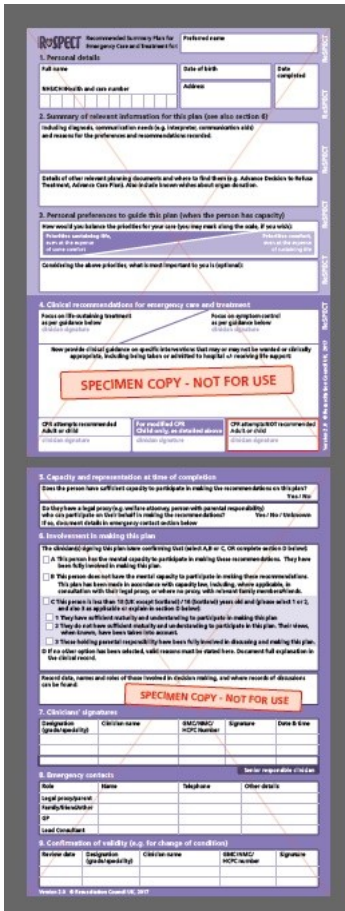


What the ReSPECT Form has on it, and what it instead should have on it

A Palliative Care Consultant asked me recently to explain why I'm so set against ReSPECT – I think he added 'apart from the Form', but you cannot really start anywhere except with the Form. To begin with: we can be sure that clinicians will see the form – we cannot be sure how much of the other 'ReSPECT material' will be looked at.



Just a few points.

Section 2 of the form includes a box covered by this wording:

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). Also include known wishes about organ donation.

Now, the ReSPECT form currently 'lives with' the patient, and the ReSPECT form is intended to be read 'during clinical emergencies'.

As the ResPECT Team admits – the ReSPECT form is **not** 'legally-binding' during an emergency.

But an Advance Decision is legally binding – and if the ADRT were applicable, then the ReSPECT form would be irrelevant.

So, instead of what it says - 'where can an ADRT be found' - that section on the ReSPECT Form should say:

Details of other relevant planning documents and where to find them (e.g. Advance Decision to Refuse Treatment, Advance Care Plan). It is strongly recommended that if you have an Advance Decision, you attach it to the front of this ReSPECT form. Also include known wishes about organ donation.

Section 3 of the form, allows the patient to describe 'preferences for treatments' but the patient does not sign the section: the patient should sign that section – the ReSPECT Team's 'rationale' for the patient not signing, is sheer nonsense.

Section 4 of the form is a total 'legal mess'. If the clinician is making a 'clinical recommendation' - for example 'in my opinion this patient is so frail that attempted CPR could never be successful' then the clinician should definitely be signing. But if, for example, a Welfare Attorney with authority over life-sustaining best-interests decisions, has stated 'attempted CPR would not be in the best interests of this patient' then if that is what the form is recording, **the attorney** should be the person who signs there. If there is not a welfare attorney or court deputy with authority over best interests, and section 4 is a record of a best-interests recommendation, then ideally we need both the clinician and also family, friends, to be signing that section – and, what they should be stating, is what I have explained elsewhere:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/283/>

It is surely logically the case, that **in the absence of an attorney or deputy with authority** over best-interests decision-making conferred by 6(6), after the discussions between the various parties involved in the ongoing care of an already incapacitous person, **there will often be a group of people** – loosely, I'll here write 'a group composed of family and clinicians' - **who can each individually say** 'my decision would be 'whatever' - and I think I can claim to have made that decision in compliance with section 4(9)'.

That situation is only clear, if all of that group believe the same recommendation would be in the patient's best interests: but in such a situation, logically the most 'compelling and legally defensible' thing on the form, which would then be read by someone such as a 999 paramedic, would be along the lines of:

'We the undersigned, have discussed whether it is likely to be in this patient's best-interests for CPR to be attempted, and we hereby sign to confirm that we all believe that DNACPR is in the patient's best interests – we also confirm that to the best of our knowledge, no sufficiently well-informed person has expressed the opinion that attempted CPR would be in the patient's best interests'

SIGNED BY EVERYONE – family and clinicians.

Section 5 has wording I am unhappy with:

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations?

Welfare attorneys with authority over best interests, should surely expect there to be no ambiguity on forms such as this one, about who is making the decision about best interests: if I were a welfare attorney I would refuse to go along with this form, unless I was signing if it recorded my own anticipatory best-interests decision. In fact, I would consider making my own Anticipatory Best Interests Form, which would start with something like:

For the attention of clinicians: I am the Welfare Attorney of this patient, and I am empowered under the LPA to make any necessary best-interests decisions about treatment. I direct you to sections 6(6) and 6(7) of the Mental Capacity Act. My anticipatory best-interests decisions are listed below – I also consider that it is in the best interests of the patient for this document to remain with the patient, and at the front of his medical notes (above any other 'advance planning' except for Advance Decisions).

6B of the ReSPECT form, should in my opinion be signed by both the lead clinician and also by 'legal proxies' and/or what the form describes as 'relevant family members/friends'. I could discuss 'who is more likely to understand if 'This plan has been made in accordance with capacity law" but I am restraining myself!

I dislike section 7 – it only has the signature/s of clinicians, which [see above] it is clear that I dislike.

Ditto section 9:

9. Confirmation of validity (e.g. for change of condition)

I am obviously perfectly happy for a clinician to sign to confirm a change of diagnosis or of prognosis which appears on a form – but if a patient changes his ‘preferences’ or if a welfare attorney changes a best-interests decision, it isn’t for the clinician to ‘confirm the validity’ of those changes.

Basically – as I have said repeatedly and at length – this ReSPECT Form **does not** correctly reflect the change in English law away from ‘clinicians know best, and clinicians make the decisions’ and to ‘patients make their own decisions, and if they cannot make their own decisions, the MCA contains some complex ‘best-interests decision-making law’.

As a contact of mine wrote in an e-mail, when we were discussing a recent change to the ReSPECT FAQs:

I have heard on the grapevine’ that the FAQ guidance is in the process of being amended to highlight the primary decision-making role of these people appointed by the person. A small change but I’ll be delighted when I see it. I appreciate this still doesn’t do anything to address the position of other people who also know the person far better than the professionals. However the guidance is at least being revisited with a view to balancing the professional/lay rights regarding appointed proxies. It’s a start.

I do think, incidentally, that the more people know about their rights to make decisions in advance about future care or treatment, and how to do this, the better. This is the tenth birthday year of MCA implementation: maybe we can all tell our local communities about the rights it gives us? In my view, and despite the admittedly slow burn on this one (putting it politely), this will in future be recognised as the greatest change that the MCA has brought about - the change from paternalism ‘Nurse knows best’ to making it clear we can make our own decisions, and telling us how.

The **ReSPECT Form** still doesn’t make it immediately obvious that now:

Patients make their own decisions – and unless ‘mental incapacity ‘has been proven’ nobody ‘validates’ those decisions;

If patients cannot make their own decision, any valid and applicable Advance Decision should be followed;

If there isn’t an Advance Decision and best-interests decision-making becomes necessary, then if there is an empowered welfare attorney or court deputy that person makes the best-interests decisions, **including ‘anticipatory best-interests decisions’**, and again nobody ‘validates’ those decisions;

ONLY IF NONE OF THE ABOVE APPLIES, should anyone else – emergency clinicians or family-carers – be ‘making best-interests decisions’: the ReSPECT Form is about ‘clinicians making decisions during emergencies’, so we have now reached ‘the territory the form applies to’ - *but, the ‘rule’ isn’t ‘the senior clinician makes the best-interests decision’ as ReSPECT claims, the rule is ‘if you made and acted on a decision, can you claim compliance with section 4(9) of the MCA?’*.