

The 'Ownership' of Decisions and Records of Decisions

Anyone who has read my forceful objections to the ReSPECT Form, will be aware that 'ownership' of the recorded decisions or 'recommendations' (as 'indicated by' the signatures on the form) is my main objection to the form.

Someone sent me something in a Twitter direct message recently, and censoring the swearing I was told:

Problem is that some consultants are a "law unto themselves". When earlier this year I handed my ADRT to a nurse for my file she said it would have to go to the consultant for him to approve and sign - oh no it f*ing won't!**

There isn't any concept inside the Mental Capacity Act, which is where the law for Advance Decisions (ADRTs) is defined, of anyone 'approving' an ADRT – hence the strongly-expressed objection to the idea that the ADRT needs to be seen and approved by the consultant. As distinct from 'the consultant should be aware of the ADRT' [and some member of the hospital staff, should be responsible for ensuring that all of the doctors and nurses who need to be aware of the ADRT, are aware of it].

Whether an ADRT has to be approved before it can be inserted within medical records, is a slightly different question: I think it seems reasonable to check that the ADRT is valid (is witnessed, etc) before putting it – or, in fact, putting **a copy** of the ADRT [because the original should stay with a mentally-capable patient] – in 'the records'. It isn't difficult to decide if an ADRT is valid, although there is a potential issue with clinicians and an ADRT which is intended to refuse a treatment in all circumstances. Logically, 'I refuse CPR' with no stated circumstances, is refusing CPR in all circumstances, but some clinicians dispute that. What the MCA actually says is this:

25(4) An advance decision is not applicable to the treatment in question if—

*(a) that treatment is not the treatment specified in the advance decision,
(b) any circumstances specified in the advance decision are absent, or
(c) there are reasonable grounds for believing that circumstances exist which P did not anticipate at the time of the advance decision and which would have affected his decision had he anticipated them.*

I will also point to section 24(1)(a) which points out that the treatment being refused must be specified, whereas circumstances **may** be specified:

24(1) "Advance decision" means a decision made by a person ("P"), after he has reached 18 and when he has capacity to do so, that if—

(a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him,

If we stick to refusals of offered treatments – making the assumption that unless the NHS cannot afford to do so, potentially clinically-effective medical interventions will be offered – then the legal justifications for withholding an intervention are:

- 1 A mentally-capable patient has refused the offered treatment;
- 2 The patient is now mentally-incapable, but it is understood that the patient while capacitous expressed a refusal of the treatment which cannot 'be reasonably doubted' at the time the treatment is being considered;
- 3 Neither of the above apply, and a defensible best-interests decision is that the treatment should not be applied.

If we wish to include 'the treatment couldn't be clinically successful' (technically 'completely ineffective clinically' for the purposes of this analysis) then we also have;

- 4 The treatment could not be clinically effective.

Those four justifications, have different 'owners': the patient owns no 1, the patient owns no 2 but it is 'a projected forwards-in-time' ownership, for no 3 a best-interests decision is owned by the person who makes it, and no 4 isn't actually a decision (it is a prediction, or an expert opinion) but the clinician who makes the assertion clearly owns it.

I usually 'do cardiopulmonary resuscitation' for this type of analysis, and for CPR a capacitous patient clearly owns her own ADRT refusing CPR, and no 4 is clearly owned by the clinician who asserts that 'CPR couldn't work': but no 2, while in theory still owned by the patient, and especially no 3 [unless there is someone empowered by MCA 6(6) to make the best-interests decisions], are much more tricky in terms of 'ownership'. If we concentrate on CPR, then the DNACPR Justification Hierarchy which looks correct to me, and which I have been publishing since about 2014, is as follows:

The DNACPR Justification Hierarchy

1 A face-to-face discussion with a mentally capable patient, which takes place during the clinical events which lead to his CPA, the outcome of which is that the patient issues a DNACPR Instruction which those who were involved in the discussion can interpret correctly

2 An apparently valid and applicable Advance Decision refusing CPR which has not been discussed with the patient

3 A DNACPR decision made and communicated by either a single Welfare Attorney (where only one has been appointed), or agreed and communicated by all Welfare Attorneys
(Note: for non life-sustaining treatments, a Court Deputy can fit here between 3 and 4 – see section 20(5) of the Act))

4 A DNACPR decision made by any person who is sufficiently informed of the patient's clinical situation and likely wishes, to enable that person to defensibly consider section 4 of the MCA.

5 A DNACPR action, which is based upon information supporting the reasonable belief that something within categories 1 to 4 makes DNACPR the best available behaviour

6 If none of the above apply, but it is clear that attempted CPR would be clinically futile, then DNACPR

7 If none of 1 to 6 apply, CPR should be attempted

There is some intricacy in that, because it was written as a justification hierarchy which someone such as a suddenly-involved 999 paramedic should be influenced by – it isn't the same, if you yourself are 'inside the hierarchy' (notably, if you can defensibly make a best-interests decision about CPR {in other words you fit in at no 4} then it is your own decision which **you yourself** should follow: it isn't necessary to further discuss the intricacies which may not be immediately obvious, here). Also, no 6 isn't an 'MCA justification' so it can appear either where I placed it, or else at the top of the hierarchy.

It seems to me, that if the documents within NHS record-keeping are intended to inform decision-making, the legal status of the documents should reflect the legal situation of the people who contributed to the documents: **in that respect, most 'NHS documents' connected to CPR fail 'that test', as do many documents which do not deal with CPR.**

Notably, the main ReSPECT Form fails my test: it only carries the signatures of clinicians, which implies that everything on the form is 'owned by' clinicians – and it is very clear, that an awful lot of the ReSPECT Form is owned by the patient, by a legal proxy, or is not owned by any single person.

It is almost impossible to design a 'DNACPR document' that embodies my own understanding of our [English and Welsh] law, to make it concise, and also to make it useful if its readers do not possess a good understanding of our law. I have discussed that issue elsewhere, and I will not discuss it again here: instead, I will discuss my own suspicions about the consequences of incorrectly-designed forms.

For example, surely the absence of the signature of a Welfare Attorney on the ReSPECT form, would encourage nurses to 'behave in a legally-flawed and potentially 'dangerous to themselves' way', in this situation?:

I've pointed out in my survey write-up, what I myself would do if I were a welfare attorney, and I was confronted by a ReSPECT Form - pages 128 – 130 here. If a loved-one had decided that I should make any necessary best-interests decisions, and I had accepted the burden of doing that, then I would not put up with anyone attempting to thwart that.

*Suppose I was an attorney, at a hospital bedside, and some clinical event occurred which required a best-interests decision to be made 'almost instantly' - so I was present, a couple of nurses were present, and your ReSPECT form was present. **And there was no time to involve a doctor, or anyone else.***

In my opinion, your ReSPECT form, because it only has the signature of a doctor on it, would encourage the nurses to dispute my decision-making authority: not acceptable, and if they acted against my expressed best-interests decision then I would feel compelled to try and get the nurses prosecuted [if they intervened after I had said 'don't treat']. I don't want attorneys to be forced to do that – but unless you let appropriate signatures appear on forms, I can't see how otherwise to rectify the current situation.

Similarly, it could be perceived that this 'determination to retain 'clinical control of' the documents and records, **in reality indicates an attitude [or mindset] of ownership of the patient**: that 'your loved-one is now my patient'.

That isn't, I think, what most relatives and family-carers during end-of-life believe – consider these two Twitter Polls I carried out:

A mentally-capable adult is 'dying' ['end-of-life' = 'sometime within predicted final year of life'] at home. Who should the family-carers living with their dying loved-one be taking instructions from? Please retweet - an analysis of answers would be 'interesting'.

From the dying patient 92%
From the GP and nurses 2%
From nobody 6%

Total votes cast 60

An 82 years old man is diagnosed as terminal. He and his 79 years old wife 'invite clinicians to help while he dies'. Does that invitation of itself, imply that if he loses the ability to make his own decisions, he wants the clinicians, and not his wife, to make them?

Yes it does 8%
No it does not 92%

Total votes cast 79

And, what do nurses and 999 paramedics make of 'what the family should do?' in a situation like this one (this was posted on Nursing Times online by someone, a few years ago):

My 87 year old father suffered with chronic heart and renal failure, he spent years going in and out of hospital at the GP request. He had decided that enough was enough, he didn't want to have more tests, catheters, cpap so took the decision not to allow mum to call an ambulance when he was nearing the end of his life. He died at home surrounded by his family.

In my view, it is clear that the father is making the decision here – and, he clearly was 'adequately informed' because he had a history of '*years going in and out of hospital at the GP request*': if he doesn't want an ambulance calling, because he thinks he is about to die and he wants to die if that is the situation, then his family should do what he tells them to do. Not all relatives would in reality do that – but, I can't see how those that do, can legitimately be subsequently 'accused of doing something wrong'.

Of course, if the family don't call anyone, and he collapses but doesn't die, then at some point the family would need to involve the NHS (I took the situation, as being effectively the instruction 'I think I'm dying now – let me die in peace, without the NHS trying to keep me alive').

That isn't 'shared decision-making' - it is following the father's decision.

One of the clinicians who has been very active in developing and promoting ReSPECT, wrote in her PhD thesis, as the first of three reasons for not attempting CPR :

DNACPRs (Figure 1) exist to provide immediacy and clarity of instruction in the event of a cardiorespiratory arrest and are made in three circumstances:

A. When a patient with capacity refuses CPR (or a patient currently without capacity has recorded their refusal of CPR in a valid and applicable advance decision).

For some reason, doctors still seem to be writing [or, at its weakest, implying] that if a person who is at home explains to a relative 'if you think my heart has stopped, I definitely don't want anyone to try cardiopulmonary resuscitation', for some reason that doesn't count. Well – **it definitely counts, if you are the relative being told that by a loved-one.**

I touched on the issue of 'ownership of decisions and records' in the second half of my [piece](#) 'It's the listening, stupid!' and I didn't go into great detail, I simply outlined the principles which I consider acceptable forms should incorporate. And I mentioned that the different approach to forms and records which I am describing, needs more discussion.

Currently, I spend a lot of time complaining about the current version of the ReSPECT Form (see my very lengthy thread [here](#)), and to be honest I suspect it isn't possible to re-design the ReSPECT Form in a way which would make it acceptable to me, while also retaining the [in my mind far too over-ambitious] objectives for the form of its creators. As I wrote in 'It's the listening, stupid!':

An Alternative Approach to CPR/EoL forms

I would stress - ***this also requires adequate and correct training of all healthcare professionals, about decision-making law.***

It would be possible to include within 'a DNACPR document' all of the justifications for withholding CPR: patients, attorneys, GPs etc could all sign appropriate sections, and then while not conflating decision-making authority provided the various sections contained the legally-appropriate signatures, a single document would cover everything. But, that probably isn't a good idea - to start with, different sections of the document 'would have different owners', and I'm sure that would result in arguments over 'who owns the document'. So, I am inclined towards only two types of document: Advance Decisions (signed by the patient) and a semi-composite document, of variable-and-uncertain 'ownership' but 'with-the-patient-residence', which covers both 'CPR could not be clinically successful' AND ALSO 'CPR is being withheld on [MCA] best-interests grounds'.

...

It doesn't make much sense, I feel, to continue with detailed suggestions, at this point: this is 'an incomplete analysis' as it stands, **but my position is sufficiently at**

odds with the 'mindset of' many doctors, that it requires feedback indicating that doctors are willing to move towards my own position, before looking at these ideas in more detail.

I will close this piece, with a bit of 'heard on the grapevine' information. I have heard that the next version of the ReSPECT Form is 'being thought about' at the moment, and I am also aware that I am not the only person who is less than happy with the signatures present on the current version of the form. I don't know whether there will be provision for the signatures of non-clinicians on the next version of the ReSPECT Form [along with more legally-informative internal descriptions of the forms various sections], but if those more legally-sensible signatures are provided for, then I for one will be pleased.

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