

ReSPECT has altered its FAQs – however, its Form still only has the signature/s of clinicians on it, which is still NOT satisfactory.

Regular readers of Dignity in Care forum pieces, or indeed of British Medical Journal rapid responses, will probably be aware that I have long argued that ReSPECT does not correctly reflect, or embody, English ‘consent law’ as defined within the Mental Capacity Act. I have sent e-mails to people in ‘the ResPECT team’, and I made the necessary legal and logical points at length in my response to the ReSPECT consultation (at a time, I think, when ReSPECT was still titled ECTP), explaining the flaws within ReSPECT for two or three years now.

On Saturday I opened an e-mail from one of my contacts, which told me:

*I heard good news last Friday at a DoLS conference in London. At last apparently the ReSPECT guidance is corrected - although I've not looked, due to the snow making me even busier than usual, but I think it's probably OK now.*

I downloaded the ReSPECT FAQs on Saturday, and the ReSPECT Form, and although I have not read the FAQs completely yet, I have looked at the changes in the sections about Welfare Attorneys and Court Deputies. You can find the FAQs at:

<http://www.respectprocess.org.uk/faqs>

I posted some tweets about the new FAQs and about the signature issue, on my Twitter account on Monday and Tuesday of this week – these two links are effectively a compressed version of this piece, which you are reading:

[https://twitter.com/MikeStone2\\_EoL/status/942686580862484480](https://twitter.com/MikeStone2_EoL/status/942686580862484480)

[https://twitter.com/MikeStone2\\_EoL/status/942688500809457664](https://twitter.com/MikeStone2_EoL/status/942688500809457664)

Of course, you will not find the original FAQs if you visit the ReSPECT website – you will only find the current version, so it will help if I show here the original relevant section, which I downloaded on September 12<sup>h</sup> of this year. Originally – and as I repeatedly made clear to ResPECT, misleadingly – the FAQs said:

**If the person has capacity for the relevant decisions, they must be involved fully with the process of shared decision-making. Many people want to have the support of family, friends or carers in the discussion, and some may choose to have a family member or friend advise them on what choices to make.**

**If they don't want their family or other carers to know about their condition or their choices, they should make sure that the healthcare team knows about this so that their wishes for confidentiality can be respected.**

**If a person lacks capacity and has appointed a legal proxy with powers to make decisions about life-sustaining treatments, the clinical team must involve them in making shared decisions on behalf of the**

**person. Where there is no legal proxy, the clinical team must consult family or friends about a person's situation and previously expressed views or wishes, in order to make decisions that are in that person's best interests and for their benefit. However, the responsibility for making those decisions rests with the senior responsible clinician. The family must not be burdened with thinking that they are being asked to make these decisions.**

I disagree with an awful lot of that – it implies, incorrectly, that 'family' cannot defensibly make best-interests decisions about the withholding or application of a medical treatment, which simply isn't a logical conclusion if you read the MCA, but the section which was clearly legally flawed and deeply misleading is this:

**If a person lacks capacity and has appointed a legal proxy with powers to make decisions about life-sustaining treatments, the clinical team must involve them in making shared decisions on behalf of the person.**

That is clearly very-deeply legally-flawed: if a proxy (either a [Health and] Welfare Attorney or a Court Deputy) possesses legal authority over best-interests decisions (via the LPA and explained in sections 6(6) and 6(7) of the MCA) then **the proxy would be making the decision – the proxy would not be involved in making decisions with the clinical team, the proxy would consult the clinicians and then the proxy would make the decision/s.**

The revised FAQs now say this:

## **What is a legal proxy and what is their role?**

### **England & Wales**

**A health and welfare attorney must be consulted if one has been appointed (and all such attorneys should be consulted, where that is practical, if more than one has been appointed). They stand in the shoes of the person, so that their view should ordinarily be taken as if it were the view of the person themselves as to what they would want. If the attorney has the power to consent to or refuse life-sustaining treatment, and makes clear that they would exercise that power on behalf of the person to refuse treatment in particular circumstances, then in general no recommendation should be made for such treatment to be administered in those circumstances. There may be exceptional circumstances when the senior responsible clinician considers that the attorney is not acting in the best interests of the person in their approach to the making of the recommendations, such that their views should not be taken into account. If the dispute with the attorney cannot be resolved by discussion or mediation, it is likely that any such case would need to be taken to court for a decision as to what treatments should (or should not) be offered or continued.**

**Where emergency treatment has been started as a result of a recommendation, then as part of the continuing review of the person's care and updating of the ReSPECT recommendations, the attorney should be consulted as soon as practicable to confirm whether they agree that the treatment should continue. If the attorney does not agree, then, again save in exceptional circumstances, the treatment must stop (including life-sustaining treatment if the power of attorney specifically contains the power to refuse such treatment).**

**A health and welfare deputy should also be consulted if one has been appointed in the same way as an attorney. However, a deputy can never refuse life-sustaining treatment on behalf of the person.**

**This is much better – very belatedly –** and although it isn't perfect [next year I will be explaining that while in very exceptional circumstances the decision of a proxy might reasonably be disregarded, *the ReSPECT Form is entirely unsatisfactory in such a situation*] it is made clear that the proxy is the decision-maker:

**If the attorney has the power to consent to or refuse life-sustaining treatment, and makes clear that they would exercise that power on behalf of the person to refuse treatment in particular circumstances, then in general no recommendation should be made for such treatment to be administered in those circumstances.**

Technically, the proxy is not actually 'consenting or refusing' although ReSPECT can be excused for getting that wrong (the MCA itself gets that wrong, in its section 11: in reality, as is obvious if you read sections 4 to 6 of the MCA, 'the proxy makes and expresses a best-interests decision in the knowledge that a medical treatment is being offered').

Deciphering that sentence, it amounts to, provided we are only considering potentially clinically-effective treatments at the time the form is being completed :

'If the ReSPECT Form recommends a best-interests decision which a proxy is legally-empowered to make, the form cannot exist if the proxy's decision is not the decision recorded on the form'.

If you read the FAQs and look at the sections covering the form when the patient is mentally-capable, you will conclude that the form cannot exist if the patient does not consent to its existence [with the caveat I mentioned above, re potentially clinically-effective treatments].

In a nutshell – the form can only exist if capacitous patients, or empowered welfare attorneys, agree to the form's existence.

**Now, there is a 'crucial point' about that: nobody will be reading forms which do not exist!**

I am a great believer, in designing forms which involve the Mental Capacity Act, or cardiopulmonary resuscitation, in a way that imparts a correct understanding of the law to the form's readers. The ReSPECT Form is currently signed only by clinicians – but, it CANNOT EXIST TO BE READ if the form would not be a record of a decision made by the

patient or an attorney (or deputy) when the patient or attorney is legally the decision-maker.

This **IMPLIES TO READERS** that 'the senior clinician' who signs **THE ONLY FORMS WHICH CAN EXIST AND THEREFORE CAN BE READ** is always 'the decision-maker' - but the FAQs, which will undoubtedly be looked at less often than the Form will be looked at – contradict that.

**That is deeply unsatisfactory – we need to have the right signatures on the ReSPECT Form itself**, as I pointed out in a BMJ rapid response (the wording below is an extract from my response, not the complete response – and at the time, what is now called ReSPECT was called ECTP) :

<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.*

It is clear from that piece, that I want not only the signatures of welfare attorneys to replace the signature of the senior clinician on the form when that is legally-appropriate, but that

more widely I want provision on the form for the signatures of the patient and of family and friends – who signs, when and why, being determined by:

*signatures based on authority, responsibility and involvement, and not simply on whoever happens to be 'the senior clinician'*

This is part of a significant 'culture shift' - and one which our judges seem to now be reflecting in their recent rulings, but which 'the medical establishment' is still apparently resisting – **and the change to the FAQs re 'legal proxies' is merely a small step in the necessary direction**. One of my contacts wrote to me some time ago in an e-mail – and I [of course!] completely agree about this:

***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.***

To close this piece, I will point at something from the ReSPECT Form, in its current version (version 2.0). It asks in its Box 5:

Does the person have sufficient capacity to participate in making the recommendations on this plan? **Yes / No**

Do they have a legal proxy (e.g. welfare attorney, person with parental responsibility) who can participate on their behalf in making the recommendations? **Yes / No / Unknown**

This 'who can participate in making' phrase is misleading – it doesn't make it immediately clear that sometimes the patient or the legal proxy is in control of 'the recommendations'. Lots of people 'participate in' the creation of the 'recommendations' - but only capacitous patients, and suitably-empowered welfare attorneys or court deputies, possess 'genuine legal authority' over Informed Consent and Best-Interests Decision-Making.

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