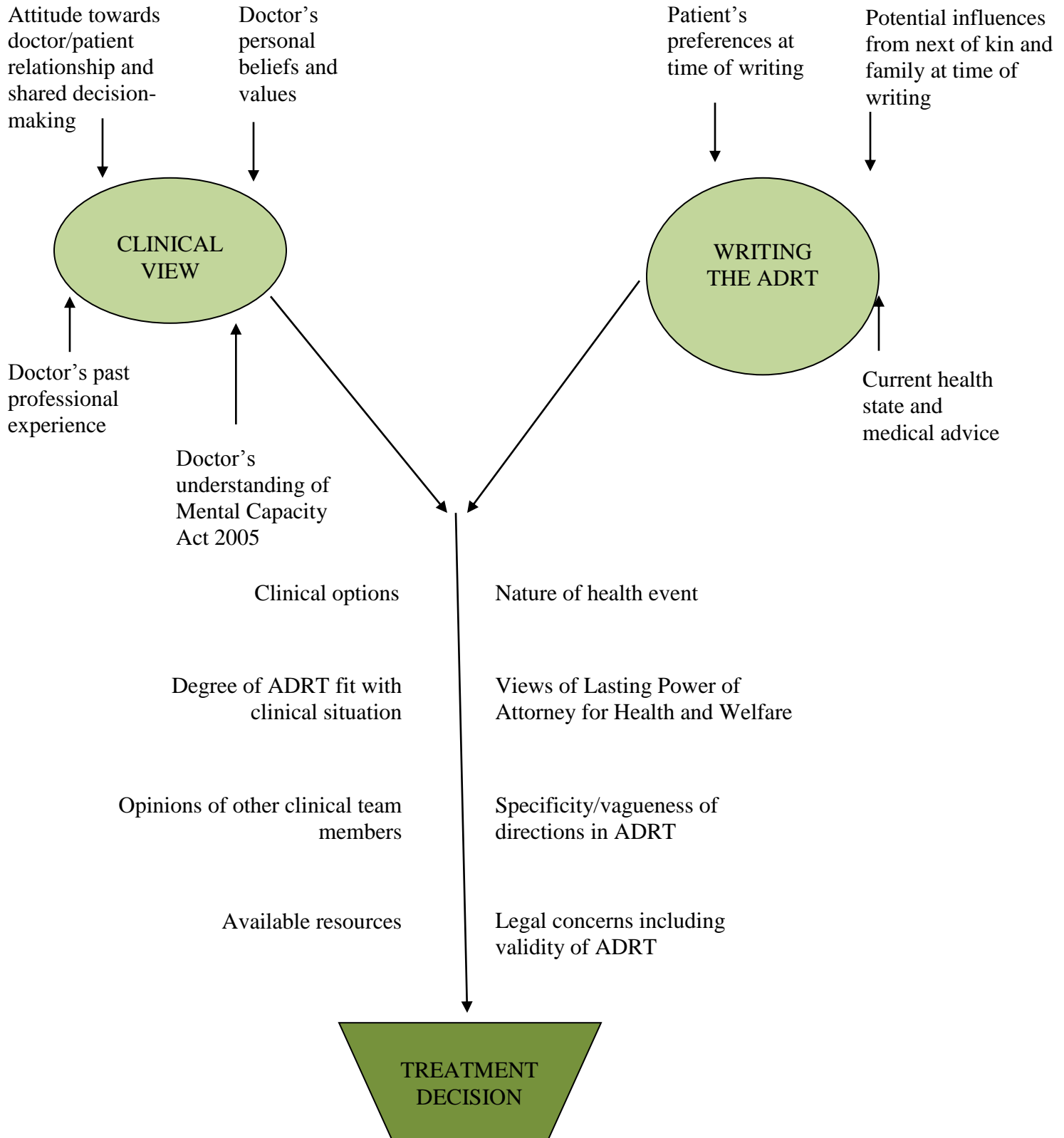
- Male consultant  
20 yr experience      *3: I think, well it's reasonable for that individual to want some degree of control over their life even if I disagreed with it, it's not, it's not forcing to do some, to give a treatment which I think is, is pointless and cruel it's simply asking me to err, fit in with their, with their wishes, so I don't treat pneumonia; well that's fine.*
- Female trainee  
4 yr experience      *4: There's lots of clinical assessments where you can fall on either side of the fence aren't there? You know, one little thing can sway you one way or the other.*
- Male trainee  
6 yr experience      *5: It becomes harder for the health professionals, much harder because having an advance directive setting a ceiling of therapy is helpful and is err reassuring to the clinician if it's in line with what they're thinking, if in contrast that ceiling of therapy appears suboptimal it would be very difficult, very difficult.*

### Professional attitudes

- Female trainee  
4 yr experience      *6: I don't think I'm particularly paternalistic but, yes, I think you know that we look to accountants to help us make financial decisions and estate agents to help us sell our houses and I think in the same way we have to take some of the responsibility for decision-making, it's something that we've got, got experience of.*
- Female trainee  
5 yr experience      *7: I suppose in a way you're taking the responsibility from the, well the responsibility for decision-making isn't all yours any more it's um, you know the patient has taken that away from you.*
- Female consultant  
33 yr experience      *8: How can the lay public understand all the intricacies of what we decide? They won't understand basic science, they don't understand interventions, they can't understand lots of issues*
- Male consultant  
34 yr experience      *9: I think it's not all elders that are the issue, people with learning disability who to you and I probably have not a very good quality of life but are quite happy and I think that's, I think that's very difficult to judge if one isn't the person oneself.*

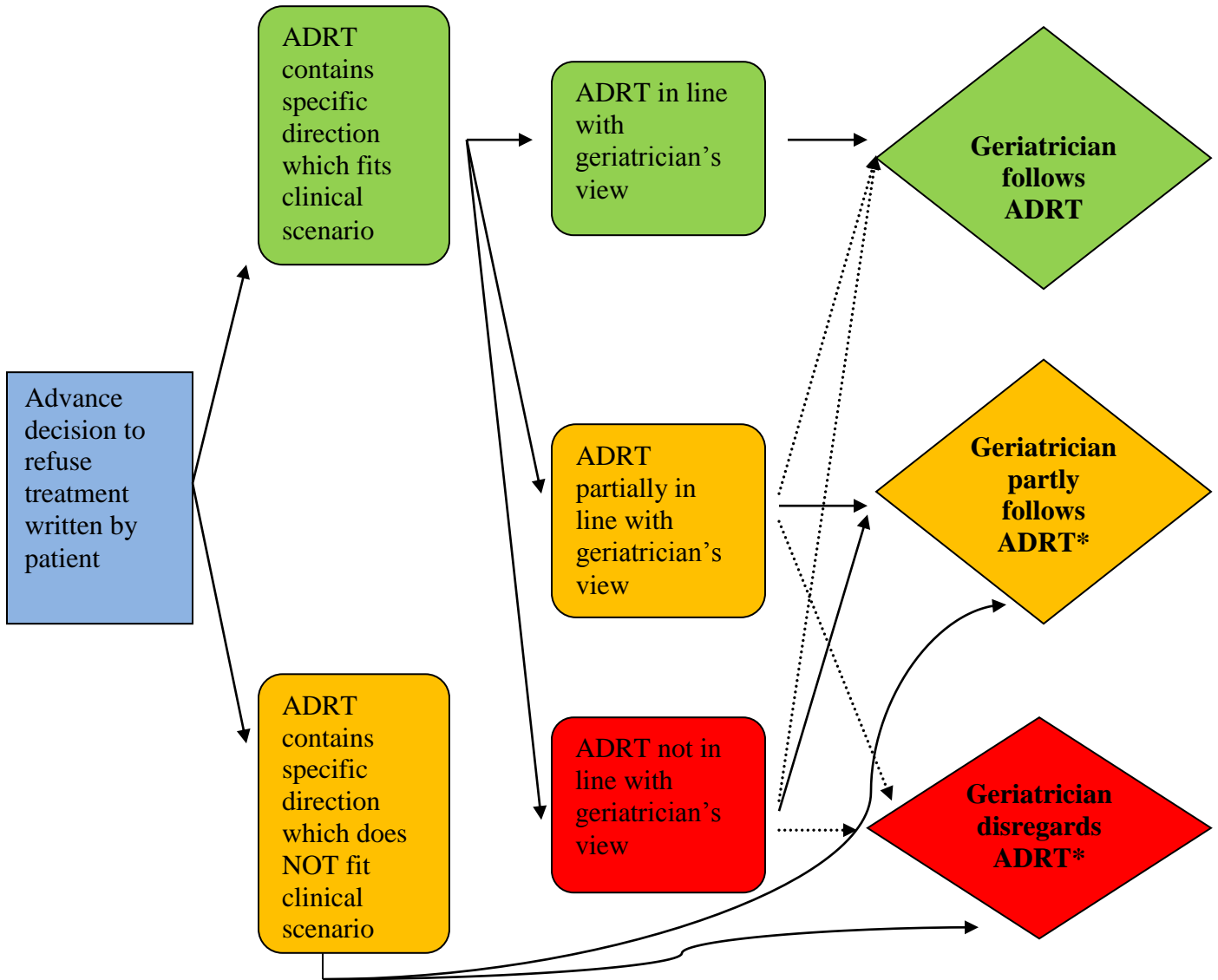


**Figure 1. Factors influencing clinical decision-making in the context of an advance decision to refuse treatment**



**Figure 2. Geriatricians' hypothetical decision-making pathways for using advance decisions to refuse treatment.**

The filled lines show the path the data suggest is most likely, the dotted lines represent other possible, though less likely routes. NB Outcomes marked \* are in breach of the Mental Capacity Act and risk litigation or prosecution.



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## Supplementary data

### Topic Guide for geriatricians working in England

#### *Background data*

Age, grade, place of work, number of years working in geriatric medicine.

#### *Knowledge of ADs*

Do you know what is meant by an AD?

Are you aware that MCA 2005 was enacted in October 2007?

#### *Experience of ADs*

Have you been aware of any patient(s) who had an AD?

Do you have experience of a situation where an AD was available to assist a decision?

Do you have any experience helping draft an AD or witnessing one?

#### *Attitude to ADs*

What is your view of the principle of ADs?

How do you view their role in assisting decisions?

Do they have a role in facilitating discussion with patient/relatives?

Can you see any problems or potential problems in their use?

#### *Attitude to LPA*

Can you see any problems in theory/practice with LPA?

Does it help to clarify who to discuss decisions with?

Do you think it would change how you communicate with rest of the family?

Do you think doctors have a role in taking the burden of decision making?

#### *Types of situation*

I'd like you to imagine a situation where you have a valid AD declining treatment in a patient with advanced dementia presenting to hospital with pneumonia.

Would you be happy to withhold ventilation as stated in the AD?

Would it make a difference if antibiotics were declined in the AD rather than ventilation?

Would you still be happy to follow an AD and withhold treatment if the severity of the dementia was not stated?

From our discussion we have assumed that the patient would be likely to die with or without treatment, would it affect your decision to follow the AD if the patient was likely to survive if

treated?

And if it was uncertain whether the treatment would change the outcome?

Would you be happy to follow the AD and withhold treatment if the care staff or family members reported the patient though demented was very happy/had a good quality of life?

What would you do in the same situation where an AD declining treatment clearly applies, but their relative wishes that the patient to be treated?

Now I would like you to think about a situation where an AD clearly stating patient does not want treatment in the current situation but it has not updated for several years.

Would this make any difference to how you used the AD?

If clinically you felt that treatment should be given would it make any difference if the AD had not been recently updated?

Now imagine a situation where an AD clearly states that a patient does not want treatment in the current situation but their relative states that the patient had recently changed their views.

Would this influence whether you followed the AD?

*Conflict with personal judgment or beliefs*

What do you think you would do if a valid AD was present declining a treatment you felt would be of great benefit to the patient?

Would the type of treatment make a difference?

Would your religious or personal beliefs influence your ability to comply with an AD refusing appropriate treatment?

*Drafting/content of ADs*

Who do you think has responsibility for initiating discussion on advance care planning (patient, GP, geriatrician) in general and in older people?

Do you feel ADs are most useful when they contain broad statements about values/acceptable quality of life or statements relating to specific situations/treatments?

Do you feel doctors would interpret ADs to accord with what they feel is appropriate treatment to give or withhold?

Do you think patients would have any awareness that content of AD may be used as only one part of decision making process?

Would you consider having an AD yourself or advising a family member on drafting one?

Would an expiry date be helpful to ensure still valid?

Would you feel more comfortable if an AD was signed by physician?

Are you aware of a policy regarding ADs where you work?

Do you think training/ info you have had is adequate?

Where would you seek advice or information?

What do you perceive as the barriers to wider use?

AD – Advanced Directive

LPA – Lasting Power of Attorney



