How I think about End-of-Life Planning, and why I cannot unreservedly recommend the new version of the ReSPECT form

A new version of the ReSPECT form was published recently, and one of the main ReSPECT doctors was, it seems, surprised when I tweeted that I could not recommend it. The doctor said the new form is more Patient-Centred – which is true. But my objection, is that the form is still overly Clinician-Controlled and Clinician-Verified.

I cannot easily say how I would modify the ReSPECT form: it is as if someone showed me a helicopter and asked 'how would you improve it?' and my reaction would be 'the problem is we need a jet fighter – and it is impossible to modify a helicopter and turn it into a jet fighter!'.

Things might become clear, if I explain a little about how I think, when I look at anything connected to EoL planning. I have things in mind – which you can think of as 'tests' - which include the following:

1) Is Patient Autonomy described correctly, and clearly?

2) Is Best-Interests Decision-Making described correctly [in a legal context], and crucially is it made clear that whenever possible we should all be attempting to avoid any best-interests decision-making from occurring, by harvesting anticipatory decisions from patients while they are still capacitous, and then simply applying those decisions in the future?

3) Are what I will call 'operational documents' (things such as DNACPR forms and the ReSPECT form – as opposed to, for example, guidance documents which would mainly be used during training) constructed in such a way as to:

3(a) make it very difficult to complete the form incorrectly, incompletely or more generally unsatisfactorily

3(b) impart to users of the forms, a correct understanding of the law and also of what here I will term 'operational complexities'

3(c) correctly 'reflect' the situations(s) within which the form will be used, and the differences between these situations.

4) be compatible with the way that end-of-life can suddenly 'swerve in a new direction' - are the forms 'nimble and responsive to sudden events'.

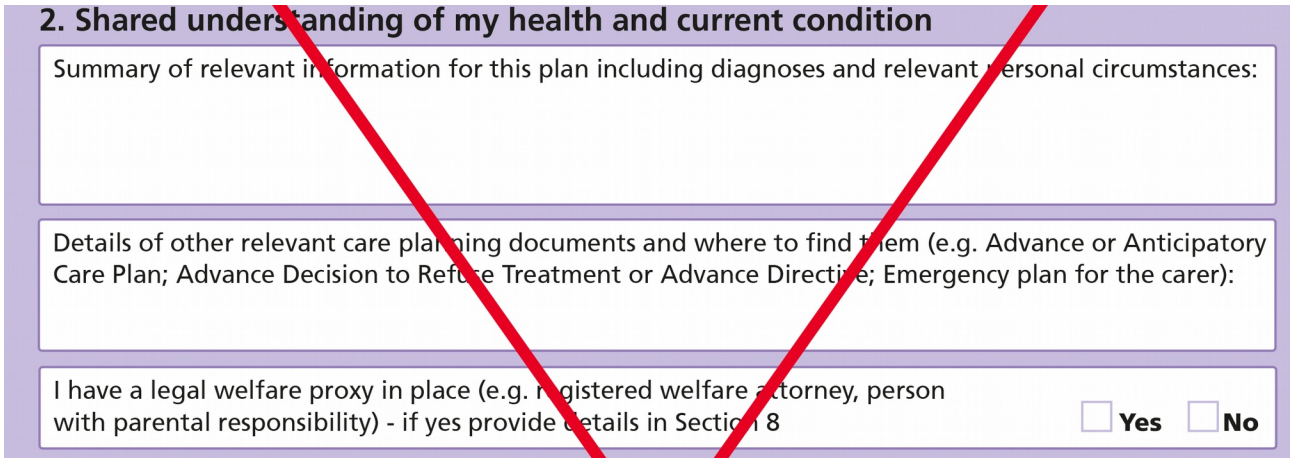
So, when I look at the new ReSPECT form, what do I see – from my perspective as a former End-of-Life Carer while my parents were dying at home?

I have never really liked the name – Recommended Summary Plan for Emergency Care and Treatment. I would probably prefer something like 'Information for consideration during clinical emergencies' because I dislike the words 'recommended' and 'plan'. But the label, is a relatively minor problem.

Section 1 of the new form, is fine as to the boxes – but I am less keen on the wording beneath them:

I dislike 'a record of agreed recommendations' and it seems that there cannot be a form completed if the patient is unconscious long-term. I think Planning Ahead forms can be useful, but I consider that you should have separate forms for adults who are capacitous when the form is created, and for adults who are effectively incapacitous when the form is completed. The ReSPECT form is intended to cover both situations (and also children, the entire UK, etc) and it then becomes very difficult – **in my view impossible with a short form** – to satisfy my 3(b).

Section 2 of the new form is this:



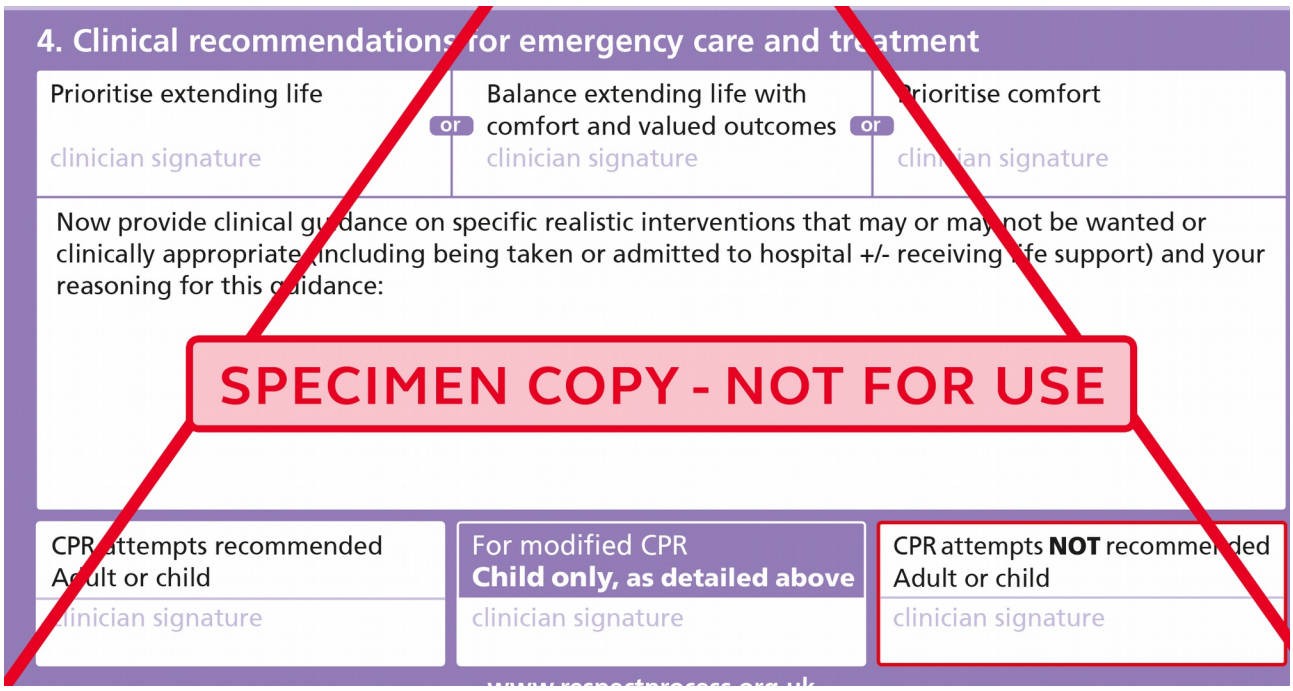
I am not keen on the term 'shared understanding' but more importantly, **the form does NOT ADEQUATELY STRESS** my 2).

I have a disagreement with a lawyer, about verbal refusals of life-sustaining treatments if the contact between the patient and clinician is 'ongoing', which gets very 'nerdy/logical', but if a treatment is refused on a written Advance Decision (ADRT) then if the ADRT is valid and applicable, anything written about that treatment on a ReSPECT form should not even be looked at. Basically, a patient who has both an Advance Decision and a ReSPECT form, and keeps both together, should clip the ReSPECT form **to the back of** the written ADRT – and clinicians should be trained to read the ADRT **first**.

It is not at all clear to me, that ReSPECT 'respects the legal position of ADRTs'.

My only issue with section 3 of the form (apart from its limited space) is that it does not give the patient the option to sign it – patients should be able to complete section 3 themselves, and to also sign that section of the form.

Section 4, I dislike:



I dislike ‘clinical recommendations’ in the heading, and I object to the ‘clinician signature’ in the three alternative boxes along the top. It should, if the patient is capacitous, allow for the patient to sign in the appropriate box along with the clinician. If the form was completed when the patient lacked capacity, those top boxes should allow for many combinations of signatures [which I will not explain here beyond saying the signatures could include patient, relatives and friends, welfare attorneys (‘LPAs’) as well as clinicians – in essence the signatures should reflect that best-interests decision-making has been carried out correctly, and the inherent legal situation of anyone expressing a best-interests determination: and best-interests is NOT ‘a clinical thing’].

By contrast, the central box – which can contain the opinion of a clinician that certain interventions would be ‘unrealistic based on existing clinical considerations’ - **SHOULD** be signed by the clinician who is expressing that expert clinical opinion: ***and mysteriously that section does not require a clinician to sign it on the form***.

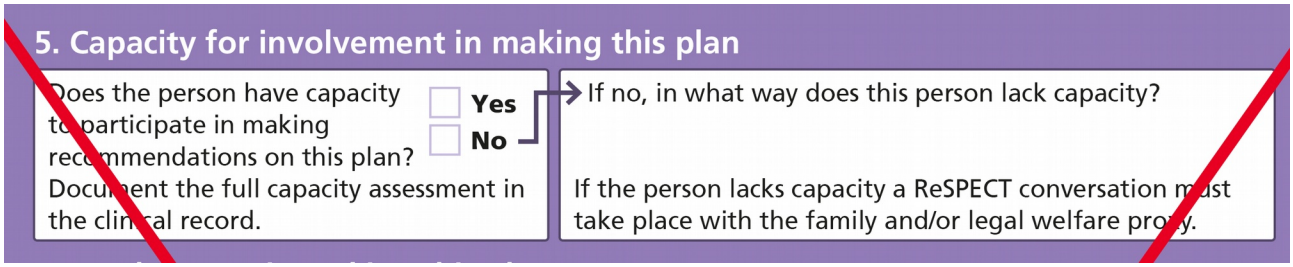
As for the lower row – the ones about CPR – then I have several comments. First, I am NOT commenting on the central box, beyond stating that my comments are for a form for adults – the law is different for children (and I would argue for a separate form for children).

Second: the same comment as I have already made about the top row of boxes.

Third: I have been told by more than one relative, that the first time they came across it, they ‘had no idea what CPR meant’.

I wonder, if instead of using only CPR or cardiopulmonary resuscitation on forms, wording such as ‘attempts to restart my heart if it has stopped beating’ should be used on forms which include CPR?

Section 5, is very problematic:



I dislike the wording ‘capacity to participate in making’ . Capacitous patients make and express their own decisions, after being adequately informed of treatment options (which are not necessarily decided by the clinician – if the NHS is not funding a treatment, it cannot be offered by a doctor) by the clinician: it isn’t really a ‘shared decision’, it is a process of the patient deciding after being informed by the doctor. It is [for England and Wales] more a case of documenting ‘why incapacity is being asserted’ than of ‘capacity being assessed’ (as the document ‘implies’) because under the MCA capacity is assumed by default.

The final wording in the section, fails my 2 and 3(b).

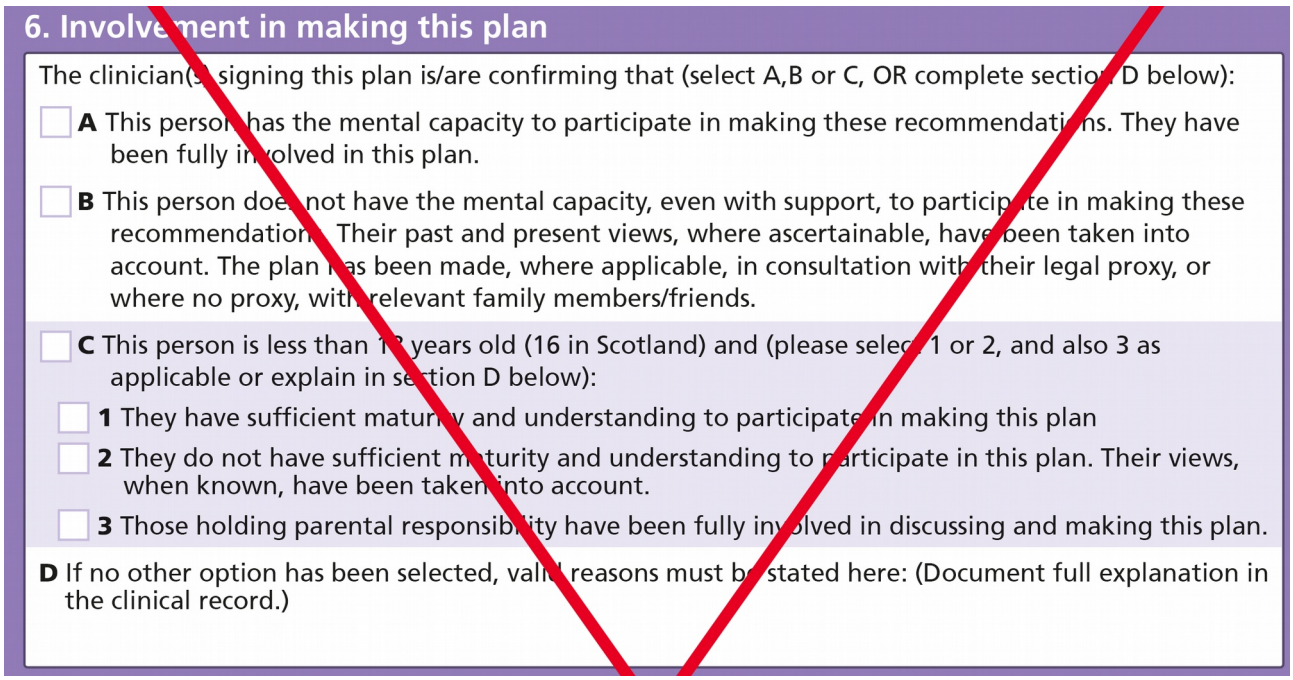
While the conversations must [if at all possible] take place because of the MCA’s best-interests requirements, if a legal proxy possesses authority over a best-interests anticipatory decision which appears on the form (the form does not contain such a ‘label’ - **but IT SHOULD**) then the law requires that the legal proxy has conversations with the clinicians – **to inform the decision made by the legal proxy**. If there is not a suitably-empowered legal proxy, then a best-interests determination (annoyingly, in strict legal terms there cannot then be a ‘decision’ - I was really annoyed, when that was pointed out to me a few months ago!) made by any person who wishes to rely on the legal protections given by the MCA must have involved those conversations. But nothing in section 4 of the MCA (the relevant section, along with 6(6) and 6(7)) makes the clinician ‘the best-interests decision-maker’ if there is not a suitably-empowered legal proxy (the Code of Practice ‘implies’ that the clinician is the decision-maker – and the Code is wrong in my opinion).

Section 6 is shown at the top of the next page.

I dislike A for the reasons I have already explained - ‘participate in’ is not a good description of decision-making while the patient/person is capacitous.

I dislike B for similar reasons, of it not being correctly reflective of the MCA. It is clearly potentially misleading, for anyone who does not already understand the MCA – for example, the final sentence in B implies that the role and involvement of a welfare attorney whose authority extended over all medical treatments is similar to that of ‘relevant family members/friends’. Which is simply not true. And, the meaning of the word ‘relevant’ is not clear, either (it certainly does not mean ‘next of kin’).

C involves children, and I am not commenting on children, and I approve of the presence of D – I have seen too many forms with sections left inappropriately blank.



6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that (select A,B or C, OR complete section D below):

A This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.

B This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.

C This person is less than 18 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):

1 They have sufficient maturity and understanding to participate in making this plan

2 They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.

3 Those holding parental responsibility have been fully involved in discussing and making this plan.

D If no other option has been selected, valid reasons must be stated here: (Document full explanation in the clinical record.)

This section in a wide sense, is about confirmation 'that the process has been correctly followed' - again, I would prefer that more of the non-clinical people involved in the process, were signing to confirm that (not just the clinician/s). Although, if the individual boxes all carry the legally appropriate signature/s, it is not in fact necessary for anyone to sign to indicate the overall process has been correctly followed [if you think about it].

I am happy with box 7, except I consider it should say 'Person with clinical responsibility' instead of 'senior responsible clinician'.

Section 8 does now allow for some non-clinicians to sign on this form:

8. Emergency contacts and those involved in discussing this plan

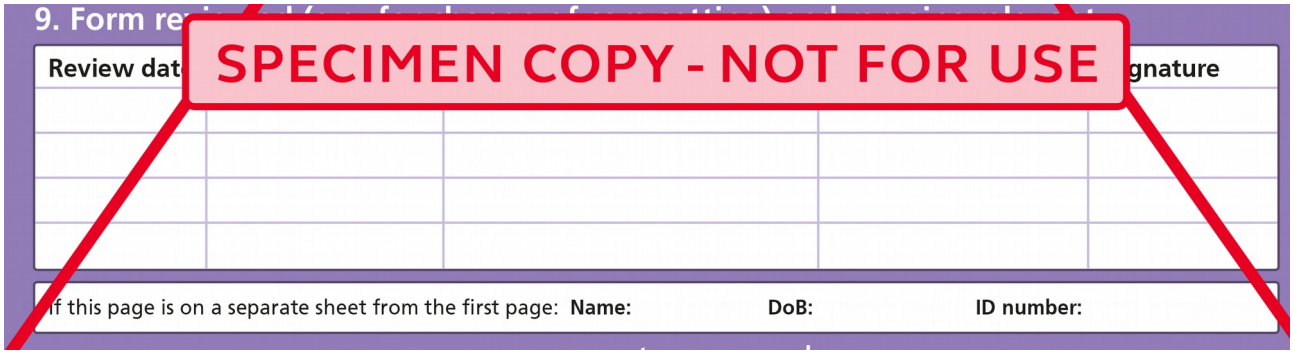
Name (tick if involved in planning)	Role and relationship	Emergency contact no.	Signature
Primary emergency contact: ☐			optional
☐			optional
☐			optional
☐			optional
☐			optional

I would prefer clarity between involved in discussing, and involved in formulating of the plan (very loosely, in the context of 'recommendations' which should more informatively be regarded as 'anticipatory best-interests 'decisions'', the distinction is between individuals who provided information, and individuals who could reasonably claim to have formed and expressed a defensible best-interests 'decision'). So I would prefer the banner to say:

8. Emergency contacts and those involved in formulating this plan

I also, have never been at all keen on the imposition of a primary emergency contact – it should be for the patient or relatives/friends to decide if there is one, or several, 'primary' emergency contact/s.

The closing section of the form, is difficult for me to comment on, because as first published the banner is partly obstructed:



In general, there are arguments both ways around the issue of 'review dates' on forms such as this one – and in all honestly, the 'review date' issue is entangled with other issues such as the level of training of the clinicians using the form.

To close, I will comment a little on my

3(c) correctly 'reflect' the situations(s) within which the form will be used, and the differences between these situations.

4) be compatible with the way that end-of-life can suddenly 'swerve in a new direction - are the forms 'nimble and responsive to sudden events'.

There are different types of 'emergency' - some treatment 'emergencies' might require a decision to be made within an hour or two, whereas others (notably CPR) require a decision to be made effectively within a matter of seconds. And a patient who lives alone, and arrives at a hospital A&E alone (no relative, friend or 'family-carer) but with a ReSPECT form, is in a very different situation from that of a person who collapses at home, if a person living with the patient summons 999.

The ReSPECT form is more useful and relevant for the living-alone-patient who arrives at hospital unconscious, than it is for the unconscious patient who collapsed at home and whose spouse phoned 999: if a 'family-carer' called 999, then the first thing paramedics should do is to fully involve the family carer. I have avoided including links in this piece, but I will insert a link here:

https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/I-have-a-suggestion-for-how-family-carers-and-999-paramedics-could-be-reconciled-for-CPR-decision-making-feedback-from-family-carers-welcomed./1031/

To close, I will mention that I have recently collaborated on a paper which should be published very soon (it has been peer-reviewed and accepted for publication), with a hospital doctor (the lead author), a consultant paramedic, and a barrister. Unfortunately it seems likely to be published behind a pay-wall, but the paper is relevant to the ReSPECT form, and once it has been published I will be discussing that paper.

Written by Mike Stone September 2020

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