

End-of-Life and Perspective part 1: Ownership

I have been at loggerheads with 'ReSPECT' for several years, and my objection can be seen as hinging on 'ownership': when I look at what I will call 'the Main ReSPECT Form', what I see is 'ownership of the entire form by clinicians'. I received an e-mail from ReSPECT in March 2018, and the e-mail is shown and discussed towards the end of this PDF – the ReSPECT people who sent the e-mail to me, apparently cannot understand why I find that form unacceptable. While, for the life of me, I cannot understand why they think the form wouldn't raise the hackles of patients, relatives and especially of Welfare Attorneys.

The Main ReSPECT Form, is quite difficult to categorise: in England, it could loosely be described as combining 'advance statement', 'anticipatory best-interests decision' and 'expert clinical opinion' in a mix which depends on the patient and the situation. It definitely isn't an Advance Decision, and it definitely isn't a 'traditional' DNACPR Form (and it is also for various reasons, quite complex to describe the exact nature of 'traditional' DNACPR forms).

I pointed out in a BMJ rapid response, when ReSPECT was at the time called ECTP, why I disliked the presence of only clinical signatures on the 'prototype' ECTP form – here, I have made a section which relates to my theme of 'ownership' bold text:

<http://www.bmj.com/content/352/bmj.i26/rr-5>

The recent ruling by Mr Justice MacDonald (see ref 3) has made it clear that mentally-capable patients make their own decisions, which are not then to be questioned by others, and I have pointed out above that sometimes it is legally clear that a welfare attorney [or, but never for CPR, a court deputy] is the decision maker. The Winspear ruling starts its point 4 with 'Although the precise terms of that conversation are a matter of dispute,' and exactly who said what during Tracey, is very uncertain indeed. The ECTP prototype does mention conversations between clinicians, patients and relatives - but it does not suggest that such records of conversations, should be 'signed off' by 'all sides': the ECTP wants only clinicians to sign. Similarly, the ECTP does not seem to want attorneys and deputies to sign to confirm their decisions - again, it wants the clinicians to do the 'signing off'.

This is both legally dubious - people should sign for whatever they are responsible for, so a clinician signs for a clinical prediction, a welfare attorney signs to 'authenticate' his/her own best-interests decision, etc - and anachronistic. This type of 'clinical control' of 'patient records' reinforces inappropriate distinctions between clinicians and involved laymen, it potentially introduces 'bias', and it definitely does not promote the necessary cooperation and integration between the clinicians, family, friends, and if they are present attorneys and deputies, which decent 'joined-up' care requires.

Once, husbands 'owned their wives' - but no longer: and clinicians do not 'own their patients'. Until patient records contain within them the 'right' signatures (at the very least, the possibility of the right signatures being present: I accept that it might be difficult for patients and family members to sign such documents, but they should definitely not be prohibited from signing them) - signatures based on authority,

responsibility and involvement, and not simply on whoever happens to be 'the senior clinician' - there will in my opinion never be satisfactory integration between the many people who are typically involved in supporting, and caring for, patients. The complexity of best-interests decision-making, and my mother's death (see ref 4), convince me that we should be pushing for patient-expressed decisions made in advance: so it is Advance Decisions which need to be promoted. But there seems to be an agenda to encourage patients to create 'written advance statements', which – unlike a written advance decision – cannot 'just be followed in an emergency'. In contrast to this push to promote the essentially 'very challenging in application' 'written advance statement', nobody seems to be trying to address the problem I mentioned in reference 5 of a patient at home expressing a decision to only a family carer.

The Main ReSPECT Form can be found at:

https://www.respectprocess.org.uk/_pdfs/ReSPECT-Specimen-Form.pdf

3. Personal preferences to guide this plan (when the person has capacity)

How would you balance the priorities for your care (you may mark along the scale, if you wish):

Prioritise sustaining life,
even at the expense
of some comfort

Prioritise comfort,
even at the expense
of sustaining life

Considering the above priorities, what is most important to you is (optional):

4. Clinical recommendations for emergency care and treatment

Focus on life-sustaining treatment
as per guidance below
clinician signature

Focus on symptom control
as per guidance below
clinician signature

Now provide clinical guidance on specific interventions that may or may not be wanted or clinically appropriate, including being taken or admitted to hospital +/- receiving life support:

SPECIMEN COPY - NOT FOR USE

CPR attempts recommended
Adult or child
clinician signature

For modified CPR
Child only, as detailed above
clinician signature

CPR attempts **NOT** recommended
Adult or child
clinician signature

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You can see sections 3 and 4 of the form above, and you will note that only 'clinician signature' appears on the form: not 'patient signature', not 'attorney signature', and definitely not 'relative/friend/family-carer signature'.

Section 3, is filled-in by the patient – it is what most clinicians would describe as ‘an advance statement’: setting aside my belief that whenever possible we should be trying to get from patients Advance Decisions and not ‘advance statements’, it is very clear that the patient ‘owns’ his own ‘advance statements’ - **the patient completes and owns section 3, so the patient should sign that section.**

Section 4, for the purposes of English and Welsh law, can only be described as ‘a complete legal mess’. It seems to potentially combine at least two different legal situations, under a peculiar heading of ‘clinical recommendations’:

1) Recommendations that a clinical intervention should be withheld because for a pre-existing clinical reason, the intervention could not be clinically effective, and

2) Recommendations that a clinical intervention should be provided – this entire form is pointless if you can simply obtain consent from the patient for the intervention at the time, so the only way to describe those recommendations is as ‘anticipatory best-interests decisions’ (which, therefore, can be both ‘do it’ and also ‘do not do it’).

The ‘ownership’ of 1) is simple: if a doctor writes on a form ‘do not attempt CPR – CPR could never be clinically successful for this patient’ then the doctor owns that assertion, and **the doctor should sign it.**

The ownership of 2) is more complex: if a welfare attorney or court deputy has legal authority over the best-interests decision-making, then the attorney or deputy would be making the decision recorded in box 4, and therefore the attorney or deputy would ‘own’ the decision – therefore, **the attorney or deputy should sign it.**

Despite widespread assertions to the contrary, there isn’t ‘ownership’ of best-interests decision-making unless an attorney or deputy has been given legal powers by section 6(6) of the MCA – I would point the reader at 3 linked-tweets here:

https://twitter.com/MikeStone2_EoL/status/906073527236907009

I had been collecting my objections to ResPECT in the thread at:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/>

for some time, before the Supreme Court issued a clarification which I can now add to my analysis.

The Supreme Court ruling can be found at:

<https://www.supremecourt.uk/cases/docs/uksc-2017-0202-judgment.pdf>

There are only two even vaguely-reasonable interpretations of the Supreme Court's ruling, and either way, it seems to 'knock out' a justification which ReSPECT has put forward for the presence on its Main ReSPECT Form on only the signatures of clinicians

The Supreme Court has recently issued its clarification, following the withdrawal of

something called PD9E – it is very difficult to argue that the Supreme Court did anything other than to make clear that 'family and friends **can make** satisfactory best-interests decisions' if you read what the Supreme Court said.

And if we accept that family and friends can arrive at perfectly-satisfactory best-interests decisions, instead of claiming [incorrectly – as should be obvious, if only people bothered to read section 6(6) of the MCA, which is the only place where the MCA imparts legal-authority for best-interests decision-making] that 'the senior clinician makes the best-interests decision', then the questions are different, and crucially include:

How can the best-achievable best-interests decision be arrived at?

Instead of starting from that question, most professionals start by making very different assertions: one in particular, which doesn't fit with the logic of 'start by asking 'How can the best-achievable best-interests decision be arrived at?' at all, is to assert that 'first we need to identify who will [in the future] be making the best-interests decision'. I would instead ask 'How can we ensure that anyone faced with a best-interests decision to make, will be able to make a good decision?'.

As it happens, when you ask the logically-correct questions about best-interests decision-making, the answers are often either 'inconvenient' or very complex – but, this does seem to be both correct and also obvious, as well as never being stated in this way by clinicians:

*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.

Expressing that differently – involve and inform everyone available who could defensibly make a best-interests decision, and if they ALL AGREE then accept and act on the decision, but DO NOT make a claim that a particular individual made the decision.

That isn't 'the process has been over-seen by the clinicians' as I view it – I see that as the clinicians facilitate the process, and while it clearly fits with what the Supreme Court said:

126. In conclusion, having looked at the issue in its wider context as well as from a narrower legal perspective, I do not consider that it has been established that the common law or the ECHR, in combination or separately, give rise to the mandatory requirement, for which the Official Solicitor contends, to involve the court to decide upon the best interests of every patient with a prolonged disorder of consciousness before CANH can be withdrawn. If the provisions of the MCA 2005 are followed and the relevant guidance observed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court. ...

the Supreme Court is rather less questioning than I am, on the issue of 'will the professional guidance be correct?', so I would have gone for:

If the provisions of the MCA 2005 are followed, and if there is agreement upon what is in the best interests of the patient, the patient may be treated in accordance with that agreement without application to the court. ...

There is a provision covering 'professional guidance' in the MCA 2005, so in fact I haven't removed anything – although the interaction between the MCA and 'professional guidance' is deeply complex, and deeply 'problematic in practice'. Too 'nerdy' and off-topic, to discuss in detail here.

By far the simplest conclusion to be drawn from the Supreme Court ruling, is the court agrees that family and friends, if informed about the clinical situation and options, and provided they are aware of what the MCA requires by way of best-interests decision-making and comply with those requirements, must be able to make legally-satisfactory best-interests decisions about life-sustaining medical interventions: other conclusions are perhaps possible, but they involve, to use my phrase here, 'an awful lot of weird, convoluted argument' (for example, perhaps the court was implying that the family can object 'because the family believe the best-interests process was not being properly complied with' - it isn't obvious how the relatives could sensibly make that assertion, unless the relatives understood the best-interests process, in which case 'why wouldn't the relatives be making best-interests decisions?').

NOTE: I am saying 'make' best-interests decisions - I am NOT saying 'impose' best-interests decisions (and there is a third distinction - 'acting on your own best-interests decision' which isn't identical conceptually to either 'making' or 'imposing on others' {you would be 'imposing your decision on the incapacitous person' but for this discussion, the incapacitous person is not part of 'others' - 'others' means other individuals who can also make 'defensible' best-interests decisions}). In fact, there is a fourth situation - how to justify the following of someone else's best-interests decision, if you yourself cannot defensibly make a best-interests decision: I've just covered that one, in the italicised section on page 4.

Neither ReSPECT nor the majority of doctors, are willing to openly defend 'medical paternalism' since the Montgomery court ruling. But ReSPECT has sought to justify the signature of the senior clinician on the Main ReSPECT Form, even when the form records things written onto the form by a capacitous patient, or when it records an anticipatory best-interests decision which was made by a legally-empowered welfare attorney, with the

argument that 'the senior clinician is signing to confirm that the 'the process' has been correctly complied with'. The Supreme Court's PD9E clarification, now allows me to deal with that supposed 'justification' for the form being signed **only by** the senior clinician.

The only two obvious possible interpretations of the Supreme Court's clarification, are the straightforward one of 'adequately-informed individuals, be they family, clinicians or friends, can make legally-satisfactory best-interests decisions', and the rather weird suggestion that 'the family and friends cannot make a best-interests decision, but they can decide if the 'best-interests process' has been correctly performed'. Obviously, nobody who doesn't understand the process, could make a defensible best-interests decision - so, the simpler 'family and friends can make best-interests decisions' also means that family and friends can understand if 'the best-interests process has been correctly performed'.

So - I agree that it helps if readers of the Main ReSPECT Form see signatures on it, which appear to confirm that the law was complied with in the form's creation: but as the Supreme Court has made it clear that family and friends ['normal' laymen - not just attorneys and deputies] can understand 'if the process has been correctly performed' then the argument that 'the senior clinician signs to confirm that' collapses - **it becomes, as I had pointed out, 'family, friends and clinicians should be signing to 'confirm' compliance with the law'.**

So in many situations, family and friends should be signing section 4 of the Main ReSPECT Form, in addition to clinicians.

All of the above, is about placing the correct signatures on the form, from the perspective of 'responsibility': but there is no reason to not also include further signatures which reflect not responsibility, but instead 'involvement'. I have recently tweeted about that:

https://twitter.com/MikeStone2_EoL/status/1034359101386616833

Instead of designing documents which stress 'single ownership', in the same way that most guidance for end-of-life tries to promote greater discussion, 'sharing' and 'dissemination', we should change the design of documents to reflect 'involvement and understanding'.

In many cases, 'ownership of' either a document, or part of a document, is clear. For example, an Advance Decision is very obviously 'owned by the patient who created it'. It isn't clear that 'DNACPR Forms' have a unique owner, although if the form states the equivalent of 'do not attempt CPR because there is a clinical reason why CPR could never be clinically successful' then the clinician who is making that assertion, obviously 'owns' that section of the form.

But, even where ownership is clear: that is no reason to not have signatures which convey 'involvement'. There is a legal requirement for some written Advance Decisions to be witnessed, but I see no reason why the author of an ADRT could not go further. The ADRT could be designed so that several people could witness the author's signature: a husband creating his ADRT, might design it so that his wife, his son, his GP and the lead district nurse of a DN team which was treating him, **could all witness** his signature. And because a written ADRT cannot be 'asked to clarify its wording' after the author has become unconscious, the ADRT could also contain a section which stated 'I have discussed the meaning of this ADRT with the following people, and if you are not on this list, then any person on this list probably understands my ADRT better than you do' - followed by a list of people who the patient had 'explained' his ADRT to. That list could contain the signatures of the people the author of the ADRT had explained its meaning to, followed by the author's signature as confirmation of the discussion. **That isn't the author somehow relinquishing ownership – it is confirmation of the understanding of certain other people.**

Good end-of-life care, is a 'team effort': documents which assign 'authority' correctly, but which also 'explain wider involvement and understanding of the situation', must surely be a better approach, given the sheer complexity of end-of-life.

I polled Twitter about signatures on forms using the piece above:

https://twitter.com/MikeStone2_EoL/status/1034359110358188043

All of the votes were for 'more signatures on the forms' but only 4 people voted.

From my perspective, this 'exclusion of non-clinical signatures' seems to 'sideline the relatives, friends and family-carers', as well as being 'legally offensive' to welfare attorneys and court deputies: it certainly wouldn't have helped with my own unsatisfactory experience after my mother's death at home:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/315/>

From my perspective, for EoL at Home we need to stress that what matters the most is the 'ongoing contact with the patient and with each other' (my 'model' based on that, I call the Core Care Team) as opposed to 'professional or lay status'.

I posted a PDF about the Core Care Team in March 2014:

<https://www.dignityincare.org.uk/Discuss-and-debate/download/258/>

Finally, before the Appendix, I am of course aware that 'ownership' is in reality the same as my usual approach: when I point out that the Mental Capacity Act in reality mainly explains who has legal authority [or otherwise] over which decisions, it is obvious that 'ownership of the decisions' is just another way of expressing that.

Written by Mike Stone, September 2018.

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Appendix: an e-mail to me from some senior ReSPECT people

I have been making clear my dislike of certain aspects of 'ReSPECT' for several years, going back to when it was called 'ECTP'.

There are many aspects of 'ReSPECT' which rather confuse me: I have sent questions about ReSPECT to the RC(UK), and received answers not from RC(UK) but from ReSPECT; and I have sent a request to ReSPECT, and been directed by ReSPECT to the RC(UK). I also come across 'ReSPECT is a process' but you cannot discuss things with 'a process' - you can only discuss issues, with actual people.

However, whatever 'ReSPECT is', many clinical and other organisations seem to 'support it', and its 'process and paperwork' is being adopted by various NHS Trusts across the country, despite its flaws as I perceive them:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/An-issue-with-ReSPECT-which-I-will-be-pointing-out-to-the-Public-Guardian/960/>

I was sent an e-mail which commented on my 'feedback to and criticisms of' aspects of ReSPECT, and I was particularly irked by a part it: by its assertion that the reasons I dislike aspects of ReSPECT, such as by the presence of only the signatures of clinicians on the Main ReSPECT Form, because to me it should be blindingly obvious why I object to a form, which 'carries the wrong signature'. Documents which seem to indicate that 'the senior clinician controls things' will make experiences such as mine

<https://www.dignityincare.org.uk/Discuss-and-debate/download/317/>

more, not less, likely: and, for the relatives involved, more, not less, unsatisfactory and damaging.

I obtained permission to publish the earlier e-mail, in an e-mail of 9 April 2018:

Dear Mr Stone,

Thank you for your email.

We did regard our emails as private correspondence but we have no objection to you sharing them publicly.

Kind regards,
Zoe
Peter-Marc
Juliet
Catherine

This is the e-mail from ReSPECT to me, on 22 March 2018:

Dear Mr Stone,

ReSPECT is a significant project that clinicians, patients, lay carers, social carers, and patient and professional organisations passionately believe to have the potential to improve the emergency experience for patients and their families across the UK. The project attempts to do something that is hugely complex and has never been attempted before at this scale but is entirely about helping patients and their loved ones identify what really matters to them and to be assured that those values and goals of care will be communicated and will influence emergency clinical decisions when they are not in a position to do that. It is as much about ensuring that realistic wishes to have emergency treatments considered are known and respected as it is about the choices to refuse such emergency treatments.

The ReSPECT process has been, and continues to be, developed iteratively, with feedback from formal evaluations and individual users. Several of your points have been extremely valuable, and we hope we have changed the FAQs accordingly to address some of your concerns. As we receive feedback we will continue to improve and revise the ReSPECT form and the FAQs. This feedback is coming from clinicians, lawyers, patients, relatives, lay and social carers, patient organisations such as National Voices and the Alliance; and from charities such as Mencap. All of them are as passionate as you about representing individual choices and complying with capacity legislation. Many also recount harrowing experiences, but they do not all agree with you. For example, there is a majority opinion that the ReSPECT form itself - which is only one part of the ReSPECT process - is not, and must not aspire to be, a consent form or a legal ADRT document; there is a different place for that, and to try and make the ReSPECT form become an ADRT would stand in the way of its other functions.

The ReSPECT process prompts and supports realistic and person-centred conversations to happen early between patients, their families and their health and social care team. Where the form is present to inform emergency clinical decision-making, it supports relatives to know and understand that the right thing is happening as their loved one had requested and planned for, whether the relatives are present in the crisis or not.

This whole project presents the opportunity to transform the emergency care experience for countless patients and their families across the UK in a way that no DNACPR, ADRT or narrowly specific legal document will ever achieve. To read that the ReSPECT "team" are only interested in increasing clinicians' power and taking power away from patients and carers questions the competence, motivation & integrity of all those involved, many of whom are patients, bereaved relatives or their representatives. We are, in truth, somewhat bewildered by your repeated negative attitude, which contrasts sharply with the spirit of collaboration that will be crucial to achieving change to promote the level of high-quality care that both we and you wish to see - please remember we are all people too, and we are striving to improve patient care and patient and family experience.

Your point about using the ReSPECT form to better identify how to rapidly access any ADRT or ACP document is well made and is already being addressed

as part of the digital work. We are also looking at the ways we might use the form and the supporting patient information to highlight the importance of attaching the physical ADRT or ACP document to the paper ReSPECT form for exactly the reasons you mention.

Best wishes

Zoe Fritz, Chair of ReSPECT Strategic Steering Group
Juliet Spiller, Co-chair of ReSPECT Expert Working Group
Peter-Marc Fortune, Co-chair of ReSPECT Expert Working Group
Catherine Baldock, Project lead for ReSPECT

I will not analyse that e-mail in detail within this appendix - suffice it to say, that if ReSPECT changes its Main ReSPECT Form to include signatures which correctly describe both decision-making authority and also involvement during EoL, and in general will stop implying that end-of-life decision-making is more 'under clinical control' than the Mental Capacity Act describes (in other words, if ReSPECT will stop 'asserting clinical ownership of non-clinical things' and when ReSPECT also starts describing the law correctly), then I would stop objecting to ReSPECT.

But until it does change, then so long as I still have the energy and enthusiasm, I will continue to draw attention to the defects I perceive in ReSPECT.