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4 September 2017

Dear Mr Eccles,

I am writing to you to express concerns I have about the interpretation of the Mental Capacity Act within a process/document called ReSPECT, which clinical bodies are in the process of adopting: ReSPECT is a wider-in-scope approach to 'emergency care' which is widely seen as a replacement for DNACPR forms.

DNACPR forms, were specifically intended to prevent attempted CPR: ReSPECT is supposedly intended to guide decision-making about a wider range of possible clinical interventions 'during emergencies' (the original name of ReSPECT, 'Emergency Care and Treatment Plan' (ECTP), was more 'obvious').

I have been engaged in debate with the ReSPECT team, both directly and within the British Medical Journal, for several years, because I consider that ReSPECT does not correctly reflect the transfer of our legal situation towards patient autonomy and away from 'clinical paternalism'. Many of my objections to ReSPECT can be found in my piece at:

<http://www.bmj.com/content/356/bmj.j876/rr-7>

At the end of that piece, I posed a question:

To Close: (hypothetical)

I have been sharing a home with my now 'dying partner' for 20 years, although my partner has only been 'dying' for about six months. I have talked to my partner a lot during this six months, and during those 20 years. The GP has talked to my partner a little, especially recently. We both talk to the district nurses who have visited a couple of times a week for the last 6 weeks - but they are often different nurses each visit.

My partner has just collapsed. I have called 999 to find out why my partner has collapsed. I am now standing over a 999 paramedic, who is doing something to my unconscious partner. Why on earth, should I accept that this paramedic decides what happens next ?

When I read the MCA, from the perspective of a possible patient or of a person who is a family carer and a potential attorney [under the LPA], what I see is:

- a) Everyone who is involved in an ongoing way with a mentally-incapacitous person must attempt to always act in compliance with section 4 of the Act: the requirement is to defensibly claim compliance with 4(9);
- b) Lay people must be able to satisfactorily make best-interests decisions about medical interventions – best interests is a replacement for consent, and it is obvious both from section 4 and in particular from 6(6) that whatever arriving at a best-interests decision involves, it does not require the decision-maker to be clinically qualified {the converse would in fact be surprising: best interests is the replacement during incapacity for informed consent during capacity, and nobody has ever argued that consent to brain surgery is impossible if the patient could not perform brain surgery};
- c) While still capacitous, I can arrange for a person of my choosing to become my attorney, and my attorney's role is to make best-interests decisions after I have lost my own capacity: and once expressed, my attorney's decisions must be followed except in the situation of life-sustaining treatments and even then only WHILE a decision is being sought from the court;
- d) I can find nothing in the Act, which implies that best interests should not apply during 'emergencies': it can be argued that it is implicit in section 4, that anyone involved in an ongoing way should be acquiring the necessary understanding which would be needed to make a defensible best-interests decision **during** an 'emergency';

I need to add only one more point, before I can describe my objections to ReSPECT:

- e) The traditional 'defence' to 'intervention without consent' used by emergency clinicians, is 'necessity' – and 'necessity' is a defence based on unavoidable 'ignorance'. Compliance with section 4(9) – in other words best interests – is a defence based on 'acquired understanding'. Logically, 'best-interests must legally be superior to necessity'. And the mere existence of the ReSPECT form – which is intended to guide the behaviour of 'previously uninvolved' clinicians during 'emergencies' – implies that ReSPECT must agree with me on this point.

It follows from e), that in my scenario above, the collapsed person's partner might be able to make and express a defensible best-interests decision, because of those earlier discussions with the patient [in other words, the partner understands 4(6)] – but the 999 paramedic, could not possibly consider 4(6) 'during an emergency': if the paramedic is not to fall back on necessity, the only person who can defensibly **make** a best-interests decision there, is the partner.

Now, ReSPECT, and DNACPR forms, 'record anticipatory best-interests decisions'. It is possible for a clinician such as a 999 paramedic to **read** the record of a decision – which is therefore usually 'a recommendation to be

followed' during 'an emergency': so the question then becomes 'how does the reader, justify following the recommended course of action?'

ReSPECT and the earlier DNACPR forms, are invariably signed **only by** 'one or more senior clinicians'. But what such forms **should be** providing is a compelling 'legally-based' reason, for a clinician who cannot make a best-interests decision, to follow the decision on the form.

A few years ago, I asked hospitals whether their DNACPR forms allowed an attorney whose authority extended over CPR, to sign instead of the senior clinician if the decision was a best-interests decision. The answer was invariably 'no' and the justifications were logically and legally flawed – my survey can be downloaded from:

<https://www.dignityincare.org.uk/Discuss-and-debate/Dignity-Champions-forum/My-Survey-of-Hospitals-in-2014-about-an-aspect-of-their-DNACPR-Forms/949/>

My own local hospital, UHCW, has adopted the ReSPECT form. I recently asked the same question: does your ReSPECT form allow an attorney to sign it instead of a clinician, if it records best-interests decisions which were made by the attorney.

The reply I received was:

The matter of signatures on ReSPECT forms is addressed in the FAQs on the ReSPECT website at <http://www.respectprocess.org.uk/faqs.php>.

By signing a ReSPECT form, the clinician completing it is confirming that – in the case of a person who lacks capacity to discuss and agree the entries on the form – they have complied with capacity law. For the minority of people with a legal proxy empowered to make decisions about life-sustaining treatments, that will include discussing the treatment options with that legal proxy to enable them to make a fully informed decision that is in the person's best interests.

There is a logical issue with this – **nobody should be 'self-certifying compliance' with the MCA on a form** (a form might detail how you have complied – but such details are definitely out-of-place on a form designed to be read during an emergency) **and it is not for anybody to verify that another person has satisfied section 4(9) either**: it is certainly not for a clinician, to 'verify compliance with the MCA on the part of an attorney'. Sections 6(6) and 6(7) describe the law re clinicians and attorneys: they contain 'challenge' in 6(7), but they do not include 'verification'.

More importantly, **because of 6(6) if the attorney signs the ReSPECT form, the 'recommendation' about what is likely to be in the patient's best interests directly carries the legal authority of the attorney 'to the reader's eye'**: there is no genuine 'legal authority' over best-interests decision-making, carried by the signature of a clinician.

It is 'logically clear' that when appropriate, it should be the attorney who is signing ReSPECT, and **not** the clinician.

I wrote about this issue, when ReSPECT was still called ECTP:

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

The Resuscitation Council UK is currently hosting a consultation about a proposed 'universal' ECTP (ref 1). I dislike many features of the 'prototype' ECTP, for example that a patient can only be either 'FOR CPR' or 'NOT FOR CPR': it is very clear, from considerations of consent law or from the Mental Capacity Act's description of Advance Decisions, that a patient's refusal or acceptance of CPR [or a CPR best-interests decision] could be conditional - it can be 'CPR should not be attempted unless 'specified conditionality'" (although it is 'technically' very difficult to write an ADRT refusing CPR with that structure - you can apparently {see MCA 25(4)(b)} only write 'I refuse CPR if 'specified conditionality)'). It is equally clear that if there is a suitably-empowered welfare attorney, best-interests CPR decision-making falls to the attorney [and not to anybody else {MCA 6(6) and 6(7), and MCA Code of Practice 7.29}] if CPR might be clinically successful (and I do not consider 'we will not offer CPR, because in our expert opinion CPR could not be successful in restarting the heart' as being a 'best-interests decision': it doesn't seem to be a decision at all, if the prediction is correct, because the outcome is death with or without CPR). The ECTP prototype also mentions shared decision making, which I greatly dislike as a phrase (ref 2).

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 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.

ReSPECT has only got the signatures of clinicians on its forms - that simply cannot be correct, unless the analysis I have presented above is flawed,

Regards, Mike Stone