Mike's Cheeky Blog: a proposal for a different type of DNACPR document.

There is ongoing discussion and debate about 'DNACPR documents', and also a closely-related debate about the decision-making for CPR.

Professor Wayne Martin fairly recently told the BBC that because DNACPR forms are not legally binding, the first step should be to get rid of DNACPR forms. I agree that contemporary DNACPR forms are not legally binding – but I don't think we can not have some sort of 'DNACPR form'. I'm going to start, by explaining what I think we should consider to be a CPR/DNACPR form (really, CPR and DNACPR are simply the two binary outcomes if you consider cardiopulmonary resuscitation: you either attempt CPR {ACPR} or you do not attempt CPR {DNACPR}).

I think, using the terminology of a CPR form as being a form which pertains to CPR (so, using my previous terminology, a CPR form relates to CPR – and ACPR and DNACPR are then the two possible outcomes),

any form for a specific patient, which explicitly mentions CPR and where the form might influence whether or not CPR is attempted if the patient has a cardiopulmonary arrest, IS a 'CPR form'.

In my limited experience, when patients or relatives who understand what CPR and DNACPR mean see those terms on a document, they immediately arrow-in on that section of the form. I'm also reasonably sure that without 'a DNACPR form' most nurses in England would be very-reluctant to withhold CPR.

Contemporary DNACPR forms are peculiar beasts: they exist as a means of trying to prevent inappropriate CPR, but they cannot legally be 'orders' - the term DNACPR Order used to be widely used, and still is used by some people, but most people no longer describe those forms as DNACPR Orders. For exactly the reason which Professor Martin pointed out.

So: **how do we create a form which is intended to prevent attempted CPR, but which cannot be an order to not attempt CPR?**

ReSPECT – which readers will have noticed is a 'CPR form' using my definition – uses the idea of a clinician making a recommendation about CPR: so not an 'order' but not something I like, either.

I propose that we have CPR forms which record information, not recommendations. And that the information recorded on the form, is in essence '**What I would do if the patient had a cardiopulmonary arrest NOW and I was present**'.

The '… and if I was present' is important. If a loved-one is in hospital, and the hospital's clinicians are refusing to attempt CPR, then even if all of the patient's family are in favour of attempted CPR, unless at least one of the patient's relatives happens to be present in the hospital when their loved-one arrests, CPR will not be attempted. If the patient is at home, then if the patient's GP would attempt CPR, but the patient's family-carers are all of the opinion that it would be wrong to attempt CPR, then unless the GP happens to be present when the patient arrests, CPR will not be attempted. Etc: **you can only attempt or withhold, or promote or attempt to prevent CPR, if you are present when the loved-one/patient has a cardiopulmonary arrest.**

If my dad is in hospital, and the hospital's doctors and nurses have decided they will not attempt CPR, then even if I would attempt CPR I'm not likely to be present when my dad arrests. If I'm alone at home with my dad when he arrests, then whatever I decide to do re CPR is what will happen, because nurses and doctors who might have a different view from mine are not present.

Three fundamental questions about a form – be it a 'DNACPR form', an FCP form or the ReSPECT form – are:

1) which individuals **are not guided by** the form?

2) [for CPR especially] which **individuals might be present** at an arrest?

3) which individuals **possess a 'deep understanding' of the issues** which are recorded on the form?

If we are considering CPR-at-Home, then the answer to 2) is 'most probably family-carers [especially if they are living with the loved-one/patient] and perhaps the GP or District Nurses/HCAs' - and family-carers and the GP (and perhaps the Lead DN) are also in 1). And live-with family-carers and the GP should certainly be in 3). Clearly Welfare Attorneys and Court Deputies should be in 1) and 3) if the patient is already incapacitous, and certainly ideally while the patient is still capacitous.

We could refine those answers: but I'm mainly interested [certainly at this point] in the family-carer/999 paramedic interface, so here my point is that **family-carers are in all three** groups – and **999 paramedics are not in any of** the three groups.

I fundamentally dislike the ReSPECT form. I dislike that it is 'a clinical record of agreed recommendations': I dislike that it contains recommendations for or against CPR, which are signed by a clinician – and that elsewhere on the form it points to where other care planning documents [which <u>could not possibly be properly considered</u> by a 999 paramedic who arrived to find the patient in arrest] could be found; I dislike that the patient is not allowed to complete **and sign** the 'What matters to me' section (section 3); I dislike 'Does the person have capacity to participate in

making recommendations on this plan?' and 'The plan has been made, where applicable, in consultation with their legal proxy ...'.

I don't see, how a clinician can have the gall to make 'recommendations' about treatment, on a form, if at the time the patient has capacity*: and if suitably-empowered, then in England and Wales it is the legal proxy who should be consulting the clinicians if a form is being completed when the patient lacks capacity.

I'm trying to avoid including lots of pointers to my other pieces, but here I feel it really would help if readers would look at my piece at:

https://www.dignityincare.org.uk/Discuss-and-debate/download/474/

At least many DNACPR forms, did explicitly state which of three justifications for DNACPR the form was based on. In principle there could be 4 valid justifications for DNACPR – although I've never seen one of these on a DNACPR form. The four possible justifications are:

1) Certainty that attempted CPR could definitely not restart the heart and breathing – and it has to be 'certain it wouldn't work' and not 'it probably wouldn't work',

2) The patient is understood to be refusing attempted CPR in the circumstances of the arrest (which can be '.. whatever the circumstances of the arrest, if my heart has stopped beating I refuse attempted CPR'),

3) DNACPR is a properly-arrived-at MCA best-interests determination,

4) The NHS isn't offering CPR, because if it worked the aftercare costs would be so high as to preclude the offering of more cost-effective treatments to other patients.

That fourth justification is never mentioned, so presumably it is never used in the context of CPR: but the NHS does make cost-benefit judgements before deciding whether expensive interventions will be offered to NHS patients (that is what NIHCE does).

Although it is clear that 'consulting' is appropriate if a welfare attorney or court deputy with section 6(6) authority is forming a best-interests decision, when there is not an attorney or deputy involved I think 'consult' should be replaced, at least

* *During a consultation, a clinician can recommend a particular option to a capacitous patient, but then the patient decides whether to accept that recommendation or not: this is usually called Informed Consent, although I think Informed Consent/Considered Refusal is clearer. If the patient is capacitous when a form is considered, what we should see on a form is what the patient wants to happen.*

for the purposes of how we think about the best-interests process, with the word ‘discuss’. In practice, section 4 of the MCA requires an understanding of ‘what the patient would decide, if somehow the patient were capacitous instead of being incapacitous’. If you think about this, to discover that you would need [often many] family and friends, and one or more clinicians, talking together – and, provided an individual understood the concept of MCA best interests, it is highly likely that any individual (clinician or layperson) could argue ‘the discussions have enabled me to arrive at a defensible best-interests determination’. I’m not arguing, that in general ‘what the patient would have decided’ is the same as the best-interests determination: but, I am arguing that if you have been involved in discussions to a point when ‘what the patient would have wanted to happen’ has been established, then what stands between you and a defensible best-interests determination is simply an understanding of section 4 of the MCA.

Perhaps the most ‘left-field’ of my suggestions, is that the main thing we should see on a CPR form is what the individuals most likely to be present at an arrest would do, what the patient if capacitous when the CPR form is created would want, and what an empowered welfare attorney would decide if present (however likely or unlikely it is that the attorney would be present). And also, if the patient is incapacitous when the form is created, the views as to best interests from close family and close friends who have been involved in the discussions but would probably not be present at an arrest. **Then, we leave it to the training of the reader of the form, to interpret what the form means in terms of the actions of the reader.**

Let us consider, some possible combinations of such statements on CPR forms. Obviously all of the statements on a CPR form could be in the same direction – all of the statements could be supportive of attempted CPR, or all of the statements could support DNACPR – but I will give some more interesting examples.

Example 1

The patient is at home, and his capacity is not being questioned.

I am the patient, and I want CPR to be attempted, irrespective of why my heart stops beating   James Smith   *J Smith*

I am the patient’s GP, and I do not believe that attempted CPR could restart Mr Smith’s heart – so I will not be attempting CPR   Kenneth Jones   *K Jones*

I am the patient’s son, and a live-with family-carer, and I will be attempting CPR because my dad has asked me to attempt CPR   Bill Smith   *Bill Smith*

Example 2

The patient is comatose and in hospital.

I am the patient’s son, and also his welfare attorney, and currently I believe that attempted CPR would not be in my dad’s best interests – if my dad were to arrest now, and I were present, I would state that DNACPR is in my dad’s best interests Tony Jenkins *T Jenkins*

I am the patient’s consultant, and as I am not applying for a court ruling I accept the position of my patient’s welfare attorney, so my position is DNACPR James Wood James Wood

Example 3

The patient is at home, living with his wife. The patient has severe dementia and everyone agrees he lacks the capacity to make his own decision about CPR. The son and daughter live away, but both visit their mum and dad frequently.

My husband would want to be left to die in peace.

I don’t believe my dad would want CPR – I believe DNACPR is in my dad’s best interests and I will not be attempting CPR Fred Lovelace F Lovelace

I think my dad would want CPR to be attempted Jane Adams J Adams

I am the patient’s GP, and because the family are not all in agreement, my position is that I would attempt CPR Sarah Tomkins *S Tomkins*

DISCUSSION

There are many things unsaid in my statements, and indeed on the form: but these should be either obvious to any reader, or pointed out during training. These things include:

Clearly, the people whose statements appear on the form have been in contact with each other, so – for example – **we can assume** that in Example 2 the consultant will have seen the son’s LPA documentation. In example 3, the wife hasn’t signed her statement: we don’t know why not. ‘Psychology’? But **we can assume** that statement was written by the wife – because the other three people would be aware of that.

We could perhaps assume, from the wording of their statements in Example 3, that the wife and Jane might have less understanding of the MCA than Fred possesses. Example 3 is also interesting, in that ‘complexity’ is present in example 3 whereas the first two examples are not complex. There is nothing particularly complex about examples 1 and 2 – you cannot really challenge any of the positions of the individuals, and if a reader of those examples did not understand why you cannot challenge the statements, that indicates that some training or self-learning is necessary on the part of the reader. But you can ponder the position of Dr Tomkins in example 3: in that situation, should the doctor always be pro-CPR, or not?

So, not only does this form not go beyond the legally-possible (it isn’t claiming to be an ‘order’) but I think it would prompt, or even force, clinicians to grapple with the issues around CPR/DNACPR, and to take a proper look at the law.

This would also address an awful ‘retrospective issue’, which when it occurs, often really disturbs bereaved family members. Recollections and perceptions of conversations can differ. Sometimes a doctor can believe she has just discussed CPR with a patient, when the patient believes they were discussing something else, or isn’t at all sure exactly what was being discussed. A doctor and a relative could have different positions on CPR/DNACPR, but each might mistakenly believe the other person agreed with their own position. Such confusion shouldn’t happen, if you can read on the form the statement of the other party – and while writing your own statement, you would of course read the statements of the other people.

Written by Mike Stone,   July 2023

Twitter: @MikeStone2_EoL

PS

I’m not expecting anyone to actually adopt a form that I could propose – I publish things to try and get people to ‘think rather harder’, to paraphrase Einstein. And my term ‘CPR form’ is generic: it is to prevent things such as the ReSPECT form, from claiming to ‘not be a CPR/DNACPR form’ - but to then **be used as if they were** DNACPR forms.

But, IF I created a CPR form, and gave it a banner, then I would be very happy to link it to TalkCPR. I think my ‘banner’, in a large and friendly font across the top of the form, and a friendly green in colour, would be ‘<u>We</u>’ve talked about CPR’ followed by a tick. The underlining of ‘We’ is to make it clear that many people can be significant for CPR – and the tick is there to sort of emphasise that talking is needed. So, something like this for the heading of the form:

We've talked about CPR ✓

Obviously a working form, would need to have the usual sections for patient identification, and contact details, etc.

But I don't want to make it appear that end-of-life and decision-making is easier than it actually is. So I'm struggling to concisely explain whose statements about 'what I would do if the patient arrested now' should be on the form: it depends on the physical situation (obviously people living with the patient should ideally be there), who is 'close to the patient' (partners, children, etc), are there any welfare attorneys whose authority would extend over CPR, and the various involved clinicians. And certainly on the lay side, it is 'invited to' describe what you would do on the form: so the absence of a statement, does not imply non-involvement.

I think, I would have to describe the 'I would do' section with something like this:

We have tried to invite everyone relevant, to state on this form what as individuals they would do if the patient had a cardiopulmonary arrest at the time this form was being created – but, some individuals who would probably be involved, might have declined to make a statement.

I would probably put an explanation of the word 'relevant' in a notes section of the form, which would probably be a second/reverse page.

So, in outline, the main page of the form would be something like what I show below, with a reverse or second page giving further explanation of how the form 'works'.

We've talked about CPR ✓

Patient Identification Section

We have tried to invite everyone relevant, to state on this form what as individuals they would do if the patient had a cardiopulmonary arrest at the time this form was being created – but, some individuals who would probably be involved, might have declined to make a statement.

The patient is at home, and his capacity is not being questioned.

I am the patient, and I want CPR to be attempted, irrespective of why my heart stops beating James Smith J Smith

I am the patient's GP, and I do not believe that attempted CPR could restart Mr Smith's heart – so I will not be attempting CPR Kenneth Jones K Jones

I am the patient's son, and a live-with family-carer, and I will be attempting CPR because my dad has asked me to attempt CPR Bill Smith Bill Smith

Contact Details Section

This section is pre-printed on the form.

This part would be hand-written and signed.

The form would also need a means to indicate that people were trying to keep it up-to-date, by some combination of re-dating regularly if nothing had changed, updating individual statements, or if necessary completing a new form.

It might need a section for 'The doctor considers attempted CPR could not restart the patient's heart and breathing' but I've never been clear why a reader of the form needs to be told why the doctor considers that to be true: if the form is kept up-to-date, then that statement - 'I am the patient's GP, and I do not believe that attempted CPR could restart Mr Smith's heart – so I will not be attempting CPR Kenneth Jones K Jones' should be sufficient. Logically, how can a clinician who has never before seen a patient who is at the time in arrest, dispute the opinion of a doctor who had previously had plenty of time to consider whether CPR could be successful?